

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Medium MR unit
*DATE:
*ID: Patient09
*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 BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Only what I'd read in magazines, books; I'd been to the doctors for well woman checks and, going back quite a few years, the nurse actually did the breast checks for you; and then probably, maybe even six years ago, we were then shown how to check a breast ourselves. I'd got an auntie who did have breast cancer: she is now dead but I'm going back, ooh, 20-odd years ago when she was first diagnosed. She's been dead, what, probably ...

Daughter: Five, six years.

Patient: Yes, yeah. And that really is it, just what I'd read in magazines, what you'd see on the television, I wasn't concerned about breast cancer when it happened to me.

INT: RIGHT, OK. AND HAVE YOU HAD ANY FAMILY MEMBERS, DID YOU SAY THAT ...?

Patient: I'd got an aunt.

INT: YOU'VE GOT AN AUNTIE, YEAH, ANYBODY ELSE?

Patient: No.

INT: OK, WHAT DID THE AUNTIE, WHAT HAPPENED TO HER IN TERMS OF OPERATIONS?

Patient: She found a lump herself, she had a breast removed - again we're going back, as I said, 20 years ago when there weren't the other options anyway as far as I'm aware.

INT: NO, THAT QUITE RIGHT, YEAH.

Patient: Erm, and she was fine but the cancer did come back, as I say, probably about 10 years, 14 years ago.

Daughter: Fourteen since she was first diagnosed.

Patient: Yes, yeah. But her quality of life was very good and, as I said, that was the only decision [???

INT: AND THIS WAS ALL IN CHESTERFIELD, WAS IT?

Patient: No, she lived in Wiltshire.

INT: AH RIGHT, OK. ERM, AND HAVE YOU ANY FRIENDS OF THE FAMILY WHO'VE HAD BREAST CANCER AT ALL?

Patient: No, I have a colleague at work whose sister has had breast cancer and she lives down in Cornwall. She had, I think she did have to have a lump removed, didn't she?

Daughter: Yeah, the lumpectomy.

Patient: She did the lumpectomy. She was only in her 40s, so younger than me, but I don't really have any close friends, no.

INT: OK. AND CAN YOU TELL ME HOW, YOU KNOW, HOW DID YOUR SORT OF STORY BEGIN, THEN? HOW DID YOU, DID YOU FIND OUT YOU HAD BREAST CANCER?

Patient: Erm, I'd got a letter to say I'd got my first mammogram at the Whitworth Hospital and went along there, not expecting anything, just it was a routine check as you go for your smear test and everything. And then about a fortnight later the letter came back to say that they wanted just to investigate further. Having said that I did have a friend who had the same thing happen last year and she went back and it was nothing, so you sort of think, 'Oh, well, mine's going to be like that,' and that was how I found out. I couldn't feel the lump at all, so it was just picked up from the mammogram.

INT: THAT WAS YOUR FIRST ONE, WAS IT, YES?

Patient: That was the first one because I was 50 last year.

INT: RIGHT, OK. ERM, SO YOU WENT BACK FOR, WAS THIS THE SECOND MAMMOGRAM? IS THAT ALL YOU HAD? DID YOU HAVE ANY OTHER TESTS WHEN YOU WERE THERE?

Patient: On, the first visit was to the Whitworth Hospital where the mobile unit came, and that was when it was picked up.

INT: AH RIGHT, I SEE.

Patient: The second visit was back to the Chesterfield Hospital and I had another mammogram, an ultrasound and a biopsy, and interview with Mr Chadwick who said it looks suspicious and also the doctor doing the ultrasound said it looked suspicious so I sort of asked the question, 'Well in percentage-wise, what does this mean?' really thinking back to the friend who'd had the same thing the year before and it hadn't been suspicious and they said, 'Well, more suspicious than not suspicious, you know, you're up in the percentage, the high percentage.'

INT: RIGHT, OK.

Patient: And that was it, really. As I say, the needle biopsy was done, which was fascinating seeing the little cells in [??] and then we went away, we came home for a week and then went back the following Friday to talk again with Mr Chadwick for the results.

INT: AND WHEN HE SAID IT WAS SUSPICIOUS OR HIGHLY SUSPICIOUS, AS YOU SORT OF LATER FOUND OUT, WHAT WAS GOING THROUGH YOUR MIND AT THIS POINT?

Patient: Erm ... it didn't really sink in to any great extent. Victoria was out in the waiting room and I went out to her and just said, 'It says suspicious,' but as regards sort of frightening thoughts or anything like that, no, I didn't have those. I was just 'Well, what happens next week will be,' and that was really the only thoughts that I did have. Having said that, erm, the next day ...that was when I went to Torquay, wasn't it?...

Daughter: Yes.

Patient: ... it sort of kicked in more then, because you then have the thoughts, 'Well, if it is cancer, how are people going to cope at home, you know, and all this sort of thing - really looking upon it as a terminal cancer, you know, how

were people going to cope, but it wasn't actually at the hospital or really that day that those feelings came, it wasn't until later.

INT: AND DURING THAT WEEK, YOU WENT BACK A WEEK FOR YOUR RESULTS, IS THAT RIGHT?

Patient: Yes.

INT: SO DURING THAT WEEK, DID YOU, OBVIOUSLY YOU MUST HAVE TALKED TO YOUR FAMILY ABOUT IT AND ...

Patient: Yeah, I went on holiday to Torquay because we'd already arranged that, erm, only my husband and myself. We talked about it there and you found that things coming up on the television more relevant because it just sort of hits you then, but we thought the best thing was to go away and just sort of take it, 'Well we'll see what happens the next week as to what it is,' you can't do anything till you've been told what is going to happen, and that was it really./

Daughter: Can I just ...

INT: YEAH.

Daughter: ... Sorry, can I say one thing, that I don't know whether you thought of it, but they did tell you straight away the size of the lump, didn't they?

Patient: Yes.

Daughter: At the, when they said it was suspicious, they said, 'Well, it's only small,' and I think that was an important part in you coping with it, because all the way through they said to you, didn't they, 'Well it's only small, your chances are brilliant,' sort of thing.

Patient: Yes.

INT: RIGHT, YEAH.

Daughter: As supposed to someone, I mean obviously they have to do a lot more tests, but that was something that you sort of hung on to, I think.

Patient: Right.

Daughter: Did, well, do you think, am I butting in for you?

Patient: Well, no. Those thoughts aren't there in my head at the moment, but I do know that that is probably what I did think. And you went on the internet, didn't you, and did quite a lot of research ...

Daughter: Yeah.

Patient: ... whilst I was away? Now I've not done that, but Victoria found it was useful for her to do that.

INT: RIGHT.

Daughter: Yeah, yeah.

INT: RIGHT, OK. DURING THAT WEEK, BEFORE YOU GOT YOUR RESULTS, DID YOU AT ANY POINT HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF SURGERY ... WHAT KIND OF SURGERY YOU MIGHT GO FOR?

Patient: Had I been given the choice then?

INT: NO.

Daughter: I don't think so, no.

Patient: No, well then probably not.

INT: RIGHT, OK.

Daughter: I don't think you did.

INT: SO WHEN YOU WENT BACK FOR YOUR RESULTS TO THE CLINIC, CAN YOU TELL ME, JUST RUN ME THROUGH WHAT HAPPENED WHEN YOU WENT TO THE CLINIC AND ...?

Patient: Yeah. Erm, Victoria came in to see Mr Chadwick with me that day ...

Daughter: Yeah, yeah.

Patient: ... and he sat and drew diagrams and said that it was a lump, it was cancer. He went through the various options that I could take. He also had the mammogram up on the board so he was showing me that. He did an examination as well ... and he, as I say, gave me the options of either having the lump removed and going for follow-up treatment ...

Daughter: Radiotherapy.

Patient: ... at Weston Park, and which would be a five-week, he said a five-week ...

INT: FIVE DAYS, FIVE WEEKS.

Patient: Yes. Or the mastectomy.

INT: RIGHT.

Daughter: He also went through the pros and cons of each one, didn't he?

Patient: Yes, and wrote this down, didn't he?

Daughter: Yeah, he wrote it down for you.

Patient: We came away with this on a piece of paper. Erm ... the ... Victoria asked whether, if I did go for the lump removal and the follow-up treatment, whether I could go to Derby to do that because I don't travel very well and she knew that that really would influence me slightly.

INT: ARE YOU CLOSER TO DERBY?

Daughter: Not particularly but I can drive to Derby easier than Sheffield [chuckles] because I'm at the University there, and Mum would also travel, because you're not, you don't travel very well in a car, do you?

Patient: No.

Daughter: So it was a bit of a worry when you're not feeling very well after it as well.

Patient: Plus ... now you see thoughts are coming back when you said did I know anyone else who'd had breast cancer ... [chuckles]

INT: OH RIGHT, YES, [???

Patient: A friend of mine, not a close friend but she did have a lump removed at Christmas and she did have follow-up treatment but she was based at Derby Hospital anyway.

INT: OH RIGHT.

Patient: So maybe that was in my mind. Weston Park also, I've got sort of associations with a friend who went there for radium treatment and it was, not wasn't successful because it wasn't breast cancer, but I think all those thoughts are there anyway.

INT: THIS PERSON WENT TO WESTON PARK?

Patient: Yes.

INT: YES.

Daughter: But with a different type of cancer.

Patient: But she had cervical cancer, but, erm ... and so I wasn't really thinking of having the lump removed anyway and the follow-up treatment because deep down I knew I wanted the breast removed. But they were sort of options to think about and it did slightly influence me in the fact that you would have five weeks of five days, and you wouldn't be able to go back - you probably could go back to work but you wouldn't be feeling the same as I feel now - touch wood - and I mean I'm very lucky to feel as I do feel. But that sort of influenced me as well.

INT: I THINK WITH RADIOTHERAPY YOU GET PROGRESSIVELY TIRED, THAT'S WHAT I'VE HEARD. IT STARTS OFF WHERE YOU GET LITTLE BOUTS OF TIREDNESS BUT THEN BY THE END OF IT YOU REALLY ARE SORT OF ... YOU KNOW, IT DOES TAKE IT AWAY. IT'S QUITE OBVIOUS, IT'S QUITE A STRONG TREATMENT OVER A PERIOD OF TIME. NOT AS FAR AS CHEMOTHERAPY BUT ... OK. AND YOU WENT IN THE CLINIC, THERE WAS YOURSELF, VICTORIA AND YOU WERE THERE IN THE CONSULTATION WITH MR CHADWICK, WAS THERE ANYBODY ELSE THERE AT THE TIME?

Patient: Yes there was ...

Daughter: Two.

Patient: ... two nurses, weren't there?

Daughter: Yes.

Patient: One was the breast nurse, Donna, and Donna came with a ...

Daughter: There was the other one in the room, though. Was she just like an assistant who went to ...

INT: DID SHE HAVE A UNIFORM ON?

Daughter: She had like a white uniform on. She was the one that kept coming out and calling people from the waiting room.

INT: RIGHT, THE CLINICAL ASSISTANT OR STAFF NURSE OR SOMETHING.

Daughter: Yeah, I don't think she was a breast nurse.

Patient: No.

Daughter: Because that was Donna, wasn't it?

Patient: Donna was, wasn't she?

Daughter; Yeah.

Patient: And she came out from the consultation with us and walked down the corridors and spoke to us and said, 'I'm going to take you to make your pre-med appointment ...'

INT: AH RIGHT, YEAH.

Patient: ... 'erm, I'll show you what it's, how it's done,' didn't she?

Daughter: Yeah.

Patient: And she said, 'I will probably meet you next week when you come for the pre-med and I'll talk to you then, but I didn't see Donna at that pre-med, but you probably will get on to that anyway but ...'

INT: SO IT WAS MR CHADWICK THAT, WHO BROKE THE BAD NEWS ...

Patient: Yes.

INT: ... SO YOU, THAT YOU HAD CANCER, AND YOU SAID THAT HE DREW SOME DIAGRAMS AND SHOWED YOU YOUR MAMMOGRAMS AND THINGS, YEAH, IS THAT RIGHT?

Patient: Yes.

INT: HOW USEFUL DID YOU FIND THOSE DIAGRAMS AND THE MAMMOGRAMS, LOOKING AT THOSE? DID YOU FIND THEM HELPFUL IN ANY SORT OF WAY?

Patient: I think probably Victoria found it more helpful than me because my mind was more sort of going, well not terribly clear at the time, but it was useful to have it when I came back to look at it, but again I think I'd made the decision anyway.

INT: THE DECISION, YEAH, MM. AND, I MEAN, HOW DID YOU FEEL ONCE IT HAD BEEN CONFIRMED THAT YOU HAD CANCER?

Patient: I think probably you knew anyway that it was, that was what they were going to say and again you thought, 'Well I'll tackle it, whatever someone says, then, you know, that's the next step along the line and I'll know what I've got to tackle,' and that was it really.

INT: AND WHEN THEY WERE TALKING TO YOU ABOUT YOUR TREATMENT OPTIONS AND YOUR DIAGNOSIS, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENTS?

Patient: I would have said I understood fairly well, yes, yeah.

INT: RIGHT OK. WAS THERE ANYTHING THERE YOU FEEL THAT YOU DIDN'T UNDERSTAND OR THAT WAS DIFFICULT TO TAKE IN?

Patient: No, not really. Did you think anything?

Daughter: No, all I was going to say is he did speak, you know, a lot about whether it had spread and, but, that was actually at the pre-med, wasn't it? I'm

jumping ahead, because he said, he felt your lymph nodes and they didn't feel inflamed.

INT: RIGHT, OK.

Daughter: And then that, to me was quite a comfort for him to say that, you know, because obviously, having [???] one thing, having it spread is another, and, you know, it was sort of, that was quite a comfort, you know, I think he did do that well ...

Patient: Yes, yes.

Daughter: actually, because he did spend a bit of time going over it.

Patient: Oh yeah, there certainly wasn't any rush or anything like that, you didn't feel ...

Daughter: No, but I am jumping ahead to when he consulted you in the pre-med, it wasn't in the time when he told you, was it?

INT: ERM ...

Patient: Oh, I know, you asked about whether we could go privately if we [chuckles] - don't laugh, if we could go any quicker, could we go privately?

INT: [???

Daughter: I didn't realise how quick the NHS would actually do it.

Patient: Well, Dad told you to ask, didn't he?

Daughter: Yes.

INT: THAT'S FINE [???

Patient: But, I mean, because it was done within, what, two weeks? Well, less than two weeks, wasn't it?

Daughter: Yes, yeah. They booked you in on that day he told you, didn't he, when they would pencil you in for?

Patient: Yes, yes, so I mean that didn't crop up at all, that scenario, anyway. But ...

Daughter: Erm, I just thought to say and I've forgotten.

INT: THAT'S OK, IF YOU REMEMBER JUST SHOUT IT UP. AND THEN YOU WENT WITH DONNA AFTERWARDS TO THE BREAST CLINIC, WITH THE BREAST CARE NURSE DOWN TO, TOOK YOU TO PROBABLY A QUIET ROOM, DID THEY OR SOMEWHERE? DID THEY TAKE YOU IN A ROOM?

Patient: No, I didn't speak to the breast nurse in a room separate at all at that time.

INT: OH, THAT'S WHEN YOU GOT YOUR DIAGNOSIS?

Patient: Yes.

INT: YEAH, SO, JUST TELL ME WHAT HAPPENED WHEN YOU, AFTER THAT CONSULTATION WHEN YOU WENT WITH DONNA, WHAT HAPPENED THEN?

Patient: She just walked down the corridor with us, erm, to where we had to make the appointment for the pre-med assessment and, as I say, she did say she'd see us the next week, she'd be around on the Thursday morning, erm, and she just took you through booking in and getting your medical number and everything like that, but I didn't have a separate talk with her at that time.

Daughter: The only thing she did say in the corridor - butting in - was if you wanted her at any time during the next week ...

Patient: Yes.

Daughter: ... you could ring. You know, she gave you a card with her number on.

Patient: Yes, that business, not business card, but the car with the two numbers. There was Mary Buxton and Donna's number on there. Yeah.

INT: AND DID YOU AT ANY POINT TALK ABOUT TREATMENT OPTIONS WITH DONNA IN THAT MEETING? DO YOU REMEMBER?

Patient: No, no.

INT: OK. DID THE BREAST CARE NURSES GIVE, APART FROM THE CONTACT CARD, DID YOU GET ANY OTHER INFORMATION? ANY LEAFLETS ABOUT SURGERY OR ANYTHING LIKE THAT?

Patient: No.

Daughter: No, we didn't because you said ...

Patient: No, because I remarked on that, that I wondered if there were any leaflets that sort of went through various things, but, no, I didn't get anything.

INT: DID YOU REMARK IT TO DONNA?

Patient: No.

INT: AH RIGHT, OK. ERM, AND DURING THE CONSULTATION YOU WERE HAVING WITH MR CHADWICK, WHO DO YOU THINK DID MOST OF THE ACTUAL TALKING, WHO DO YOU THINK DID MOST, ASKED MOST OF THE QUESTIONS?

Patient: What between myself and him?

INT: YEAH, MM.

Patient: I don't know whether it would be weighted either way, would it?

Daughter: He certainly did a lot of explaining to begin with, didn't he ...?

Patient: Yes.

Daughter: ... on where the lump was, what your options were, drew the diagrams. In terms of asking you anything, I don't think he asked really, did he? You asked him a few questions at the end ...

Patient: Yes.

Daughter: ... and I did, but ...

Patient: No, maybe he didn't ask questions, I mean what could he have asked?

Daughter: Well, what sort of questions?

INT: MM, YEAH, NO I JUST ...

Patient: At that sort of juncture. I don't know ...

Daughter: Yeah, I can't really, it's hard to remember, isn't it?

Patient: Oh I know there was something that did crop up was, I said I wanted the mastectomy there and then and he said, 'Well you've got until the pre-med on the following Thursday to think about it, so it's not done and dusted ...

Daughter: Yes, it wasn't [???

Patient: ... in that way, so I mean he didn't take it, and in fact he had put me in to have a marker assuming that I was just going to have the lump removed.

INT: RIGHT, OK.

Daughter: Because I think he said, didn't he, one bit of thing - he wasn't sort of telling you to do one, obviously it was Mum's choice and he made that perfectly clear, but he did say with the size of the lump a lumpectomy would have been fine ...

INT: RIGHT, YEAH.

Daughter: ... you know, he would have backed that, as he would have backed the mastectomy.

Patient: Yes, he, you know ...

Daughter: It was your choice.

Patient: ... it was obviously up to me, but ...

Daughter: Yes, which he did say that, that was a comment he did make.

Patient: Yews, yes. So I mean I didn't make the decision there and then, it was in the end until the following Thursday.

INT: OK. ERM, HOW DO YOU FEEL YOU GOT ON WITH MR CHADWICK?

Patient: Very well.

INT: YEAH?

Patient: I found him easy to talk to, he explained things well and ...

Daughter: Approachable.

Patient: He was approachable, yeah. You found that, didn't you?

Daughter: Yeah, he was.

Patient: Yes, yeah.

INT: AND DO YOU FEEL THAT HE LISTENED TO YOU, AND HE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND THINGS?

Patient: Yes.

INT: YEAH?

Patient: Yeah. And, as I say, he gave us plenty of time, you know, to talk about, you didn't feel rushed in any way.

INT: AND WAS IT DONNA THAT YOU SAW? HOW DID YOU GET ON WITH DONNA?

Patient: Well I only met her that very, for that very short time.

INT: RIGHT.

Patient: I didn't actually with her in a room and talk to her.

INT: NO, YOU NEVER SAW HER AGAIN AT THE PRE-ASSESSMENT EITHER?

Patient: No.

INT: NO, OK. ERM, [???] MISSED SOMETHING OUT HERE, WE'VE SORT OF JUMPED ON QUITE A BIT NOW [???]

Patient: We've gone from one to the other and we've got the dog snoring in the background. [chuckles]

INT: YEAH. DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES IN BETWEEN RECEIVING YOUR DIAGNOSIS AND YOUR SURGERY? DID YOU CALL THEM? DID THEY DO A HOME VISIT AT ALL, OR ANYTHING LIKE THAT?

Patient: No.

Daughter: No, Mary Buxton did visit you on the morning of your ...

Patient: Of the operation, but we probably couldn't, would you be asking me that later?

INT: NEXT, ACTUALLY, BUT YEAH ...

Patient: Do you want me to just explain about that?

INT: YEAH, I MEAN IF THERE WAS NO FURTHER CONTACT WITH THEM ...

Patient: No.

INT: OK. ERM, SO IF YOU CAN JUST TELL ME NOW ABOUT WHEN YOU WENT FOR YOUR PRE-ASSESSMENT AND THEN WHEN YOU WENT FOR YOUR OPERATION.

Patient: Right, well the pre-assessment I fainted. [chuckles] Do you want that sort of information?

INT: YOU FAINTED?

Patient: Only when they took the blood.

INT: OH RIGHT, OK. DO YOU NOT LIKE BLOOD TESTS?

Patient: No.

INT: SEE I DON'T LIKE NEEDLES, I CANNOT STAND THEM.

Patient: No.

INT: NO, I DON'T MIND BLOOD TESTS, AND I WATCH HORROR MOVIES ALL THE TIME, BUT WHEN IT COME TO THE MAD SCIENTIST GIVING [???] IN THE CINEMA, [???] AND AS I'M WATCHING SHE SAYS, 'IT'S OVER.' YOU KNOW, HEADS EXPLODE AND PEOPLE GETTING DISEMBOWELLED, NO PROBLEM, BUT I CAN'T, IT'S THE THOUGHT OF THAT METAL NEEDLE INSIDE OF YOU ...

Patient: Yes, it is the thought, isn't it?

INT: IT JUST SENDS ME COMPLETELY. SO ANYWAY, YOU FAINTED

Patient: Right, well that's by-the-by, isn't it? On the Thursday morning we all sat in the waiting room, then we went to be weighed and whatever else they do, mess with you[?], then they told you that they'd booked you into St Mary's Ward and the time that you had to go there on the following Monday. Erm, they did the blood test and then I had to go and sit quiet for half an hour and get myself together, and then we went in to see ... no, no, we didn't ... we had the man that checks your feet and ...

Daughter: Oh, the junior doctor.

INT: OH THE SpR SOMETHING OR OTHER.

Patient: Oh, I can't really remember, but he was very nice, wasn't he?

Daughter: Yeah.

Patient: Erm, and then we went to see Mr Chadwick again and talked it through with him and he said about going for the marker and I said, no, because I was, I had made the choice then of the full mastectomy.

INT: RIGHT, OK.

Patient: Erm ...

Daughter: He sort of reassured you again, that's what I was just saying earlier, you know, in terms of your long-term [???

INT: SURVIVAL.

Patient: Yes, he picked up on that.

Daughter: Yeah, I think at that time he did do that well, because I certainly went home feeling a lot better [chuckles] than when we went to hospital.

INT: RIGHT, MM.

Patient: Yes.

Daughter: And he explained also about your operation there, didn't he? About the mastectomy, what it'd involve, what it'd look like and things.

Patient: Right, you see, you've taken all that in ...

Daughter: Yeah.

Patient: ... to me it was probably just a matter of 'this is going to happen to you and this is it,' whereas the person on the sidelines is listening to more to that sort of thing.

Daughter: Well I mean he did, didn't he? He explained all that and then he said, erm, that he was happy to back your decision and things, yeah.

Patient: Yes.

INT: OH, THAT'S GOOD.

Daughter: Yeah.

INT: ERM, AT ANY POINT IN BETWEEN YOU GETTING YOUR DIAGNOSIS AND YOUR ACTUAL SURGERY, YOU SAID THAT YOU CHOSE MASTECTOMY VIRTUALLY STRAIGHT AWAY ...?

Patient: Yes.

INT: IS THAT RIGHT? DID YOU EVER CHANGE YOUR MIND AT ALL, DID YOU EVER THINK TWICE ABOUT WHAT YOU WERE DOING OR DID YOU EVER ...?

Patient: No.

INT: NO? OK. ERM, LET ME THINK, NOW [???] SO YOU'VE BEEN TO SEE MR CHADWICK AND THEN YOU TOLD HIM THAT IS YOUR FINAL DECISION, THAT WAS RIGHT, YEAH?

Patient: Yes, yeah.

INT: SO WHAT HAPPENED AFTER THAT THEN?

Patient: Erm, that was on the Thursday and so I was booked in for the Monday, and we turned up on the Monday morning and I was admitted. Victoria came with me and it was, it surprised me that Victoria could stay for quite a lot of the morning. No-one sort of said to her, 'Oh you've got to leave,' you know, 'we're getting you ready for whatever.'

Daughter: Because your operation was half past one, I think, wasn't it?

Patient: Yes. And in fact you stayed until almost 12 o'clock, didn't you?

Daughter: Yeah.

Patient: Erm, there was three, there was another lady in the bed next to me who had come in and she was talking to various people and hers was just to have a lump removed which they thought was benign, didn't they?

Daughter: Yeah. But you had seen her at the pre-med ...

Patient: Yes, I had.

Daughter: ... hadn't you, this lady, so you thought automatically, 'Oh, she's got cancer as well,' didn't you?

INT: OH RIGHT.

Patient: So you were sort of in the next bed, and that was ...

Patient: Because Victoria and I both said the same thing, when we heard her talking that she didn't think hers was cancer, both ...

Daughter: In that ward, on that ward [chuckles] I mean, it was a bit ... I know this sounds silly but it was a bit like a kick in the throat. I mean obviously we were pleased for somebody else that she hadn't got it, but 'cos we'd gone along thing, 'Oh, right, she's got the same as Mum ...'

INT: OH RIGHT, YES, YEAH ...

Patient: [???

Daughter: ... when they were lying in that bed before the operation the doctors came round and said, 'Oh well, we don't think this is cancer,' and it was a little bit ... we both said, didn't we, we both remarked on it?

Patient: Yes, yes.

Daughter: Just for a few minutes it was a bit like ...

Patient: It was only just an instant hit, but you thought, 'Oh there's somebody there without cancer when ... but I'm here with cancer,' which was an odd sort of feeling ...

Daughter: Yeah.

Patient: ... but we both felt it.

INT: DID YOU THINK THAT WAS LIKE A CANCER WARD? IT WAS LIKE A WARD FOR PEOPLE WHO HAD CANCER?

Patient: I don't really know what I thought, because I was the first person being booked in. So, yes, I suppose I did think, because I'd seen this girl at the pre-med ...

Daughter: And lots of others that you thought were coming in on the same day.

Patient: Yeah, I assumed that all those people at the pre-med on the Thursday were there because they'd had a lump discovered in their breast - now that might not have been right, you see, I don't know.

Daughter: We don't know, do we?

Patient: But I mean at the end of the day it did turn out that I knew this girl anyway [chuckles] in the next bed, so, erm, and then in the other two beds there were the two ladies who in actual fact did have mastectomies the same as me. During the morning the anaesthetist came round and talked to you and also a student doctor from Sheffield University asked if she could talk to me about, erm, how you discovered it and all this sort of thing, which we did. And Mary Buxton, the cancer nurse also came and spoke to me and she was the one who said, when I was talking to her about not ever having an operation before and not knowing what to expect, she did say 'Ask ...' this sounds really silly but, 'Ask for an anti-sickness pill' because you can ask for this and not a lot of people know about it.

INT: RIGHT, OK.

Patient: So I did do, and ...

INT: HAD YOU NEVER HAD AN ANAESTHETIC BEFORE?

Patient: No, and that was what was worrying me more than the operation itself, to be honest.

INT: MM, THAT'S WHAT A PATIENT SAID THIS MORNING, YEAH.

Patient: Mr Chadwick came round and spoke to me as well. He said, 'I'll see you this afternoon,' and I said, 'I hope I don't see you this afternoon, I'm hoping I'm going to be asleep,' [chuckles] and that was it really.

INT: AND HE DID THE OPERATION, MR CHADWICK?

Patient: Yes, and that was reassuring because I've had him all the way along, for absolutely everything.

INT: A BIT OF CONTINUITY THERE.

Patient: All the consultations, the operation, going back and everything.

Daughter: But not everybody did, did they?

Patient: No. And that was very reassuring.

INT: AH, THAT'S GOOD. ERM ... IN BETWEEN YOUR DIAGNOSIS AND YOUR SURGERY, I THINK YOU SAID YOU DIDN'T LOOK FOR ANY FURTHER INFORMATION DID YOU?

Patient: No.

INT: AND YOU LOOKED ON THE INTERNET, IS THAT RIGHT?

Daughter: That's right, yeah.

INT: DID YOU FIND ANY INFORMATION ANYWHERE ELSE: BOOKS, MAGAZINES, TELEVISION, CALL ANY SUPPORT GROUPS, TALK TO ANYONE ABOUT IT?

Patient: No.

Daughter: I did.

Patient: Did you?

Daughter: Sorry, you answer because ...

Patient: Erm, all I can remember is that there was an article in the Mail Supplement but it was Elaine Page ...

Daughter: Oh yeah.

Patient: ... who had spoken about discovering a breast, a lump in her breast, and my husband said, 'You want to read this because she's saying everything went well and all this,' and I said, 'I can't look at that now, I'll read it later,' and each day I intended to read it but I didn't, and I didn't read it until I'd had the operation and come home, actually a lot time after. So, no, I didn't really read anything. But you did?

Daughter: Yeah, I read a lot on the internet, and a lot quite medical things [chuckles] as well as, you know, the emotional side. And I actually spoke to a nurse down at our GP practice when I went just for a routine thing for myself, and she just explained the whole thing really, just briefly to me again.

Patient: And that reassured you, didn't it?

Daughter: Yeah, yes.

Patient: Yes, yeah.

INT: AH RIGHT, OK. SO TELL ME NOW ABOUT WHAT HAPPENED AFTER YOUR OPERATION. YOU HAD THE OPERATION AND YOU, HOW DID, HOW WERE YOU WHEN YOU CAME ROUND?

Patient: Fine.

INT: WERE YOU OK, WERE YOU?

Patient: Yes ...

INT: DID YOU TAKE THE ANTI-SICKNESS PILL?

Patient: Yes.

INT: OH RIGHT, OK.

Patient: I wasn't sick, didn't really feel as if I'd had an operation, I felt a bit of a fraud really, [chuckles] I didn't have any pain. You came in at night, didn't you, you and Dad, and I was just, I'd got the oxygen mask on but ...

Daughter: You looked well.

Patient: ... I mean we could talk. Well I hadn't, you didn't really look any different to how [???] and all I had was Paracetamols and, as I say, I didn't have any pain, I mean I've been so lucky.

INT: MM. WERE THE DRAINS OK AND THAT?

Patient: Oh, yeah. [chuckles] I didn't real-, I mean I didn't know about the drains so you're there obviously with the drain in, aren't you, and this bottle?

Daughter: Beforehand, you mean, you didn't know you had to have it all.

Patient: No, I didn't, no, no. And I'd said, well because I'm squeamish I can't really look at the bottle but of course you've got to pick the bottle up and walk round with it, so they did find me a pillowcase to put the bottle in, so that I was walking about without [chuckles] [???] If I'd have known my sister would have made me a little bag that I could have to walk round with. But it drained very well and in fact on, I had the operation on the Monday and on the Wednesday I was told that I could go home, but I didn't, I stayed another day, which again was unusual, but Cheryl, the nurse on the ward, came to say, 'Oh, you can go home,' but I said I hadn't had the drain out, although it had drained properly, they hadn't, at that time, taken the drain out, and knowing how I felt about these things, I asked if I could stay one more day so that they took the drain out and I knew I was OK to come home.

INT: BEFORE YOU WENT HOME, YEAH.

Patient: So I stayed until the Thursday.

INT: OH THAT'S [???] AND THEN WHEN DID YOU NEXT SEE MR CHADWICK, ABOUT A WEEK LATER OR SO OR SOMETHING?

Patient: Yeah, the following Friday, yeah, we went back.

Daughter: Yeah, not the Friday of the week you had it done.

Patient: Not, no, the following Friday.

INT: YEAH, THEY GIVE YOU, WHAT, THE HISTOLOGY OF THE RESULTS AND, IS THAT RIGHT, WHAT YOU ... [???]?

Patient: Yes.

Daughter: A lot of information, weren't there, really [???] ?

INT: CAN YOU TELL ME WHAT HAPPENED THERE?

Daughter: Well he examined you first, didn't he? He examined the scar ...

Patient: Oh yes, yes.

Daughter: You were the ...

Patient: Yeah, I'd just got the pla-, oh the plaster was on the scar and the district nurse had been twice to see me whilst I'd been here, but I couldn't look at the plaster or the scar. That wasn't because I'd had a breast removed, it was just I didn't want to look at the actual scar, as it were. If it had been ...

INT: YEAH, YEAH, YOU SAID YOU WERE SQUEAMISH, THAT'S RIGHT, YEAH.

Patient: Yes, yeah. If it had been a scar on my arm, leg or whatever, I still wouldn't have been able to look at it.

INT: RIGHT, OF COURSE, YEAH.

Patient: Erm, but they took the plaster off there and Mary Buxton, the cancer nurse, was there as well, and I said, 'Oh, I'll look now,' and Mr Chadwick was there and I looked and there was just the scar across obviously and that was then OK.

INT: RIGHT, YEAH.

Patient: He said that it was the, he did say the best possible news, did he use that terminology?

Daughter: Yeah, he said, 'It's the best possible news you could have with something like that,' ...

Patient: Yes.

Daughter: ... and that you at ease then, didn't he?

Patient: Yeah. Although he had examined me first and you were sitting there, weren't you, waiting. Now you've said that, yeah. Erm, that the cancer hadn't spread and the operation had been successful and that the scar was healing very well and ...

INT: DID THEY TAKE ANY LYMPH NODES, DO YOU REMEMBER?

Patient: They were going to take lymph nodes, weren't they, and I think they did.

Daughter: I would have thought so, I mean when I said to the nurse at the GP's surgery, 'Why do they do that?' and she said, 'Oh it's common practice, they take lymph nodes from everybody with breast ...' so I don't know, I would have assumed that they have, but ...

INT: MM, YEAH, BECAUSE THE LYMPH NODES ARE AN INDICATOR IF IT'S SPREAD.

Patient[?]: Yes.

INT: INTO THE LYMPHATIC SYSTEM.

Patient: Yes, yes.

Daughter: He said he was going to take, didn't he?

Patient: Yes.

Daughter: You know ...

Patient: Yes, that was on the list of things that he ...

Daughter: [???] auxiliary samples.

Patient: Auxiliary sample, yes.

INT: AH RIGHT, YEAH, WELL HE'LL HAVE TAKEN THEM, OK.

Daughter: And also you got numbness, he said you might get numbness under the arm and you have had that.

Patient: Yes.

Daughter: [???] they've had to cut there.

Patient: Yes, but then as to how many lymph glands were taken I don't know because again the others in the hospital had a lot more pain and a lot more discomfort than what I had, so you don't know whether, you know, you haven't had as many taken.

Daughter: He said originally, didn't he, he would three or four of the bigger ones? That was his original thing, but then he never actually said what he'd done [???]

INT: AND IN TERMS OF FOLLOW-UP TREATMENT, WHAT HAPPENED AFTER, THERE THEN?

Patient: He said that ... [chuckles]

INT: [???]

Patient: ... he would, they hadn't had the results back from the tests as to whether I could have Tamoxafen and if the results were OK then he would suggest that I had Tamoxafen for five years. This was only really a back-up because not all hospitals would actually say I needed to have it, but ...

Daughter: Because of the type of cancer that they found, he said that it was a very low grade one ...

INT: RIGHT, OK.

Daughter: ... and that they were happy really for you not to have it.

Patient: Yes.

Daughter: They were that positive that it wouldn't come back.

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

Patient: Yes. So ...

Daughter: But you [???

Patient: I have now ...

Daughter: [???

Patient: Yes, yeah, I did get the letter through probably about 10 days ago to say, yes, I could have the Tamoxafen and we just picked up a prescription from the GP and I've started taking it.

INT: RIGHT. AND THERE'S NO RADIOTHERAPY OR ANYTHING LIKE THAT?

Patient: No.

INT: NO, THAT'S GOOD.

Patient: I go back at the end of August for the consultation ...

Daughter: He did say, didn't he, chemotherapy would be completely over the top, [chuckles] that was the word he used.

INT: WELL THAT'S GOOD, THAT'S GOOD NEWS, NOTHING WRONG WITH THAT.

Daughter: Yeah.

INT: THAT'S VERY GOOD NEWS. ERM, THINKING ABOUT THE ACTUAL SURGICAL OPTIONS, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE YOU WANTED IN TERMS OF SURGERY?

Patient: Yes.

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

Patient: There were probably various things.

INT: MM, YEAH, WHAT WOULD THEY BE?

Patient: The first one thinking about my aunt ...

Daughter: Who had had the mastectomy.

Patient: Yes. The second was that I knew that that was what I wanted to do anyway, whatever I'd read about other people or what they had done, I knew that that was my, that was the choice that I wanted to do. Erm ...

Daughter: You thought of it as a bit of back-up, didn't you? Sort of they remove the whole breast, you thought there was less chance of something re-occurring, well obviously no chance in that breast. [chuckles]

Patient: Yes. Also I did have the option. I mean I've since spoken to people who've had mastectomies and one person in particular found it very difficult to cope with, but they didn't have the choice.

INT: RIGHT.

Patient: They did have to have it.

INT: [???

Patient: Yeah, now my case is very different because you had got the choice and you made the decision yourself, alongside Mr Chadwick, but I mean he didn't push you either way.

Daughter: No. And also the radiotherapy was a little bit worrying you, weren't it?

Patient: Yes, yeah. Plus, it was as if, once I'd done that, it would be done and dusted. It would be sorted, whatever the result was at the end of the day, you'd sort of ...

Daughter: You would have done the, the big thing, as opposed to whereas sort of now you'd still only be a week or so into your radiotherapy, wouldn't you?

INT: OH YEAH [???

Daughter: [???

Patient: I kept thinking it would be the end of the August and you would still be going for treatment.

INT: RIGHT.

Patient: And to me that was just something that I didn't really want to think about.

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

Patient: The care has been ... well I can't fault the care really.

Daughter: Mm, [???

Patient: In any way.

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

Patient: Yes.

INT: IS THERE ANY PART OF THAT CARE THAT DIDN'T MEET YOUR EXPECTATIONS IN ANY WAY?

Patient: No.

INT: NO?

Patient: No.

INT: NO?

Daughter: The nursing staff on the ward were very good, weren't they?

Patient: Yes.

Daughter: The consultant was very, very good, Dr Chadwick.

Patient: The nursing staff as a whole were very good, I mean there were examples were some weren't quite as good as the others, but I really couldn't fault the care that I had, no.

INT: OH THAT'S GOOD. ERM, IF YOU WERE TOLD YOU HAD THE POWER AND THE MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE AS CHESTERFIELD, WHAT WOULD IT BE, DO YOU THINK?

Patient: To change something?

INT: YEAH, THE POWER AND MONEY TO CHANGE ONE THING AT THE BREAST SERVICE THERE?

Patient: ... That's difficult for me because I've got a good scenario ending and, as I say, everything went well for me. Maybe - and this is really way, way down the line, it's nothing to do with the health care or anything like that but - simply waiting to go in, as you were, was in a very confined space and you ...

INT: WAS THIS TO HEAR YOUR RESULTS, BEFORE ...?

Patient: Yes.

Daughter: In Mammography at Chesterfield Hospital, the actual Mammography waiting room, you're talking about.

Patient: Yes, yeah. And also you were, it became apparent more after sort of probably the second visit, but you were sitting with people that either were at the same stage as you or could have been waiting for the final result, but you didn't know that, that there was people waiting for that. When I went back for that final result you'd got people who were on the first stage of having the first mammogram or the ultrasound or whatever, and maybe in that way that could change. But ...

Daughter: I was, you know, that's one thing I'd say as well, that sort of settle[?]. The waiting room itself was very small and at times people couldn't sit together with their partners or the person they'd brought, which was, I mean I don't know what they could do about that, because it is the building, isn't it?

INT: YEAH.

Patient: Yeah, that sounds so mundane, though, for an answer to the question that you've just asked.

INT: NO, ANYTHING YOU WANT REALLY.

Patient: But that is the thing for us.

Daughter: I mean I, one thing I'd like to say is like the waiting, if you had the power and money, the waiting times between each consultation you could reduce that perhaps but, having said that, I think you found it quite valuable to have that bit of time between each stage ...

Patient: Yes.

Daughter: ... if you'd have gone back, sort of say if you went privately perhaps you'd go back within a couple of days ...

Patient: Yes.

Daughter: ... I don't know whether that would have been quite enough time for things to sink in from the first stage.

Patient: Yes, you needed enough time to think things over and so ...

Daughter: So I don't know if I shouldn't change that.

Patient: ... and certainly I mean the time schedules that I went through within, what, a month you'd had the diagnosis and you'd have everything done, so you couldn't really have said that you wanted it any quicker anyway.

Daughter: No. Well I suppose one ... can I just say one more thing [chuckles]?

INT: YEAH.

Daughter: One thing you would change if you'd got money would be to get a radiotherapy thing at Calow Hospital.

Patient: Yes.

INT: OH RIGHT.

Daughter: Therefore you could have travelled much easier.

Patient: But that, again, I don't think would have made me have the lump removed ...

Daughter: Oh, [???] no.

Patient: I would still have had the mastectomy, but that ...

Daughter: Yeah, but it would have helped.

Patient: Yeah.

INT: RIGHT, OK. THAT'S FINE. MONEY WELL SPENT. [CHUCKLES] NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW FIRST ABOUT THEIR DIAGNOSIS?

Patient: They need to know the options that are available with the diagnosis and I think they need to feel, well I don't know ... to me it was important to feel comfortable talking to the consultant, but I suppose in the first meeting you don't have that anyway, that only builds up as you go through.

INT: YEAH, THE RAPPORT YOU FEEL WITH THE PERSON.

Patient: Yes, yeah.

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

Patient: I think it's important to know that ...

Daughter: The success rate.

Patient: Yes, the success rate is, you need to know that, don't you?

Daughter: Because we did ask that purposely, didn't we? Well, no, we didn't, we asked how many people went, because with Mum having the choice, how many people

had the choice of mastectomy, how many people chose to have a mastectomy and how many chose to have the lumpectomy, and he said 'Oh 50 per cent ...

Patient: Fifty-fifty.

Daughter: ... either way.

INT: RIGHT, OK.

Patient: Which we thought the mastectomy would be lower down the scale, so again, you know that was ...

Daughter: That was, [???] I think that's important and the success rate.

Patient: Yes, yeah.

Daughter: And perhaps, what do you think, the long-term effects of it? Such as if you had the lumpectomy the chances of it coming back in the same breast, whether, everybody's got a different type of disease, you know, whether it ...

Patient: Yes, yeah.

Daughter: I don't know, you know, the nitty-gritty of it, but whether they could say ...

Patient: And also I think it is important that you know a little bit about, well really just the hospital procedure and things, if you haven't been in hospital before, because that was one of the worrying things for me, as I say, you know, the anaesthetic and things which again all sound very silly when you compare it to the fact, you know, that you've gone in for a cancer operation, but I think you do need to feel ... well at ease with ...

INT: YEAH, COMFORTABLE [???] ...

Patient: ... with the situation.

INT: ... WHAT'S GONNA HAPPEN.

Patient: Because then that makes you feel a lot better anyway, and also, you know, when you're getting better it [???]

INT: MM, I THINK, YOU KNOW, ONE OF THE, I THINK THE THING THAT FRIGHTENS EVERYBODY REALLY IS THE UNKNOWN.

Patient: Yes.

INT: THEY'RE FRIGHTENED OF THE UNKNOWN, YOU KNOW, BECAUSE IT'S SOMETHING THAT'S OUT OF YOUR CONTROL ALMOST.

Patient: Yes.

INT: YOU KNOW, IT'S JUST A THING OVER THERE THAT'S GOING TO HAPPEN AND HOW AM I GOING TO GO THROUGH IT, REALLY.

Patient: Yes.

INT: AND I THINK THAT FRIGHTENS, UNKNOWN CAN BE ANYTHING FOR ANYBODY.

Patient: Yes.

INT: IT'S A VERY TERRIFYING THING, I THINK.

Patient: Yeah. But then we again were talking the other day, weren't we, and we were saying the person going through it, such as me, you do take each step because each step does have to be taken, as it were, so 'Yes, this is it, this is what I'm doing next week, this is it,' whereas for the person who's with you just looking at you, they have this feeling of, well as you say the unknown really and ...

Daughter: I mean I think our attitude throughout it all, me and you, and Dad [chuckles] was sort of everything they told and when you came away from the hospital after each visit it was like, 'Right, what've we got to do about it? What's the next stage?' It wasn't sort of dwelling on 'Oh my God, there's something wrong,' what could be ... we weren't really having those feelings, were we?

Patient: No.

Daughter: It was more, 'Well, all right, what's the next step? How are we gonna prepare you for the next step?' and 'How are they gonna do it?' not such as, you know, all the things that we thought you might dwell on before this ever happened to us.

Patient: Yes, yeah, when you're actually in the situation you do tackle it ...

Daughter: Yeah, you cope with it and it's ...

Patient: ... and it's differently.

INT: MM. AND I MEAN YOU MENTIONED YOUR DAD, YOU KNOW, YOUR HUSBAND, HOW HAS HE BEEN THROUGH ALL THIS?

Patient: He's been fine [chuckles] apart from the fact that he's also quite squeamish.

INT: OH RIGHT.

Patient: But, again, I've relied a lot on Victoria simply because she's been here. I mean Nigel is self-employed so as regards sort of work schedules and things it's been easier for Victoria to say, 'Well I'll come with you to the hospital,' or whatever, erm, and ...

Daughter: He's never actually had any contact with the doctors ...

Patient: No, he hasn't.

Daughter: ... although he did come and visit you obviously. [chuckles]

Patient: [chuckles] Obviously.

Daughter: But he isn't very good with hospitals, is he?

INT: OH RIGHT.

Patient: No, but ...

Daughter: Well, no, I've always been with her first.

Patient: Yes, yeah.

Daughter: But he's coped OK I think, hasn't he?

Patient: Yes, yes. In I mean a very different way obviously but, yes, yeah.

INT: FINAL QUESTION IS, ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED, ANY IMPORTANT POINTS THAT WE HAVEN'T GONE OVER?

Patient: ... No, I think probably you've sort of covered everything. Maybe in a week's time you'll think, 'Oh, I wish I'd said that,' but I mean ...

Daughter: I think that one thing that sticks in my mind is how important as an onlooker it was for them to tell us their true perceptions of what was going on because they, like I say, they always said about the size of the lump and that was helpful, and the fact that the lymph nodes didn't feel inflamed, and that was really important I think, and they did say those th- ... I mean they couldn't obviously confirm any of that ...

INT: NO, NO, OF COURSE.

Patient: It was very important to you that was, wasn't it?

Daughter: Yeah. I was worried about sort of longer down the line, thinking probably further ahead than ever you were.

Patient: Yes, I think I was more concerned with well, what's happening this week ...

Daughter: What's the operation.

Patient: what's happening next week, yes, yeah.

Daughter: So, yeah.

INT: OK, I'LL TURN OFF THEN.

[End of interview]