

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE: 18/11/2004

*ID: Patient17

*INTERVIEWER: DJW

INT: FIRST OF ALL, THANK YOU FOR AGREEING TO BE INTERVIEWED. I'D LIKE TO START NOW 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? SO WHAT WAS YOUR EXPERIENCES PRIOR TO THIS?

Patient: Prior to my experience was fear really ...

INT: MM, RIGHT, YEAH.

Patient: ... because of, of my sister.

INT: YEAH.

Patient: Erm, my sister had a mastectomy, erm, and sadly we did lose Anne because it spread to her bones and various other parts of her body, but, erm, she, we never really went into depth, I never dare look at her scar or anything.

INT: RIGHT, OK.

Patient: Because it was fear, you know, and for many years I ... which I still do examine myself, but it became a bit of a phobia and both me and my sister both said at the particular time that we both slept in us bras because we daren't take them us bras off because ...

INT: [???

Patient: ... yeah, because of, of, you know, actually finding something.

INT: YES.

Patient: We think, we thought because we'd got us bras on we might have got a little bit of the security. So really, fear more than anything else of breast cancer. Knowing that a lot of people survived but an awful lot of people also died through it.

INT: MM. SO IT WAS THIS FEAR, WAS IT THE ASSOCIATION OF POTENTIAL DEATH ...

Patient: Yes.

INT: NOTHING TO DO WITH THE OPERATION [???] ...

Patient: Nothing to do with the operation or anything, just ...

INT: 'COS IT IS A VERY STRONG LINK TO THAT WORD, ISN'T IT?

Patient: It is.

INT: YEAH.

Patient: It is, because I know, you know, with my experience now, you know, people, their face, they don't have to say anything, you know, and everybody presumed I'd had a mastectomy, you know, they didn't ... obviously we're all [??] and we don't know that there is other options for people to have. So ...

INT: RIGHT, OK. SO YOU SISTER HAD IT, DID ANYBODY ELSE IN YOUR FAMILY HAVE BREAST CANCER, DO YOU KNOW? [??]

Patient: I had, I had two cousins: one cousin like on my Dad's side which is quite a strong, er, link with the diseases; the other with my cousin and her Mum had ovarian cancer, which is like another blood line sort of thing. Both survived, both still surviving, er, one had a mast-, they both had mastectomy, one's just had reconstruction.

INT: RIGHT, OK.

Patient: So, but, both, both surviving at the moment.

INT: RIGHT, OK. AND HOW LONG AGO WAS THAT, DO YOU KNOW?

Patient: Ooh, Carole must be a good eight years and Jan, I'd say she must be about four years.

INT: RIGHT, OK.

Patient: Yeah.

INT: AND YOUR SISTER, WHEN WAS THAT AGAIN? JUST REMIND ME.

Patient: My sister was, it must have been late '80s.

INT: LATE '80S?

Patient: Yeah.

INT: OK. AND WERE THEY ALL IN THE CHESTERFIELD AREA OR WERE THEY ...

Patient: Yeah. Oh, er, except for Jan who lived, well Jan's a bit of an adventure girl, she goes quite, sailing on a boat, you know, and that, but she is based down south.

INT: RIGHT, OK. OK. AND WHAT ABOUT FRIENDS, WORK COLLEAGUES, ANYTHING LIKE THAT? HAVE THEY, DO YOU KNOW ANYBODY WHO'S HAD BREAST CANCER IN THAT RESPECT?

Patient: I have, but I don't know if it's something, because you sort of blank it out in your mind, but when you hear that, you know, obviously, you know, you're there for them sort of thing, er, but it's never been anyone what's been really close.

INT: RIGHT.

Patient: Who I've worked with. It's all been I've heard about it, you know, sort of thing, so, no, it's not been, it's not been here.

[Interruption for telephone call]

INT: OK. SO, CAN YOU JUST TELL ME SORT OF HOW YOU CAME TO FIND OUT THAT YOU HAD BREAST CANCER, I KNOW WE'VE SPOKEN A BIT EARLIER BUT IF I CAN GET IT ALL DOWN ON THE ...

Patient: It's OK. Erm, I'm 50 in two weeks and so it was my routine 50th mammogram and I went to the Primary Care Trust in Chesterfield and had a mammogram, OK, and they said if you didn't hear anything within four weeks to get in touch with them. And four weeks passed and I didn't hear anything so I just rang them up and they said that, erm, they'd found, they'd send my results on in a couple of days. Er, when they did, I had the letter come and it said that I'd got to attend Chesterfield Royal for a further mammogram, and I attended the clinic and had a mammogram and a biopsy and ultrasound.

INT: RIGHT.

Patient: Er, there was definitely something there, obviously it had got to go to be analysed so it was a week's wait sort of thing, and, erm, when I did go back the consultant told me that the findings were malignant.

INT: RIGHT, OK. SO WHEN YOU GOT THE LETTER TO GO BACK, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: I just tho-, it told you in the little leaflet what came with it that so many have to make a second visit, you know, and I thought ...

INT: THAT'S RIGHT, YEAH.

Patient: ... but at the same time, er, I go to reflexology and for some time, Brian, my reflexologist, had been picking toxins up on my left breast.

INT: RIGHT, OK.

Patient: And I, and when she said to me, when I went back and she said to me, 'It's your left breast,' I just said to her, 'Well I'm not surprised,' and she says, 'Why, have you had symptoms?' I says, 'Well, no,' I said, but I told her that, and I also have been very tired.

INT: RIGHT.

Patient: And I'd gone to the doctors, asked if I could have a sugar test or, you know, 'cos I says, 'I just feel so tired, as though something's not quite right with my body.' So, you know, and with the reflexology, I mean, I'm a big believer in alternative medicine, you know, if you can help yourself, go and do it.

INT: MM, ABSOLUTELY.

Patient: Yeah.

INT: RIGHT. AND HOW LONG HAD THIS BEEN BEFORE YOU FOUND OUT ...?

Patient: This had been a good year before, but like Brian said, they're toxins, you know, and this is what reflexology's all about, you get rid of toxins in your body, and so never really put much, because I'd got no symptoms, you know ...

INT: YEAH, OF COURSE, MM.

Patient: And the lump, erm, when it was actually found, was so small that Mr Holt examined me but he said he couldn't find it. So obviously by the time it was big enough to find, we would have gone on, you know, progressed on with the ...

INT: YEAH, OF COURSE. AND WAS, WAS THAT IN THE LEFT BREAST, WAS IT?

Patient: Yeah.

INT: YES, RIGHT, OK. ERM, SO YOU WENT BACK FOR YOUR, YOU WENT FOR THE MAMMO-, THEN YOU WENT FOR THE MAMMOGRAM, IS THAT RIGHT?

Patient: Mm.

INT: CAN YOU TELL ME A LITTLE BIT MORE DETAIL ABOUT WHAT HAPPENED WHEN YOU WENT THERE, FROM WHEN YOU WENT IN AND ... TRY AND SORT OF WALK ME THROUGH IT.

Patient: When I went in, yes, I was asked, my friend went with me from work, and when we went we was asked to wait in the clinic and then I was asked to go into the, to the room. And the, the lady told me, she said, 'Well, you know, we have found something on the plate,' but obviously until they've done further tests they can't tell what it is. And I just got myself worked up to such a state that I fainted.

INT: OH.

Patient: Yeah. And the crash team was on standby and this, that and 't other, and everybody was going a bit berserk, [chuckles] you know, I just worked myself up to such a state ...

INT: RIGHT, OK.

Patient: When I came round obviously I had to have the mammogram and, erm, and then I went back, sit in the waiting room, and then, then I had a ultrasound biopsy. I was fine through that, [chuckles] it was just the fact, the thought, and I don't know why, you know, just the thought of the fear of, of the mammogram again.

INT: AHA.

Patient: But, er, after that I was fine, you know, I'd a dressing, put the dressing on and things like that, but, but, er ... I was OK.

INT: YOU WEREN'T FRIGHTENED OF THE BIOPSY, BECAUSE I THINK YOU SAID EARLIER, BEFORE WE STARTED RECORDING, THAT YOU SAW YOUR SISTER HAD A BIOPSY, IS THAT RIGHT?

Patient: When I had, things have progressed so much, but when I went with my sister, Anne, it was at the Chesterfield Royal and, er, she was in the room having the biopsy and I was sat outside and they called me in and I was quite shocked to see Anne sat there with blood oozing down her breast ...

INT: RIGHT, YEAH.

Patient: ... you know, obviously, erm, did they just take the biopsy out, you know, it's just so different now, that you go into a darkened room, erm, and you lay down, and there's someone there to reassure you.

INT: RIGHT.

Patient: You know, and the ... whether it was a man or a woman who does it, actually does it, but he was very, very kind, you know, and he calmed you, calmed you sort of thing. Whereas Anne it had all seemed very bright and rash, you know, sort of thing, and with the sight of the blood actually.

INT: YEAH, SURE, OF COURSE.

Patient: So, and they were on all finding out who the patient was because we both looked terrible when we came out of there, you know.

INT: RIGHT, OK.

Patient: Not a very good person to take anywhere me. [chuckles] But, erm, yes, and so when, when they said biopsy obviously that flashed through my mind, that, you know, 'Oh, I remember that.' But you're thinking back, well this is over 10 years ago, you know, 15 years ago, what's it gonna be? And it wasn't as bad as what I actually thought, erm ... certainly not on the scale as what Anne went through. But, like I say, everything is progressing, everything.

INT: MM. SO YOU HAD YOUR BIOPSY AND THEN WHAT HAPPENED AFTER THAT?

Patient: When I had my biopsy, erm, I had to wait obviously another week. I went to see, went to see the consultant and he explained that, er, the tissue sample would be sent away.

INT: RIGHT.

Patient: And they'd make me an appointment to come back in a week's time for the results.

INT: WHICH CONSULTANT WAS IT?

Patient: Mr Holt.

INT: MR HOLT, YEAH,.

Patient: Yeah, yeah. And he's very nice and very understanding, er, and the breast cancer nurse was there as well and they both introduced themselves to me before I'd gone in actually, Donna and Mary, and they gave me their direct phone number and said that I could get in touch with them at any time, if I'd got any worries or anything what I didn't quite understand, because I think sometimes when you're going through something like that, you're there but you're not, because you think, 'This is not happening to me, this one, this is somebody else,' you know, 'and they must have got me mixed up or something.' My husband was with me, Dave, and he, well he listened for me 'cos I always says four ears are better than two, and, you know, if I, and I say, 'Did he say that?' you know, and I might not have heard it because, well it's shock more than anything else.

INT: OF COURSE.

Patient: So, but, Mr Holt did explain that the results would be back in the week, and they was.

INT: RIGHT, OK, SO YOU HAD A WEEK THEN FOR YOUR RESULTS?

Patient: Yeah.

INT: I MEAN HOW WERE YOU DURING THAT WEEK WHEN YOU'D HAD YOUR BIOPSY AND THINGS?

Patient: I wasn't too bad actually because I think heart in heart's sake, you just think, 'Well, I don't think there's anything like that a matter with me,' you know, 'I think I'll be all right.' Er, obviously, a bit anxious and can't wait for that actual week to pass, er, which, which it did, it passed very quickly and Dave and I went back to the, to the Royal for the results.

INT: MM, IN THAT WEEK DID YOU TALK TO ANYBODY ABOUT, YOU KNOW, WHAT YOUR FEARS MIGHT BE OR WHAT THE RESULTS YOU THOUGHT MIGHT BE, OR ANYTHING LIKE THAT?

Patient: I didn't because I'm a sort of a person that, some people say it's my way of dealing with the situation, but, having survived cancer, I never mention the word cancer. Erm, you know, to me, erm, it wasn't a ... it wasn't happening to me. I spent five weeks in Weston Park when I was 25 and, you know, and I don't think we ever mentioned that word, although it was a cancer hospital, and when other people say, you know, 'You've had an operation for breast cancer,' then, you know, you think, 'I haven't, haven't I?' You know, 'Yeah, yes, I have yeah.

INT: [???

Patient: Yeah, yeah. So I spoke quite a lot to my sister who lives just round the corner from me, my other sister, and she kept, you know, everybody just kept saying, 'You'll be all right. There's nothing up with you, you'll be fine.' You know, and that's how we went along with it.

INT: RIGHT, OK.

Patient: Yeah. But people say it's my way of dealing with it.

INT: THAT'S FINE, YEAH.

Patient: Yeah.

INT: ERM, AND THEN YOU WENT BACK TO HEAR YOUR RESULTS, CAN YOU JUST TELL ME A BIT MORE DETAIL ABOUT WHAT HAPPENED THERE?

Patient: When I went back for my results, there was Mr Holt and the breast cancer nurse there, and Dave and myself, and, erm, he just, he came out, straight out with it, sort of thing, you know, sort of thing, he said, 'We've got your results back from your biopsy and it was malignant.' Well you just look at him then, you're thinking, 'It's malignant ... right. That's bad, that,' [chuckles] you know, 'That's bad, it's not good, that.' And, erm, he said the tumour was small, er, and that he said that, he virtually, he told me that it could be removed through a lumpectomy. And I was quite relieved and I told him so, and I told him what had happened, you know, with my sister and I said, 'People never got the chance of how they was having this operation,' and I'm not that sort of person who'd say to you, 'Well, take it off, I don't want it any more,' you know, 'Just get rid of it.' To me I was quite relieved that he was giving me that option.

INT: RIGHT, OK.

Patient: But, at the end of the day, I would have gone along with anything he'd said, because I knew that whatever he suggested would be for my own, my own good.

INT: YES, YEAH.

Patient: Because, with it being on my left hand side, there was a question of would they be able to do radiotherapy afterwards because it's near to my lungs and my heart.

INT: OF COURSE, YEAH.

Patient: Erm, what would happen? So then, erm, an appointment was made with the oncologist, yeah?

INT: ONCOLOGIST, YEAH, MM.

Patient: To see where the actual tumour was positioned, to see if I could have radiotherapy afterwards actually just to determine if a lumpectomy was going to be possible.

INT: RIGHT, OK.

Patient: Yeah. So I said, you know, 'Whatever, whatever goes, I'll go along with it,' but at least they know that I just didn't want a mastectomy if possible.

INT: MM. SO DID THEY, DID THEY MENTION MASTECTOMY AS WELL, DID THEY?

Patient: They mentioned the mastectomy, yes, because of where it was positioned ...

INT: RIGHT.

Patient: ... and whether it was going to be, he was going to be able, he drew little drawings, diagrams for me to show me actually where it was, er, and then made an appointment for me to see Mr [??] from Weston Park, for him to examine me to give the final verdict.

INT: OK, RIGHT.

Patient: Yes, which was good. Yeah.

INT: MM. SO HOW SOON AFTER THAT DID YOU SEE MR [???]?

Patient: It was only, I'd say it was only about four days after that, 'cos I suppose they needed to know, you know, what they was gonna actually do, because, although, you know, they keep saying, 'Well come back next week' and 'Come back next week,' these weeks mount up sort of things, and you need to get something moving, er, and the prognosis was very good from him, who said, erm, you know where it was positioned they would be able to do the lumpectomy.

INT: RIGHT, OK.

Patient: Which you sort of go, 'Phew' you know, because ... I still can't get through, through this thing that having a mastectomy is like mutilating someone, you know, is ...

INT: THAT'S HOW YOU FEEL?

Patient: That's how I feel.

INT: YEAH. RIGHT.

Patient: Yeah. And this is the thing again, you know, some people may just say, 'If you get rid of it everything'll be over then.' But, no, I didn't think, I don't think like that. And if you can save it, save it.

INT: RIGHT, YEAH. SURE.

Patient: So ... yeah.

INT: OK. SO, YOU WENT IN, YOU SAW, ERM, MR HOLT, AND HE MENTIONED THAT THE TUMOUR WAS MALIGNANT AND STUFF, ER, AND THEN HE TALKED TO YOU ABOUT TREATMENT OPTIONS, MASTECTOMY AND THE WIDE LOCAL EXCISION, THE LUMPECTOMY ... AND THEN, SO WHAT HAPPENED IMMEDIATELY AFTER THAT?

Patient: Immediately after that I just kept agreeing with him, [chuckles] you know ...

INT: [???]

Patient: He was saying things and I just kept ... 'Yeah, yeah,' sort of thing. And when the sort of the consultation had finished, erm, I was left with the, with Donna, the breast cancer nurse and she took me into a small room, which was like, you know, with a box of tissues, I suppose it's like a little relatives' room or something like that. And then she went through if I'd understood everything he'd said to me. Did I understand my options? Did I understand what, erm, you know, what he'd actually said to me, you know, about the tumour and how big it was and this, that and 't other, you know? They'd got a rough idea and that, and I just found it all very helpful because we, both myself and Dave both walked out there like in limbo sort of thing, because you'd had all things thrown at you and then you'd got to go home and tell your family, you know ...

INT: RIGHT, SO DID YOU FEEL THAT YOU UNDERSTOOD WHAT HE'D SAID, THE CONSULTANT, ABOUT THE OPTIONS AND THE CANCER?

Patient: I did, I understand, you know, where he was coming through, I think in 't back of my mind really I was more relieved that there was a chance I could have a lumpectomy instead of having a mastectomy ...

INT: RIGHT, YEAH.

Patient: ... er, and he did say that it was small, it was found early, obviously through the, you know, the mamm-, ...

INT: SCREENING.

Patient: ... the routine mammogram, and I just count myself very lucky because when I had cervical cancer it was found through a smear test.

INT: RIGHT, OK.

Patient: So, if you're gonna have it once, have it once, if you're gonna have it twice, you might as well find it early again.

INT: AH, YEAH.

Patient: You know, and, and survive, sort of thing.

INT: YEAH. I THINK THE SCREENING PROGRAMME'S GOOD REALLY.

Patient: It's excellent.

INT: MM, IT PICKS THINGS UP EARLY, DOESN'T IT?

Patient: Because there must be so many people what are walking round who, with things what obviously they don't know they've got.

INT: YEAH, SURE.

Patient: So ...

INT: AND YOU SAID THAT WHEN HE WAS TALKING TO YOU ABOUT THE, ER, THE CANCER AND THE TREATMENT AND THINGS AND HE DREW SOME DIAGRAMS? IS THAT RIGHT?

Patient: Yes.

INT: DID HE USE ANY OTHER VISUAL AIDS SUCH AS MAMMOGRAMS? DID HE USE ANY PICTURES OR ANYTHING LIKE THAT?

Patient: He showed me the plate.,

INT: THE MAMMOGRAM?

Patient: and he showed me ... yeah, with the, it was like a flying saucer and the some more tiny ones grouped round it sort of thing, er, and he did show me where they were. Erm, after that, you know, it was just like, we've got ... everything was sort of left up in the air because of finding out how it was position.

INT: YEAH, BEFORE YOU SAW THE ONCOLOGIST?

Patient: Yeah.

INT: YEAH.

Patient: Yeah. So that's, that's where we'd left us, sort of thing.

INT: RIGHT, OK.

Patient: Yeah.

INT: AND, ERM, WHEN HE ACTUALLY SORT OF CONFIRMED THAT YOU HAD BREAST CANCER, I MEAN WHAT WERE YOUR FEELINGS AT THAT POINT? WHEN IT HAD BEEN CONFIRMED?

Patient: Fear again, once again, you know, and, erm, I don't think I actually asked Mr Holt, but I certainly asked the oncologist, I said was I going to die? And he said, 'I can't tell you that,' he said, 'because none of us know when we're going to die,' you know, so, but the breast cancer nurse just said, 'Course not!' you know.

INT: WHO WAS THAT THEN?

Patient: The breast cancer nurse.

INT: YEAH, WHICH ONE, DO YOU KNOW?

Patient: I think it was ...

INT: IF IT'S A YOUNG ONE THAT'S DONNA ...

Patient: It was Donna I think.

INT: YEAH?

Patient: Yeah, because ...

INT: TALLISH, DARK, SHORT HAIR,

Patient: Yes, she is [???

INT: SLIGHTLY PUNKY SORT OF LOOK.

Patient: Yeah, yeah. And she says, 'Course not!' And I says, 'No, I'm not,' I says, 'I refuse,' I says, 'You're not getting rid of me that quick.' And so, but, yeah, fear, fear of the unknown really, you know, fear that I'd got to go in hospital to have an operation and I don't like them. [chuckles]

INT: NO, RIGHT. [CHUCKLES] ERM, SO YOU'D BEEN TO SEE THE CONSULTANT AND YOU HAD SOME TIME WITH, WAS IT DONNA YOU SAID AFTERWARDS?

Patient: Yeah.

INT: YEAH. AND, ERM, DID SHE GIVE YOU ANY FURTHER INFORMATION, ANY WRITTEN INFORMATION, ANYTHING LIKE THAT?

Patient: I'd got, I got a pamphlet telling me about the procedures what I'd actually had done, you know, the biopsy and the ultrasound, and then I was given a leaflet on breast cancer itself, you know, just to sort of basic highlights, you know, what the next procedure was going to be.

INT: RIGHT, OK. YEAH.

Patient: But it's a very friendly unit and ... you certainly don't, you're not alone, let's put it that way, and the amount of people what are actually at the unit, you know you're not alone, you know, people must be diagnosed, obviously diagnosed every day and, er, it's not nice.

INT: YEAH, SURE. ERM, AND THEN THOSE LEAFLETS AND PAMPHLETS, DID YOU READ THEM?

Patient: I did read them, yeah.

INT: YEAH. DID YOU FIND THEM USEFUL IN ANY SORT OF WAY?

Patient: Yes, I did actually. Er, and especially the leaflets, when, erm, when you're entering, going to be entering hospital, you know, actually, er, the procedure then sort of thing. It's in like stages of what's going to happen to you when you actually go into hospital. Because the one thing about having a lumpectomy, which wasn't very pleasant, was that, just before you actually go down for surgery, you have to go down to have a wire inserted ...

INT: OH, A NEEDLE MARKER, MM.

Patient: Which wasn't very ... I nearly fainted again as well then. No, I ended up on 't floor again.

INT: OH DEAR.

Patient: But, er, I just get myself worked up to such a pitch, and I can't help. And, er, I think that was worse than the operation really, that was definitely, but all this, you know, it's like, it is explained to you, but obviously some's going in and some's just going straight over your head because it's not happening to you, it's happening to someone else.

INT: YEAH, OF COURSE. A LOT OF PEOPLE REPORT THE SAME THING WHEN THEY GET, ESPECIALLY WHEN, ESPECIALLY WHEN THEY'VE JUST BEEN DIAGNOSED.

Patient: Yeah.

INT: THAT, ERM, YOU KNOW, THEY FEEL IT LIKE, THEY'VE BEE, LIKE IT'S DROPPED, A ROCK DROPPED IN WATER AND EVERYTHING ELSE IS SORT OF SWIRLING AROUND THEM AND THEY'RE JUST OF LIKE, 'WHAT'S HAPPENING?'

Patient: Yeah, because obviously the consultants, they're as open as they possibly can, and they sometimes, I sometimes think, 'Wow,' you know, 'Don't beat about 't bush, mate, just get in there with it.' And that's what they do, they just go for it.

INT: MM. AND, ER, JUST MOVING ON NOW, SORT OF, SO YOU WENT TO SEE THE ONCOLOGIST AND HE GAVE YOU, IT WAS OK TO HAVE THE LUMPECTOMY.

Patient: Lumpectomy.

INT: AND SO HOW SOON AFTER THAT DID YOU HAVE YOUR OPERATION, OR DID YOU GO BACK AND SEE MR HOLT OR WHAT?

Patient: I don't think I went back to see Mr Holt after that because I got the results in July, I had the actual operation, er, August 20th, so in the four weeks sort of thing things were happening each week, you know, sort of thing, er going to see the oncologist and then the assessment, pre-assessment and things like that, so it all came round pretty quick, and, you know, back of your mind all you're thinking is that as soon as this thing is removed, soon as you can get on with the rest of your life, sort of thing. So it was all pretty quick after that, and the actual date for the lumpectomy was August 20th.

INT: RIGHT, OK.

Patient: Yeah.

INT: SO, AND DID MR HOLT DO THE OPERATION, DID HE?

Patient: Yes, he did. Yes. Like I say, he'd had, I did sign, and you actually - that was another thing as well - at one time I would think that when you signed for an operation, that you actually signed for, if the surgeon goes in and finds things have advanced, that you sign for extras ... do you know what I mean? ... but you would have signed for a mastectomy if they were ...

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

Patient: ... but you don't now.

INT: NO.

Patient: No, you sign, you get what you've signed for and I think that means that you're in control, erm, you don't, erm, he did a diagram, he showed me the diagram, he showed me what he was going to do, he showed me how the marker was going to be inserted, and then where the scar was going to be and the lymph nodes as well. And, er, he, it was all very, very good the way he actually ... and I signed for what I was gonna get - not that when he got in there things could have been advanced and he might have to do a mastectomy, because it's the first thing you do when you wake up from surgery, you feel if you're still whole, you know, because you think ... but no, you are, I feel in that way you are still in control ...

INT: RIGHT.

Patient: ... of your, of the actual proceedings. Well if things have to go on from that. And he also told me about the margin.

INT: RIGHT.

Patient: Where the, what they would take and he said that, and he really, he says 'Nine out of ten, and I mean nine out of ten people we get the sufficient margin,' he says, 'but sometimes we may have to do the procedure again,' you know, to get more tissue. But thankfully in my case he didn't have to do because he got enough.

INT: MM. OH THAT'S GOOD THEN. SO DID YOU GO TO ANY KIND OF PRE-ASSESSMENT CLINIC, DID YOU?

Patient: Mm.

INT: YEAH? CAN YOU TELL ME ABOUT THAT PLEASE, WHAT HAPPENED THERE?

Patient: I went to the pre-assessment clinic at the Royal and, er, you're weighed and have a blood test and, erm, and then you have a little chat with the nurse about, about your history, obviously ...

INT: IS THIS THE CLINIC NURSE OR THE BREAST CARE NURSE?

Patient: This is the clinic nurse.

INT: THE CLINIC NURSE, RIGHT.

Patient: Yeah. The clinic nurse, she asks you questions about, er, past illnesses and things like that, then you go and see I would say a junior doctor who examines your chest, makes sure everything's OK, you know, what medication you're on if you're on any. Er, and then we was asked to go back and sit, and then we saw Mr Holt again.

INT: OH, WHAT, AT THE PRE-ASSESSMENT?

Patient: Yeah, yeah.

INT: OK.

Patient: We saw Mr Holt and he just confirmed that everything was going to go as planned and that, you know, he would see me again in the theatre.

INT: SO WHEN DID YOU SIGN THE CONSENT FORM, DO YOU REMEMBER?

Patient: I think I signed the consent form at that actual appointment.

INT: AT THE PRE-ASSESSMENT, YEAH?

Patient: Yeah.

INT: SO DID HE, DID HE SAY, YOU KNOW, THIS IS WHAT YOU'RE DEFINITELY GONNA HAVE OR ...?

Patient: Yeah. It was all there, all the little diagrams were there, all my writing what he'd told me about, he told me what he was going to do and, erm, about the margin, about, erm ... whether it would have to be repeated, would be another, you know, something else to do, but, erm, I came out, because I did go on my own, and I felt as though I'd understood what he'd actually told me.

INT: RIGHT.

Patient: So I thought, 'That's a blessing,' because obviously [chuckles] I just get a bit lapse.

INT: YEAH, SURE. WELL I THINK IT'S, WHAT'S HAPPENING YOU'RE GETTING THE INFORMATION REPEATED.

Patient: That's right.

INT: SO AND EVENTUALLY, YOU KNOW, SOME OF IT [???] THROUGH TO YOU.

Patient: It sinks in. It sinks in.

INT: AND THEN A BIT MORE STICKS [?] THAT'S IT.

Patient: That's it, yeah.

INT: MM, [???] ERM, SO TELL ME WHAT HAPPENED ON THE DAY OF THE OPERATION WHEN YOU WENT IN FOR YOUR OPERATION?

Patient: The day of the operation I had to be there for eight o'clock and Dave took me in and he stopped with me quite a while and, erm, I had to wait then for the mammogram unit to like sort of open so that I could go down for the marker.

INT: OH RIGHT, OK, YEAH.

Patient: And, er, and I got undressed and I was sat on the bed, er, and then Dave left and about, I should say about 10 o'clock they came and fetched me from the ward, er, and took me down to the mammogram unit where I had the marker inserted, er, after a bit of a, you know, fainting [???] and, er, and went back up to the ward.

INT: RIGHT.

Patient: Where, they do sort of give you a rough idea where you are on the list, on the operating list, so how long's it actually going to be, how long you're going to be waiting. Er, was given a pre-med and waited sort of thing. I think it was about 12 o'clock that they actually came, came to fetch me, and Mr Holt was waiting for me in the, the anaesthetist's little place outside the operating, and he asked if I was all right, and, er, and that was it.

INT: MM, OK.

Patient: Sleepies.

INT: AND THEN WHAT HAPPENED WHEN YOU WOKE UP? HOW WERE YOU?

Patient: When I woke up, 'cos I always thank God that I wake up.

INT: YES, OF COURSE, THAT'S WHAT THE WOMAN SAID THIS MORNING.

Patient: Yes, I always say ...

INT: BECAUSE SHE WAS MORE FRIGHTENED OF THE OPERATION THAN THE CANCER.

Patient: Yes, yeah. And it was really weird because I shall never forget it because, er, when I woke up I fair wanted the nurse, because I was in the recover, still in the recovery, and I fair wanted this nurse to know that I was awake, you know, 'I'm awake, I'm awake,' and I'd got like this, my body temperature must have been that low that I'd like got this heater up the covers, and she was warming my body up with this heater, and I just said, 'I'm awake, I'm all right, I'm awake.' And it is, 'Thank God,' 'cos, you know, I mean, anaesthetic to me, God, I don't think you could be any nearer to death if you tried, really, you know, and I was so relieved that I'd actually come through this operation. It was only, well, a minor operation or not, but to me it was major. [chuckles] So I was awake and that's all that mattered, and got taken back up to the ward. Yeah.

INT: OH RIGHT. AND HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: Oh, only overnight.

INT: AH, [???] NEXT DAY.

Patient: Yeah.

INT: OK.

Patient: Yeah. And quite painful and I'd got a bit of a leak on, the one in my lymph nodes sort of thing, but, er, the stitching was going to be taken out by the district nurse, so I went back home the following day. Yeah.

INT: DID YOU HAVE ANY DRAINS OR ANYTHING IN, DID YOU?

Patient: No. No, drains. Er, and I was given an appointment to go back ... let me just think about this one ... I think it might, I think that was the following week, I just can't, can't remember that one, but to go back to find out what the next course, really course of action was, you know, to make sure that the tissue what they'd taken was sufficient for their, their examination.

INT: RIGHT, OK.

Patient: But, er, it was. But it turned out that the, the tumour was larger than what they thought and it was a stage three.

INT: RIGHT, OK.

Patient: And, erm, I've never been quite, I don't think I ever asked any questions about this stage three, because I think it speaks for itself.

INT: RIGHT.

Patient: Er, and ... through having cancer before, when I was in Chesterfield Hospital I was in like a stage three, but when I was admitted into Weston Park Hospital it was a different stage because they were more able to deal with the situation.

INT: OH RIGHT.

Patient: You know? Was it in the same stages or was it, it just seamt that, you know, and so, but when they said it was stage three and I thought, 'Well that spe-, actually speaks for itself,' and I think that's when I actually asked the bloke in the oncology if I was, you know, was I going to live.

INT: RIGHT.

Patient: Because of him telling me that.

INT: RIGHT.

Patient: But when I went back and they'd said that the tissue what they'd taken was sufficient and the margin was clear, that that was good, and all the lymph nodes were clear as well.

INT: THAT'S GOOD.

Patient: So that was good.

INT: YEAH, BECAUSE THAT MEANS IT HASN'T SPREAD?

Patient: That's right, yeah. So a big sigh of relief and, you know ...

INT: AND WAS IT MR HOLT THAT GAVE YOU THAT INFORMATION, WAS IT?

Patient: Mm.

INT: YEAH?

Patient: Erm ... now I have to think, because my mind sort of goes a blank after that one. Erm ... yeah. I'm sure it was, sure it was, it must have been Mr Holt. But then I had to go and see the oncologist again.

INT: RIGHT.

Patient: Who also told me ... and then it became known that, er, the tumour wasn't oestrogen fed.

INT: RIGHT, OK.

Patient: And, because it wasn't oestrogen fed, I knew I was going to have radiotherapy, erm, and I knew I was going to have chemotherapy, but as far as I was led to believe it was non-aggressive chemotherapy and I would keep my hair.

INT: RIGHT.

Patient: And when it turned out it was, it wasn't oestrogen fed, it meant I couldn't have Tamoxafen ...

INT: THAT'S RIGHT, YEAH.

Patient: ... as a follow-up, and also it meant I'd have to have quite an aggressive chemotherapy.

INT: RIGHT, OK.

Patient: He said, 'You may think it's ...' Mr Holt said, 'You may think it's very ... erm ... you've had a lumpectomy, the lumpectomy is clear, you know, the margin's clear, your lymph nodes are clear, now we're wanting to give you radiotherapy and chemotherapy ... but we've found out that it's beneficial to ladies of your age to have this and it was better for you,' so once again you go along, you know, with what they say and that, and that's what I did. But I've always said the biggest, when they told me that it was going to be aggressive chemotherapy and I was gonna lose my hair, that hurt me more than being diagnosed.

INT: MM.

Patient: I mean I've never had long hair and, you know, and that, but I've always done my hair, never gone out without doing my hair, and that, and I just sat there and I says to him, ' Well I shall want a wig,' [chuckles] you know, 'I shall want a wig.'

INT: THERE'S A LOT OF WOMEN SAY THAT.

Patient: Yeah, he says, 'Don't worry about it,' he says, 'We'll sort that out [???].

INT: YEAH, THERE'S A LOT OF WOMEN SAY THAT 'I GOT DIAGNOSED, I WAS PRETTY UPSET, SAILED THROUGH THE CANCER, SAILED THROUGH THE OPERATION AND HAD CHEMO AND LOST MY HAIR AND JUST FELL APART.'

Patient: Yeah.

INT: YEAH, BECAUSE IT'S ...

Patient: Yeah, sobbed my socks off.

INT: YES. YEAH, IT'S [???]

Patient: Yeah, really did. Didn't cry after I'd found, when I was diagnosed, but cried all round the hospital about I found I was gonna lose this itty-bit of hair. If I'd got long, flowing curls down my back I could understand it, but I hadn't. So it was gutting, really gutting.

INT: YEAH, SO [???]

Patient: Yeah, yeah. It's just your appearance, it's just how you feel at the time, isn't it? You know, your hair, really, if your hair looks a mess you feel a mess.

INT: MM. WELL PEOPLE SAY 'BAD HAIR DAY'.

Patient: That's right. I don't care now, just take it off.

INT: [???] IT'S PROBABLY NOTHING TO DO WITH YOUR HAIR ...

Patient: I just take it off. [chuckles]

INT: YEAH, EXACTLY SO. BUT, ER, I THINK ALSO IT'S LIKE AN OUT-, IT'S AN OUTWARD APPEARANCE SORT OF THING.

Patient: Yes.

INT: IT'S AN INDICATOR.

Patient: It's you, isn't it?

INT: YES, IT'S [???]

Patient: Definitely.

INT: ERM, SO, ER, SO WHERE, WHERE ARE YOU NOW IN YOUR TREATMENT PATH, WITH RADIOTHERAPY AND CHEMO?

Patient: My chemo now, I've just had my third treatment.

INT: YEAH. HOW MANY HAVE YOU GOT TO HAVE?

Patient: I've got one more to have.

INT: RIGHT.

Patient: On December 2nd. Then I've got like a month's break and then I go for my planning at Weston Park for my radiotherapy on 4th January.

INT: OH, THAT'S QUITE GOOD.

Patient: Is it really?

INT: [???]

Patient: [chuckles] Yeah. So I've got a little bit of a break and I've got Christmas so, er, to have a rest before I actually start the radiotherapy.

INT: [???]

Patient: Pardon?

INT: GET CHRISTMAS OUT THE WAY.

Patient: Yeah.

INT: BECAUSE THE LADY I WAS SPEAKING TO THIS MORNING SAYS SHE'S GOT TO GO THROUGH THE CHEMO THROUGH CHRISTMAS, SHE'S GOT TO GO ON CHRISTMAS DAY AND ALL THIS KIND OF THING.

Patient: Oh, bless her. Yeah.

INT: WELL, UNLESS IT FALLS ON A WEEKEND [???] BUT TRY AND AVOID CHRISTMAS.

Patient: Mm. It's every Thursday at Chesterfield.

INT: MM.

Patient: Yeah. They're very good at Chesterfield with [???] ...

INT: THAT'LL BE AT WESTON PARK, THE RADIOTHERAPY?

Patient: The radiotherapy's at Weston Park, yeah, yeah. Yeah, I've got a niece, she's ten and the question she has asked me is absolutely unbelievable. It doesn't sound like a ten-year-old. She's sat there as if, you know, she's doing research.

INT: AH, RIGHT.

Patient: [???] I says to her, I said, 'I think you're gonna be a doctor or something,' [chuckles] it really is mind-blowing stuff she comes out with.

INT: ERM, OK. SO, ERM, THINKING BACK TO THE TIME, LET ME SEE, WHEN YOU WERE, AFTER YOU'D HAD YOUR DIAGNOSIS AND YOU SAW THE BREAST CARE NURSE AND CAME HOME, UP TILL WHEN YOU HAD YOUR OPERATION, ERM, I MEAN DID YOU SPEAK WITH ANY FAMILY OR FRIENDS ABOUT, YOU KNOW, WHAT HAPPENED AND ...?

Patient: I spoke with my sister, erm, Pat. She's about nine years older than me. Obviously she was very concerned because, because of Anne ...

INT: YEAH, YOUR SISTER.

Patient: ... you know, everybody who said, erm, who asked, who knew sort of thing, and at that particular time there wasn't many people who'd ac-, who actually knew. They knew I wasn't, I'd gone through some sort of a, you know, something, er, and, but when they found out that, erm, I'd had this lump removed sort of thing, everybody was like relating me to Anne, you know, 'Oh, your sister died of that, didn't she?' And I just said to them, 'No, she didn't,' you know, 'She didn't actually die of that,' and they'd go, 'Oh, right.' It's like I said at the time, I think we're all pretty ignorant to the fact of, you know, of actually, erm, of this disease, really. But, erm, I certainly spoke to my sister about it, certainly spoke to my daughter about it, er, who, who were all very supportive, er, and ...

INT: HOW OLD'S YOUR DAUGHTER?

Patient: My daughter's 32.

INT: AHA.

Patient: Yeah. And, er, she trained to be a nurse, so, you know, she knows, sort of thing, and very supportive. And at the particular time my niece, Cheryl, erm, we'd had some information from Weston Park about doing an abseil down the Hallamshire Hospital.

INT: AH RIGHT.

Patient: And, er, and Cheryl says, 'I'll do it,' and I says, 'Don't be daft, it's too high,' you know and she says, 'No,' she says, 'I'm going to do it for you.' And I rung the Derbyshire Times up and I said to them, you know, 'Do you want to know what my niece is doing at the weekend? She's abseiling down this building,' you know. And, erm, the assistant editor at Derbyshire Times used to go to school with my son and, er, he sent a photographer up to take us photograph ...

INT: [???

Patient: We ended up on the front page of the Derbyshire Times. So everybody knew about it then, didn't they?

INT: AYE, YEAH.

Patient: Yeah, and everybody was ringing up and saying, you know, 'Are you all right?' and, well, we've just sent a cheque off for £1,320 to Weston Park through the sponsorship.

INT: OH THAT'S FANTASTIC.

Patient: And Cheryl rang Sean [?] up again to put a thank-you in the Times to everyone, and we're on page 10, we've got half a page again.

INT: OH [???] YOU'RE LOCAL CELEBRITIES NOW.

Patient: Here we go again. [laughs] So, erm, so everyone got to know then you see. And my friends were saying, 'Well, to say you were trying to keep, you know, hidden, sort of thing, I ...'

INT: YOU'LL BE GETTING A PHONE CALL OFF ANT AND DEC BEFORE LONG.

Patient: Yeah. [laughs]

INT: I'M A CELEBRITY, [???

Patient: But, erm, well I just said that it were a small price to pay, you know, for a good cause.

INT: AYE.

Patient: You know, and I couldn't let Cheryl do it for a pittance. She couldn't jump off that building for nothing, er, and that, and it were a fantastic picture.

INT: NO, I BET IT WAS, YEAH.

Patient: So, erm, she, erm, so it's in again this week and I said to Cheryl, 'Get ready for the cheques again,' so she says, 'I'm waiting.' So that's it, isn't it? So we just think that we've done a little bit of good, so there's some good come out of the darkness sort of thing, you know.

INT: ABSOLUTELY, YEAH.

Patient: Yeah. But, er, ... so, that were that.

INT: AND, ERM ... THINKING ABOUT THE TIME IN BETWEEN YOUR DIAGNOSIS AND OPERATION, DID YOU, ERM, LOOK FOR OR WERE YOU GIVEN ANY FURTHER INFORMATION ABOUT BREAST CANCER? EITHER DID YOU SPEAK TO A GP, DID YOUR FRIENDS OR RELATIVES GIVE YOU INFORMATION? ANY BOOKS, VIDEOS, MAGAZINES? DID YOU LOOK ON THE INTERNET? ANYTHING LIKE THAT? TV PROGRAMMES?

Patient: At that particular time there was quite a, there was quite a lot of, erm, in the papers, er, I think every now and again you just get this like surge. I mean I know October's Breast Cancer Awareness month, so you do then, but this wasn't. Er, there was quite a big article in the You magazine with the Mail about, erm, someone what had been diagnosed, and they were, and we have the Mail, and it, there was in there. I read them but, it's like my says, you read things and it's like anything else, some of them survive, but of course, some people don't survive and it was upsetting me to read about people not actually surviving - not only for myself but for them as well, you know, sort of thing. And my sister says, she says, 'Don't, don't read it.' I says, 'Yeah, but you sort of what to know as much as ...

INT: AS YOU CAN.

Patient: ... information as you can. I go on the internet and I did have a look on the internet, but I think I scared myself a little bit so I come off there, [???] I thought I'd wait actually until, erm, you know ... and in that, like I say, in the hospital they do give you pamphlets and the different exercises to do after your operation, but I sometimes think you get a bit blinded by science and you frighten yourselves.

INT: RIGHT.

Patient: You know, what is actually gonna happen.

INT: MM, YEAH. WELL THERE'S NOT A LOT OF IT THAT'S PROBABLY RELEVANT TO YOU ANYWAY.

Patient: That's right, that's right, yeah. And I just thought, you know, when I got the results sort of thing that when, er, when things were clear, even though it might be a stage three, even, you know, if things are clear, that's good, you know, and that's got to be good for you. So ...

INT: YEAH., ESPECIALLY IF IT HASN'T SPREAD.

Patient: That's right. As an individual person, if it's not in the lymph nodes, if they're all clear, you think, 'Thank goodness for that,' you know. And that's why I said at the beginning, what would have happened if I hadn't have gone for the mast-, the mammogram? You know, what would have happened if I was one of the people who was at the back of the queue, because I wasn't 50, but, er, and as I say I just, I just thought myself very lucky, very lucky.

INT: THINKING ABOUT THE TIMES THAT YOU WERE TALKING WITH MR HOLT, OK, HOW DO YOU FEEL YOU GOT ON WITH MR HOLT?

Patient: Very well. Very kind gentleman, as for instance, erm, Dave and myself, I think it was my first chemo, er, we were walking down the corridor of the hospital and someone came past us and just turned and spoke to us and it was Mr Holt. And I thought that was very nice of him, because either we were, you know, we must have looked that ... that he remembered us, sort of thing, but I thought after the amount of people he must see in a week in that department, to come and, to make himself known to Dave and myself and say, 'Are you all right?' He asked me where I was in my treatment: I said I was just going for my first chemo, and he says, 'You'll sail through it, absolutely sail through it.' And he just winked at us and walked off. And I just said to Dave, I says, 'Well, isn't that nice?' [chuckles] you know, because I thought he's a busy man, you know, he sees all these people and he's got time to stop and speak to us. So, yeah, I found him a very nice gentleman.

INT: AND DID YOU FEEL THAT HE WAS LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND THINGS?

Patient: Yes, definitely.

INT: YEAH.

Patient: Yes. Erm, because I did explain to him about Anne the very first time I saw him and how my fears were, erm, when he was saying about, you know, the lumpectomy, mastectomy, you know, and I explained against that at one time they'd have just whipped it off and asked questions later, which in my mind they would. But, because I'd been given that chance, you know, and we were both grateful, both myself and Dave, because I think Dave's been very, he's been very supportive and he's been very, erm, he's been very brave with me, but at the end of the day we got what we wanted really. Do you know what I mean?

INT: YEAH.

Patient: So, yes, Mr Holt, I think he's a lovely man, very nice.

INT: AND THINKING ABOUT THE TIMES YOU SPOKE WITH THE BREAST CARE NURSE, DID YOU SEE THE SAME ONE EVERY TIME OR DID YOU SEE DIFFERENT ONES?

Patient: No, I saw, I think I saw Mary first and then Donna, and then they sort of went on holiday so they were like overlapping when I saw them.

INT: OH, OK, I SEEN, YES.

Patient: Yeah, yeah.

INT: I MEAN HOW DO YOU FEEL YOU GOT ON WITH THE BREAST CARE NURSES?

Patient: Very nice because they made themselves known, they weren't somebody what were like sat in a, you know, in a room sort of thing, and, erm, I just ... well, like I said, they gave them their direct telephone number and if you needed them at any time to get straight in touch with them and I did actually ring them once, er, and they were very understanding. Yeah, yeah. So, like I say, it's a very friendly unit and sometimes you can feel that, you know, that it's there, that the friendship is there in that place.

INT: RIGHT, YEAH.

Patient: Rather than it being clinical, you know, and, erm, because I think where the oncology, where his clinic is actually based, that's a very dismal place in there.

INT: WHERE'S THAT AGAIN?

Patient: That's, erm, is it Outpatients 1 or something?

INT: [???] I'VE [???] BEEN THERE.

Patient: Yeah, it's a very dismal place and it's blue - and it is blue. Do you know what I mean? You think ... it's blue.

INT: I'VE NEVER BEEN THERE, TO BE HONEST, SO ...

Patient: Yeah. And that's at Chesterfield, and, erm, and then they go and sit you in this room and you may be waiting 10, 15 minutes, you know, and obviously I'd always got Dave with me, but I thought if I'd have been on my own it would have been a bit harrowing, sort of thing. But, er, yeah, but, there's always, there always seems to be somebody to follow up, to just ensure that what you've heard you've understood.

INT: RIGHT.

Patient: And if you haven't, they try and go through it you again, you know, and if you hadn't heard it that time, like you say, they keep telling you until you do actually understand it. Yeah.

INT: ERM, THINKING ABOUT, ERM, YOUR TREATMENT OPTIONS AND THE DECISION TO WHAT SURGERY YOU WERE GONNA HAVE, ONCE YOU'D HEARD THE OPTIONS AND LISTENED TO MR HOLT AND WHAT-HAVE-YOU, TELLING YOU ABOUT THEM, HOW SOON DO YOU THINK IT TOOK YOU TO MAKE YOUR MIND UP WHAT SURGERY YOU WERE GONNA HAVE?

Patient: Erm, after I'd clear it with Mr Holt, that it was the best thing for me, sort of thing, straight away actually. I didn't have to think about it. Erm, there wasn't, the thought wasn't there that I wanted a mastectomy.

INT: RIGHT, OK.

Patient: Er, if Mr Holt knew that it was in my best interest to have a mastectomy, I would have had one.

INT: RIGHT, OK.

Patient: But we'd talked it through, he said, you know, the way it was positioned, er, the size and this, that and 't other, that it was, you know, 'cos, let's face it, I might have said, 'Ooh I want a mastectomy,' and if it's not necessary, why have it?

INT: YEAH, SURE.

Patient: You know, that's, that's in my mind. But like we said again, some people just can't wait for it to be gone.

INT: YEAH, THAT'S RIGHT.

Patient: Yeah.

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

Patient: No.

INT: IN BETWEEN THAT AND THE OPERATION?

Patient: No, no.

INT: OK. ERM, SO, THINKING ABOUT THE OPTIONS THAT YOU HAD, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED?

Patient: Yes.

INT: YEAH?

Patient: Yeah, definitely. I was very pleased that it had progressed so well, you know, that people now was actually getting the option.

INT: RIGHT, OK.

Patient: Because, like, when he said that he may have to repeat the procedure, you know, if he hadn't got enough margin from round the tumour, it could have happened two or three times, you know, but then you're thinking, 'How many times would you allow that to happen before you thought, well the best thing for you to do was to have, have a mastectomy?' But I was very pleased that I was given the option. Very pleased.

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

Patient: I think, at the end of the day, what helped me to make the decision was Anne.

INT: RIGHT.

Patient: Back to Anne. It will always go back to Anne, because, at that particular time it wasn't there to make, the decision wasn't there to make because, because research hadn't gone that far and, erm, the best thing for you, in your interests, was to have a mastectomy. Erm, the only thing that worries me - well it doesn't actually worry me - is that my cousin Carole had a lumpectomy, er, and she had radiotherapy afterwards and her breast became so sore that she eventually had a mastectomy.

INT: OH RIGHT.

Patient: Not because the cancer had returned, but because her breast was in such a mess through the radiotherapy.

INT: RIGHT, OK.

Patient: But she did have an awful lot of radiotherapy.

INT: OH RIGHT, OK.

Patient: Thirty-something, which ...

INT: THIRTY SESSIONS OR SOMETHING?

Patient: Yeah.

INT: AND HOW MANY ARE YOU GOING TO HAVE, DO YOU KNOW?

Patient: I'm having 25.

INT: TWENTY-FIVE.

Patient: Yeah. So we'll just have to come to that hurdle when we come to it.

INT: RIGHT, OK. AND WHEN DID SHE HAVE THAT, THEN?

Patient: I start, I go for my planning, you know my road map ...

INT: [???

Patient: ... on my birthday. [chuckles]

INT: AND WHEN, SORRY, WHEN DID CAROLE, WHEN DID SHE HAVE THAT?

Patient: Carole had, erm, about eight years ago.

INT: RIGHT, OK.

Patient: About eight ago. Yeah, I can always remember her going in hospital for a lumpectomy, er, and then she started on her radiotherapy and I always remember taking her dogs for a walk round the dam with her and she said, 'I can't wait for it to be gone,' because it was that sore. So, er, Mr [???] did say, erm, 'We've got to be sure about this,' the positioning and things like that, 'We've got

to be sure about this,' he says, 'because I don't want you coming in x number of months' time and asking me to remove, you know, for your breast to be removed because it's so sore.' And I thought, 'Yeah, 'cos that happened to Carole.'

INT: YES, MM.

Patient: But that happened to Carole eight years ago. Yeah, and to me now things have progressed. So, like when I had radiotherapy before, erm, with the cervical cancer, er, it took, it damaged good cells, tissue, as well as bad, so I ended up having a hysterectomy afterwards, not because the cancer had returned, because I was getting abscesses at the back of my womb.

INT: YEAH, DAMAGE THROUGH THE ...

Patient: Yeah.

INT: ... THE RADIOTHERAPY.

Patient: Yeah. So, these are all things what are gonna come in the future but hopefully we're gonna get over them. Yeah. I've got a very positive attitude and I'm not ready for going yet so I'm not going, I refuse.

INT: I'M SURE YOU'RE NOT.

Patient: I'm not.

INT: ERM, SO, OK, LAST FEW QUESTIONS JUST TO FINISH OFF WITH.

Patient: OK.

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

Patient: I think the care I've received have been very good. Er, well excellent really. Erm, through being diagnosed to the operation and then the aftercare afterwards and up to the chemotherapy where everything's on hand for you, you know. There are videos, books, pamphlets, anything you want, tips on wigs, tips on scarves, tips on anything you need to know, you know, and at the end of the day everybody's different because it's a certain part of the treatment what's going to affect you most. So, and it's [chuckles] it has been my hair actually, you know, what's affected me the most. And to have, to see other people, erm, coming to the chemo unit and everybody's admiring everybody else's wigs and, you know, some have got bandanas on and some have got this, this on, you know, and you think ... and then some just take their hats off and they've got no hair. I thought, 'Phew, I couldn't do that.' And that's the first thing what met me when I actually walked into the unit, was this lady sat there with no hair. And I thought, 'God, she's got no hair,' you know, and I might not have got any hair underneath this wig, but God's sake, I've got a wig on, so that's all that matters to me. You know, but, yeah, I think, I think the care has been very, very good and, like I say, I do count myself very, very lucky.

INT: AND IF YOU WERE TOLD THAT YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE AT CHESTERFIELD THAT YOU WENT THROUGH, WHAT DO YOU THINK THAT MIGHT BE?

Patient: The breakfast.

INT: IN HOSPITAL?

Patient: Yeah. [chuckles]

INT: WAS THE FOOD NOT GOOD, WAS IT?

Patient: I know it's a silly thing to say, but I felt like I were a prisoner actually, yes, because you all get out to, erm, to go into a room and what they do, they put all the stuff in and knot [?] it and throw it on 't table, and you all have to help yourself, [chuckles] and I sat and I thought, 'It's like I'm in prison. I bet they do this in prison.' But, joking apart, yeah, erm ... I just think that the only thing that can be improved on is medical research to just go on and on till they can just eradicate it altogether.

INT: MM.

Patient: Because I don't think, I know time is quite a factor, the amount of time people have to wait, you know, through, it may only be a week, but like I say those weeks do mount up, you know, and if you could get it ... but obviously things have got to grow in laboratories and things like that for people to see. But, as for anything else, no, I think, I think we're going the right way. I think it's good.

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

Patient: I think they need to know their options, of course; erm, I think, I think they need to be clear on - I can't really describe it - I just think ... perhaps you don't want to be told, but, you know, perhaps life, if, you know ... are you gonna live or are you going to die? ... because at 't end of 't day that's all you need to know, isn't it? How's this going to affect me? You know, and I think that's where positive and negative attitude comes into it. If you've got a positive attitude, erm, you look forward: if it's negative you keep turning round and looking back, which is not good. But it's, it's difficult, it's difficult to sort of, you know, where ... or what.

INT: AND A SIMILAR QUESTION IS 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: Yeah, once again, erm, option which everyone is, is, or hopefully, is being told about, erm, is everyone asking about, are they aware of the different options that, you know, what they can have sort of thing?

INT: MM, GOOD POINT.

Patient: Just some people just think that, because they've been diagnosed with cancer, a mastectomy's their only, only way out. But ... this is something what pe-, it's a learning process, isn't it, really, for us all?

INT: YEAH.

Patient: And, and it certainly makes you ... you talk to people and they might moan about the weather, they might moan about buying Christmas presents, and things like that, and you sit back and you think, 'If that's all some people have got to think about ...' you know, that's human nature, isn't it, at the end of the day?

INT: OH YES, OF COURSE, YEAH.

Patient: Yeah, so ... yeah.

INT: ERM, JUST LET ME CHECK MY QUESTIONS, I THINK WE'VE BEEN THROUGH EVERYTHING, I'M NOT SURE. ERM ... YES, I THINK WE'VE BEEN THROUGH EVERYTHING. IS THERE ANYTHING ELSE THAT YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED OR ANY POINTS YOU THINK WE HAVEN'T COVERED, ANYTHING IMPORTANT YOU'D LIKE TO [???

Patient: I don't, I don't think there's anything. I don't, I'm just, like I said before, I'm pleased that this, erm, has come to the part where now that, because people are given the option, that, you know ...

[Interruption for telephone call]

Patient: Yeah, and I just think it's the way forward and I think, because now that people are actually learning and, and I think we're very lucky in Chesterfield and District areas, you know, that this is happening. Yeah.

INT: OK. ERM, IF THAT'S IT THEN I'LL TURN OFF.