

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE: 28/10/2004

*ID: Patient18

*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 WAS WRONG WITH YOUR BREAST?

Patient: Absolutely nothing.

INT: NOTHING, RIGHT.

Patient: I had no, erm, family, friends, who had breast cancer. I have family who have had cancer, and died from cancer, and so hearing breast cancer we thought, you know, that the prognosis was going to be very poor.

INT: WHAT OTHER CANCER WAS IT, DO YOU KNOW?

Patient: Erm, my first husband died of lung cancer, and my sister-in-law died in, well early 40s of leukaemia, they both died seven years ago.

INT: OK. AND, SO THERE'S BEEN NO FAMILY HISTORY OF BREAST CANCER AND ... IS THAT RIGHT?

Patient: Erm, no, well I have, I've got a problem there because I come from quite a dysfunctional family [chuckles] ...

INT: RIGHT, OK.

Patient: ... I don't know, er, the female side of my family very well because my Mum died at 42 and she took her own life.

INT: OH RIGHT, SORRY TO HEAR THAT.

Patient: So, we don't, I really don't know ...

INT: RIGHT, OK.

Patient: ... we were kind of ostracised then because my mother had committed this terrible sin. [chuckles] Yes.

INT: YEAH, RIGHT, OK. THAT IS SAD. ERM, AND YOU SAY, NO FRIENDS WHO'VE HAD BREAST CANCER AT ALL?

Patient: No.

INT: RIGHT, OK.

Patient: No, no, immediately I found out that, that this is what it was, you know, I was inundated with people who knew people but nobody who actually said, 'I've had it.'

INT: OH RIGHT ... WELL THAT'S JUST MY WATCH ... FOR SOME REASON I'VE SET THE ALARM.

Patient: Don't worry.

INT: [CHUCKLES] YEAH, YEAH, THAT IS COMMON. SOME PEOPLE SAY WHEN THEY'VE BEEN DIAGNOSED AND TELL THEIR FRIENDS, THESE PEOPLE, WILL OBVIOUSLY COME OUT THE WOODWORK AND SAY, 'OH, I KNOW SO-AND-SO ...'

Patient: Yes, yeah.

INT: ERM, AND YOUR, YOUR OWN SORT OF MEDICAL BACKGROUND, YOUR HEALTH AND THAT, HOW ARE YOU NORMALLY?

Patient: I've been extremely health all of my life, erm, I'm not a very good patient so even if I'm ill I'm healthy, er, because you've got to get well quick and, again, I think that goes back to childhood. Erm, my medical record, I had a hysterectomy in 1980, erm, I don't know the reason for that other than heavy periods because in those days the doctor just said to me, 'There's nothing nasty in there now.' But the records are at Chesterfield I presume. Erm, and I had my appendix out. Erm, two perfectly normal births, erm, and I'm just a very healthy person. Yeah.

INT: OH THAT'S GOOD. SO CAN YOU JUST TELL ME HOW IT IS YOU FIRST CAME ABOUT TO FIND OUT YOU HAD BREAST CANCER?

Patient: I was called for a mammogram on, erm, the 9th July and they did the first screening and then I was offered another appointment on 4th August which I couldn't keep, I was working, so I went on the 11th August thinking, 'Oh the machine has broken down or, you know, something's not gone right,' and really not thinking anything at all about being recalled. Erm, I went along to that appointment on my own, because I really, I wasn't anxious at all, and when I got there I thought, maybe wrongly, but I thought they were treating me with kid gloves and I was looking round with waiting room [chuckles] and it seemed that they were being extremely nice to me, and I thought, 'Why are they being nice to me in this way?' They may have been being nice to everybody else but I felt, you know, 'Something's not right here,' I began to get vibes from it. So they did, oh, and I'd had a letter saying that I would most probably be there all morning and I said to my husband, 'They don't me stay all morning if they're just going to do another x-ray,' and he said, 'It only says maybe, so don't worry yourself,' you know, so all of the time we were playing this down until I actually got there. And then they did the x-ray and after that they said that they would very much like to do a scan.

INT: WAS THIS THE RADIOGRAPHERS OR WAS IT THE CONSULTANT THAT SAID THAT?

Patient: Erm, it was, it was not my consultant, it was the other one, erm, can't remember his name. There's Mr Holt and Mr Somebody else.

INT: CHADWICK?

Patient: Chadwick. Erm ...

INT: SO MR CHADWICK SAID THIS?

Patient: It was Mr Chadwick, yes. Er, so they took me in for the scan which I thought was very exciting 'cos I'd never seen a scan, and again, you know, I just was not, not phased by it at all, and he started doing it and I said, 'Can I have look please because I'd like to see what you're looking at ...' I was interested, intrigued what this was about. And, erm, 'cos I felt so well. And, erm, he said, 'That's ...' he was very good and he was very factual and he said, 'That's what's causing us concern, that dark spot there,' and I think that was, I think that was the first stage where I thought it may be cancer, but I can't remember whether he used the word or not. I think he just mentioned it as a concern at that stage. Erm, and he said what he would like to do was a biopsy just to check it and I, I may have said to him, 'Is it possibly cancer?' knowing that it may not be malignant anyway, you know, so, er, and if they were doing a biopsy, well they'd find out that it wasn't malignant. Erm, so they did biop-, he did the biopsy immediately after the scan, erm, and then I ... I think I saw, I wasn't making notes at this time because it was nothing that day, you know.

INT: RIGHT, YES, OF COURSE, YEAH.

Patient: Erm ... they offered me an appoint-, I saw Mr Holt I think. Anyway, they offered me an appointment the following week, a week later, when they would confirm what the biopsy said.

INT: RIGHT, OK.

Patient: And, erm, I left the unit and walked out of Chesterfield Hospital, which is a long walk, I park across the road in the lay-by so it is a ...

INT: YES, IT IS QUITE A WALK.

Patient: ... it's a good walk along there, and that was the first time really when it hit me, you know, 'This could be serious.' So I rang my husband straight away and said, 'John, I don't like the sound of this, I really don't want to panic you but, you know, they want me to come back next week ...' and those kind of things, and he said, 'I'll come with you next time,' and he was sorry that he'd not gone with me, you know, and I was ...

INT: [???] I BET HE WAS, YEAH.

Patient: Yeah, because I was thinking, 'Well it's my fault he's not gone with me, 'cos it's me that said there's nothing wrong.' And ... erm, I told you I'd get tearful just thinking about ...

INT: IT'S OK.

Patient: ... you know, that John [???] and, erm, anyway, I walked across the road and there was a lady walking her greyhound and this dog came up to me, and I'm a doggie person, and she started talking to me about this greyhound, how she'd adopted it, and I just said to her at the end of this, about 20 minutes' conversation, 'You don't know how much you've helped me.'

INT: MM, YEAH.

Patient: And as finally ... erm ... and for the rest of that week we laughed and we joked about it, you know, and said, 'Well whatever it'll be, you know, it'll be. You'll be all right,'... and didn't tell my ... erm, my two sons because their father had died with cancer.

INT: OH OF COURSE.

Patient: Can I just stop a minute?

INT: YEAH, THAT'S FINE, JUST TAKE YOUR TIME. MM.

Patient: OK?

INT: YEAH, THAT'S FINE. SO, I MEAN, LET'S RECAP FOR A LITTLE SECOND. YOU HAD, YOU WENT FOR YOUR TESTS AND THINGS, ERM, AND YOU SAW MR CHADWICK, DID YOU, IS THAT RIGHT?

Patient: Yes.

INT: YEAH. AND THEN AFTER THAT DID YOU SAY YOU SAW MR HOLT?

Patient: I think I saw Mr Holt that time.

INT: DO YOU REMEMBER ANYTHING ABOUT WHAT YOU SAID TO MR HOLT OR WHAT HE SAID TO YOU?

Patient: No, well, I think he just confirmed ... I'm not even sure that I saw him, but they were confirming to me that I would need to come back next week, but it was a bit of a blur to me today because I just wasn't expecting any of this, I thought they were just going to recall me and say the machine had gone wrong, you know.

INT: YEAH, MM, OR YOU'D MOVED OR SOMETHING [???] CAUSE A BLIP, YEAH.

Patient: Yeah, yeah.

INT: AND DID YOU SEE ANY OF THE BREAST CARE NURSES THAT PARTICULAR VISIT? DO YOU REMEMBER SEEING THEM?

Patient: Well, the strange thing was, there were two women in the room and, erm, and I mean obviously when they're talking to women or examining women there's somebody else in the room, and I was very conscious of these two people being in the room, but I can't remember speaking to either of them.

INT: [???

Patient: And one of them left whilst the interview was taking place, because I was, I was, I was perfectly normal talking to, away, you know, chattering away, I'd just seen this [???] because I remember having this pleasant conversation, 'Oh, yes, I'll come back next week,' you know, [chuckles] and I think it was Donna that left. There were two breast care nurses.

INT: SO IT WAS THE BREAST CARE NURSES THAT WERE THERE?

Patient: Yes, it was.

INT: [???

Patient: I knew afterwards that that's who they were, yes, I think Mary stayed behind and Donna had to leave the room for some reason. Yes.

INT: RIGHT, OK.

Patient: But I can't remember having any conversation with them at that stage.

INT: YEAH, OK, THAT'S FINE. AND AFTER THAT, YOU WENT OUT AND YOU MET WITH WOMAN WITH THE DOG.

Patient: Yeah, and then the worst thing was my sons, you see, because of their father, and my youngest son is a football referee so he works away, professionally ...

INT: OH, RIGHT.

Patient: Mm, yes.

INT: IS HE IN THE PREMIERSHIP OR COCA COLA?

Patient: Yeah, he did the Euros.

INT: DID HE? OH RIGHT.

Patient: Well he was a linesman at the Euros.

INT: RIGHT.

Patient: And, erm, and I said to my husband, 'I don't one to tell one son before the other one, I want to tell them both together,' because my sons are very loving towards me and, erm, er, if I told one and didn't tell the other, the other one would feel, 'Well why has she told that one?' you know, and John said I was worrying about nothing but I had to get this right. And then ...

INT: WAS IT ... AT THIS POINT HAD YOU ACTUALLY BEEN TOLD THE DIAGNOSIS?

Patient: No.

INT: RIGHT, OK.

Patient: No. Erm ... I told my best friend and she was very supportive, erm, and Glen was coming back, er, the night before I went for this interview.

INT: MM, THIS IS YOUR SON?

Patient: Yes, he's the younger one. And he was getting back at Manchester at ten o'clock at night, and he rang me, he always rings as soon as he lands. And I said, 'I need to see you tonight, Glen,' and he said, 'What for?' er, and I said, 'Look, I'm not telling you over the phone,' - he'd got to drive back from Manchester,' - but I want to see you and Andrew together. And he said, 'Mum, this is serious.' And I said, 'Well, no, it's serious but I want to see you before tomorrow.' Erm, so immediately they rang each other. Yes.

INT: [CHUCKLES] RIGHT, YEAH, THEY DO.

Patient: There's something wrong with Mum, and my eldest son said, 'I hope it's not cancer.'

INT: RIGHT, AH, SO THEY HAD A BIT OF A SUSPICION/

Patient: Well, because I would never insist on seeing them like that. So my husband went over and saw both of them: my younger son was absolutely shattered, tired because he'd, you know, he come back ... I think he'd been in Italy, and he'd come back and then had to come from Heathrow and, you know, then drive over here. And there I was saying that I was going tomorrow and I would know tomorrow whether I'd got cancer or not, but not to worry because, erm, if I had got it it was very, very small, very minute, and they'd caught it very early. And, erm, Andrew, my older son, was asking a lot more questions of me and, erm, he was very searching. Erm, and I told my brother, because I have got a brother, and my son then rang my brother, and my brother's response was, 'She may not be telling you the truth,' because of course his wife had died of leukaemia.

INT: OH RIGHT, OF COURSE.

Patient: And he said, 'She may not be telling you the truth. It may be more serious than she's saying. She may be protecting you.' And that really hurt because he'd put that doubt ...

INT: ABSOLUTELY, OF COURSE, YEAH.

Patient: ... in their mind, but I could understand why he did it, so I've never challenged him or anything over it. I could under-, he was trying to prepare them for something that may be worse.

INT: MIGHT BE WORSE, YEAH. MM.

Patient: So that really brings us up to going to the hospital. [chuckles]

INT: YEAH, WELL I WAS GONNA, THE NEXT QUESTION I WAS GONNA ASK YOU WAS CAN YOU PLEASE TELL ME ABOUT THE TIME WHEN YOU WERE FIRST DIAGNOSES REALLY, CAN YOU JUST KIND OF WALK ME THROUGH THAT DAY? AND YOUR HUSBAND WENT WITH YOU THIS TIME, DID HE?

Patient: Yes, he did, yes. Erm, we walked up from the hospital and it was, it felt surreal really as I was walking towards the hospital. I was saying things to him like, 'Well I know how people feel when they're waiting for their sentence now,' because of my work, you know, I worked with sexual offenders, when they're waiting to find out what they're being sentenced to, and people have said they're not guilty and, you know, things like that. And I was saying, 'It's like having a death sentence hanging over you, not knowing ... and when we come out we'll know and we'll feel different when we come out to how we

feel going in,' and we were having this really bizarre conversation like that between us, you know. Erm,
...

INT: YES. UNCERTAINTY'S A VERY FEARFUL THING.

Patient: Yes.

INT: YES.

Patient: And then, and then we went in, erm, I couldn't, no, I'm not, I still hadn't recorded anything at that stage I don't think, no I hadn't ... I went in and we saw Mr Holt straight away, erm, Mr Holt gives you lots of reassurance, just on meeting him. I think he is a fantastic person, I'm in awe of him & his skills really, and his manner. And we sat down and he said it was cancer, it was very, very small and he thought that they would be able to deal with it with a lumpectomy and I, I said, 'Fine, fine, if that's what needs to be done, do it.' Erm, and he said, 'We'll do it a week on Thursday,' which was like eight days I think. I said, 'Oh no, you can't do that, I'm working.' I was thinking they were going to do it next January, you know, 'cos ... [chuckles] and I said, 'I'm working,' I said, 'I've got two reports to do, er, and if I don't get them in these children won't, you know, it's their future,' 'cos they were before the courts for care proceedings,' and he said, 'In these situations you have to put your health first,' and nobody talks to me like that - I talk to them, but nobody tells me that, and he really pulled me up by my bootstraps, just with that sentence. And, erm, and John is a very quiet man and I can't remember John saying anything, I think he was just ...

INT: IS THIS YOUR HUSBAND, YES?

Patient: Yeah, I think he was just shocked. Erm, and they were saying, 'No, it will be a week on Thursday and we'd like you to go and have a chat with Mary.' he did show us the x-ray so we could see the dark ...

INT: RIGHT, OK.

Patient: ... erm, and then Mary took us, that's the breast cancer nurse, took us into this little room which was like going into a sitting room and I thought, 'This is like work, this is work,' you know, 'I do this with people at work, take them into a nice room,' [chuckles] and I was getting angry that they were treating me, because I wasn't ill. And, erm, she was very nice, very pleasant, and explaining that I would have to go to this other room, this other ward or whatever it was, surgery, the following week, and they would book me in and all that kind of thing. But I wasn't upset, I mean, I was ...

INT: THAT'D BE THE PRE-ASSESSMENT CLINIC/

Patient: Yes, yeah. I wasn't, erm, crying or anything, I was just, 'OK, they're going to take a lump out of my breast and then that'll be all over,' and that was that. So I went away again, erm, and when we came home we treated it very much, very, very low key like that; rang round everybody, said to everybody, 'Don't worry, it's a very, very small lump, got nothing to worry about, they've caught it at the very early stages, and Mr Holt's given me lots of reassurance I'm going to be all right, and I'll only be in overnight, and ...' all those positive messages and everybody was thrilled for me. But, no, that's what it was. And that was that bit. [chuckles] So where do you want me to go now.

INT: WELL, LET'S JUST RECAP A LITTLE BIT ON THAT THEN. ERM, SO YOU WENT IN, YOU SAW MR HOLT, AND YOU SAID THAT HE WAS VERY REASSURING FOR YOU, ERM, AND YOU MENTIONED THAT IT WAS A VERY SMALL CANCER AND THEY COULD TAKE IT OUT WITH THE LUMPECTOMY, IS THAT RIGHT, YEAH?

Patient: Yes.

INT: WHO ELSE WAS IN THE ROOM AT THE SAME TIME WITH ...?

Patient: The breast cancer nurse was there.

INT: IS THAT, WAS THAT MARY?

Patient: Yes.

INT: WAS IT, YEAH?

Patient: Yeah.

INT: AND THERE WAS YOUR HUSBAND. WAS ANYBODY ELSE THERE?

Patient: I can't remember anybody else being there.

INT: RIGHT, OK. AND, ERM, I MEAN WHEN HE FINALLY DID CONFIRM THAT IT WAS CANCER ...?

Patient: He did it immediately.

INT: HE DID IT IMMEDIATELY, YES?

Patient: Yes.

INT: SO, I MEAN, WHAT WERE YOUR FEELINGS THEN, BECAUSE UP UNTIL THIS POINT YOU SAID YOU'D BEEN JOKING AND LAUGHING A BIT ABOUT IT AND TRYING TO PUT IT DOWN, HOW WAS YOUR FEELINGS WHEN IT WAS FINALLY [???

Patient: It remained the same because he was so reassuring in his manner, 'This is nothing to worry about, we've caught this very early,' and I was ringing round everybody - in fact I put it on, you know, we have a professional website - 'For goodness sake, go for your mammograms - this is what's happened to me,' you know, and, you know, 'If you don't go for your mammogram you may be in the position that I'm in and they've caught it very early,' and I just, you know, was then inundated with colleagues coming back saying, 'thanks, I have one due,' you know, that kind of thing. I was elated and so thrilled that we have this magnificent service that could pick it up so quickly. Yeah. So, no, I wasn't anxious at all.

INT: NO, OK THEN. ERM, AND WHEN HE WAS TELLING YOU ABOUT THE CANCER AND HE WAS TELLING YOU ABOUT OPERATION AND THINGS AND THAT, HOW MUCH DID YOU FEEL YOU UNDERSTOOD ABOUT WHAT HE WAS SAYING?

Patient: I understood everything that I thought I should understand at that stage because I'm not someone who sits and doesn't ask questions if I'm, if I'm not sure I would ask them to say it more clearly. And what he was saying was it was a very small lump, erm, a lumpectomy would be OK but if I really wanted to have a full mastectomy I could have one ...

INT: RIGHT, OK.

Patient: ... and I was saying, 'No, no, I'd do exactly what's needed,' you know, and if a lumpectomy's enough that's fine by me, you know. Yeah. Erm ...

INT: AND, ERM, DID YOU ASK ANY QUESTIONS, YOU MENTIONED QUESTIONS, MY NEXT QUESTION WAS GONNA BE DID YOU ASK ANY QUESTIONS?

Patient: Erm, I don't, I think I may have asked at that stage whether it would be better to have the whole breast off or, you know, just in case cancers developed elsewhere, and I, I was reassured - the choice was mine, but I was reassured that a lumpectomy was enough.

INT: RIGHT, OK.

Patient: And I had every confidence in him, yeah.

INT: RIGHT, OK. AND WHEN YOU SPOKE WITH, ERM, MARY, AFTERWARDS, DID YOU GO, DID SHE SPEAK ABOUT THE OPERATIONS AT ALL OR ...

Patient: I honestly can't remember that conversation.

INT: RIGHT, OK.

Patient: Or I can remember her telling me I'd got to go to the ...

INT: THE PRE-ASSESSMENT.

Patient: ... the pre-assessment clinic, and talked to her, I should have gone on holiday to Prague, I'd booked a weekend and I talked to her about should I cancel this holiday, I remember talking about that. I didn't think I really talked about the cancer itself, erm, because it really didn't that much to ... maybe subconsciously I was just blocking it.

INT: RIGHT, OK.

Patient: Yes.

INT: ERM, AND YOU SAY YOU WENT TO PRAGUE THAT WEEKEND?

Patient: No, I should have gone ...

INT: DID YOU CANCEL IT, DID YOU?

Patient: I should have gone, erm, four days after the operation so I cancelled it, yeah, and I asked, you know, would they sign to say that I was not able to go and, it was those kind of very general

questions that I was asking, and trying to work out how I could get my work in before, [chuckles] before I had the operation.

INT: SO, AND, ERM, SO, AFTER YOU SPOKE WITH MARY, THEN YOU CAME HOME, IS THAT RIGHT?

Patient: I came home, yeah ...

INT: HOW SOON AFTER THAT DIAGNOSIS DID YOU HAVE THE OPERATION?

Patient: Right. Erm, it was confirmed on the 18th and I went on the 23rd to the pre-assessment clinic, and the operation was on the 26th, so it was 8 days.

INT: ABOUT A WEEK, 8 DAYS, A WEEK. YES.

Patient: Yes.

INT: ERM, AND IN BETWEEN THAT DIAGNOSIS AND YOUR OPERATION, I MEAN, WHAT WERE YOUR THOUGHTS THEN? HOW WERE YOUR FEELINGS?

Patient: I was, I was just so pleased that they'd picked it up so early and that that this was just a little blip in my health and, erm, I was told, you know, because I'd, I remember Mr Holt saying to me, I told him I'd had a hysterectomy and he said, 'Well this operation is nowhere near as intrusive as a hysterectomy,' and asking he how I was after that, and I said I was absolutely fine, erm, he said, 'Well this is, this is going to be nothing compared to the hysterectomy.' So, you know, all the way through I was very, very reassured that this was nothing, it was like having a cyst taken away, you know.

INT: RIGHT, YEAH, MM. AND, ERM, LET ME JUST THINK ... IN BETWEEN THAT DIAGNOSIS AND THE ACTUAL OPERATION, DID YOU LOOK FOR ANY FURTHER INFORMATION ABOUT BREAST CANCER OR ITS TREATMENT OR ITS OPERATIONS ...?

Patient: No, not at that stage.

INT: DID YOU VISIT THE GP?

Patient: No. No. What, I do remember, I think it must have been Mary saying to me, 'A lot of people go onto the internet, erm, after this interview. What I would say to you is, if you have any concerns, ring us because you'll get a lot of information on the internet that's not absolutely accurate, and everybody is very different.' So I purposely did not go on the internet at that stage, because I didn't want to worry myself ... I was, I felt confident in what they were saying and I would do exactly what they said. They knew what they were doing, I didn't know. [chuckles] Yeah.

INT: ERM, AND, ERM ... AND DID ANYBODY GIVE YOU ANY BOOKS OR VIDEOS, DID YOU WATCH ANY TV SHOWS, READ ANYTHING IN MAGAZINES OR [??]? ?

Patient: Oh, well, it's like, it's like when I bought my car, suddenly every car on the road was the same make as mine.

INT: [??] [CHUCKLES]

Patient: Yeah. And every newspaper I picked up was about cancer and every programme, you know.

INT: IT'S BREAST AWARENESS MONTH.

Patient: Yes, yes.

INT: IT'S BREAST CANCER AWARENESS MONTH.

Patient: And, you know, even in soaps and things like that, people had got cancer, you know, and I was think, 'Goodness me. Have I been missing all of this?' and feeling rather guilty really that I'd not taken any notice, er, of what other people were going through. Yeah.

INT: YEAH, WELL [??] WITH MY GIRLFRIEND, WE WERE IN THE TOWN CENTRE IN SHEFFIELD WE WENT SHOPPING, AND THERE WAS ALL THESE PEOPLE AROUND THE TOWN CENTRE DRESSED UP IN FUNNY COSTUMES COLLECTING MONEY FOR CANCER RESEARCH UK, AND OF COURSE THEY PAY MY WAGES. [CHUCKLES] I JUST, I PUT SOME MONEY IN OBVIOUSLY, AND I SAID, 'ACTUALLY I'M GIVING THIS BACK, I'VE GOT IT FROM THEM.' [CHUCKLES] IT IS, THERE'S A LOT OF INFORMATION OUT THERE, IT'S A BIT HARD TO MISS REALLY.

Patient: Yes, yes. So, no, I didn't before that operation, I just went with what the hospital had told me.

INT: Right, OK. AND SO WHEN YOU WENT FOR THE PRE-ASSESSMENT, CAN YOU JUST TELL ME WHAT HAPPENED THERE PLEASE?

Patient: Erm, they weighed me and measured me and told me that I was fit enough for the operation, and that was it, even though ...

INT: MM, AND DID YOU SEE THE BREAST CARE NURSES AT ALL THERE?

Patient: I don't think so, I can't remember seeing them. Yeah. I may have done but I can't remember.

INT: AND IN BETWEEN SEEING THE, GETTING YOUR DIAGNOSIS AND YOUR OPERATION, THE PRE-ASSESSMENT CLINIC, DI YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES ...?J

Patient: No.

INT: DID YOU CALL THEM FOR ANYTHING?

Patient: No, no.

INT: RIGHT, OK. BUT YOU FELT THAT YOU COULD DO IF YOU NEEDED TO?

Patient: Yes, oh yes, I didn't need to, erm, I really had nothing to worry about, that's what I told myself, yeah. And then I'd got these reports, and I worked, I worked and worked and worked, I was working from waking up in the morning at 8 o'clock till midnight, and I was doing three months' work in

a week, so that I could have my reports ready for court, and I did it, I managed it. I've just got one case that finished on mid-November and I had five cases on: I had to hand one back and I did the other three cases in that week.

INT: MM. AND HOW WERE THE BOYS WHEN YOU TOLD THEM WHAT HAD HAPPENED AT THE CLINIC ...?

Patient: Fine, absolutely, and they were pleased that they'd caught it early. They, I mean, they were very trusting.

INT: OH, EXCELLENT.

Patient: Yeah, yeah. Yeah, I mean I just ... I didn't realise I had such a loving, caring family until this happened really, yeah, yeah, and that makes me feel good knowing the background I come from, and that, you know, my sons can show me this love quite openly, doesn't matter, you know, if you were sitting there it would be very obvious, yeah.

INT: YES. OH THAT'S REALLY NICE THAT. AND, ERM, WHEN, OH, WHEN, ERM, MR HOLT WAS TALKING ABOUT THE CANCER AND ITS OPERATIONS, DID HE USE ANY VISUAL AIDS AT ALL? DID HE SHOW ANY MAMMOGRAMS, ANY PICTURES, DID HE DRAW ANY DIAGRAMS ...?

Patient: Yes, he showed me the, he showed me my chart, erm, with pendulous breasts which I thought, 'Ooh, they look awful,' [chuckles] and he showed me where the cancer was, yes, so he showed me exactly, this is you, which is what we're concerned about, this is the x-ray, that's what we're talking about, do you understand it, erm, is there anything you're not sure about. We need to get a clear edge around it, and so, yes, he was being very explicit.

INT: RIGHT, OK.

Patient: Yeah.

INT: RIGHT. AND DID THE BREAST CARE NURSE, DID SHE USE ANYTHING, ANY DIAGRAMS, PICTURES ...

Patient: No.

INT: DID SHE GIVE YOU ANY WRITTEN INFORMATION OR LEAFLETS OR ANYTHING LIKE THAT?

Patient: Yes, yes, she gave me, erm, a pack with information in and also her little card.

INT: RIGHT, OK.

Patient: Yeah, erm, in case I wanted to contact them at any time, her little card, at any time, however small, it didn't matter, just give them a ring, erm, and that was very reassuring but I didn't need it.

INT: MM. AND, ERM, THE INFORMATION LEAFLETS, THE PACK THEY GAVE YOU, DID YOU READ THE INFORMATION IN THERE?

Patient: Yes, yes.

INT: DID YOU FIND IT USEFUL AT ALL?

Patient: Erm, yes, it was interesting but, as far as I was concerned, nothing to worry about. You know.

INT: SO, WE'VE DONE THE PRE-ASSESSMENT CLINIC, AND THEN CAN YOU JUST TELL ME, JUST WALK ME THROUGH WHAT HAPPENED ON THE DAY OF THE OPERATION WHEN YOU WENT TO HOSPITAL AND THINGS?

Patient: Yeah. I don't know whether you're aware, but I had two operations, do you know that or not?

INT: I DIDN'T ACTUALLY. OK

Patient: Right. So this is the first one.

INT: THE FIRST ONE, OK, RIGHT.

Patient: Erm, right. My husband insisted on taking me in, he was joking and he just makes me laugh when I'm you know, when I'm upset or anxious, erm, and he was joking on the ward and things like that and just left me there and, erm, I took my embroidery with me, I was sitting embroidering in the, in the lounge waiting and Mr Holt came to see me, erm, and said that they would be doing the operation that afternoon and was I worried about anything and, no I wasn't, and, you know, 'Let's get it over and done with,' kind of attitude.

INT: RIGHT, MM.

Patient: And, erm, the anaesthetist came to see me, erm, very, very caring man, he was, I now know it was Mr Rolf, erm, I think it's Rolf, the senior one. Erm, and he gave me a pre-med sedative - I hope I'm using the right terms - and, and that was that. I just got ready for the operation and went down and had the operation, no problem whatsoever, and came up and was happy as Larry and I can go home tomorrow, and that was it.

INT: [???

Patient: Yeah.

INT: DO YOU REMEMBER WHEN YOU SIGNED THE CONSENT FORM FOR THE FIRST OPERATION?

Patient: Yeah, I signed it when I was in the ward the first time, Mr Holt came to me and clearly went through exactly what he was going to do, erm, and asked if I had any questions, er, and then I signed the consent form with him. I also asked him, I had a little wart under my arm here, [chuckles] which I hated ... my Grandma had one, when I was a little girl I used to be afraid of her little wart, and I had one ... so I said to him, 'Whilst I'm in, under the anae-, will you take that off for me as well?' [chuckles] and he said, 'Oh, yes, you know,' he says, 'Yes, we may as well,' and he did. And so that was very nice of him. Yes.

INT: AH, OK, YES.

Patient: He did tell me that they would take two lymph nodes just to be absolutely sure, erm, and after the operation I was told they'd actually taken four, four lymph nodes, so, but, better to be safe than sorry, that's how I felt about that. Yeah.

INT: AND, ERM, SO YOU CAME ROUND AFTER THE OPERATION, AND HOW WERE YOU AFTER THAT? WERE YOU OK?

Patient: Yeah, just ready to go home. Nothing, it was good.

INT: AND HOW LONG WERE YOU IN HOSPITAL FOR?

Patient: Overnight.

INT: JUST OVERNIGHT AND THEN GO OUT THE NEXT DAY?

Patient: Yes, yeah.

INT: RIGHT, OK. ERM, ...

Patient: And this was all feeding into, you know, for my, particularly for my sons, this is nothing to worry about, knowing that my brother had put this fear in them, this is nothing to worry about, they wouldn't let me come home overnight, you know, if it was anything to worry about, so, you know, it was all fitting into the pattern I wanted it to fit into.

INT: YES, OF COURSE, AHA, RIGHT, AND DID THEY, WELL THEY PROBABLY WOULDN'T HAVE TIME, DID THEY HAVE TIME TO COME AND SEE YOU IN THE HOSPITAL?

Patient: No, nobody came, only my husband came, that was it. Yeah, yeah ... then it all started to go wrong. [chuckles]

INT: OK. SO, AFTER YOU'D GOT HOME ...

Patient: Yes.

INT: ... HOW SOON DID YOU SEE, BECAUSE YOU GO BACK TO THE HOSPITAL FOR YOUR RESULTS OF YOUR OPERATION ...?

Patient: Yeah, but there's, well stop me if it's not helpful to you, but that was the Friday I came home, it was Bank Holiday weekend, and the district nurse came in to see me on the Saturday and she said to me, 'You're in the worst phase now,' and I said, 'No, I've had the operation,' ...

INT: OK.

Patient: And she said, 'Not knowing ...' and suddenly it hit me that there be more to this than I knew.

INT: RIGHT, OK.

Patient: And I, and I, that's the first time, it was like somebody had hit me, [???] 'Well this could be serious,' you know. And I said, 'Well, I hadn't really thought of it like that,' and when she went I was just devastated really, I became very, very distressed.

INT: YEAH, I CAN IMAGINE.

Patient: Erm, because I hadn't thought of it in terms of, she was talking about the lymph nodes and, you know, it could, it could have spread and you won't know until after then ...

INT: RIGHT, OK.

Patient: ... and I just, I'd just missed that.

INT: YEAH, RIGHT, OK.

Patient: You know, er, and she was the first person that really made me frightened.

INT: RIGHT, OK.

Patient: Yeah, yeah. Right.

INT: DID, AT THAT POINT DID YOU THINK OF CALLING THE BREAST CARE NURSES OR ANYTHING LIKE THAT?

Patient: No.

INT: RIGHT, OK. IT'S JUST I NEED TO CHECK THAT, THAT'S ALL. SO HOW SOON AFTER THAT DID YOU GO BACK AND ACTUALLY HEAR YOUR RESULTS?

Patient: Erm, I went back on the 8th, erm, and I wrote down - because she'd put this fear into me then - and I wrote down all of the questions that I wanted to ask him.

INT: RIGHT, OK. SO WHAT KIND OF QUESTIONS DID YOU WANT TO ASK?

Patient: Right. What type of cancer is this? Erm, what is its growth rate and pattern? Which other organs are at risk? The side effects of him removing four lymph nodes? Is it realistic to expect a reduction in my immune system? What steps can I take to assist not having a reduction in my immune system? Erm, I'd noticed a tiredness, you know, increase in tiredness and lethargy, was that associated with cancer or was it just the after-effects of the operation? If cancer can be detected by a mammogram, er, why don't they do x-rays of other parts of my body to find out whether it's there? Treatment that was available to me? What the prognosis was? And last, my holiday insurance claim. [chuckles] Right, so I was very clear what I wanted to know then, although, you know, it was a horrible that the district nurse did, she made me really, you know, think this could be more than, than I'm thinking it is at the moment. And he answered all of those questions for me.

INT: MM. SO WAS IT MR HOLT YOU SAW THEN?

Patient: It was Mr Holt.

INT: SO CAN YOU JUST TELL ME ABOUT THAT CONSULTATION, WHAT HAPPENED WHEN YOU WENT THERE? WHO DID YOU GO WITH, THINGS LIKE THAT?

Patient: Erm, I went with John, erm, and I've actually got it written down ... right, 'Hospital appointment with Mr Holt. He explained that the tumour they'd removed was larger than was originally thought. The scan hadn't shown the depth of it or the speed of its growth. He showed us the scan taken after the wire was inserted on the day of the operation. Erm, his concern is that the removal of the surrounding tissue was very close to the edge ...' and I've put 'Presumably of the cancer.' He kept talking about it being close to the edge and it wasn't till we came away I said to John, 'The edge of what?' and he said, 'Oh I asked him that,' whilst I was with the breast cancer nurse, I said, 'What did he say?' He said, 'I can't remember.' [chuckles] So, so we weren't sure what the edge meant at that stage. 'Therefore he will operate again in two weeks' time, no date given. Another test to be undertaken next week on 16th of the 9th called the oestrogen receptor test.' I thought he'd said that I would have an interview with the radiographer who would give me further advice and apparently he'd said the oncologist and I'd got the wrong name. 'Erm, and the alternatives to consider: removal of tissue and edges, erm, ...' and that was going to be discussed with the radiographer, the oncologist.

INT: YEAH, MM.

Patient: 'Or, removal of the whole breast,' oh, sorry, 'Removal of the tissue and edges, followed by radiotherapy.'

INT: RIGHT, OK.

Patient: Erm, and that would be 6 weeks daily he told me. 'The alternative was removal of the whole breast in which case radiotherapy wouldn't be necessary. Also Tamoxafen to be taken orally for five years and frequent mammograms.' And I've put 'Good news: my lymph nodes, four were perfect and there is no sign of spread to other parts of my body. The cancer is restricted to my breast only.' And I've just put a question for next time, 'Is the other breast at risk?'

INT: RIGHT, OK.

Patient: Yes, yes.

INT: ERM, AND THAT'S ALL THAT HAPPENED ON THAT CONSULTATION?

Patient: And that's what happened, yes.

INT: AND DID YOU SEE A BREAST CARE NURSE AT ALL THAT TIME? DO YOU REMEMBER?

Patient: She was always, she was always there. Yes, it was Donna by then.

INT: OH, IT WAS DONNA, RIGHT, OK.

Patient: No, yes, yes, yeah.

INT: RIGHT, ERM, SO WHEN YOU WENT, WHEN YOU WENT TO SEE MR HOLT AT THAT CONSULTATION, I MEAN, YOU GOT THAT NEWS, HE ANSWERED YOUR QUESTIONS AND HOW,, WHAT WERE YOUR FEELINGS AT THIS POINT?

Patient: Erm, well I was, it was still doubtful whether they were going to do another lumpectomy to take further tissue or take the whole breast off, erm, and I wouldn't know that until I saw this other person the following week.

INT: THE ONCOLOGIST.

Patient: So I was quite happy.

INT: RIGHT, OK.

Patient: Erm, I was very confident in what they were saying, and I knew they'd do the right thing. I didn't know what was happening. Yeah.

INT: RIGHT, MM. SO WAS IT A WEEK LATER YOU SAW THE ONCOLOGIST, IS THAT RIGHT?

Patient: I saw the oncologist on the 16th, yes, it was eight days alter I saw him. Now, before I saw him, erm, I saw the sister, because they were dressing it, I'd had some leakage from the, from the wound, yeah ...

INT: RIGHT, YEAH.

Patient: ... erm, and I was seeing the sister and they were, the district nurse was coming here, and I said, 'Look, you know, 'I can come down to the surgery,' so as, I went down to the surgery and on the day before I saw this oncologist, I know I'm going to get tearful now I think ...

INT: RIGHT OK.

Patient: ... I went down to the surgery and saw the sister, and, erm, she said to me, 'Has anybody talked to you about breast cancer?' And I said, 'Erm ... well no, not really,' not knowing really what she wanted me to say, you see. I said, 'I know, I know what they're doing,' so she said, 'Sit down, I'll tell you about it.' And she said to me, 'You should be making notes about what's being said so that that you remember,' [chuckles] and she sat me down and she told me about every form of cancer, I've written it in here somewhere, every form of cancer that there could possible be, and that when I went to see the oncologist I would have to make a decision about what they were going to do. And I said, 'But I'm not in a position to make a decision, I don't know enough about it. I want them to tell me.' She said, 'They won't tell you and when you go home tonight you should discuss with your husband what you want to happen,' and she was telling me about the effects of cancers in different parts of your body and, and at the end of it, erm, she just went through, it was like having a seminar on cancer really. And at the end of it I just stood up and shook her hand and said, 'Well, thank you, thank you for giving it ...' and I was so shocked at hearing all this and, erm, 'Thank you, I'm really grateful because nobody's told me about cancer in that way.' And, and I came out and I just felt my heart [?] all the way home, I just, I was just beside myself, and I thought ...

INT: WELL YOU'D ALREADY BEEN TOLD OF COURSE THAT YOUR LYMPH NODES WERE CLEAR, SO THERE WAS NO SPREAD REALLY.

Patient: Yes, yes.

INT: ERM, AND I SUPPOSE YOU DIDN'T REALLY NEED THAT KIND OF INFORMATION.

Patient: And ...

INT: DO YOU FEEL YOU NEEDED THAT INFORMATION?

Patient: No, at the time when she was telling me it I thought, 'She's doing this for the right reasons, she's prepared me,' and as I was coming home I was thinking to myself, 'Mr Holt's written to my GP and told my GP something different to what they've told me.'

INT: MM.

Patient: 'She wouldn't need to tell me all that information if I hadn't got cancer somewhere else.' Erm ... I just wanted to get in here because I knew I was safe in here and nobody could touch me.' ... I just didn't know what to do then because I thought I was dying ... and er ... and when John came home, I told him all that she'd said, and I said, 'I want to know the truth, John, have they, have [???] that everybody knew except me.'

INT: MM, RIGHT.

Patient: Erm, and er ...

INT: DO YOU WANT TO TAKE A FEW MINUTES THEN?

Patient: Yes, please.

...

Patient: When I went to see the oncologist I saw Donna and I said to Donna that I was very concerned about what the district nurse had told me and was there something more than this, you know? And had they written to my GP? And she said, 'No, we don't write to your GP until afterwards,' and she said, 'I really worry sometimes about the nurses and people out in the ...' she said, 'They may never have come across a cancer or it may be their first one, and I really would like to do some training for people out there ...'

INT: YEAH, THE COMMUNITY.

Patient: Yeah.

INT: [???

Patient: Erm, she said, 'Because I think they need it. No, you've got nothing to worry about,' and, erm, and she was extremely reassuring, you know, and I wanted to my faith ... and she said, 'Look If you have any questions at all in the future, ask Mary or I,' she said, 'You know, don't go to them if ...' and really it was frightened of going any more because I'd had this experience here of ...

INT: WITH THE DISTRICT NURSE, MM, OF COURSE.

Patient: Yeah, and then it was her, her boss that had sat me down and told me all about this awful cancer. Oh, and the other thing I'd done, when I left her, and she'd told me about all these cancers, erm, there's a chemist across the road and I'd been in that chemist the week before and see on the wall there were some little books on cancer, and, erm, because I, you know, I didn't want to know all about cancer, I went and bought one. I left her and immediately went and bought a book, 'Understanding cancer,' because I wanted then to know what cancer was, erm, and I found that extremely useful that little book. Yeah, yeah. So it explained a lot of the terminology to me, it was like that, yeah.

INT: YEAH.

Patient: So that was that.

INT: RIGHT, OK.

Patient: Then I went to the oncologist. [chuckles]

INT: OK, CAN YOU TELL ME ABOUT THAT BIT OF IT?

Patient: Yeah, erm, I was kept waiting an awful long time for him, erm, I went to see him on the 16th September and I was outside and there were two other women and on looked as if she was at death's door and they were talking about their cancers and she'd obviously had an horrendous time, and I didn't find that really helpful, [chuckles] sitting there listening to them ...

INT: WAS JOHN THERE AGAIN, WAS HE?

Patient: No, I went on my own, I really wanted to go on my own, I didn't want John to be there.

INT: RIGHT, OK.

Patient: I thought they were just going to tell me that, you know, they were going to take another little area around from where they'd taken it, and, erm, and I must have been well over an hour late for the appointment, just waiting, and then I realised because this oncologist was just giving as much time as anybody wanted, that's what was making him late, so I wasn't angry when I, you know, when I went inside, or annoyed or frustrated or anything. I thought, you know, 'This is another very caring man.' And, er, so I saw him and, erm, I'd written my questions down for him as well.

INT: RIGHT, OK, SO WHAT DID YOU WANT TO ASK HIM?

Patient: What are the percentage chance, what's the percentage chance in there being another cancer forming in the left breast and in the right breast? If it develops in the right breast, erm, is further removal of lymph nodes necessary? Would a left mastectomy cure the cancer? Is it better to have a double mastectomy? Erm, what stage had my cancer reached, for example T2?

INT: IS THESE THE TERMINOLOGY YOU PICKED UP FROM THAT BOOK?

Patient: ... and this is because I'd picked them up in here, you see. What was my prognosis, erm, and why had they chosen Tamoxafen if I needed Tamoxafen, what was, what was it about that drug that they thought was right for me? So, erm, he answered all of those questions for me and he explained

that, erm, although, at that stage I was still thinking they were just going to take another layer of tissue, he explained that, because I have fairly large breasts, if they tried to do radiotherapy, they couldn't be sure that they would get enough good tissue around because of the breast moving before they did the radiotherapy, and he said, erm, the alternative would be for you to have a full mastectomy. And I said, 'Well, I'm 90 per cent there anyway, I'm now thinking I wish you'd have done a mastectomy in the first place, and then, you know, I would have been clear,' because I was learning more about it. So I said, 'You don't, you don't need to talk me any further, I'll have a mastectomy.'

INT: RIGHT, OK.

Patient: And that was when I, when I decided that.

INT: RIGHT, OK.

Patient: Erm, and John told me when I came home I shouldn't have gone to that appointment on my own, he would have gone with me, but I was fine, you know, erm, but when I was going to chapel, people, you know, I was just talking about, 'Well,' you know, we'll know it's clear now.' Yeah, and I wasn't upset at all.

INT: RIGHT, OK. SO, THEN WHAT HAPPENED AFTER THAT?

Patient: Right. What happened after that one? Right, that was on the 16th September, on the 18th September I was in Chesterfield shopping and saw in Boots a breast cancer care, there was a lady standing with a little tiny stall ...

INT: OH RIGHT.

Patient: ... with leaflets and, erm, and I went to her and I said, 'Please could I have some of your leaflets, I'm going to have a mastectomy on Thursday?' and she said, 'Oh, yes,' then she was telling me then all about Cancer Care and how if I wanted a mentor or anybody like that they would provide that service and, er, if my husband wanted to speak to anybody, and she was a really lovely lady. And then she said to me, 'I've had reconstruction,' and I just looked at her and I thought, 'This woman is marvellous,' you know, and I came out feeling ten feet tall, just from talking to that woman. Erm, and I knew everything was going to be all right when I went into hospital, but she played an important part, just standing and talking to me woman to woman. I then went on the site that she'd given me, that's the first time I went onto the internet, I went onto the site and IT was ...

INT: WHICH ONE WAS THAT? WAS THAT BREAST CANCER ...?

Patient: Care, is it Breast Cancer Care? I'd have to go and get the leaflets to tell you. Erm, there's like an open forum, you can discuss things, and it put me back with this sister that I'd seen, the nursing sister at the doctor's surgery, and I thought, 'I don't want to know all this information,' so I didn't get in touch with anybody.

INT: RIGHT, OK.

Patient: But ideally I would have liked to have met somebody who was going through what I was going through, but I hadn't got the courage to do it because I was frightened of who I would meet. Yeah, yeah.

INT: I THINK THAT'S UNDERSTANDABLE.

Patient: Erm, then I had the second operation on the 23rd September.

INT: DID YOU HAVE ANY MEETING WITH MR HOLT OR MR CHADWICK OR ANYBODY IN BETWEEN THAT VISIT TO THE ONCOLOGIST?

Patient: No, no.

INT: OK, SO YOU'D GOT YOUR DATE SORTED OUT?

Patient: Yeah.

INT: AND WAS IT MR HOLT THAT DID THE OPERATION?

Patient: It was Mr Holt that did the operation, erm, again he was absolutely fine. He came and went through what they were going to do, erm, in my mind I was thinking even at that stage I wish they would do a double mastectomy, er, and he was saying, 'Well, you know, really, we don't like to remove healthy tissue, but ...' and I said, 'Well I can understand that,' and I would just go along with whatever they said really. The anaesthetist came and she was very brusque, and, erm, very efficient in her manner - young girl, an Asian girl - and went away, and I was fine, just waiting for my operation. I told her that I thought I was more anxious than I was at the previous operation and I thought I needed something to calm me, and she gave me something, so that was all fine. And then it came to the time of the operation, it was, I should have been, had the operation at four o'clock, and they came for me and the, the nurse asked me my name and my address and date of birth and did I know what they were going to do, and I said, 'Left breast mastectomy.' She said cheerio to everybody in the ward and went, and then she handed me over to, I think it must have been a porter, I'm not quite sure, but she was with him. Whoever it was asked me again and by this time I was in the corridor going down for my operation, and I couldn't say 'left breast mastectomy,' I just sobbed, absolutely sobbed. These people were going to mutilate my body and I wasn't ill, why were they doing this to me? You know, and it was so irrational the thoughts that were in my head, erm, and I was thinking, 'Don't, don't let them do this,' you know, it was like, like I was in a horror movie, that somebody was going to do something to me that wasn't necessary. And, erm, and I was sobbing, and we went down and then somebody else asked me name, address ... this was when, when you go into the bit before the operation room, [chuckles] and somebody in there asked me did I know what I was having and I just couldn't say, I couldn't say, 'left breast mastectomy.' Anyway the nurse stayed with me, erm, about 50 minutes whilst I was really, I was really distraught and, er, she was excellent. She talked to me about ...

INT: WAS THIS THE BREAST CARE NURSE OR THE ...?

Patient: No, this was just an ordinary nurse off the ward.

INT: OK.

Patient: And she talked to me about holidays, dogs, house, where we lived and she brought me down and I was absolutely fine. And I said to her, 'What I can't do is tell you what I'm here for, and if somebody, if I go through there and they ask me again, I know it'll happen again. Just those words, because you're mutilating my body and I can't say it.' So she, I mean, quite rightly, she said, 'Well we

have to be sure, you know, because of, if they do the wrong ...' and I knew all of that, but I said, 'Look, I know why I'm here, I don't want to ask me.' [chuckles] Anyway we went through into the ante-room to the operating theatre, and the anaesthetist was waiting for me obviously, she'd had to wait a long time, and there was somebody called Carl who is one of the technicians in the operation theatre, and he just said to me, 'Do you know which side we're operating on?' and I said, 'Left.' And I was fine. I could say left, but I couldn't actually say any more than that.

INT: RIGHT, OK.

Patient: So that was sort of, I was happy with that. But I did tell Mr Holt afterwards really that was the most horrific time really.

INT: YES.

Patient: I really did not want to keep telling them what they were going to do to me.

INT: YEAH.

Patient: And then the anaesthetist couldn't get my vein. I have, she called them wobbling veins, and I've awful veins, but the first anaesthetist had got it, no problem at all, this one she injected me six times [chuckles] ... I'm not exaggerating ... because she couldn't get the vein. And this Carl was telling her and was saying, 'No, you've not got it, it's bruising, can't you see it's bruising?' and I'm just think, 'God, let ... you know, please get this over and done with, I've had enough of this now.' If I could have got up I would have gone, you know. And my arm was bruised from there to there and it was coming out in bruises as she was doing it, there's still one there that's just slightly [???] and Carl said, 'Her arm is beginning to swell,' and I said, 'If you go in this die you'll get it,' and she knew best, that's how, the only way I could put it. And in the end Carl said, 'That's it, you've got it.' He was telling her and, and then she came from behind here with a black mask. Now I've not, I'd not told anybody in the hospital but my Mum had gassed herself ...

INT: OH RIGHT.

Patient: ... and the, the one thing that frightens me, even when I had my children, I didn't have gas and air, was the smell of gas, and do you know, she come, she come with this and ... and it was awful because the first [???], when I had the first operation, he gave me an injection and I was out like that, I never saw another thing. I knew they would have had to use a mask but she came round with it and plonked ... and I just took as many gulps as I could because I thought, 'If I'm going to die I'll die, I don't care now,' you know ... erm ... and it was horrendous. Erm, and I came round in the ward after that. That was, you know. Erm, and that was that bit. [chuckles] But ... so I had the second operation on the 23rd and I was, that was the, I discharged on the 27th, so I was in four days there. Fantastic care, no complaints whatsoever, you know, the nurses were wonderful. Erm, oh Donna had said to me, talking about breast cancer nurses, Donna had said to me the last time I'd seen her before this operation, did I wear a full bra, and I said, 'Oh yes I do, because with being big breasted I have to wear a full bra,' and then when I came home I thought, 'Well I don't really know what a full bra is,' [chuckles] so there's a corsetiere in Chesterfield so I went to see her on the Saturday when I'd been in for ... and said, 'Can you show me what a full bra looks like?' 'Oh I know why you're asking,' you know, so she went and got this scaffolding bra out and showed it to me. She said, 'This is what you need.' And so I bought one. So when I saw Donna for this operation, I said, 'I've got a full bra, Donna, I've bought it,' I said, 'It's like my Granny used to wear, I don't wear bras like that.' So she said, 'Oh,' she says,

'You don't need one of those. I'll go and get you your mast-, your prosthesis now and fit it for you.' And she was really brilliant, she went down and she brought it back and she showed me and ... and, erm, and then she brought some very pretty bras that they've got at the hospital, er, and explained the system they have with their bras, and she was so lovely. She's just a very, very soft and warm person, you know. [chuckles] I thought, you know, here's me thinking I was going to have to wear this horrible bra and she was reassuring me again, you see, that I didn't need to do that. Yes.

INT: RIGHT, OK.

Patient: Right.

INT: OK. SO ...

Patient: I hope I'm telling you what you want to know.

INT: NO, NO, THAT'S JUST FINE. YOU'VE HAD YOUR SECOND OPERATION, CAME ROUND, YOU WERE OK ...

Patient: Yes.

INT: ERM, DID YOU GO BACK AGAIN TO SEE MR HOLT OR MR CHADWICK AT ALL?

Patient: I was discharged on the 27th, I went on the 5th which was there, erm, 5th October and what I was telling him then was that I was finding it very uncomfortable to sleep, erm, I had pains under my arm and a piercing pain where my nipple used to be. Erm, and then, and I said is that like when people have a leg amputated and they still think, you know, that their leg is there.

INT: MM, PHANTOM LIMB.

Patient: Phantom, yeah. And he said, 'Yes, it's the same thing.' And I felt very bruised on my lower ribs. Erm, I asked him to mark my file stating that I had difficulties with my veins in case I ever needed another anaesthetic and I asked could I meet the anaesthetist because I know through my work, if I'm speaking to a client, I'd rather them tell me what it is that I've said that's upset and I learn far more than somebody else telling me.

INT: RIGHT, YEAH, OF COURSE, YEAH.

Patient: I said I'd like to talk to her about the service that she provided, and he said, 'Oh yes, you'll be able to do that, that would be fine.' And then he came to see me and said, 'I'm sorry, she was only a locum ...' ... and she was a locum.

INT: RIGHT, OK.

Patient: '... and she won't be here again, but would you tell me what the problem was?' So I said, well I really didn't want to tell tales about her, erm, but you know in those circumstances I did tell him you know, what it was that I would have said to her. And he said, 'Would you mind if I pass that information on to Mr Rolf?' who was, that's how I knew his name, the senior one. So that was that. Psychologically at that stage I was feeling very insecure, very lonely, isolated, erm, I felt the world wasn't a safe place to be in any more. Erm I felt I was a freak, and I was saying to him that I'd rather

have no breasts at all than one pendulous breast. I hate looking at the breast that I've got. Erm, on the positive side, I felt very loved and cared for by John and protected by John. I'd had lots of support from lots of people, erm, and I made a note [chuckles] 'I have not felt suicidal and I thought I might.'

INT: RIGHT, OK.

Patient: Because in the past when, you know, when my marriage broke up, things like that, my Mum is a reassurance to me, I'm not frightened of death at all. And if my Mum could do it I could do it, you know, so I thought faced with this, that might have been something that was coming into my thoughts, but it wasn't. Yeah.

INT: RIGHT, OK.

Patient: But I had, I had, I think it was 45 cards, flowers were coming galore, the amount of support that I had just from receiving cards coming through the door, was wonderful. I didn't know I was loved by so many people. And that's so important, you know, if the world could know, even if it's only, you know, on the street, I bet every neighbour on the street, and we've only been here two years, we don't 'neighbour, but when one neighbour knew next door, I was getting cards coming, you know, that was, that was phenomenal.

INT: I WAS GOING TO ASK YOU, I MEAN, SORT OF, YOU'VE BEEN THROUGH QUITE A JOURNEY, I CAN SEE THAT, AND IT'S BEEN A VERY EMOTIONAL TIME FOR YOU, I WAS GOING TO ASK YOU SORT OF WHAT WAS THE ONE THING THAT'S KEPT YOU GOING THROUGH ALL THIS, I MEAN?

Patient: The support that I've had from other people.

INT: YEAH.

Patient: I've always been a person, and again it's because of my childhood, I don't need support from anybody, I'm a strong person, and if you spoke to anybody in my family I'm the strength, they would come to me, you know. They
d come to me with any problem, it doesn't matter what it was they would always come and tell me the truth, even if it was illegal, you know, [chuckles] 'cos they knew that I wouldn't, I wouldn't ... I'd be honest with them but I'd support them. And suddenly here I was being supported by all these people, and it was lovely. I really lov-, I just wallowed in it. Erm, that's, that's the most positive thing that I've learnt from it. Let people care for you and look after you, and I talked about it, I didn't, you know, didn't try to hide it at all from anybody, and I think that was very important - well it was important to me, you know. And I think it gave permission to other people as well that they could talk to me. Yeah.

INT: ABSOLUTELY. SO, JUST TO SORT OF FINISH OFF YOUR STORY, WHERE ARE YOU NOW THEN? YOU'VE HAD YOUR MASTECTOMY, YOU'VE BEEN BACK TO SEE MR HOLT, WHERE ARE WE NOW THEN?

Patient: I have very good days and I have very bad days. I still wish that I'd had a double mastectomy. I get a lot of pain and I did ring up Donna last week, erm, and say, 'I'm having an awful lot of pain, can I just come down for reassurance that everything's all right?' That was on the Wednesday morning and she said, 'Yes, come at half past twelve, after we've finished the morning session, and I'll have a look

for you,' because it's beginning to pucker, the scar's beginning to pucker. And it is red there and sore. And I went at half past twelve and she said, 'Mr Holt's stayed behind as well,' and I thought, 'This man is marvellous.' Er, and he had a look as well, he said, 'No, there's nothing to worry about, everything's going fine,' and I said, 'How long am I going to have this pain?' because I've got pain killers, I don't like taking tablets [chuckles] and I says, 'I don't really want to become addicted to tablets and things,' and he said, 'It could go on for six months.' And that was ... that was really quite hard to accept that, you know, erm, if I take the pain killers the pain goes off, so, you know, it's my own fault if I don't take the pain killers, isn't it?

INT: YES, OF COURSE, YEAH. MM. ARE YOU TAKING THEM REGULARLY OR IS IT JUST TAKING THEM WHEN YOU GET THE PAIN? OR WHEN IT GETS TOO MUCH OR ...?

Patient: I usually take a couple at night, although I've not taken any yesterday or last night because I didn't think I wanted to take them.

INT: RIGHT, OK.

Patient: And I was all right. But I find it extremely uncomfortable in bed. If you saw my bed, erm, my husband have always slept separately 'cos he's an open air freak, he likes windows open and I freeze and so, so I have to be cocooned in my bed [chuckles] you know. And I'd got three cushions, pillows, because my breast, this breast, pulls the scar.

INT: YEAH, OK.

Patient: Being a heavy breast, if I turn it pulls the scar.

INT: IT PULLS [???] YEAH.

Patient: And if I keep my bra on then it hurts underneath where they've removed, you know, so there's no two ways about it really. So I've found now, if I get a pillow, I put a pillow on ...

INT: TO SUPPORT YOUR BREAST.

Patient: ... support that one, but of course you turn over in the night, you see, and then it does it again.

INT: RIGHT, OK.

Patient: And I just, I think women with breasts like mine, I just wish I'd had the other one taken off. And I think the other thing is, looking at myself in the mirror, I look a freak now ...,

INT: RIGHT, OK.

Patient: ... whereas I think if they were both taken off and I don't always wear my prosthesis because it presses on it, so I put it on today because you were coming but, but I mean normally I don't wear it now and, you know, you just catch sight of yourself and, and you look odd, you know.

INT: MM, RIGHT.

Patient: Yeah, I hate it. I really, really do hate it. Donna gave me another prosthesis last week because it was very heavy the first one she gave me, and she gave me this lighter one which isn't big enough, but it's more comfortable. So, she's done what she can. Yeah.

INT: AND, ERM, WHAT ABOUT FURTHER TREATMENT, ARE YOU HAVING RADIOTHERAPY OR NOT?

Patient: I don't need radiotherapy and chemotherapy.

INT: RIGHT, OK.

Patient: All I need is the Tamoxafen.

INT: TAMOXAFEN. ARE YOU STARTED ON NOW, ARE YOU?

Patient: I've had, I've finished 30, I'm only my 31st tablet because I've just finished the first course. Yeah.

INT: OK. AND HOW ARE YOU GETTING ON WITH THAT THEN?

Patient: I'm getting on fine with it. I take it first thing in the morning and that's what I was advised to do, so I put a glass of water and my tablet at the side of my bed at night. The first thing I do when I wake up is take it, and that's it, it's out of the way, because I don't take tablets, erm, there's one day I forgot when John called me in here to do something and I completely forgot to take it, so if I don't take it as soon as I wake up, I know I would hit and miss it.

INT: RIGHT, OK.

Patient: I've had a cold sore, sorry, an ulcer on my tongue and I think that's one of the side effects, but that's gone now. Erm, I do get quite low, I don't like it when I've a whole day on my own, erm ... erm, but, you know, you've just got to get on with it and that's it.

INT: OK.

Patient: Yeah.

[Break in recording]

INT: OK, AFTER RECESS. ERM, THINKING A LITTLE BIT ABOUT THE TIMES NOW THAT YOU SPOKE WITH MR HOLT ...?

Patient: Yes.

INT: OK. DID YOU FEEL THAT HE WAS LISTENING TO YOU, THAT HE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS? HOW DID YOU GET ON WITH HIM THEN?

Patient: Erm, he immediately makes eye contact with you. Erm ... he was listening, he answered every question that we had to ask. I liked him because he was very factual in his approach. Erm, he wasn't, there was no emotion in the way he was describing, this was his job, erm, I just found him completely

reassuring, trustworthy, everybody I spoke to had a good word for him. The lady next door but two works at the hospital, immediately I said I was under Mr Holt, you could tell it was a very warm response and that was somebody who worked in the hospital.

INT: OK.

Patient: Erm, I just, I just haven't got a negative word to say about him. I just think that he is an amazing man, yeah, in the right job. Yeah. I said to him on the, he came to see us on the ward and it was just after seven o'clock in the morning and that was the morning after I'd had the second operation, and I said to him, 'Goodness me, you must work long hours,' and he said, 'I like my job.' And I thought that says everything. Yeah. Yeah.

INT: AND THINKING ABOUT THE TIMES YOU SPOKE WITH MARY AND DONNA, SAME SORT OF THING, HOW DO YOU FEEL YOU GOT ON WITH THEM? DO YOU FEEL THEY WERE LISTENING TO YOU AND THEY UNDERSTOOD YOUR NEEDS, YOUR CONCERNS AND THINGS?

Patient: Yeah, they're very different characters, so I would imagine that people respond to them quite differently - Mary to be much quieter, reassuring, she was the one that put my prosthesis on for me in the ward and at that stage she was saying, 'Gosh, doesn't it look good? Come and have a look,' and she was saying to the nurse on the ward, 'Come and have a look at this, don't you think this is good?' you know, and I came out of that hospital feeling a million dollars, I really did. Er, she did that. Donna, when I first saw Donna, er, I thought, she's very - do you know Donna?

INT: YEAH, I'VE MET THEM ALL.

Patient: She's very punkish in her appearance, you know.

INT: YES, YES.

Patient; And so I was a little bit apprehensive about that, er, because I meet social workers who look like that, [chuckles] you know, and I'm one of the old brigade of social workers, you know, and I was thinking, erm, 'I hope she's on the same wavelength as me,' and I've found her to be exceptionally supportive. She's definitely in the right job and I would go to Donna with anything, you know. When I rung her up she didn't make me feel small or anything. Immediately she was there, and I just feel that I could ring her up, you know, ten times a day and she'd listen to me if I wanted her to. Yeah.

INT: OH THAT'S GOOD. ERM, AND THINKING ABOUT YOUR FIRST OPERATION, OK, AND, ERM, HOW LONG DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHAT, YOU KNOW, WHAT SURGERY YOU WERE GONNA HAVE? HE MENTIONED THE LUMPECTOMY AND MASTECTOMY AND HOW LONG DID IT TAKE YOU TO MAKE YOUR MIND WHICH WAS THE RIGHT ONE FOR YOU?

Patient: Erm, immediately, with the first operation, because I just went along with, this is a very small thing and you just need a lump removing, as I said, to me it was a cyst.

INT: RIGHT, YEAH.

Patient: And they were going to take it out and that was the end of that. So there was no, there was no fear there at all.

INT: AND THINKING ABOUT THE FIRST OPERATION, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, HEARD OR READ, THAT HELPED YOU MAKE THE DECISION? IT'S A VERY SIMILAR QUESTION BUT ...

Patient: Erm, what was the most important thing? That it was small and nothing to worry about.

INT: RIGHT, MM.

Patient: That was, that was it. Yeah. At that stage.

INT: ERM, AND THINKING ABOUT THE SECOND OPERATION, YOU WENT TO SEE THE ONCOLOGIST AND THEN AGAIN YOU WERE, I THINK YOU WERE GIVEN A CHOICE, YOU COULD HAVE HAD THE WIDE LOCAL EXCISION OR THE ACTUAL, THE MASTECTOMY ...

Patient: Yes.

INT: ERM, HOW SOON DID IT TAKE YOU TO MAKE UP YOUR MIND ABOUT WHAT YOU WERE GONNA HAVE AND WHAT WAS THE MOST IMPORTANT THING THAT YOU HEARD OR WERE TOLD OR READ THAT HELPED YOU MAKE THAT DECISION?

Patient: Erm, when he told me that they couldn't be sure that they would get it with another lumpectomy, I found that very reassuring because the one thing I'd said to John was, 'I don't want operation after operation,' this was when we, before we knew anything, the very first time we were walking up to the hospital and I said to him, 'John, I want you to promise me, if I got cancer that's spread, I don't want treatment after treatment after treatment. Andrew and Glen - that's my sons - have been through enough seeing their father. If it's spread I want this to be a quick death.' Erm, and that's really ... I've lost the question now that you asked me and it was important ...

INT: YES, IT WAS, THINKING ABOUT THE DECISION YOU HAD TO MAKE WHETHER TO HAVE A FURTHER EXCISION OR THE MASTECTOMY SECOND TIME ROUND ...

Patient: Right.

INT: ... WHAT WAS THE MOST IMPORTANT THING THAT YOU HEARD OR WERE TOLD OR READ THAT HELPED YOU MAKE THE DECISION WHAT OPERATION TO HAVE, AND HOW SOON DID YOU MAKE THAT DECISION?

Patient: Right, when they said to me they could take another layer but they weren't quite sure that the radiotherapy would work, etc, I'd already made my mind up before I went to that meeting with the oncologist, I'd discussed it with John and I said, 'I'm 99 per cent certain I'm going to ask them to take this breast off, because then I know I've not got to go back for another operation on it,' erm, and he was quite happy about that, and John's attitude was, 'You will only have one pillow instead of two,' which I thought was a lovely way of putting it. [chuckles]

INT: OH RIGHT, YEAH.

Patient: Erm ... and so when I went to see the oncologist, when he told me that they weren't sure that they would be able to, you know, get this clearance, I just said to him, 'Well I was 99 per cent certain

before I saw you that that's what I wanted you to do.' It was then, between then and the operation I began to think I wished they would take both breasts off. And I still feel that. I wish they had taken both ... I really regret that. Yeah.

INT: RIGHT.

Patient: I don't want another operation. Yeah, that's how I feel at the moment anyway.

INT: RIGHT, OK.

Patient: And I don't want to be in this, looking like a freak ...

INT: RIGHT, RIGHT SURE. ERM, I MEAN, DID YOU SPEAK TO THE BREAST CARE NURSE OR ANYBODY ELSE DO YOU THINK TO ...

Patient: Erm, I don't know what they can do really. I just get on with my life and don't allow myself to think about it.

INT: MM.

Patient: But, erm, I've always been a fairly proud person ... I'm going to be too upset.

INT: OK, [???

[Break in recording]

Patient: Yeah, I've always been a very proud person and, erm, tried to make the best of myself in everything that I've done, for my Mum, whatever I've done in my life it's been for my Mum, and suddenly I'm this freakish person. Erm, I've stopped work ... I just feel people feel sorry for me and I don't want them to.

INT: RIGHT, OF COURSE. DO YOU HAVE ANY IDEA WHEN YOU'RE GONNA GO BACK TO WORK?

Patient; I'm not going to go back to work.

INT: YOU'RE NOT GOING TO GO BACK?

Patient; No, no. I'm self-employed.

INT: OH, RIGHT, OK.

Patient: Erm, and I retired in November 2002 but because there was such a vast shortage of people doing what I'm doing, erm, I'm employed by CAFCAS, erm, or I was, but as a self-employed person, so I could take as much or as little work, and so after I retired in 2002 I felt very guilty that these children hadn't got people representing them in court, so I went back to work. But now, Mr Holt saying to me, 'Your health comes first,' has made me thing, 'Yes, my health does come first,' and whilst all this is going on I'm no good to those children anyway, so ...

INT: OF COURSE.

Patient: ... yeah. So, er, I'm not going back to work, and I feel incredibly safe in this house. The world can't touch me in here.

INT: RIGHT, OK.

Patient: Mm.

INT: ERM ...

Patient: My husband doesn't know some of these things.

INT: REALLY.

Patient: No.

INT: AND DO YOU THINK YOU'RE GOING TO TALK WITH HIM ABOUT THAT?

Patient: No. No, I wouldn't want to upset him.

INT: OK.

Patient: No.

INT: JUST A COUPLE OF QUESTIONS, JUST TO FINISH THE INTERVIEW OFF WITH.

Patient: Right.

INT: DO YOU, THINKING ABOUT THE TWO DECISIONS THAT YOU MADE, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED BETWEEN THE ...

Patient: I didn't want any choice.

INT: YOU DIDN'T WANT ANY?

Patient: No. No, I just wanted them to tell me what was the right thing for me. They were the people who had the knowledge, the information, the skill. It was my body, erm, and I, I really didn't know what was best for me, so whatever they led me to believe would be best, that's what I would go along with. The only thing being that I said to John, 'I do not want to go through years and years of treatment, with Glen and Andrew watching me die basically. I'd rather get it over and done with quickly. Yeah.'

INT: AND, ERM, LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED RIGHT UP UNTIL, YOU KNOW, NOW, ERM, HOW DO YOU FEEL ABOUT THE CARE THAT YOU HAVE RECEIVED?

Patient: The care from the hospital, erm, has been 110 per cent or even more, it's been fantastic. I have no criticism at all to make of the hospital. In terms of the GP practice, and it's very difficult because Donna said 'Would you like me to have a word with them?' and I said no because I've got to have an ongoing relationship with them, and what they said to me, I've think they've said it with the

right motives in mind, it was just the wrong way of putting it and the wrong time, and particularly just those two occasions, the nurse here saying, 'Now you've got the worrying time,' and I didn't need that, and then the sister sitting me down and telling me all about these cancers, erm ... the night, that was the day before I was seeing the oncologist and I still cannot understand why she did that, other than she'd got more information than I'd got and I still, I still have a little niggly doubt in my mind that ... that something may have been said to them, and I try to dispel it.

INT: YES, OF COURSE.

Patient: You know, but she really, she did frighten me. Yeah. So, I would say I agree with Donna, people in the community do need more training. Yeah.

INT: RIGHT, OK. AND THINKING ABOUT THE BREAST SERVICE AT CHESTERFIELD, ERM, IF YOU WERE TOLD YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THAT SERVICE, WHAT DO YOU THINK THAT WOULD BE?

Patient: ... Ooh, what would I change? I'd really have to search to find anything to change. Erm ... I've just been treated so well by them. The one thing I would change possibly, and I know, not to ask me what they're going to do when I'm going down for the operation.

INT: RIGHT, YES.

Patient: That's the one thing that was really bad.

INT: OR SEVERAL TIMES ANYWAY.

Patient: Yes, yeah. Erm, but I've told Mr Holt that anyway. [chuckles]

INT: RIGHT, THAT'S OK.

Patient: Erm, in terms of the actual service ...

INT: WELL HE'LL CERTAINLY APPRECIATE THAT KIND OF FEEDBACK.

Patient: Yes.

INT: BECAUSE THEY'RE ALWAYS WANTING TO IMPROVE THE SERVICE.

Patient: Yes.

INT: I'VE INTERVIEWED ALL OF THEM AT CHESTERFIELD, WELL, I'M SAYING ALL OF THEM, THERE'S FOUR OF THEM REALLY, THE TWO NURSES AND THE TWO CONSULTANTS, AND SORT OF, I MEAN, THAT'S THE END OF INTERVIEW SO I CAN'T LEAD DOWN THE LINE NOW, SO I CAN SORT OF GIVE YOU MY OPINION, AND I THINK YOU'VE HIT THE NAIL RIGHT ON THE HEAD WITH THEM, YOU KNOW, I FOUND THEM TO BE A WONDERFUL BUNCH OF PEOPLE.

Patient: They are.

INT: YEAH, AND I'M SURE THEY'LL REALLY APPRECIATE THAT KIND OF FEEDBACK.

Patient: Yeah, and I, you know, you read about this woman in Wales who was begging for money more or less, you know, erm, because she hadn't been able to go and have her examination, it was some, it was about the same time as I was having mine, and I just wanted to tell everybody what a wonderful service we're having in Chesterfield, you know, and it's just amazing. Yeah, mm. I didn't like, I don't know whether it's relevant or not, but they have, I now know how they use hospitals on a Saturday and they use it for terminations, erm, and they had women coming on the ward who were having terminations, I now know it take six hours and things like that and, I was thinking, I've got enough to think about without, you know, talking to this poor girl in the bed next to me saying, 'It's your decision' and really social working.

INT: YES, MM.

Patient; But that's a logistical thing, you know. If they've got beds they've got to use them, haven't they? And ...yeah, but, so it'd be nice if they could go somewhere that was, you know, not a general kind of ward, but I understand why that happens. I'm nit-picking because I couldn't, couldn't, I couldn't fault them at all, and my family can't either. No, they thought they were wonderful.

INT: YES, OK. NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW FIRST OF ALL ABOUT RECEIVING THEIR DI-, WHEN THEY'RE RECEIVING THEIR DIAGNOSIS?

Patient: I think it varies according to the individual, and I think you have to go along with, erm, what, how the individual is presenting and hearing the information, the amount of information that you give to them. You go with them.

INT: LOOKING BACK NOW, WHAT SORT OF INFORMATION DO YOU THINK YOU WOULD HAVE LIKED TO HAVE HAD? IT'S ALWAYS EASY IN RETROSPECT, I UNDERSTAND, BUT ...

Patient; I would like to have known that it was going to be necessary to remove the whole breast from the beginning. Erm, and I think sometimes they gave me too much information and too much choice, for me. Erm, and I was saying, I said to John when we were talking about it last night, 'They're the experts, and all I wanted them to do was to get on and do their job, and tell me when they were absolutely sure,' so when they first said to me, 'It's very small, it's nothing to worry about, we've caught it very early,' it's now a big bigger and it's deep and it's fast-growing, and it was like building up, you know, to this point where they were going to remove the breast. Now, you know, I think, I genuinely believe that that's how they discovered it as well, because they couldn't a lump in my breast, erm, and they could only see it on the scan, you couldn't feel it, it was deep, and so I think they were giving me as much information and I know that they have to do that these days, don't they, you know, give you as much information and with your tablets it gives you all the side-effects and everything, sometimes I feel it's a bit of an overload, erm, but it depends on the individual. I just wanted somebody to make the decision for me and I would have accepted whatever they said.

INT: RIGHT, OK. 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: Erm, well it's useful to know everything that's available. The one thing that, erm, that I still don't know about is reconstruction, for example, and I'm told, I did ask and they said that there's likely to be somebody coming to Chesterfield who's doing reconstruction.

INT: OH, RIGHT.

Patient: Yeah.

INT: DID THEY SAY WHEN THAT WAS GONNA BE?

Patient: Yes, and I can't remember.

INT: OH RIGHT.

Patient: Yeah. Erm, but, and I've spoken to, I've spoken to somebody and they said that they know of somebody who had reconstruction at the same time as they had the removal, erm, and now I wish that had have been available to me, because I find it horrendous now, looking at myself. So I would have liked to have known more about reconstruction really.

INT: RIGHT.

Patient: Erm ... I think that's it really, I can't think of anything else.

INT: THAT'S OK.

Patient: Yeah.

INT: THE LAST QUESTION HERE IS, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED, ANY IMPORTANT POINTS YOU THINK WE HAVEN'T COVERED?

Patient: No.

INT: ANY QUESTIONS THAT'S COME UP IN YOUR MIND OR ...?

Patient: No, I don't think so. Can I just have a quick look ...

INT: ABSOLUTELY, YES, TAKE AS LONG AS YOU WANT.

Patient: ...at this list. Erm, [???], no, there's nothing, erm ... I had things like the blood pressure was all over the place when I was in hospital and they thought I'd had a minor stroke at one stage, and I, I was worried about my blood pressure, but those are, those are things that happen to you in everyday life, you know, it wasn't really to do with the cancer. Erm, it was just a very difficult period really, and I wish I'd had one operation and not two.

INT: YEAH, SURE, OF COURSE. MM.

Patient: Yeah. No,

INT: OK.

Patient: It's been fine.

INT: IF THAT'S IT, CAN I TURN OFF?

PATIENT: Yes, thank you.