

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: High MR unit

\*DATE: 04/10/2004

\*ID: Patient45

\*INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED. I'LL START WITH QUESTION ONE, WHICH IS CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED SOMETHING WAS WRONG WITH YOUR BREAST?

Patient: Erm, erm, I'd family members had breast cancer ...

INT: RIGHT, OK.

Patient: ... didn't actually know anything about the insight into breast cancer.

INT: RIGHT, OK.

Patient: But my Mum had died with breast cancer, I've had a cousin just die: I've had a lot of family members.

INT: RIGHT, OK. WAS THAT FAIRLY RECENTLY, WAS IT?

Patient: Erm, no my Mum died quite a while ago, er, but my cousin was recent, two months ago.

INT: OH RIGHT, OK. I'M SORRY TO HEAR THAT.

Patient: Erm, after a long fight ...

INT: RIGHT, OK.

Patient: ... against it.

INT: AHA. AND YOUR MUM, WHAT, DID SHE HAVE AN OPERATION FOR THAT, DID SHE?

Patient: Yeah.

INT: AND WHAT DID SHE HAVE?

Patient: She had a mastectomy.

INT: RIGHT, OK.

Patient: But then she was clear and then it come back in abundance.

INT: RIGHT, OK.

Patient: And my cousin, that turned into leukaemia, but both of those two, they're both, erm, didn't get, didn't have mastectomies, they didn't go to any form of doctor straight away.

INT: OH RIGHT, OK, SO THEY DIDN'T SEE THEIR GP OR ANYTHING?

Patient: Erm, no, from what I can gather.

INT: RIGHT, OK THEN.

Patient: I don't know whether people are just telling me this to make me feel better.

INT: RIGHT, OK.

Patient: I don't know.

INT: NO. RIGHT.

Patient: So ...

INT: AND YOUR COUSIN HAD A MASTECTOMY AS WELL, IS THAT RIGHT?

Patient: Yeah.

INT: YEAH, OK. AND DID, WERE THE BOTH IN DERBY AT THE TIME?

Patient: No.

INT: NO, OK.

Patient: No, I'm from Nottingham originally.

INT: OH RIGHT, OK.

Patient: So my Mum was in Nottingham and my cousin Huddersfield way, erm ... yeah. Er, near Huddersfield, Honnerly [?], that's ...

INT: OH RIGHT, YEA, YEAH. AND WHAT ABOUT ANY FRIENDS, HAVE THEY HAD BREAST CANCER THAT YOU KNOW OF, ANY FRIENDS OR COLLEAGUES OR ANYTHING?

Patient: Erm, no, it's funny how, when it happens to you, how everybody crawls out the woodwork, [chuckles] there's a lot of people ...

INT: THAT'S TRUE, YEAH.

Patient ... erm ...

INT: [???

Patient: I didn't know there was so many.

INT: YEAH, OK.

Patient: You know. So, yeah.

INT: RIGHT, OK. AND CAN YOU JUST SORT OF TELL ME HOW YOU FIRST CAME TO REALISE THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Right. I didn't know there was anything wrong.

INT: OH RIGHT, OK.

Patient: I had routine mammograms, yeah, routine mammograms and I went for a routine mammogram, I've mammograms every year because my family, because of it running through ...

INT: RIGHT, OK THEN.

Patient: ... my family. And, erm, it was picked up from there.

INT: RIGHT, OK. SO YOU WERE PICKED UP ON THE SCREENING PROGRAMME?

Patient: Yeah.

INT: YEAH. OK. ERM, SO IF YOU JUST TELL ME HOW THAT ACTUALLY HAPPENED THEN? CAN YOU JUST GO THROUGH IT FOR ME?

Patient: I went for a routine mammogram and I normally have a mammogram and then I have, erm, ultrasound.

INT: RIGHT, YEAH, A SCAN.

Patient: And I was waiting for the ultrasound and, as I say, I went in the room thinking that's what they was gonna do and they asked, this, erm, doctor or whatever he was, asked me where my lump was, and I said, 'I haven't got a lump,' and he said 'We've found something.'

INT: OH RIGHT, OK. WAS THIS A RADIOLOGIST OR A CONSULTANT ...?

Patient: I think he was like an under-, 'cos then he took me to another room to have a chat with a surgeon ...

INT: RIGHT, OK.

Patient: ... and he had a feel. They couldn't feel it but it was there on my mammogram and it was there on the ultrasound.

INT: RIGHT, OK.

Patient: So I had a biopsy there and then.

INT: RIGHT, OK. SO WHEN HE, IS THAT WHAT HE SAID, 'WHERE'S YOUR LUMP?' IS THAT WHAT HE SAID?

Patient: Yeah, he said, 'Where's your lump then?' I says, 'I haven't got a lump,' but, erm, ...

INT: RIGHT. WHAT, I MEAN, HOW DID YOU, HOW DID YOU FEEL WHEN HE SAID THAT, I MEAN?

Patient: Erm, well, at the same time I could see my mammogram thing on the thing ...

INT: OH I SEE, [???

Patient: ... so I could see something.

INT: RIGHT, OK.

Patient: But it didn't hit me what he meant then. It didn't like, it didn't sink in what he meant. And then this doctor examined me and he said, 'Well we can't feel it but we know it's there, so we've like you to have a biopsy.' It still didn't hit me what was happening, and you always think that it never happens to you, you always ... I always thought, although my Mum had had it, it's not my Mum's side, they think it's hereditary and they think it's my Dad's side where my cousin and my auntie is.

INT: RIGHT, OK.

Patient: Erm, but you always think it's not going to happen to you. That, and then they did the biopsy there and then.

INT: RIGHT, OK. DO YOU REMEMBER WHICH SURGEON IT WAS?

Patient: The surgeon who - I've seen all three - the surgeon who actually, erm, told me I'd have a biopsy, and then this whoever he was, I think he was another doctor, he did the biopsy ...

INT: YEAH, IT'D BE AN SpR, HOUSE OFFICER OR SOMETHING LIKE THAT.

Patient: ... but the one who actually had a feel and said, 'I think we'll do a ... we're gonna do a biopsy now,' is Mr Holliday.

INT: RIGHT, OK, YEAH.

Patient: Then I was going on holiday the next day, so they said, 'Go on holiday,' but as I say I came out and it didn't, it didn't hit me till I came out from having this biopsy, they told me to make an appointment for my results and then I just went to pot. But immediately there was a breast cancer nurse there who straight away took me to, I was upset ...

INT: I'LL BET YOU WERE.

Patient: ... and I never got to the desk to make the appointment.

INT: NO, I BET YOU DIDN'T.

Patient: Erm, 'cos it just suddenly hit me what had happened to me. It was all happening so quickly ...

INT: YEAH, I KNOW, EXACTLY, IT'S SORT OF, MUST BE QUITE A SHOCK WHERE [???] ...

Patient: Because I hadn't got a lump ...

INT: YEAH.

Patient: ... you think you're gonna get a lump first. Erm, so, I, erm, the breast cancer nurse immediately was fetched, as soon as I got upset, I didn't get as far as the desk and she took me to this nice room with settees and that in and had a chat and she was absolutely brilliant, and I will really ...

INT: SO WHO WAS IT, DO YOU REMEMBER?

Patient: My breast cancer nurse is called Karen Cousins.

INT: OH, OH YES, SORRY, FORMERLY FLINDERS, YES, SHE'S BEEN MARRIED. [CHUCKLES] I WAS THINKING, 'KAREN COUSINS, I DON'T KNOW WHO THAT IS,' BUT YEAH, IT'S HER NEW NAME. YEAH.

Patient: You know her, do you?

INT: YEAH-YEAH, YEAH.

Patient: She was really, really good for me. She explained that, you know, all the different options if it was then, and had a good chat with me, erm ... yeah. So, and then I like went on holiday.

INT: RIGHT, OK.

Patient: Because they told me it would take a week anyway for my results to come through.

INT: RIGHT, OK.

Patient: I think the worst thing out of anything, I told them I was going on holiday, the worst thing out of anything - and I really don't want to call the hospital in a way - but it was bad management in another way because I'd told them I was going on holiday. On the Thursday I got a call on my mobile while I was on holiday saying they'd got my results and a surgeon wanted to see me tomorrow.

INT: SO WHERE WERE YOU? WHERE WERE YOU ON HOLIDAY?

Patient: In Devon.

INT: IN DEVON. RIGHT, OK. AND HOW LONG HAD YOU PLANNED TO GO AWAY FOR?

Patient: A week.

INT: A WEEK.

Patient: As soon as I said, 'Well I'm on holiday,' they said, 'The surgeon wants to see you at nine o'clock tomorrow,' and I said, 'Well I'm on holiday, I told them I was going away,' and she said, 'Oh, it doesn't matter then, keep your appointment,' 'cos my appointment was for the Tuesday. 'It doesn't matter then, keep your appointment, we'll see you a week on Tuesday' but that threw me then.

INT: YEAH.

Patient: And I said, 'What is the result?' She said, 'We'll discuss it when you come.'

INT: YEAH, THEY WOULD DO.

Patient: And I thought, I knew it was bad news then. But that was the only thing what really felt, really threw me was because I was on holiday and from then onwards, I was, you know, the person I was with offered to bring me back, but I thought, 'No, two days won't make a difference, they've told me to leave it now,' erm, so that's what I did, I left it till my Tuesday appointment that I'd got.

INT: RIGHT, OK. THAT WAS LIKE A WEEK AND A BIT LATER?

Patient: Yeah, it was the Thursday I got the call, and I went on the Tuesday, so it wasn't, it was only a few days, you know, before my appointment anyway.

INT: YEAH, SURE. SO WHEN YOU, WHEN YOU FIRST WENT AND GOT YOUR MAMMOGRAM AND THEN THEY HAD TO DO THE ULTRASOUND AND THE BIOPSY, YOU SAID YOU SAW KAREN, THE BREAST CARE NURSE, DO YOU REMEMBER EXACTLY WHAT YOU TALKED ABOUT? DO YOU REMEMBER WHAT SHE SAID?

Patient: I can't. My head that day was in a complete spin. I didn't know whether I was coming or going 'cos I wasn't expecting it. Erm, I know she explained all, if it is ...

INT: IF IT WAS CANCER, YEAH.

Patient: ... you know, erm, and how things had progressed from when my Mum had it 20-odd years ago, you know, but as for anything else I honestly ...

INT: YEAH, YOU CAN'T REMEMBER.

Patient: I can't remember.

INT: NO, THAT'S OK.

Patient: I know she put my mind at ease, I know that she was really good, erm, with that, but I just, I can't remember.

INT: NO, THAT'S OK, DON'T WORRY. ERM, SO YOU HAD, OBVIOUSLY YOU WENT ON HOLIDAY, YOU CAME BACK AND YOU HAD THE APPOINTMENT ON THE TUESDAY ...

Patient: Yeah.,

INT: ... DID YOU HAVE, WHEN YOU WERE ON HOLIDAY I MEAN, DID, WHAT KIND OF THOUGHTS DID YOU HAVE ABOUT WHAT HAD HAPPENED AND ...?

Patient: Er ... mm ... it was a bit difficult really because I really tried to put it to the back of my mind and I've had a rough two years of it before this.

INT: RIGHT, OK.

Patient: My husband decided to tell me after 22 years of marriage he'd been seeing a woman for three years.

INT: OH NO.

Patient: That was, well it'll be two years at Christmas, and then I've had trouble with my daughter who's 14 ...

INT: OH DEAR.

Patient: ... and this was like the end of the straw. In, a year ago I'd met somebody, erm, a friend, a male friend, and I'd actually gone on holiday with him, and it was the first time we'd actually had some time on our own.

INT: RIGHT.

Patient: And I thought, for his sake as much as mine, I've got to put this to the back of my mind. It might not be ... and I know this is really, really stupid, but, as I came out from my mammogram, another woman came out after me and then they had her in first for the ultrasound, before me, and I kept thinking, 'They've got the wrong mammogram,'

INT: OH I SEE, RIGHT, OK.

Patient: Because this, the same woman who did my mammogram took the mammogram plates into the doctor for this woman as well, and I kept thinking, 'They've got the wrong, they've got the wrong woman for the mammogram.' I know it's stupid, but that's how my brain worked.

INT: OH BUT YOU CAN SEE THE CONFUSION HOW IT ARISED [ʔj], THOUGH, YEAH.

Patient: Yeah, so ... erm, at the back of my mind I kept thinking, 'They might have got it wrong.' And I hear so many, I've heard so many people who've had cysts and things like that, that I thought, everybody kept saying, 'You don't know till you get your results - stop, don't get yourself worked up about it,' and, you know, I am a whittler anyway, but, erm, I did try and put it to the back of my mind as much as I could because of the situation I was in.

INT: YEAH, SURE.

Patient: I was on holiday with a, you know, a bloke, I didn't want to spoil that for him ...

INT: NO, OF COURSE.

Patient: ... as well as me, and I was ready for a holiday, you know.

INT: YEAH, ABSOLUTELY, YEAH.

Patient: So ...

INT: SO WHEN YOU GOT BACK AND YOU WENT FOR THE APPOINTMENT ON THE TUESDAY, WASN'T IT, YOU WENT?

Patient: Yeah.

INT: CAN YOU TELL ME JUST FROM WHEN YOU ACTUALLY GOT TO THE HOSPITAL SORT OF WHAT HAPPENED, JUST TAKE ME THROUGH IT?

Patient: When I got to the hospital, I went with a friend then, a girl friend, and sat in the waiting room and somehow from that phone call I knew that it was gonna be bad news, and I don't know why. But I saw Karen, my breast cancer nurse, I saw her walk, walk across to where the doctor's room is, and I thought, 'This is gonna be bad news,' and, erm, when I got in, they called me in, my friend came, they asked me if my friend want-, if I wanted my friend or not, and, erm, so she came in with me, and there was the doctor, Mr Sibbering, then ...

INT: RIGHT, OK.

Patient: ... Mr Sibbering, a nurse, and my breast cancer nurse was all in there. And he just, erm, told me that it was cancerous, but it was very small, and he drew a diagram showing me how small it was.

INT: RIGHT, OK.

Patient: Erm, I don't know he knew that, he told, I'm sure he told me what size it was ... can they tell from a biopsy if it's ...?

INT: ER, WELL I THINK THEY'LL BE ABLE TO TELL FROM PROBABLY THE ULTRASOUND OR THE MAMMOGRAM, I THINK THEY'VE GOT A WAY OF MEASURING SOMETHING.

Patient: Right.

INT: I'M NOT QUITE SURE ABOUT THAT BUT I THINK THEY CAN DO IT. DID HE SAY HOW LARGE IT WAS?

Patient: Yeah, it's 14 millimetres.

INT: RIGHT, OK.

Patient: Which wasn't very big. And, erm ... it's my nerves ...

INT: RIGHT, OK.

Patient: Erm, yeah, 14 millimetres it was, and ...



INT: DO YOU WANT TO GO AND ANSWER THE DOOR AND WE'LL STOP NOW AND THEN WE CAN COME BACK, OK?

Patient: Yeah.

[Break in recording]

INT: WELL, WE'D START-, YOU WERE STARTING TO TELL ME ABOUT YOU WERE GOING INTO TO HEAR YOUR RESULTS, YOU SAID THAT YOU SAW KAREN GO ACROSS INTO THE ROOM, YOU WENT IN WITH YOUR FRIEND, AND THERE WAS MR SIBBERING, THE BREAST CARE NURSE AND ANOTHER CLINIC NURSE, I THINK, THERE.

Patient: Yeah.

INT: AND YOU SAID THAT HE TOLD YOU IT WAS CANCEROUS AND THAT IT WAS 14 MILLIMETRES, THAT'S WHERE WE'D GOT TO. SO JUST TAKE IT FROM THERE.

Patient: Right. He told me it was [???] yeah, and then he said, erm, he explained that they needed to take it away and that there was option, I could have a lumpectomy or a mastectomy ...

INT: RIGHT, OK.

Patient: ... erm, and he explained about each one, what it was, and, erm, told me that after that, depending on what the results would be, what the things would be after that, like radium, Tamoxafen, chemo, or simple x-rays, erm, quite a few x-rays.

INT: MM, YEAH.

Patient: So he did tell me, I'm sure he explained to me in quite, you know, what, everything I needed to know he explained to me, but, like, when they tell you you've got it, your mind sort of goes off on one. That's why I took a friend in.

INT: YEAH, SURE.

Patient: Because she remembered everything. Erm, but then he did go into tell me that, er, because it's hereditary, he thinks that it could be hereditary, erm - at this stage he doesn't know - that if they found out that it was hereditary - that he perhaps would come back to me, if I had the lumpectomy, erm, that, erm, I would perhaps have to have the full breast removed if it was found that it was hereditary, because my, erm, thingy would be quite high, the risk factor would be very high.

INT: RIGHT, OK.

Patient: So he did explain that to me, the choice was still mine ...

INT: YEAH, MM.

Patient: ... but he did explain that to me. He also explained that in a year's time they could offer me reconstruction surgery, but if I had radium treatment, that the chances of having reconstruction surgery was further down the thing, because of the radium treatment ... erm, tightening the skin. And

he explained all that to me for, like, the, after the mastectomy. He, erm, told me that, erm, that if I had a lumpectomy I probably, or I would have to have radium treatment, erm, and then he said, 'I don't expect you to make a decision now,' but he just told me the facts and everything about it, and then he sent me off with Karen and I went back to the room where I went the first time with Karen again. Erm, and that's where, then the discussion continued with Karen and ...

INT: RIGHT, AND WHAT DID YOU TALK ABOUT THERE THEN?

Patient: ... my friend ... she explained, she went back over everything he'd said, erm, I'm sure that's where she gave me the first ... oh, he, before I left Mr Sibbering he told me about my arm would be stiff and he said, 'The natural reaction for anybody is to keep your arm stiff when you've got pain in it, but you can't, we don't want you to do that,' and he explained all that to me as well.

INT: RIGHT, OK.

Patient: And then when I get to Karen, I'm sure that's when I got this pack.

INT: RIGHT, OH, IS THAT LIKE AN INFORMATION PACK?

Patient: Well, yeah, [chuckles] she like gave me that with the first lot of information in, a book all about ... and again she went through, they wasn't biased, they wasn't towards one or the other.

INT: YEAH, MM.

Patient: Yeah, that's it, breast unit, and then a couple of other things in there. But she was not, they both wasn't, but they was these factors, because if it was hereditary ...

INT: YEAH, SURE.

Patient: So Mr Sibbering didn't actually say, 'Have a mastectomy,' but what he told me that if it was he ...

INT: IF IT WAS HEREDITARY.

Patient: ... I probably would have to go back and have the breast off anyway.

INT: RIGHT, OK.

Patient: So, but he didn't say, 'You've got to have a mastectomy.'

INT: RIGHT, MM, YEAH.

Patient: And Karen was the same but she went back through the fors and against, erm, and then explained other things to me, little things, I suppose women's things really, and my friend asked, my friend was there who's really good and asked me lots of, asked lots of good questions that I didn't think, I still didn't remember but she's reminded me since, 'Can't you remember your breast cancer nursing saying ...' Erm ...

INT: WHAT SORT OF QUESTIONS DID SHE ASK? DID SHE? DO YOU REMEMBER ANY OF THEM?

Patient: Er ... I think we went more into reconstruction surgery, about that, erm, I can't remember ... I can't remember at all. No.

INT: THAT'S OK.

Patient: Yeah.

INT: IT'S JUST I WOULD BE INTERESTED TO KNOW WHAT SHE ACTUALLY ASKED ABOUT. UP UNTIL THIS POINT, WHEN YOU HEARD YOUR DIAGNOSIS AND THE OPTIONS, HAD YOU YOURSELF HAD ANY THOUGHTS ABOUT WHAT, IF IT WAS GOING TO BE BREAST CANCER, IF IT WAS GONNA BE BAD NEWS, WHAT YOU WOULD DO ABOUT IT IN TERMS OF ANY KIND OF TREATMENT OR SURGERY? HAD YOU HAD ANY THOUGHTS IT YOURSELF?

Patient: No.

INT: NO. RIGHT, OK. ERM, AND, ERM, YOU SAID THAT HE DREW YOU A DIAGRAM, IS THAT RIGHT, YEAH?

Patient: Yeah, he showed me about the, he showed me how big the, you know, the cancer was and that, and he talked about lymph nodes as well. I keep thinking of things once I start talking.

INT: NO THAT'S OK, I KNOW. AND DID HE USE ANY OTHER VISUAL AIDS? DID HE HAVE YOUR MAMMOGRAMS UP ON THE WALL, DID HE HAVE ANY PICTURES OR ANYTHING LIKE THAT THAT HE SHOWED YOU, OR JUST THE DIAGRAM?

Patient: No, he just drew, you know.

INT: INT: RIGHT, OK. AND WHEN YOU SAW KAREN AND YOU WERE TALKING TO HER, AND YOU WENT THROUGH EVERYTHING AGAIN, DID ... SHE GAVE YOU THE PACK, DID SHE DRAW ANY DIAGRAMS OR DID SHE SHOW YOU ANY PICTURES OR ANYTHING LIKE THAT?

Patient: No.

INT: NO. OK, NOT THAT YOU REMEMBER, YEAH? THAT'S OK.

Patient: Yeah, definitely not.

INT: ERM, AND WHILE YOU WERE TALKING TO KAREN AND MR SIBBERING, ERM, HOW, DID YOU FEEL, HOW MUCH DID YOU UNDERSTANDING ABOUT WHAT YOU WERE BEING TOLD?

Patient: Erm, I understood it all, it was just taking it all in.

INT: YEAH.

Patient: 'Cos your mind starts whizzing round, you know, erm, and it's, I mean, definitely when I was with Mr Sibbering, he like, I heard 'You've got cancer,' and it like, then your mind starts to start

spinning, and a lot of what he told me afterwards, well I think I remember but at the beginning I didn't. It, like, you mind goes off on one then, you know, erm, everything you think of, you know.

INT: I WAS GOING TO ASK YOU NEXT WHAT WERE YOUR FEELINGS KNOWING THAT YOU, IT HAD BEEN CONFIRMED THAT YOU HAD BREAST CANCER?

Patient: Dumbfounded. Really, really shocked ...

INT: BECAUSE YOU SAID ...

Patient: ... because I'd had no lump.

INT: YEAH. AND YOU'D SAID EARLIER THAT YOU DIDN'T THINK IT WAS GOING TO HAPPEN TO YOU AND ...

Patient: Yeah, you never do. Well, you just don't. You never think that it don't, it's not, you never think it's gonna happen to you. Erm, and of course the situation I've been, I've had a real rough two years of it.

INT: YEAH, I KNOW, YOU SAID.

Patient: And, erm, I thought, 'Well this is the icing on the cake, this is.' That's, you know, one of the things I did, what did go through my mind, 'What next?' 'cos every time something happens I've said, 'What's next?' and now this.

INT: RIGHT, YEAH.

Patient: So ... yeah. Er, your mind goes into like a panic mode to start off with, you like, well I did, I like panicked, 'What about the kids?' and, you know, erm, 'How'm I gonna manage?' and things like that.

INT: MM, YEAH.

Patient: Er ... and I like dumbfounded, you can't really think straight, you know.

INT: YEAH.

Patient: But that time with Karen, erm, it does make, 'cos your head's in a whirlwind and it's spinning round, but then you go out that room and sit down in a nice environment, not a clinic room, a nice, comfy room ...

INT: WITH SETTEES AND STUFF AND ...

Patient: ... and sit there and you, you can feel yourself relaxing a bit.

INT: YEAH.

Patient: Erm, and because Karen, I don't know whether she, she seems so up on everything and she's so, erm ... I can't explain her, but out of anybody these breast cancer nurses they are brilliant, and I

will sing their praises, all of them, you know, 'cos Karen went on holiday the day after I had my op, so I've seen the others while ...

INT: OH RIGHT, OK, YEAH.

Patient: ... she's been on holiday. Karen's back now so I'm seeing her again. But it's nice to see that same person and that face, and I feel like I can talk to her as well. I know that I could ask her about anything, erm, and she's also been concerned about the family - it's not just about this, you know, erm, because when I found out, when I had my biopsy, the bloke I'm I was seeing, he was with me, so like the second time, my friend was with me and she said, 'Who's that man who was with you before?' and I said, 'A friend,' she said, 'I think it's a bit more than a friend, isn't it?' and since then she's been concerned about his feelings and my kids and things like that as well, which is one of my concerns, you know.

INT: ABSOLUTELY, YEAH.

Patient: So ... mm.

INT: AND DID SHE GIVE YOU ANY CONTACT DETAILS, ERM, LIKE A CARD OR A NUMBER YOU COULD CALL ON HER?

Patient: Yeah, straight away, she gave me her calling card with her name on, with her name written on the back, and I've her number, and she said if there was any questions any time I can phone her, but she don't work weekends.

INT: RIGHT, YEAH.

Patient: Erm, and on, she gave me a booklet which was very, very informative ... that one ... and that explained everything, a lot of things you would want to know is written down in here.

INT: YEAH, AND DID YOU READ ALL THAT INFORMATION YOU GOT?

Patient: Yeah.

INT: YEAH? MM.

Patient: Yeah, I'm just about to go back, 'cos I've had another one now about chemotherapy, and I read it when I first come home, but it hadn't sunk in ...

INT: RIGHT, YEAH.

Patient: ... so I'm gonna read it again today.

INT: RIGHT, OK.

Patient: But that was a real help that was, because you'd got it all the time to refer back to.

INT: YEAH, SURE.

Patient: And a lot of the things they said was in here, is in here, erm, but it's like when you come away you forget things, you know. But, yeah.

INT: SO, AFTER YOU SAW KAREN, YOU WERE WITH YOUR FRIEND, YOU COME HOME AFTER THAT, YEAH?

Patient: Yeah.

INT: AND HOW SOON AFTER THAT MEETING DID YOU HAVE YOUR OPERATION?

Patient: Came home ... I came home, [???] ooh, the Tuesday ...

INT: YEAH, IT WAS A TUESDAY.

Patient: ... the following week I had my op. But in between that, in between that I had go to an assessment unit. Came home on the Tuesday, the following Wednesday, erm, I had to go an assessment unit, then see a physio and then had an appointment with Karen ...

INT: OH, RIGHT, OK.

Patient: ... again, so I saw Karen again. That's something else, every time I've seen Karen she's had all my appointments lined up, I've not had to wait for 'em coming through the post, she's had them there.

INT: RIGHT, OH RIGHT.

Patient: And that day I went to pot I never went to the counter, she took me to this room, she says, 'I won't be a minute, I'll sort everything out for you,' left me for a few minutes in this room, come back, my appointment was made for me to go back for my results. When I went for my results she'd already got an appointment for the assessment unit and everything. And that is ... is a big relief, not waiting for that postman to come, 'When am I going in then?' and 'When is my ... when is my, have I got to go for this assessment?' and that is a real big help, well was for me mentally.

INT: SURE.

Patient: Erm, because it was all done for me, it was there, every time I saw Karen she'd got everything.

INT: RIGHT, THAT WAS GOOD.

Patient: Erm ...

INT: AND YOU WENT IN FOR YOUR OPERATION, IN BETWEEN THAT WEEK APART FROM THE PRE-ASSESSMENT CLINIC DID YOU CALL THE BREAST CARE NURSES OR ...?

Patient: No.

INT: ... AND DID YOU GO AND SEE THEM OR ANYTHING?

Patient: No, apart from seeing Karen ...

INT: ON THE PRE-ASSESSMENT CLINIC.

Patient: On the pre-assessment ... erm, in her room again, pre-assessment clinic, and she needed to know then what I was gonna have done.

INT: RIGHT, OK.

Patient: Erm, I had a lot of talking with, erm, friends and family. I near enough knew when I left that day after Sibbering had spoke to me ...

INT: RIGHT, OK.

Patient: ... but there was still that, 'Well, shall I go for a lumpectomy?'

INT: RIGHT, OK. YEAH.

Patient: Erm, and I thought, well ... this is another question, isn't it?

INT: [???

Patient: Like how I made my decision ...

INT: YOU'RE ANSWERING THEM AS YOU GO ALONG, AYE, THAT'S FINE, MAKE MY JOB EASIER. [CHUCKLES] YOU JUST KEEP TELLING ME WHAT YOU'VE GOT TO SAY. IT'S FINE.

Patient: Yeah, so throughout that week before I went for the assessment unit I'd got to make this decision, which ... erm, ... that was one of the things that was like going through my head all through that week.

INT: MM, YEAH.

Patient: Erm, but I spoke to, you know, I've got a sister, I spoke to her and friends and family and, it's funny how a lot of people react differently about what issues ...

INT: I WAS GOING TO ASK YOU HOW THE FAMILY TOOK IT AND STUFF AND ...

Patient: Yeah, about whether it were a mastectomy or lumpectomy though, how a lot of people have 'Oh, I would only have the lumpectomy,' and then you've got like my sister saying, 'You've got no choice, you've got to have that mastectomy,' and you've got all these people coming with different ideas, but at the end of the day it's me what's got to make that decision.

INT: OF COURSE, YEAH.

Patient: You know.

INT: AND DID YOU LOOK FOR ANY OTHER INFORMATION APART FROM WHAT YOU WERE GIVEN? DID YOU LOOK AT ANY MAGAZINES, ANY BOOKS, DID YOU GO ON THE INTERNET AT ALL, DID YOU VIDEOS, TV PROGRAMMES, ANYTHING AT ALL?

Patient: No, because I didn't really have time. With like, my mind was in a whirlwind, erm, I had the rest of the day off when I found out I'd got cancer and then the next day I went back to work, 'cos I thought I need to take my mind, I'm just gonna be moping round the house and feel sorry for myself, and I'd be better off going to work and taking my mind off things. And that's what I did.

INT: SO WHAT DO YOU WORK AT?

Patient: A secretary, Derby City Council.

INT: OH RIGHT, OK. ERM, AND YOU HAD, YOU WENT BACK TO SEE KAREN AT THE PRE-ASSESSMENT CLINIC ...?

Patient: Right, yeah, sorry I'm going off on one now.

INT: NO, NO, THAT'S FINE, THAT'S OK. ERM, AND SHE ASKED YOU FOR A DECISION THEN DID SHE?

Patient: Yeah.

INT: RIGHT, OK.

Patient: Yeah. Talked it through and by then I knew for definite I was gonna have a mastectomy, er, because of the, I might have to go back in and have to have it off anyway, if it become, because I'm gonna have the gene test so, if it becomes thingy that I have actually got the gene, then they would advise me to have it off anyway. So do I ... that means more surgery. So, I thought, well I might as well now.

INT: RIGHT, OK.

Patient: So ... but, yes, she did ask me, she didn't, she still wasn't swayed, she wasn't pushing me towards one or the other, it was definitely my decision, er, but she did say for the, they wasn't swaying toward one or the other, but she did tell me about the outcome, about being hereditary which sways you towards a mastectomy anyway.

INT: YEAH, SURE.

Patient: Erm, but I had got, you know the choice. And also there was this other element about, if I had a lumpectomy, erm, I would have to have radium treatment and, erm, and then my, having reconstruction would be lessened, but if I have a mastectomy and I don't need radium treatment I've still got that chance of having a reconstruction surgery if I need it. So there was that other aspect of it as well.

INT: RIGHT, OK. IS RECONSTRUCTION SOMETHING YOU WERE CONSIDERING?

Patient: Well, I didn't know at that stage.

INT: RIGHT.

Patient; I didn't, I couldn't really think that far ...



INT: RIGHT, YEAH, SURE.

Patient: ... that far. I thought, my, how I've got through this is, 'Let's get that out the way,' ...

INT: MM, STEP BY STEP.

Patient: ... 'Now let's go to the next stage,' you know.

INT: YEAH.

Patient: What I was hoping, because it was small, is that the one thing I didn't want was chemo, and that's the one thing I've got.

INT: OH, RIGHT, OK. WELL I WAS GOING TO ASK THAT TOWARDS THE END [???

Patient: Yeah, I'll talk that one ...

INT: ERM, OK THEN, SO, AND AFTER YOU, HOW SOON AFTER THE PRE-ASSESSMENT CLINIC DID YOU HAVE THE OPERATION?

Patient: I went to the pre-assessment clinic on the Wednesday and I had the op on the Friday.

INT: RIGHT, OK.

Patient: I went in and had the op that day.

INT: RIGHT, OK. AND, ERM, WHO, YOU SAW MR HOLLIDAY TO START WITH, THEN MR SIBBERING, WHO DID YOUR OPERATION?

Patient: Mr Sibbering.

INT: MR SIBBERING?

Patient: Yeah.

INT: OK.

Patient: Apparently it's whoever tells you you've got the cancer does the op.

INT: RIGHT, OK.

Patient: That's, that's what I've been told.

INT: WELL THAT KIND OF MAKES SENSE, I MEAN, REALLY, UNLESS THERE'S A REASON WHY THEY CAN'T, HOLIDAYS, VACATIONS, OR SOMETHING, BUT THAT'S GENERALLY THE WAY I THINK IT WORKS.

Patient: Mm.

INT: SO, ERM, JUST TELL ME, JUST RUN ME QUICKLY THROUGH WHAT HAPPENED ON THE DAY OF THE OP WHEN YOU WENT IN?

Patient: Erm, from the day of the op ... I got in and, oh I had to go early, oh, there wasn't a bed so I had to sit in the day room for a while. As soon as they got a bed available they took me to the bed ... I think they did my blood pressure and that, and then an anaesthetist come to see me and, erm, I [chuckles] I'd had, three years ago I had pleurisy and I had to have inhalers, but then, this is going off on another sideline, but he sudden-, but I haven't had, I haven't took inhalers for the past few months, not even the brown one, but they decided that they wanted to give me a nebuliser before I went to theatre, so, erm, so I was then, had to stop in bed and have this nebuliser ...

INT: RIGHT, OK.

Patient: ... for an hour or something. But, erm, so the anaesthetist come. What was nice is that my friend, my male friend, came with me and he was able to stay with me.

INT: OH, RIGHT, OK.

Patient: Yeah, and that was really, really nice. Erm ...

INT: WAS THIS, I MEAN, OVERNIGHT OR SOMETHING OR JUST DURING THE DAY OF THE OPERATION?

Patient: No, I came, on the day that, I went in at 7 o'clock in the morning ...

INT: RIGHT, YEAH.

Patient: He took me in and he was able to stay with me until I went to theatre.

INT: MM, OH GOOD.

Patient: Erm, he actually went to the theatre doors with me, so that was really nice, 'cos it scary, you know, when you ...

INT: YEAH, SURE.

Patient: ... not knowing what to expect really. They did tell me I'd have drains and that, but ... yeah, so, erm, so the anaesthetist come and then Mr Sibbering came and wrote all over bust, but he said that was to make sure that they removed the right one. [chuckles] So ... and then, erm, I went to theatre. Erm ... yeah.

INT: DO YOU REMEMBER WHEN YOU SIGNED THE CONSENT FORM TO SAY ...

Patient: Yeah.

INT: WAS THAT ON THE DAY OR WAS IT AT PRE-ASSESSMENT OR ...?

Patient: I signed one bit with Karen at the assessment thing and then I signed another one with Mr Sibbering I think, or the second part, or ... or did he ask me if that was my ... I'm sure I signed something ... yeah. I know I signed something but I don't, I don't know whether he asked me if that was, or I signed something else on the day.

INT: RIGHT.

Patient: I can't really remember, but I know I signed something with Karen and I know, he either shown me something or I signed it as well.

INT: RIGHT, OK. ON THE DAY. AND HOW WERE YOU WHEN YOU CAME OUT OF THE OPERATION?

Patient: Erm ...

INT: HOW DID YOU FEEL?

Patient: All right. Erm, it was quite, I'd got a mask thing on, erm, is it oxygen?

INT: YEAH.

Patient: I'd got that on which frightened my kids but I didn't know about it, and apparently was being a bit stupid but I didn't know I was. [chuckles] They've told me things what I did. I kept waking up looking at my hands for some unknown reason, looking at my hands then looking down there and then going back to sleep. I can't remember doing it, but, yeah, I was all right, yeah.

INT: AND HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: Erm, I had the op on the Friday and I come out on the Tuesday.

INT: SO THAT'S THREE OR FOUR DAYS, THEN?

Patient: Yeah. I should have been going out on the Monday ... and I'd started to get red along there then and one of the nurses fetched a doctor, I don't know who he was, and he said, 'Oh no, no, it's all right,' and that same day I actually, I thought I was prepared for this, and I'd seen myself in the mirror in the bathroom in the hospital, and I went to piece.

INT: OH YEAH.

Patient: So they kept me in another day.

INT: OH, I SEE.

Patient: So I didn't go out on the Monday, I went out on the Tuesday. But, yeah.

INT: AND THEN YOU'LL HAVE GONE BACK AFTER THAT TO SEE, HEAR ABOUT THE RESULTS OF THE OPERATION, AND YOUR HISTOLOGY?

Patient: Yeah.

INT: TELL ME ABOUT WHAT HAPPENED WHEN YOU WENT FOR THAT PLEASE?

Patient: Yeah, erm, they told me that I wouldn't be, that my results ... that was Karen ... I think that appointment was made before I even had the op ... I'm sure Karen explained to me that Mr Sibbering was holiday so when I went for the results it would be ... now I get her name ... Wader-- ...

INT: MISS WAHEDNA.

Patient: Wahedna, yeah. I was gonna be seeing her because Mr Sibbering wasn't going to be there, he was on holiday. So I'd to go to ... yeah, the, erm, right at the end, oncology ... no, urology ...

INT: ONCOLOGY.

Patient: Urology, is it?

INT: I THINK IT'LL BE ONCOLOGY, IS IT?

Patient: Oncology, is that chemo?

INT: YEAH.

Patient: No, it's this one, I had to go to the Urol-, Surgery and Urology ...

INT: RIGHT, OK.

Patient ... to get my results. But in between that I'd been filling up with a lot of fluid and I'd been to and fro to City Hospital to have it drained, seroma.

INT: SEROMA, YEAH.

Patient: Yeah. I had it drained. So I'd been seeing, I'd seen quite a few of the breast nurses in between that, and I went ...

INT: I THINK KAREN WAS ON HOLIDAY, YOU SAID [???

Patient: Yeah, Karen went on holiday the day I had my op, but I actually saw her when I was going to theatre.

INT: OH RIGHT.

Patient: She passed me in the corridor and got, I was in a wheelchair and ... yeah. Erm, so I'd seen a lot of the other breast cancer nurses to drain this off, erm, and then when I got, I went to this Urology place and I knew that I needed draining again, I was in agony again, and, erm, so all I wanted to do was hear my results ... my friend came with me again, my girl friend, and, erm, they took me in a room and drained me first and I remember thinking, 'Oh just tell me what ... what the outcome is,' you know, erm, but of course they had to drain this, Miss Wahedna drained it and then said, 'right, when you're dressed come back into the other room.' I can remember rushing to get my clothes on to get into this room just to know what the outcome was. And all the way along I'd been thinking, 'I just hope I don't

have to have chemo, I just hope I don't.' And, erm, she said, 'Right, the good news is that we've, we've caught your cancer ...' So I'm going 'Yes, yes ...' She says, 'Another good news is that the lymph nodes was clear.

INT: RIGHT, OK.

Patient: And so I'm like, I'm really, really happy then. She says, 'But ... the cancer isn't the cancer that's normally found in the breast, it's not hormonal cancer ...'

INT: RIGHT, OK.

Patient: ... 'So we can't give you Tamoxafen and your cancer is a very aggressive cancer,' so she says, 'So we're gonna have to give you chemo.' And I thought ... the pleasure of knowing they've caught it and then you go back down to earth with as bang, and, erm, 'cos that was the one thing I really didn't want out of anything. Course I'm scared of having it and I still am, I'm terrified for Friday.

INT: IS THAT WHEN YOU FIRST START?

Patient: I start this Friday, yeah.

INT: IT'S AT THE DRI?

Patient: Yeah. But, er, yeah. So she then went into, and she did draw me a diagram, erm, of what we mean by very aggressive cancer.

INT: OH RIGHT.

Patient: Because she said that, erm, she said it was very small but, and she said about my mother cell, that you get this mother cell in cancer and that it starts other, other cells grow off it and they normally are the same as the mother cell and then it isn't until it's progressed that these cells then form their own identity and become abnormal and different to the mother cell. And she said, 'With yours you've got the mother cell and immediately the cells are abnormal.

INT: OH, RIGHT, OK.

Patient: So she explained all that to me. Erm ...

INT: WELL THAT'S INFORMATION I NEVER KNEW, THAT.

Patient: Right.

INT: NO, NO. I MEAN I KNEW, I KNOW SOME OF THE BIOLOGY BUT ID DIDN'T KNOW THAT, THAT'S VERY INTERESTING. YEAH.

Patient: And she said that I couldn't have Tamoxafen because she said you might as well just flush it down the toilet. She said it would not do anything ...

INT: RIGHT, OK.

Patient: ... because it's not hormonal cancer.

INT: YEAH.

Patient: So she said 'It's just pointless you having it.'

INT: RIGHT, OK.

Patient: Erm, and she said ... I should have asked her but she said, 'And there's no need for radium.' I take it that's because they've caught it. I don't know.

INT: I'M NOT SURE, PROBABLY. I'M NOT SURE ABOUT THAT.

Patient: I don't know, you know. But she said, you know, erm, 'As a precaution we need to do chemo because of it being so aggressive, and because of your age,' she said. 'There's three factors,' she said, 'why we're gonna do chemo' One is my age, she says, 'You're young,' she says, 'and we want you to live for a few more years yet,' and two is because of the type of cancer it is, and three is because it's very aggressive. So ... but you could have knocked me for six when she told me that. Of anything that's what I didn't want.

INT: AND HOW LONG WILL THAT COURSE LAST?

Patient: Erm, nearly six months. It's .. I'm having it every three weeks, six shots at it. So it works out to about - if I have it on time - the end of January.

INT: OK. AND DID SHE EXPLAIN ANY SIDE EFFECTS THAT MIGHT COME FROM IT OR ...?

Patient: Well that was explained then ... ooh, she did explain briefly and I was given another thing then.

INT: ANOTHER INFORMATION ...?

Patient: Another, about chemo, then, and I was took in a room with a breast cancer nurse again, down at the Urology bit, erm, but not mine obviously, but one I'd seen before. Erm ... and, 'cos I was worried, the first thing you think of is oh your losing your hair and all that. That isn't my problem now, that isn't my biggest worry now.

INT: RIGHT, SO WHAT'S YOUR BIGGEST WORRY?

Patient: My immune system dropping.

INT: OH RIGHT.

Patient: That is scaring me.

INT: ER, YOUR WHITE BLOOD CELL COUNT AND STUFF, YEAH?

Patient: Yeah. I don't know why I'm scared to death. So ... but, yeah, and yet my boss has just been through it, not the same chemo as me, she's just had a hysterectomy and chemo and she was great with it, but I don't know why ...

INT: YEAH, IT'S A VERY VARIABLE THING. I MEAN IT DEPENDS ON THE STRENGTH OF IT, DEPENDS ON HOW THE BODY REACTS TO IT AND STUFF. SOME PEOPLE SAIL THROUGH IT, THERE WAS A LADY I WAS SPEAKING TO A WHILE BACK WHO WAS JUST TERRIFIED OF LOSING HER HAIR ...

Patient: Yeah.

INT: ... ABSOLUTELY TERRIFIED OF IT, AND I MEAN SHE'S ACTUALLY IN THE SERVICE, I MEAN SHE LOOKS AFTER BREAST CANCER PATIENTS, YOU KNOW, RIGHT UP TO THE POINT, YOU KNOW, WHERE IT'S, THEY'RE PALLIATIVE, THEY'RE DYING, AND SHE SAID, 'OF ALL THE THINGS I'M WORRIED ABOUT IS LOSING MY HAIR,' SHE SAID, 'IT SOUNDS AWFUL, DOESN'T IT?' SHE SAID, BUT IT'S A VERY COMMON THING FOR A WOMAN TO BE WORRIED ABOUT THAT. AND SHE'S JUST FINISHED NOW ...

Patient: Right.

INT: AND SHE SAID SHE SAILED THROUGH IT. SHE SAID, 'OH I HAD VISIONS OF MYSELF LIKE COMPLETELY HAIRLESS SORT OF THING, YOU KNOW, EYEBROWS AND EVERYTHING, AND SHE SAID IT NEVER HAPPENED. SO, IT JUST DEPENDS ON THE, IT'S VERY INDIVIDUAL. SO ...

Patient: Yeah. But, er ... yeah. I've got my head round that, hair loss, you know, but ... yeah, it's just, it was the one thing I didn't want, and to hear that ...

INT: YEAH, SURE.

Patient: ... was as bad as finding out you'd got cancer in a way.

INT: AHA.

Patient: I don't know.

INT: ERM, OK. SO, I THINK YOU'VE ANSWERED NEARLY EVERY QUESTION, I THINK [???

Patient: I go off on one, don't I?

INT: NO, YOU'VE GONE NICELY THROUGH THE WHOLE PROCESS REALLY. THINKING ABOUT THE TIMES THAT YOU, ERM, SPOKE WITH MR SIBBERING, YEAH WHEN YOU SAW HIM, DO YOU FEEL HE LISTENED TO YOU? DO YOU FEEL HE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS?

Patient: Yeah, yeah.

INT: HOW DO YOU FEEL YOU GOT ON WITH HIM?

Patient: Er, OK, yeah. He, erm, I feel like wherever he didn't, Karen took over, so I got that back-up all the time. And like when you do go and see a doctor your mind does go off on one, but Karen was always there, erm ... it's always, to me it's always frightening seeing a doctor, you know, but, yeah, I mean he was straight John Bull, he didn't beat about the bush, he came straight out with it. He told me my options, you know, and I mean I'm still seeing, I'm seeing him again this Thursday, 'cos of this, you know, erm, [chuckles] he, I've just said to you he don't beat about the bush, but I've, I'm very swollen underneath my arm, and here is where I've got an open wound still, but underneath my arm I'm quite swollen, it's very ... thing ... erm, last, a couple of weeks ago I had to see him and I said to him, you know, 'This swelling, it's not fluid is it?' and I'm like worried because they tried to, in, oh when I, before I left hospital they give you two softies but they couldn't fasten my bra to get these softies in.

INT: OH RIGHT.

Patient: And ... I was that swollen you see, but they managed to really, and I couldn't breathe with my bra to get my bra fastened to fit me with this softie, I've not been able to wear it yet 'cos I can't, I can't put my bra on because of all this. But, erm, so I said to him about this swelling, and he said, 'Let me have a look at your right, your proper ... this other arm,' so I had to put my arm out, lay on the bed and ... and he said, and he explained to me that this side's the same but my bust's holding it up.

INT: RIGHT.

Patient: He said you don't realise that your bust holds certain parts of your body up, and, erm, so I said to him, 'So you're trying to tell me I'm fat, it's fat?' And he, he laughed and said, 'Well you're very plump there,' he says, 'so I didn't want to say you're fat ...' [chuckles] so beating about the bush, but he didn't beat about the bush then. Yeah, he ... no, he kept, you know, he did like, it's the opposite to what I've just said, he went round the houses to tell me, but he said even thin people, Karen's explained to me as well, even thin people would have, because there is thing, muscle things there ...

INT: [???

Patient: ... that your bust holds up, yeah. But that's something that they never tell you before you have the op, so, yeah, it's something they don't explain to you.

INT: RIGHT, OK. AND, I MEAN, YOU BRIEFLY MET THE OTHER TWO CONSULTANTS THEN, MR HOLLIDAY AND MISS WAHEDNA, I MEAN, CAN YOU JUST GIVE ME YOUR IMPRESSIONS OF THOSE TWO? I MEAN YOU ONLY SPOKE TO THEM VERY BRIEFLY I KNOW, BUT ...

Patient: Yeah, erm, Wahedna seems to be very ... she'll tell you everything straight John Bull, erm ... and, I mean, she was quite nice, she looks at you in the eyes, which I think ...

INT: YEAH, SURE.

Patient: ... erm ... you know, and as I say she explained all the cancer and that to me, so I've got ... and Mr Holliday then, I only saw him very, very briefly. He came, tried to feel this lump, couldn't find it and then it was his colleague who did the biopsy ...

INT: OH RIGHT, OK.



Patient: ... and I didn't really have any dealings with him at all, erm, you know, so I can't really say for him.

INT: MM, OK. AND THINKING ABOUT THE TIME YOU SPENT WITH, ERM, I MEAN YOU PREDOMINANTLY SPOKE TO KAREN, DIDN'T YOU, THE BREAST CARE NURSE? I MEAN HOW DID YOU FEEL YOU GOT ON WITH KAREN?

Patient: Yeah. Really, really good, yeah. And in fact all the breast cancer nurses. They are absolutely brilliant.

INT: DO YOU FEEL THAT THEY WERE LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS, YOUR CONCERNS AND THINGS?

Patient: Yeah, yeah. And she remembers things. I mean she's brought things up the next time I've seen her, erm, 'Well, how are you doing with that?' and they sent, the district nurse sent me last week for Karen to have a look because I've had, with, erm, this infection here, they've found an ... erm, suddenly a loop of stitches appeared here hanging ...

INT: OH RIGHT.

Patient: ... and I've had to have, they've had to cut 'em out, and then they've cut some little bits from underneath my arm out and they was concerned that there was some stitches in there, so they sent me off to see Karen last week. And, er ... Karen was there and answered all my questions about all my concerns that I've had, like, I've built up over, 'cos I haven't seen nobody for two weeks and, erm, you know, she's been there and answered all my questions and that. I was going to tell you something else and I can't ... no, it's gone, it's gone, I don't know what it is. I don't know, what was ...

INT: OH I WAS JUST ASKING HOW YOU GOT ON WITH HER, IF SHE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS AND IF SHE LISTENED TO YOU.

Patient: Yeah, yes, she did, yeah.

INT: OK. AND, ERM ... SO CAN YOU TELL ME FROM WHEN YOU ACTUALLY HEARD YOUR DIAGNOSIS, ERM, HOW LONG DID IT TAKE YOU TO MAKE UP YOUR MIND WHAT SURGERY YOU WERE GONNA HAVE? WHEN YOU FINALLY DECIDED ON IT.

Patient: Yeah, I near enough knew the day after.

INT: RIGHT, OK.

Patient: But there was this lumpectomy swimming round in my head still, but I would say within a few days I knew deep down. I knew deep down really from the word go but I'd just got to get, eliminate this lumpectomy.

INT: RIGHT, OK.

Patient: 'Cos that seemed to be an easier option because I'd still have something there, but, erm, yeah. So I would say for definite, 100 per cent definite, after a couple of days.

INT: AND ONCE YOU'D MADE YOUR MIND UP DID YOU HAVE ANY SECOND THOUGHTS? DID YOU CHANGE YOUR MIND AT ALL?

Patient: No. No. I knew it was the right way to go ..

INT: RIGHT, OK.

Patient: ... for my circumstances.

INT: YEAH. AND, ERM, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE YOU WANTED BETWEEN THE SURGERIES?

Patient: Yeah, yeah. Yeah, I had the choice of the two, so, yeah, I did.

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

Patient: Rather than the lumpectomy?

INT: MM, YEAH.

Patient: Erm ... not just one factor, like I've said, the hereditary side of it, the ... it was automatically lessening my chances to have reconstruction surgery if I feel like I need it, it was limiting my chances for that - I still don't know whether I would go through that or not - but my chance now is still there. So that was another factor. Erm ... and personally I feel, well, I don't know whether I'm right or not, but I personally thought, 'Well, let's get it all off, it's less chance to go,' [chuckles] and I don't know whether that's true or not but that was up here in my head.

INT: YEAH, MM.

Patient: You know. I probably haven't told many people that.

INT: RIGHT.

Patient: But, yeah. Er, because I was given quite a lot of information, the fors and against both, erm, I think, you know, I'd a lot of information about it from the hospital to, you know, make a decision really.

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

Patient: Really, really good. Yeah ... yeah.

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

Patient: Yeah. Yeah, I do. Yeah.

INT: AND IS THERE ANY PART OF IT YOU THINK HASN'T MET YOUR EXPECTATIONS?

Patient: Erm ... no, I think ... no, I think that most of it, erm, yeah, I think all of it has really.

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

Patient: Erm, in my circumstances, probably stopping in 't hospital a bit longer.

INT: RIGHT, OK. WHY IS THAT, THEN, DO YOU THINK?

Patient: Erm, or ... no, maybe not. I was frightened the first few days and then when this, I got filled up with fluid, erm ... no, probably not. It was nice to go home in another respect. Er, I don't know. Not have the op. [chuckles] No, I don't, I don't know.

INT: THAT'S 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 THEIR, RECEIVING THEIR DIAGNOSIS?

Patient: Erm ... to finding out that you've got breast cancer?

INT: MM.

Patient: Erm ... mm ... er ... I don't really know on that one, because I was, they need to know all the facts and like I was given the options, you know, lumpectomy or mastectomy, and how big the cancer was. Don't, yeah I think that is [???] erm, knowing that it was a small cancer gives you hope in your head ...

INT: YEAH.

Patient: ... erm, although you've still got that doubt. Erm, and being told exactly what's gonna happen to you, to me was, so you'd got nothing, you knew what was, you know, like I knew I was gonna wake up with drains coming out my side and ... you know, so ... yeah. Erm ... and I can't pinpoint one thing. Everything I was told I think I was told right.

INT: RIGHT, OK.

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

Patient: About the operations?

INT: YEAH. WHAT DO YOU THINK ARE THE MOST IMPORTANT THAT PATIENTS NEED TO KNOW ABOUT THOSE?

Patient: Like the choices, like the things what made me decide mastectomy?

INT: YEAH.

Patient: If they think that it's hereditary, I think they ought to be told that, if they find it's hereditary, that they might have to have it all off anyway, and about the reconstruction surgery, that radium treatment tightens the skin, because if then people, that can, that played a part in my decision, and if then people weren't told that ... you know, if somebody wasn't told that the radium treatment tightens the skin, and that later on, a year later they might decide to have reconstruction surgery and they're told they can't because they've had a lumpectomy and they had to have radium treatment ... then, erm, to me, yeah. Erm, yeah, I would think that ... and about the cancer as well. I mean I've wanted to know - I don't want 'em to hide anything from me, you know. So that's ... have I answered the question right?

INT: YEAH, THAT'S FINE, THAT'S OK.

Patient: [???

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

Patient: No .... I've just thought about something I should just [???] about what they should tell patients before they have the op, and I think that you should be told more about - perhaps it doesn't happen to a lot of people - but about this seroma, about filling up with fluid.

INT: YEAH.

Patient: Because at first I wondered what was happening ...

INT: RIGHT, OK.

Patient: ... er because I wasn't, it is in the book but it's very, it's not that very ... erm, clear ...

INT: YEAH [???

Patient: ... in this book, and, erm, I did wonder what was happening to me. So I would, erm, and if .. well if I need to say anything about what's happened to me, did you say? I can't ... I can't remember what you just said.

INT: ANYTHING YOU THINK THAT'S IMPORTANT THAT YOU THINK WE'VE MISSED OR NOT COVERED.

Patient: No, I think we've covered everything. I think you know about everything what's happened to me. Yeah.

INT: OK.

Patient: I think so, yeah.

INT: RIGHT THEN, I'LL TURN OFF.