

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Medium MR unit
*DATE:
*ID: Patient10
INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED AND TAKING PART IN THE STUDY. I'D LIKE TO START WITH QUESTION ONE, CAN YOU TELL ME A BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, not a lot really. I mean my friend had to have her breast off.

INT: RIGHT, OK.

Patient: And she didn't talk about it till she knew the time[?], that's about all, I didn't really understand anything at all about it. Did you, [???].

?: Not really.

INT: AND HAVE YOU HAD ANY FAMILY THAT HAVE BREAST CANCER BEFORE?

Patient: No.

INT: OH, OK. AND HOW LONG AGO DID YOUR FRIEND HAVE BREAST CANCER?

Patient: Erm, well I say I found a month before I went into [???] I felt it when I was in t' bath. Well my arm ached actually and I carry hoover and a bucket in this hand, and even put it down to aching from work, and I felt and thought there was a lump here, so I felt the other side and there wasn't, so I kept feeling this little lump, and I was there for about a month, and I thought, 'I'll go to the doctors.'

INT: RIGHT, OK.

Patient: So I went to the doctors and the doctor examined and he said he couldn't find one, but he said, 'You are going for a mammogram,' and they'd already sent me the thing for mammogram, so when I went up for the mammogram and had the first, the second mammogram, because I had one when I were 51, er, I told her and she had a feel and then she wrote it down when she sent the x-rays to Calow. And then from then on you've to wait two ... is it two or three weeks to go back? They sent me a letter saying they wanted me to go for another mammogram there. So I had a, I had, I don't know if I had two or three mammograms' then I had to have a ultrasound; then they did me, they took five biopsies; then you come home and you're bruised; and then a week later I had the results and he said, 'Have you seen your x-ray?' and I said no, so he said it was just a small, small one, and he said years ago there was ... what's the word for it?

INT: MASTECTOMY?

Patient: They used to take 'em off.

INT: YEAH.

Patient: They were very, you know, take 'em ... what's the word?

?: Very aggressive.

Patient: Yeah.

INT: OH AYE, YEAH.

Patient: They used to take me off, he says, 'But now we can give you, you know, with it only being a little one, a lumpectomy,' and they'd take, I think he said two lymph glands. So I had that done a fortnight yesterday and then we went last Wednesday for the results, because they send 'em away ...

[telephone rings]

... because they send 'em away, and he said that he's took four glands, one was ... what's the word for it?

INT: POSITIVE?

Patient: One, he wasn't very pleased with one of the lymph glands and he'd took more out than he thought, it was bigger, the cancer was bigger than he thought and he'd took more out, and he said, er, that he'd, he wasn't very pleased with the cells round it.

INT: RIGHT, OK.

Patient: So, erm, the only option is then, is to say to have your breast off, and I have, I didn't think to ask if they'd take any more lymph glands because they usually take 'em all, don't they? And that's t'only thing that I can do now.

INT: YEAH, OK. ERM, WHEN YOU FIRST FOUND THE LUMP, I MEAN YOURSELF, WHAT WENT THROUGH YOUR MIND AT THAT POINT, REGARDING WHAT IT MIGHT BE?

Patient: Well, to be truthful, I thought I might have pulled a muscle, and then I have a girl comes and she waxes me and you have to hold your breast like that, you see, while she does under your arm, so I thought maybe I'd pulled a muscle ...

INT: AH, RIGHT?

Patient: That's what I thought.

INT: YEAH, OK. AND YOU SAID THERE WAS A BIT ...

Patient: And even when I went back ...

INT: YOU SAID THERE WAS A BIT OF PAIN INVOLVED AS WELL?

Patient: Yes, my arm was aching here. But even when I, that's why I thought, and when I went back it was such a shock because I thought they'd say it was a pulled muscle or they would have said it was a cyst or something like that. That's what I thought, because my other friend [chuckles] she had it and she'd had a cyst. She said, 'Oh don't ...' she told me everything what'd going to happen, you see, exact to it, but she said she had to go and have this cyst taken out and she had five stitches and what-have-you, and then that was it for her. She had to wait for her results but she was all right. But he did tell me that mine was cancer but it was only small, but obviously they can't tell till they've cut you open, nobody can ...

INT: YEAH.

Patient: ... and then he's found that it was bigger than he thought, you see.

INT: YES, RIGHT. AND WHEN YOU WENT ALONG TO YOUR SECOND MAMMOGRAM YOU SAID THEY TOOK SOME BIOPSIES, IS THAT RIGHT?

Patient: Yeah, and the ultrasound.

INT: DID YOU SEE THE CONSULTANT AT THE SAME TIME?

Patient: I did, it was Mr Chadwick.

INT: MR CHADWICK, YEAH.

Patient: Very nice, they was all very nice. Everyone that was involved was very nice.

INT: MM. SO WHEN YOU SAW HIM DID HE GIVE YOU ANY IDEA WHAT IT MIGHT BE AT THAT TIME?

Patient: He did say what it was.

INT: OH HE DID SAY?

Patient: He did say it was.

INT: OH, HE ACTUALLY SAID AT THE TIME IT WAS A CANCER.

Patient: He did, yeah.

INT: OK.

Patient: And, but he didn't perform the operation, Dr Holt did.

INT: YEAH, MR HOLT, YEAH.

Patient: Yeah. And I saw him when I had to go back down before the operation, I had to have wires put in it ...

INT: TO GUIDE THEM.

Patient: That's it.

INT: YEAH, LIKE A NEEDLE [???

Patient: Yes, and then I had to have some, three more mammograms. Well she did two and one didn't work, she said, so I had to have another. And I wondered what them was for, I suppose that, like you say, to guide 'em, and Mr Holt came through and said that he was doing the operation.

INT: RIGHT, OK.

Patient: And he seemed very nice, you know, and it was him that came to me after and said that I could go home the next day. So, but I find, I find them all of them what's involved with it very nice. But the only thing that I didn't like was, when we went, bearing in mind we've never gone through this before, my husband sat outside - he could have gone in with me when he was giving me the results and nobody told me that he could go in with me.

INT: OH.

Patient: So when she, when I came out she took, the cancer nurse took me into a little room and said, 'Is there anything you want to ask me?' and I said 'No'. And she says, 'Is that your husband out there?' I said 'Yes,' she says, 'Do you want to fetch him in to, erm, for you to tell him in front of me,' like and I says, 'No, I'll tell him when I go outside,' and she did, I said, 'Could he have come in with me?' and she says, 'Yes,' she says, 'That was our fault, we should have told you.'

INT: AH RIGHT.

Patient: And that was the only thing that I think they should tell you, you know, your partner, your sister or whoever can go in with you, 'cos it's a shock, isn't it and you're not taking everything in what they're saying?

INT: YEAH, EXACTLY.

Patient: They probably would, you see.

INT: YES.

Patient: That's the only thing I'd say.

INT: RIGHT, OK. SO WHEN HE CONFIRMED, MR CHADWICK, WHEN HE CONFIRMED THAT YOU HAD CANCER, WHAT WERE YOUR FEELINGS AT THAT POINT?

Patient: Well I was a bit shocked because, like I say, I thought it was ...

INT: [???

Patient: ... pulled a muscle or a cyst, you know. I wasn't expecting it.

INT: RIGHT, YEAH.

Patient: But, yeah, you just have to take things, don't you? We'd already had, we'd lost my brother, my brother died a year to t'day when I went, a year day before, an't he, before I went in? And he had a brain tumour. He had cancer of t'testicles first then he had a brain tumour and they couldn't do anything it was so deep.

INT: OH RIGHT.

Patient: And my Mum died o' cancer, she had cancer of the bowels and then it went into her liver; and my cousin at Cannock, he's died of cancer of the throat and the lung; and his mother, my Mum's sister, died of cancer of the bowel, didn't she? But we don't know about all t'other relatives, do we? And my niece, she just got her results last week, 'cos she'd got a lump here, and it was a cyst, weren't it?

?: Mm.

Patient: So ... but we haven't had cancer of the breast before in t'family, have we. So I think we've got a bit used to it, haven't we? Oh, and, and my brother's, er, grandson, was only three and he had cancer of his kidneys, and so they give him chemo, took his kidney out and then give him some more chemo but he's ...

INT: WHERE WAS THIS? [???] WHERE'S HE, IS HE IN SHEFFIELD OR ...?

Patient: He did, they took him to Chesterfield, didn't they, then took him to Sheffield ...

INT: YEAH, 'COS THERE'S A CHILDREN'S ...

Patient: ... and then did they do it at Nottingham? Were it Nottingham he went?

?: [???] where the show was, wasn't it?

Patient: Yeah, Nottingham, my brother went there, didn't he?

INT: THERE'S A CHILDREN'S HOSPITAL AT SHEFFIELD, IT'S SUPPOSED TO BE QUITE GOOD, ISN'T HE?

Patient: Do you know which one he went in?

?: He went to Nottingham, didn't he, Queen's Med?

Patient: Queen's Med.

INT: AH YEAH.

?: Because they come from Belper, you see, so we tend to go [???]

INT: AH RIGHT, YEAH.

Patient: But he's OK now, isn't he? So ...

INT: YEAH, I THINK IT'S AWFUL WHEN, IT'S VERY HARD, I MEAN IT'S HARD WHEN ANYONE GETS CANCER, BUT WHEN, IT'S LIKE ...

Patient: When it's a child as well ...

INT: IT'S JUST SO ...

Patient: We'd got us brother, hadn't we, and then we'd got him. We've got a lot of, a lot of worry, an't we?

INT: OH YEAH.

Patient: I thought I was going to have a nervous breakdown, because there's seven of us in us family, and of ... the oldest one's 66, and of the young-, it had to be the youngest of us got the brain tumour. And you just don't know why.

INT: YEAH. YEAH, IT'S AWFUL WHEN KIDS GET IT.

Patient: We had a lot of things, didn't we?

?: Mm.

Patient: And then a lot of people was hanging theirselves and Rosemary's daughter's boyfriend hung hisself, didn't he?

?: Yeah.

Patient: Shane, my brother's wife's brother, he killed hisself, didn't he? I know quite a few people, I thought, 'Crikey, anything else?' we had one thing after another.

INT: MM. HAS THIS ALL BEEN OVER THE LAST TWELVE MONTHS OR SOMETHING OR ...?

Patient: It has yeah.

INT: YOU'VE BEEN THROUGH QUITE A BIT THEN ...?

Patient: We thought we'd had enough, yes, we thought we'd had enough, didn't we? And then we had this.

INT: ERM, SO WHEN YOU SAW MR CHADWICK AND HE CONFIRMED IT WAS CANCER, WHO WAS WITH YOU AT THAT TIME, WHEN YOU WENT, 'COS ...?

Patient: There was two nurses.

INT: RIGHT, YEAH.

Patient: Two nurses.

INT: WAS THAT MARY AND DONNA, OR WAS IT TWO CLINIC NURSES?

Patient: There was a, one was a breast, er, breast care I'd say, I think that was Mary, erm, I didn't meet Donna till I was having my operation. It must be another, yes.

INT: RIGHT, YEAH, OH PROBABLY A CLINICAL NURSE OR SOMETHING?

Patient: Yeah.

INT: AND WAS, WERE YOU, WAS ANYBODY WITH YOU, ANY MORE OF YOUR FAMILY WHEN YOU WENT TO HEAR THE DIAGNOSIS - YOU SAID THAT HE GAVE YOU AN INDICATION IT WAS CANCER AFTER HE TOOK THE BIOPSIES ...

Patient: Yeah.

INT: ... WAS THAT THE SAME VISIT, WAS IT?

Patient: Yes, that's when, when I said afterwards, when he'd give me the diagnosis, could my husband have come in and she said, 'Yes, we should have told you.'

INT: RIGHT, OK. AND DID HE DESCRIBE, DID HE DESCRIBE THE OPERATIONS YOU COULD HAVE AT THAT TIME?

Patient; He did, he did.

INT: SO WHAT DID HE SAY THEN?

Patient: He said, erm, if, he said, with, you know, they used to be drastic years ago and take the whole breast off, but with it being only a small bit, if I had a lumpectomy, you know, I wouldn't have to have all the breast off. So I, we'd decided to, well I decided to have that. But, I mean, it would have been marvellous, wouldn't it? I mean he's made a marvellous job, it's just that it had gone into the lymphs and [???] you see.

INT: YEAH, RIGHT, OF COURSE. AND WHEN HE WAS DESCRIBING THE OPERATIONS YOU COULD HAVE, DID HE USE ANY KIND OF VISUAL TOOLS LIKE DID HE DRAW ANY DIAGRAMS ...

Patient: Oh yes, he did.

INT: ANY PICTURES, YEAH?

Patient: Oh, yeah, everything, he explained everything, yeah. What did I do with my piece of paper? I saved it for ages.

?: Well he told you what drugs you'd be taking, didn't he, and everything?

Patient: Oh everything, everything. Everything so I could understand.

INT: [???] I'VE NEVER ACTUALLY SEEN HIM DO THIS BEFORE.

Patient: You see, there you are, there's your lump, there's your lymphs, and then he goes down, then he takes so much round it, you see ...

INT: YEAH, [???] CANCER HE TAKES A BIT ROUND, OK.

Patient: Yeah. Then you take that tablet.

INT: AH RIGHT, TAMOXAFEN.

Patient: Yeah, and then, er, he said five weeks of radium at Sheffield.

INT: RIGHT, IS THAT WESTON PARK?

Patient: Yes.

INT: THAT'D BE WESTON PARK, YEAH.

Patient: So that's what I thought I was going to have, see.

INT: THAT'S WHAT YOU THOUGHT YOU WERE GOING TO HAVE, YEAH, OK, RIGHT. I'VE NEVER ACTUALLY SEEN THAT BUT I KNOW THEY DO DRAW DIAGRAMS, I HAVEN'T SEEN IT ACTUALLY.

Patient: Yeah, it's good, isn't it, when they do that, you see, it explains it better for you, don't it.

INT: AND, WHAT ELSE WAS I GONNA ASK?

Patient: Plus my sister went on t'internet and got it all about it because my husband is so whittle, he was in a state, wasn't he?

?: Yeah.

Patient: So it helped him, didn't it?

INT: YEAH. THAT WAS MY NEXT QUESTION I WAS GOING TO SAY, HOW DID YOUR HUSBAND TAKE IT?

Patient: Oh, he didn't take it very good. It made him all worked up and that, didn't it? Very nervous. He's just accepting it a bit and I've had to shout at him. I says, 'It should be me like that, not you, you're no good to me if you're like that,' you know. But, erm, he's a lot better now I think, now he understands, isn't he?

?: Mm, yeah.

INT: AND HOW DID YOU FEEL YOU GOT ON WITH MR CHADWICK?

Patient: Very well.

INT: YEAH?

Patient: Very nice.

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

Patient: Oh, yeah, yeah.

INT: THAT'S GOOD THEN.

Patient: If I wanted to ask him anything I could have asked him, you know, but you can't think at that particular moment, can you? You're a bit numb.

INT: IT'S A BIT, WELL IT'S NOT JUST THAT, I THINK ALSO IT'S A BIT DIFFICULT TO ASK QUESTIONS WHEN YOU DON'T EVEN KNOW WHAT QUESTIONS TO ASK.

Patient: No, yeah.

INT: THAT'S ONE OF THE THINGS, YEAH, IT'S SOMETHING THAT JUST HITS YOU AND THAT'S IT REALLY, ISN'T IT?

Patient: Yeah, and you come away and you think, 'Oh, I wished I'd asked him this,' don't you?

INT: MM, AND YOU'RE RIGHT, I MEAN, IF YOUR HUSBAND HAD BEEN THERE AT LEAST HE WOULD HAVE BEEN AN EXTRA PAIR OF EARS.

Patient: Yes, he'd have been asking, yeah.

INT: DIDN'T HE GO IN WITH MARY? WAS IT MARY YOU SAW AFTERWARDS?

Patient: Yes.

INT: YEAH. TELL ME A BIT WHAT HAPPENED WHEN YOU SAW MARY.

Patient: Well she asked me if I wanted to talk about it and I said no, no, but this time, when we went back Wednesday for the results after the operation, I took my sister, my daughter, my husband, and we all went in. And they asked [???] like and they took my stitches out and then, er, it were Mary, Mary again, weren't it? But, and she was very, very helpful, weren't she? We asked her about if you could dye your hair and she told us that you could have it, a thingy after, what do you call it?

?: Reconstruction.

Patient: Reconstruction, you know, and about a wig and about your chemo and ... everything, she was very helpful.

?: You didn't, you thought she was a little bit evasive first time, didn't you?

Patient: Yeah, well, she asked if I wanted to ask her any questions and I was, I didn't know what to ask anyhow, did I?

?: No.

INT: AND SO, AFTER YOU'D BEEN GIVEN YOUR DIAGNOSIS BY MR CHADWICK, HOW LONG WAS IT AFTER YOU HAD THE OPERATION, WAS IT A WEEK OR SO, TWO WEEKS?

Patient: Two week, weren't it? I went on the Friday and ...

?: It wasn't the following week because Jim was [???]

Patient: No, it was about two weeks, just over two weeks, weren't it, for the first one? Like it'll be, it's two weeks on Monday since I had my other one, three weeks, won't it, my next one?

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

Patient: Yes, as soon as I went for my operation, Donna, Donna came and she gave me the book of exercises after your breast, you know, your breast, your operation, and then I saw her again and she said, she gave me the forms and she explained a bit about what it was, you know. So she said, 'You don't have to do it if you don't want to.'

INT: OH, THIS PROJECT DO YOU MEAN?

Patient: Yes. So I kept it for a bit because I thought I'd give myself time to get a bit better, you know.

INT: OH, YEAH, OF COURSE, ABSOLUTELY.

Patient: And then I thought, I says to Jim, 'I didn't fill that form in,' so I thought I'd fill it in because it might help somebody else.

INT: MM, ABSOLUTELY, YEAH. WELL I SAID I'LL TELL YOU ABOUT, GIVE YOU THE INFORMATION AT THE END, YEAH. AND THE BREAST CARE NURSES, DONNA AND MARY, HOW DO YOU FEEL YOU GOT ON WITH THOSE?

Patient: Oh very well, mm.

INT: THEY WERE LISTENING TO YOU AND UNDERSTANDING YOUR NEEDS AND CONCERNS?

Patient; Yeah, oh yeah. They was, wan't they?

INT: SO CAN YOU JUST TELL ME WHAT HAPPENED WHEN YOU WENT IN FOR YOUR OPERATION ON THE MORNING THROUGH TO WHEN YOU WOKE UP?

Patient: Well when I went in they said you couldn't have any drink or anything to eat or anything like that. Erm, the anaesthetist came to me and she asked me questions, you know, about everything, and then she ga-, then she went away, and then my husband's sat there and they come and fetched me to take me down to put these wires in, you see, and these mammograms. Well that took about an hour so Jim was sit behind curtains and I sort of kept saying he'll be worried to death worrying where I am, you see. Then when I came back the anaesthetist came and gave me some tablets and a little plastic thing of, container of water. So I took them and then I told my husband to go because she said I was going for my operation. This was about one, quarter past one, I was going down about three. So they fetched me at ten to three, erm, there was somebody [???] that lives up the road, I didn't know him at the time, like, and this other - I think this other nurse's name were Mary. Not a nurse, student nurse. And she took me down, and then I was talking to, there was another young girl, she was talking as well, and then I had to go through another place and they said, the anaesthetist was talking to me, they put the needle in and she was pressing something there and the lad's name was Shaun, he were Irish, and he was talking to me, and he said, I said, 'Oh, Shaun is it?' she says, 'Yes.' I says, 'I've got a brother, I had a brother Shaun, and my husband's got a brother Shaun and how was it spelt ...' and I was trying to spell it English way and he said his was Irish way. And I think he give me t' injection here, or he did something here anyhow. 'Just can you sit up a minute?' I says, 'Yeah,' and then he said, 'How do you .. oh, mine's t' Irish way.' So then this anaesthetist says to him, 'Are you Catholic?'

and I said, 'Yeah', er he said, 'Yes,' and I says, 'Yeah I am Catholic ...' and then that was it, I can't remember anything else.

INT: YOU WERE OUT WERE YOU?

Patient: And then when I woke up somebody was saying to me, I can't remember 'em saying Diane but they said, I woke up and I said, 'Are we ready then?' I thought I was just going for my operation and they said, 'You've been, duck,' I says, 'Good.' [chuckles] And then I woke up in bed and ...

INT: WERE YOU ALL RIGHT THEN AFTERWARDS, AFTER THE OPERATION?

Patient: Yeah, I was tired and I'd got the blood pressure thing on here, I'd got I think it's a salt water drip I'd got on, and oxygen mask on my mouth and my husband, I thought, 'Well Jim'll be coming in a bit,' so I just had a little kip and then he came and the first words he says to me was, 'Oh you u do look well.' I says, 'Well you can tell you're Irish,' I says, 'I've got t' oxygen mask on, thing on here,' I says, 'and two, and t'drip,' and you say, 'You do look well.' So we laughed like, and then when he'd gone I asked her for a cup of tea and some, if I could have something to eat, I was starving.

INT: OH YOU WOULD BE.

Patient: And then I never went to sleep all night. All of us in the ward stopped chapsing[?] we were all talking. Some had had operations for hysterectomy, you know, that had got complications; and then there was another girl had got appendicitis; and then this woman had come in, she was having a miscarriage. Well she were moaning a bit and we were kept awake for her and then she had to go down for an operation early in t'morning. And then other one had to go for a, what do you call 'em, a scan, and then I just saw them before I left. I give 'em all a kiss and then I come home.

INT: HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: Just ... they told me about half past nine t'next morning I could come home.

INT: OH, THAT'S ALL RIGHT THEN.

Patient: Mm, he said, Dr Holt came, he said, he look very pleased with himself so it must have gone all-, he thought it, he must have thought it'd gone all right.

INT: IT WAS MR HOLT THAT PERFORMED THE OPERATION, THAT'S RIGHT.

Patient: Yeah, yeah. And he said, 'Did you sleep last night?' I said, 'No.' He says, 'Well you'll sleep tonight.' And he says you can go home, and then that was it. I tried to get my husband and my daughter and they were both talking to each other so I had to phone my sister to go round. [chuckles]

INT: YEAH. LET ME SEE, WHERE ARE WE? WHEN YOU THINK, NOW THINKING ABOUT THE CONSULTATION WHERE YOU ACTUALLY GOT YOUR DIAGNOSIS AND THAT, WHEN YOU WERE TALKING TO MR CHADWICK, WHO DO YOU THINK DID MOST OF THE TALKING AND WHO ASKED MOST OF THE QUESTIONS DO YOU THINK?

Patient: I think he, he probably did most of the talking because he did the diagram and explain it to me and he asked me if I understood it and ... I might have asked him a few questions, you know, what I didn't understand. But I mean I didn't know what, you don't know what questions to ask 'em really, do you, if

you've never had it before. But he did explain it all very well with the diagram.

INT: AND AFTER YOU'VE HAD THE OPERATION NOW, HOW SOON WAS IT FROM THE OPERATION TILL YOU WENT BACK FOR YOUR RESULTS TO FIND OUT THE HISTOLOGY RESULTS, YOU KNOW, TO FIND OUT WHAT THE CANCER WAS OR WHATEVER?

Patient: I don't know.

INT: WAS IT A WEEK OR ...?

Patient: Ten days.

INT: TEN DAYS?

Patient: Ten days I'd say from the, I came out on the Tues-, I had it Monday, came out on the Tuesday, and I went back last Wednesday, didn't I?

INT: AND WAS THAT MR HOLT OR MR CHADWICK?

Patient: Mr Holt.

?: Holt.

Patient: Holt.

INT: OK.

Patient: [???

INT: OK. THERE WE GO. ... SO HOW SOON DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHAT KIND OF SURGERY YOU WERE GONNA HAVE?

Patient: Straight away.

INT: STRAIGHT AWAY. RIGHT, OK. AND DID YOU EVER CHANGE YOUR MIND AT ALL ABOUT WHAT TYPE OF SURGERY YOU'D HAVE? DID YOU EVER THINK 'I'LL HAVE A DIFFERENT TYPE OF SURGERY' OR ...?

Patient: No. At first, you mean the first diagnosis?

INT: YEAH, THE FIRST.

Patient: The first one, I thought ... when he said it was only small and I thought, and he said, you know, they were drastic and took the breast off, I thought it might have worked if I had a lumpectomy, you know, it'd have been all right. But now I wished I'd have said, 'Take my breast off,' because I've got, obviously I've got to go back and have it off. But it would have been a bit drastic if it had have worked, wouldn't it?

INT: EXACTLY, YEAH.

Patient: Do you see what I mean?

INT: YEAH.

Patient: So I think I made t'right choice. If it had have been, I mean he's made a lovely job, it's just like a little, you know, thin line. If it had have worked, I'd have fine, I wouldn't have had to have my breast off, you see. I think, I think it must be t'same, I mean not for everybody I suppose if they

think they're having their breast off because it was in their family or mother had it or something like that, you know, and they've got a chance of getting it, that's probably why they have theirs taken off, but I think if you could save your breast just through having a lumpectomy, sooner than have it taken straight off, I think, yes, I think I made t'right choice.

INT: OH RIGHT, THAT OK. AND WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU HEARD OR WERE TOLD OR THAT YOU READ THAT HELPED YOU MAKE THE DECISION TO HAVE THE LUMPECTOMY FIRST?

Patient: Nothing, it was just that Dr Chadwick said, you know, years ago they used to take 'em off, no hesitation whatsoever, but years ago they wouldn't have had chemo and radium and things like that, you see. They'd have had no choice, would they?

INT: YEAH.

Patient: But now you've got that choice and I think, erm, at all costs I would have liked to have kept my, what you'd call my bust, you know.

INT: YEAH.

Patient: I mean when you're young you're, I was very skinny and I hadn't got much bust. As you get a bit older you put a bit of weight on you get a bit of a bust, so you really want to keep it, don't you?

INT: YEAH, ABSOLUTELY.

Patient: If you can, but I mean obviously it's best to have it taken off now, you see, sooner than it spread and I've got chance of a few more years, haven't I, if I have it taken off?

INT: YEAH. SO WHAT DO YOU, YOU'RE GONNA, WHEN DO YOU NEXT GO IN, WHEN'S YOUR NEXT OPERATION?

Patient: Next Monday.

INT: NEXT MONDAY. AND THEN WHAT HAPPENS AFTER THAT, WHAT'S THE FOLLOW-UP TREATMENT?

Patient: Er, they said chemo.

INT: CHEMO, MM. AND HOW LONG WILL THAT GO ON FOR, DO YOU KNOW?

Patient: I don't know.

INT: [???

Patient: You see that's another thing, everybody's different.

INT: YEAH.

Patient: Plus they have to make the chemo up for everybody is different because with Shaun they did, my brother, they have to go with your weight and things like that, don't they?

INT: MM.

Patient: We know that much, we know a bit about it now, else before we wouldn't have known nothing.

INT: NO. AND THAT'LL BE AT WESTON PARK AGAIN?

Patient: No ...

INT: OH, THEY'RE GOING TO DO IT AT CHESTERFIELD?

Patient: They're going to do it at Chesterfield so that's better for me.

INT: WELL, YEAH, ABSOLUTELY, 'COS WESTON PARK'S A BIT OF A NIGHTMARE TO GET TO, ISN'T IT REALLY?

Patient: Because you go to Sheffield and, like my friend said, she comes from Brassington, and she had to have her breast off, and she had to have chemo and radium, she had to have steroids, she's had to have that, that same tablet ...

INT: TAMOXAFEN.

Patient: Yeah, she'll be on that for five years. Plus they also said she might have to have a hysterectomy because it went somewhere else, but she didn't have to have a hysterectomy which is a bit of good news.

INT: YEAH, OF COURSE.

Patient: And she said when she went in t'taxi sometimes you've got to be ready for 8 in t'morning and you have to pick other people up, you know, like ambulances, and then you've got - you're only there about two minutes for your treatment but you've got to wait for everybody else and then you've all got ... it could take you all day. So five weeks of that, I was dreading that really.

INT: YEAH, EXACTLY.

Patient: But if, if I had to go I'd have to go. But when they said I could have chemo at Chesterfield it's even better for somebody to take me every day, you know. Especially when your husband works, you can't expect him to be off everyday, can you?

INT: NO, NO, OF COURSE [???] AND IT'S A SHORT DISTANCE TO GET THERE AS WELL I MEAN SO ...

Patient: Course it is, yeah.

INT: YEAH. I MEAN WESTON PARK'S A FANTASTIC HOSPITAL BUT IT'S ABOUT TIME THEY GOT A DECENT CAR PARK ...

Patient: It is.

INT: ... IT'S TERRIBLE.

Patient: It's a pity they didn't do everything at Calow, isn't it? It is Calow, isn't it?

INT: MM.

Patient: You know they built on and they could do t'radium and everything there. For a lot of people - it's all right for people that live in Sheffield, isn't it? But even people from Chesterfield don't know where Sheffield a lot, you know, where the hospital is.

INT: AH YEAH, OF COURSE. YEAH, I'VE HAD PATIENTS FROM ROTHERHAM AND BARNSELY ON A DIFFERENT, DIFFERENT PROJECT, YEAH, AND I REMEMBER ONE PERSON FROM LIKE REALLY FAR OUT IN ROTHERHAM, TOOK THEM SOMETHING LIKE THREE BUSES AND TWO HOURS TO GET TO SHEFFIELD AND GET BACK AGAIN.

Patient: Yeah, and your treatment only takes a few minutes, you see, because they can only give you so much each day and you've got to go say five weeks, ten weeks, it's a drag, isn't it?

INT: AND YOU SAID THAT, WAS IT ON THE INTERNET YOU LOOKED UP INFORMATION FOR IT, IS THAT RIGHT?

Patient: Yeah, ah.

INT: AND DID YOU FIND ANY INFORMATION FROM ANYWHERE ELSE ABOUT CANCER AND ITS TREATMENT? BOOKS, MAGAZINES, VIDEOS, [??]? ?

Patient: No, only from my friends. No, because there's quite a few, there's a lot of people, it seems to be happening to a lot of people. If it's not that it's cancer of testicles, isn't it?

INT: MM?

Patient: And now I've got my daughter's, one of her friends, the husband's got, what is it? Test-, what is it called?

INT: IS IT PROSTATE?

Patient: Prostate, that's it. [??] there seems to be a whole lot of it about, dun't there?

INT: I THINK PROSTATE CANCER'S ACTUALLY INCREASING IN MEN NOW, ERM, WHICH IS A BIT WORRYING FROM MY POINT OF VIEW, SO ...

Patient: Well it is, it is for us friend ...

INT: WELL MY DAD HAD BOWEL CANCER. I THINK MY GRANDDAD HAD IT AS WELL BUT HE NEVER SAID OWT THEN HE DIED OF A STROKE, MY GRANDDAD. MY DAD DID, [??] BUT, YEAH, BECAUSE I SAID WHEN I GET ABOUT FORTY REALLY I SHOULD START GETTING SORT OF CHECKS MADE, YOU KNOW, BECAUSE I THINK THE PAIR OF THEM HAD IT REALLY AND MY GRANDDAD NEVER SAID ANYTHING. BECAUSE BOTH MY GRANDDAD AND MY DAD ARE EXACTLY THE SAME, IF THERE WAS ANYTHING WRONG WITH THEM THEY NEVER SAID ANYTHING ABOUT IT.

Patient: No.

INT: YOU KNOW, THEY ...

Patient: No, they don't, men don't.

INT: QUIET, QUIET, SORT OF STRONG TYPES REALLY. ERM ... YEAH. LET ME THINK, WHERE ARE WE? I THINK WE'VE JUST ABOUT COVERED EVERYTHING AS FAR AS I CAN REMEMBER. ERM ... LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UP UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE THAT YOU HAVE RECEIVED?

Patient: Very good.

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

Patient: Well I think the doctors and the nurses and the surgeons, I think they're all very good, all of them.

INT: AND IS THERE ANYTHING ABOUT THE EXPERIENCE OF THIS NOW THAT HAS NOT MET YOUR EXPECTATIONS? I KNOW YOU MENTIONED ABOUT YOU WEREN'T TOLD YOUR HUSBAND COULD COME IN THE CONSULTATION, WAS THERE ANYTHING ELSE THAT YOU THINK DIDN'T MEET YOUR EXPECTATIONS?

Patient: Well when I was in hospital 27 years ago, I had a, er, I had a ... what is it? Appendicitis, was stuck to my bowel, and when they did that they did my Fallopian tube as well, so I was cut there. And they was, the care seemed to be different: they brought your meals up to your bed, you know, and I mean, I know it's all changed and you don't have hot dinners, it's all ready-done, isn't it? And then, like this time, you've got your arm like this, you've got that needle stuck in there, and you've got to go out of your bed, you've got to go to another room to eat your meal. Plus you've got to do it yourself, see. That's t'only thing that I thought it was different.

INT: AND DID YOU HAVE ANY DRAINS IN THAT THEN, DID YOU?

Patient: No, no.

INT: NO DRAINS, OK.

Patient: No, I mean, I managed, but I didn't think it was the same as it used to be.

INT: NO?

Patient: No, not as caring as they used to be, they used to be coming round and you'd ask 'em to, you know, do this for you and that - I suppose I weren't there long enough to be truthful, because I were only there from, from t'next morning. I mean probably they are if you're in a long while. So that's t'only thing I'd say. We know they've changed now, I mean they've got to do more, same as you was in hospital, I was in hospital two weeks with that, well now they'd have you up and out of t'bed and they'd, you'd be home because of thrombosis, wouldn't they? They don't do that now, you're better, you get better at home quicker, I think.

INT: THE OTHER THING IS ALSO I THINK THAT YOU CAN ACTUALLY PICK UP INFECTIONS IN HOSPITAL.

Patient: Yeah.

INT: THAT'S THE THING. ERM, AND I DON'T KNOW ABOUT THE MEALS, I'M NOT QUITE SURE, MAYBE THEY FEEL AS IF THEY MOVE THE MEALS AWAY FROM THE BEDS THERE'S GOING TO BE LESS CHANCE OF ANY INFECTION THERE ...

Patient: Well, probably.

INT: I DON'T KNOW, I MIGHT BE WRONG ON THAT, LIKE, BUT ...

Patient: Plus it's making you, I know you don't feel like it, but it's making you walk about, move, isn't it? Do something, whereas, instead of sitting there feeling sorry for yourself. I suppose it's that, isn't it? Like I say, they like to get you up out of t'bed, don't they, because of thrombosis you see.

?: Mm, yeah.

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

Patient: ... I don't know, probably, I suppose you've got to wait, haven't you, a long while every time for your, whatever appointment you've got you could be there an hour, could be an hour and a half. I know it can't be helped but it's, you're getting yourself all worked up, aren't you, while you're waiting? That's probably, I wouldn't say anything else. I thought they were all good because they could make, they made you a cup of tea if you wanted one, didn't they? Or you could go and get one, couldn't you? No, I thought they was all very good, really good.

INT: LAST COUPLE OF QUESTIONS. NOW YOU'VE BEEN THROUGH EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: Just that they be told, like I was told, you know, I mean they told you everything, he explained it all and did me a drawing, and they couldn't do any more, could they really? So's that you know what's going to happen to you, because there's nothing worse than not knowing, is there? What you going with that for? What they're doing this? It is, I don't think so, no.

INT: AND WHAT DO YOU THINK ARE THE MOST IMPORTANT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: The operations they can have?

INT: MM.

Patient: Well they've got, they're given a choice, aren't they? It depends how bad it is I suppose.

INT: YEAH.

Patient: Like my friend, you see, she had to have a breast straight off because she'd got 22 lumps for a start. Well she'd got no choice.

INT: YEAH.

Patient: And she knew that, like she says to me, 'Have it off, Diane' because it's the only way to stop it, isn't it?

INT: WERE YOU SURPRISED THAT YOU WERE GIVEN A CHOICE OF SURGERIES, OR SHOCKED IN ANY SORT OF WAY?

Patient: No, I wasn't shocked, but I was surprised because I didn't, I didn't know about, obviously, about this lumpectomy, I thought you just had, went in and had your breast off straight away, you see. And it's a good thing if it worked and you're saving your breast, because you talk to any woman they'd want to save their breast, wouldn't they? But if you've got no choice you've got to have your breast taken off, haven't you?

INT: MM. FINAL QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED, ANYTHING THAT'S IMPORTANT THAT WE HAVEN'T TALKED ABOUT?

Patient: No.

INT: NO? WHAT ABOUT YOU, ROSIE, I MEAN, FROM A CARER'S POINT OF VIEW, IS THERE ANYTHING YOU THINK YOU COULD ADD TO WHAT WE'VE SPOKEN ABOUT?

?: No.

INT: NO? OK. WELL I'LL TURN THE RECORDER OFF AND THAT'S IT.

[End of interview}