

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: High MR unit

*DATE:

* Patient_Patient23

*INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED, I KNOW IT'S TIME OUT OF YOUR PRIVATE LIFE AND WE'RE VERY, VERY HAPPY YOU DECIDED TO TAKE PART. I'D LIKE TO START WITH A QUESTION TO BEGIN HERE, CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, quite a bit actually because I had already had a right, I had had a mastectomy on the right side.

INT: OH, RIGHT, OK.

Patient: Eleven years ago.

INT: RIGHT, SO THIS IS A ... IS THIS A SECOND, IS THIS A RECURRENCE?

Patient: It's the second one.

INT: YEAH, OK.

Patient: No, it's a different one.

INT: OH, SO IT'S A DIFFERENT ONE, IT'S A DIFFERENT PRIMARY, OK.

Patient: Yeah, it's a primary, that's what the consultant said. So, yes, I did understand quite a lot this time that I didn't understand the first time.

INT: SO WHAT DID YOU NOT REALLY UNDERSTAND THE FIRST TIME, THEN, DO YOU REMEMBER?

Patient: I think when you're first told you're so stunned that you actually have cancer, erm, you don't ask questions, too many questions, you just go along with the flow. You just take the advice as it's given, but this time I asked more, many more questions.

INT: OH, RIGHT, OK.

Patient: So ... because I'd there before.

INT: AH-AH, AND WERE YOU PICKED UP VIA SCREENING OR WAS THIS ...?

Patient: Yes, a mammogram.

INT: YEAH, NO, THIS SORT OF TH ING. ERM, AND SORT OF, HAVE YOU ANY KIND OF FAMILY HISTORY OF BREAST CANCER? [???

Patient: No, a history of cancer in the family but not breast cancer.

INT: NO BREAST CANCER, OK.

Patient: My Mum had liver cancer and my Dad - well she died from it - and my Dad died from stomach cancer, and my young brother is just going through the process of bowel cancer.

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

Patient: So, erm, yes it's in the family I would say.

INT: THINKING ABOUT THE FIRST TIME THAT YOU HAD YOUR BREAST CANCER AND THIS TIME, WHAT, HOW DO YOU THINK THE TWO ARE DIFFERENT, THE ACTUAL EXPEIRENCES, HOW DO YOU THINK THEY ARE DIFFERENT IN ANY WAY, OR ...?

Patient: Personally or from the hospital?

INT: PERSONALLY

Patient: Personally, erm, my husband was alive then so I had obviously his support: this time I'm on my own so it's, it's slightly different that you have to go through. Personally, erm, I think it took a lot longer the first time to sink in and to get going again. This time I feel that I can get going, you know, after a short time.

INT: YEAH, AND IN TERMS OF THE ACTUAL UNIT, WHEN YOU WENT TO THE UNIT HOW DO YOU THINK THINGS WERE DIFFERENT THERE?

Patient: Sorry?

INT: YOU KNOW WHEN YOU WENT TO THE UNIT THIS TIME ROUND, YOU KNOW, THE TWO EXPERIENCES OF THE UNIT ... WAS IT THE SAME UNIT YOU WENT TO?

Patient: Yes it is, yeah, but they seem to have many more people working there in different areas, erm, you got lots more help this time. Also, erm, everyone was, erm, what's the words? They were willing to help, even if it was, you know, just on the phone ...

INT: YES, MM.

Patient: ... erm, they were much more helpful. I don't think they had the resources the first time and the unit didn't seem so big, but now there's lots more people in different areas to help you, which I found very good.

INT: AHA, HOW MANY YEARS AGO, THAT'S TEN YEARS AGO, 199...

Patient: Three.

INT: WAS IT 1993, WAS IT THE FIRST TIME, YEAH?

Patient: No, it was '92 actually I had a lumpectomy and followed by radiotherapy but then I had another lump the same year, then I had a full mastectomy in '93.

INT: OK. AND, ERM, THE FIRST TIME YOU WENT, WHAT KIND OF KNOWLEDGE DO YOU THINK YOU HAD OF BREAST CANCER THEN?

Patient: Erm, not too much.

INT: [???

Patient: Not too much.

INT: AND WHERE DO YOU THINK THAT KNOWLEDGE KIND OF CAME FROM?

Patient: Reading about it, er, watching programmes on television, erm, I do read a lot so I did tend to pick up everything that I could find. Asking questions. I also had a friend who'd had a mastectomy and she helped me because she was before me, so she could help me. Yes, you know, you sort of find it out for yourself more or less. But this time I didn't have to, the information was given to me.

INT: AH, RIGHT, OK. WAS THAT NOT WHAT HAPPENED IN THE FIRST TIME?

Patient: No, it was explained to a point the first time but, as I say, you didn't have all the literature and all the resources and all the people the first time. So, maybe it was my fault because I didn't ask, but as I say you're just so stunned by it all you don't think to ask anything.

INT: YEAH, OF COURSE.

Patient: It's just as you go along and over the years that you found out about different things. So, yes, I'm still interested in it obviously and I've read everything that I could find.

INT: OK. AND THIS TIME, YOU KNOW, WHEN YOU WENT AND YOU HAD YOUR SCREENING AND THEY TOLD YOU HAD IT A SECOND PRIMARY, SORT OF, WHAT SORT OF THINGS WERE GOING THROUGH YOUR MIND AT THE TIME WHEN YOU FOUND OUT?

Patient: Well I couldn't believe it but it was 11 years in between having the mastectomy and then I've got a new one again - I just, I couldn't believe, I'd been discharged from the breast clinic in 2003, erm, so I thought I was OK for a few years, and I didn't, you know, it would come back - well not come back, I didn't think it would happen again. So I just couldn't believe it.

INT: ERM ... ONCE YOU'D BEEN, ERM, WHEN YOU FOUND OUT THIS TIME THAT YOU HAD A SECOND PRIMARY, DID YOU TALK ABOUT YOUR THOUGHTS, FEELINGS TO ANYONE?

Patient: Yes.

INT: YEAH?

Patient: Yeah ... I've got a niece, she's a year younger than me and she's my person that I tell everything to.

INT: A CONFIDANTE, YEAH?

Patient: Yes, yeah, although she lives in London. But she's brilliant: she's always there for me.

INT: DO YOU SEE EACH OTHER VERY OFTEN?

Patient: Yes, I went down the week before last, just to be with the family: I was very tired but ...

INT: YEAH, OF COURSE.

Patient: ... it was just nice to be there. We didn't talk about it much because we'd already spoken about it on the phone. She's the first one I always ring if I'm in trouble or, you know, if I've got problems I ring her and we discuss it, and she's very good.

INT: OH THAT'S [???

Patient: Yeah.

INT: IS THIS ALL FAMILY?

Patient: Yes, yes, I've got a huge family.

INT: YOU HAVE [CHUCKLES] I JUST NOTICE THERE ARE MILLIONS OF PHOTOGRAPHS ROUND HERE.

Patient: Yeah. I've got four sisters and five brothers and they've all got umpteen children, so there is a lot of us, so in a way I suppose four people with cancer is not, is quite a good record in a way because there's such a lot of us [chuckles].

INT: OH, RIGHT, OK, YEAH. WELL, I MEAN, MY DAD HAD BOWEL CANCER A COUPLE OF YEARS AGO AND I'M HITTING NEARLY FORTY AND, YOU KNOW, AT SOME POINT VERY SOON I'M GOING TO HAVE TO START LIKE GETTING CHECK-UPS AND THINGS. I'M NOT SURE ABOUT MY GRANDDAD, I THINK HE DIED OF A STROKE, WELL MY DAD DID SO THAT'S NOT LOOKING VERY GOOD FOR ME I SUPPOSE. SORT OF, MY GRANDDAD I'M SURE, I'M SURE THERE WAS SOMETHING WRONG THERE AS WELL, BUT WE NEVER FOUND THAT OUT, YOU SEE. SO I SUPPOSE I'M GOING TO HAVE TO BE ON MY GUARD AS WELL REALLY.

Patient: Yes, yes. But as I say, see, I don't know my grandparents because, er, they were dead before I was born, so I don't know what they died of. As I say, there's no breast cancer in the family: I really couldn't say what people died of years ago because it wasn't put down, was it?

INT: NO, EXACTLY, YEAH, WASN'T REQUIRED AT ALL.

Patient: So I don't honestly know, you know, from the grandparents' point of view. I just know my Mum and Dad.

INT: AHA, YEAH. SO YOU WERE PICKED UP IN SCREENING SECOND TIME ROUND ...

Patient: Yes.

INT: ... CAN YOU JUST TALK ME THROUGH, YOU KNOW, WHAT HAPPENED? YOU WENT TO YOUR SCREENING, NORMAL APPOINTMENT, WHAT HAPPENED THEN?

Patient: Erm, I think, I went on 8th January for the mammogram, I got called back for the 20th January when I had another mammogram, an ultrasound and a core biopsy. They explained to me that there was something there that was unusual and they were very good explaining everything, the radiographer and the people there. They showed me the stars, there's sort of like a shiny star - I don't know if you've seen a mammogram ...

INT: YEAH, I'VE SEEN SOME OF THEM, YEAH.

Patient: ... like a shiny star, and there were three, and he explained that this was unusual so this is why I had to have the biopsy - well I didn't have to have it, you don't have to have anything, do you? It's your choice. And then I had an appointment for the 27th January when I saw the consultant and she told me, yes, it was cancer.

INT: SO WAS IT THE SAME CONSULTANT YOU SAW THE FIRST TIME?

Patient: No, no. He's now the head of the department, Mr Holliday, and this, erm, lady, is one of the consultant surgeons, Miss Wahedna.

INT: THAT'S RIGHT, YEAH.

Patient: Yeah, she's very, very nice and very good at explaining everything and your options and ...

INT: SO THE FIRST TIME YOU WENT, THEY JUST SAID THERE WAS SOMETHING UNUSUAL, IS THAT RIGHT, YEAH?

Patient: That was on the 20th.

INT: ON THE 20TH, YEAH.

Patient: Yeah, when they called me back for a second mammogram and ultrasound.

INT: THAT'S RIGHT, YEAH.

Patient: And the biopsy. They said it was unusual and they, you know, wanted obviously to go into it a bit more. So that's when they took the biopsy and I went back the following Tuesday on the 27th and she said it was cancer.

INT: WHEN THEY SAID IT WAS, YOU KNOW YOU SAW THE MAMMOGRAM AND THEY SAID IT WAS UNUSUAL, WHAT SORT OF THOUGHTS WENT THROUGH YOUR HEAD THEN?

Patient: Here we go again [chuckles].

INT: OK. SO DID YOU THINK IT WAS GOING TO BE ... ?

Patient: Yes, yes.

INT: YEAH.

Patient: It's still a shock when you're told ...

INT: AH, OF COURSE, MM.

Patient: ... but I had an idea that it was wrong, there was something wrong.

INT: WHAT, YOU HAD AN IDEA, WHAT GAVE YOU THAT IDEA THERE WAS SOMETHING WRONG?

Patient: Intuition, I think, that's all.

INT: JUST KIND OF KNOWING YOUR BODY REALLY?

Patient: Erm, not really, because you don't have any pain or anything. I rang Carole, my niece, and I said, 'I've been called back and I've had a biopsy,' I said, 'but I think this is it again,' so we'd already discussed it and then I discussed with her what I thought I would do and what she thought I should do. And that's when I came up with the answer [chuckles].

INT: THAT IT WAS GONNA BE ...?

Patient: Well Miss Wahedna said that she could take the tumour out and the surrounding area and then possibly have radiotherapy or chemotherapy after, or I could have a mastectomy with radiotherapy or chemotherapy or drugs, according to what happens once it had been taken away. So I opted for a mastectomy because I'd been through it all before, just having the part taken out, and then it came back so I had to go back.

INT: THAT WAS THE FIRST TIME IN '92, '93, YEAH?

Patient: Yeah, so I thought I'm not gonna go through all that again, and already having had one mastectomy I thought, 'I'm not gonna have just a half a breast left, I might as well have the whole mastectomy,' - to me it just seemed, well, you know, I didn't contemplate just having the part taken away 'cos I thought it's no point.

INT: YEAH, OK.

Patient: Erm, also, when you have the lumpectomy you're worried all the time, every time it's your appointment at the breast clinic you think, 'Oh ...' you know, you start to get anxious a week

before you go. It's, erm, it's worry all the time. And I thought, well at least having a mastectomy a good part of the worry is gone - I know you can still get it, this has been explained, yes, you still can get breast cancer even if you've had both breasts off, erm, so, yes, but I thought, well it gives me a greater chance to live a lot longer than just having the lumpectomy and radiotherapy and everything. So that's why I opted for the mastectomy.

INT: SO YOU OPTED FOR THE MASTECTOMY, AND WAS THERE ANYTHING, ANY TREATMENT AFTER THAT?

Patient: Yes, I went back onto Tamoxafen.

INT: RIGHT, OK, [??] THE FIRST TIME.

Patient: Because I took that for 5½ years the first time, erm, then I had a reaction to it, so they was, I was taken off it. But she said it is the best drug, so she's put me back on it and obviously everyone'll keep an eye on me, and I obviously would because I know what to look for: if I start getting a reaction then I'll be the first one ring up somewhere and go back and get some advice.

INT: SO THE SECOND TIME YOU WENT TO THE CLINIC YOU WERE SEEN BY MISS MAHEDNA?

Patient: Yes.

INT: AND SHE PERFORMED LIKE THE OPERATION AS WELL?

Patient: Yes, she did.

INT: YES, SHE'S YOUR CONSULTANT NOW, SORT OF THING?

Patient: Yes, she is.

INT: AND THE FIRST TIME YOU WENT WAS MR HOLLIDAY, WAS THAT ...?

Patient: Well he didn't, he was the consultant but he didn't actually perform the operation at the time, it was another chap called Mr Denton - I think he's left now.

INT: I THINK HE HAS, YEAH.

Patient: [??] and he performed the operation, but I then, mostly at the clinics, when I went to the breast clinic, I saw Mr Holliday or one of his other people. And he was the one that discharged me from the breast clinic last September, so I had actually seen ...

INT: SO YOU'D KEPT UP CONTACT WITH HIM THROUGHOUT?

Patient: Yes, I went every year for ten years to the breast clinic.

INT: RIGHT, AND THEN WAS THAT, WHEN YOU SAY DISCHARGED, YOUR FINAL DISCHARGE, WAS IT?

Patient: Yes, yes.

INT: YES, YOUR DISCHARGE ...

Patient: I went in September and he said he thought after ten years that I should be OK, and I was very happy because I didn't have to go, but then I got called for a mammogram and, there you go, it's all back again.

INT: MM. ERM, WHEN YOU WENT TO THE CLINIC THIS SECOND TIME AND YOU WERE TOLD THAT YOU DID HAVE A BREAST CANCER THIS TIME, DID ANYONE ELSE, WAS ANYONE ELSE WITH YOU, DID ANYONE GO ALONG WITH YOU OR ...?

Patient: Yes, a very close friend, she came with me.

INT: AND DID SHE COME INTO THE CONSULTATION WITH YOU?

Patient: Yes, she did.

INT: YES, OK, THAT'S FINE. AND WAS THERE ANYBODY ELSE IN THE CLINIC, IN THE CONSULTATION?

Patient: Yeah, there was a student nurse and an administration person, I didn't catch her name, but she's always in the breast clinic, I've seen her there before. I didn't catch her name but I know she works there, you know, she's always in and around the breast clinic when you go there.

INT: AH, OK. AND THEN, SO YOU, YOU OBVIOUSLY HAD AN EXPECTATION [???] YOU SAID YOU KNOW IT WAS KIND OF GOING TO BE BAD NEWS, IF YOU LIKE, ERM, SO WHAT HAPPENED NEXT? YOU'VE COME INTO THE ROOM, YOU'RE SITTING THERE NOW WITH THE CONSULTANT, THE NURSE AND YOUR FRIEND, SO WHAT HAPPENED NEXT?

Patient: Well, Miss Wahedna said it was cancer and then I cried, so, although you half expect it ...

INT: IT'S HARD, ISN'T IT?

Patient: ... it's still a shock, the word you have got cancer, it's just such a shock. I had tried to psych myself up into taking the bad news but you can't because there's always just one little bit of hope that maybe you're wrong.

INT: YEAH, OF COURSE, THAT'S RIGHT.

Patient: And to know that your body's let you down and that you've got cancer, which is a life-threatening disease, it's not an easy thing to take in.

INT: NO, NO, I CAN IMAGINE. I KNOW IT WAS HARD FOR MY DAD BECAUSE HE'D BEEN NEVER ILL, MY DAD: HE WAS A SAILOR, HE WENT ROUND THE WORLD AND HE WAS DOWN THE MINES AND MANAGED TO AVOID ALL THE SORT OF THINGS THERE THAT COULD HAPPEN, AND IT REALLY SHOCKED HIM, I MEAN, YOU KNOW, AND HE WAS

QUITE A HARD SORT OF CHAP, YOU KNOW, HE WAS A HARD MINER, AND, YOU KNOW, AND HE WAS NOT A PERSON WHO WOULD TALK ABOUT THINGS A LOT.

Patient: No, no.

INT: AND IT DID, IT DID CHANGE HIM A LOT, IT DID CHANGE HIM. EVEN THOUGH THEY SAID, YOU KNOW, THAT 'WE'VE CAUGHT IT VERY EARLY AND, YOU KNOW, IT'S NOT LIFE-THREATENING,' THEY SAID, YOU KNOW, 'YOU'VE CAUGHT IT REALLY EARLY, YOU'VE COME IN PLENTY OF TIME, NO PROBLEM,' BUT IT WAS, I THINK IT'S THAT WORD, I THINK IT'S THE WORD, YES, IT REALLY HAS GOT A LOT OF CONNOTATIONS TO IT. AND THEN, AND THEN AFTER THAT YOU OBVIOUSLY, YOU HAD A CRY, AND YOUR FRIEND THAT WAS THERE AND EVERYTHING, WHAT HAPPENED AFTER THAT THEN?

Patient: Erm, Miss Wahedna asked me, erm ... she explained everything to me, the two options, and I said I would prefer to have the mastectomy, and then she said, 'Right, we'll get you in and we'll get it done.' So I went in the following Tuesday, erm, which is quite a short time in between but on the other hand you really don't want to hang about because sitting at home waiting and wondering ...

INT: MM, IT RAISES YOUR ANXIETY, DOESN'T IT?

Patient: Yeah, if you could go in next day it would be ... yes, you would still be in shock, but it would be done and done with, but, erm, I went back to work on Wednesday, Thursday, Friday and then had the weekend off to get ready and I went in the following Tuesday.

INT: RIGHT, OK. AND SO HOW, SO WHERE DO, WHERE DO YOU WORK? YOU SAID YOU WERE A SECRETARY OR AN ADMINISTRATION ASSISTANT?

Patient: No, no ... no, no. No, I work for the NHS, I'm a care assistant.

INT: OH, RIGHT, YEAH, I'M SORRY, I THOUGHTG YOU SAID YOU WERE A SECRETARY OR SOMETHING IN THE NHS.

Patient: Not now, no, no.

INT: IS THAT AT DERBY HOSPITAL THEN?

Patient: No, it's over at The Grove, it's a community hospital just across the road here. It's elderly medical, if you like, but it's very, very nice, and I enjoy my job.

INT: OH, I ENJOY WHAT I DO, I MEAN I DO RESEARCH AT THE ROYAL HALLAMSHIRE AND I CERTAINLY, I REALLY ENJOY DOING THAT KIND OF WORK. SO WHEN MISS WAHEDNA WAS TELLING YOU ABOUT YOUR DIAGNOSIS, DID SHE USE ANYTHING AS MAMMOGRAMS, DID SHE DRAW YOU ANY DIAGRAMS, ANYTHING LIKE THAT?

Patient: Yes, she had, erm, she had some pictures there ...

INT: PHOTOGRAPHS OR DIAGRAMS?

Patient: No, no, diagrams. She also drew a picture and showed me what could be done, but I'd already made my mind up so I really wasn't ...

INT: THAT'S FROM YOUR DISCUSSION WITH YOUR FRIEND ON THE PHONE?

Patient: Erm, my niece on the phone, yeah, yeah.

INT: YEAH, YOUR NIECE, YEAH.

Patient: 'Cos I said to her I was going to have a mastectomy if it was, so, erm, no, Miss Wahedna already had the sort of pictures there, erm ... when you have a mammogram they seem to have some pictures there so that they can show you where the things are, so where the tumours are so, yes, she drew a picture for the, just taking the tumour and the tissue out, she drew a picture of that. Obviously she didn't draw a picture of the mastectomy, so ...

INT: NO, BECAUSE YOU'D HAD ONE BEFORE ...

Patient: Yeah.

INT: ... SO YOU'VE HAVE AN IDEA WHAT IT WAS LIKE? ERM ... I'M TRYING TO THINK ... SO SHE'S TALKED ABOUT YOUR TREATMENT OPTIONS ...?

Patient: Yeah.

INT: HOW WELL DO YOU THINK YOU GOT ON WITH MISS WAHEDNA HERSELF, THE DOCTOR HERSELF?

Patient: Very well. She's, erm, she explains things to you in a basic way, she doesn't use long medical terms. She's very pleasant, erm, I think she's got a difficult job telling people that they've got cancer but she does it in a very good way. She's not overbearing, overpowering, erm, I think she's just about got it right as to how to deal with the people. She's a nice lady, and I felt quite safe with her. I trusted her.

INT: MM. THAT'S THE KEY THING REALLY ...

Patient: Yeah, yeah, I trusted her.

INT: ... TRUSTED. AND THE FIRST TIME YOU HAD MR HOLLIDAY, I BELIEVE, IS THAT RIGHT, HOW WAS THAT EXPERIENCE, BECAUSE IT'S QUITE, TEN YEARS, TEN YEARS' DIFFERENCE IS QUITE ...

Patient: I think the first time you're just swept along, you really don't have time to, erm, I don't know, what's the word? You don't have time to think about too many things, you're just swept along by them all, but this time I was, erm, I wanted to ask more questions, which I did, and got good answers.

INT: WHAT SORT OF QUESTIONS DID YOU ASK, CAN YOU REMEMBER?

Patient: Well, if I can still breast cancer, if I had a mastectomy, and was told yes, which I didn't know, I thought once you'd had the mastectomy you were gonna be OK. Erm, how long was the operation? What's the recovery time? What happens if I'm sitting indoors and I don't feel too good, what do I do? You know, all sorts of questions about me, and I got good answers, and I have, erm, I have rung up since and asked questions of the breast care nurses.

INT: WELL MY NEXT QUESTION TO ASK IS HOW DO YOU GET ON WITH THE NURSES THEN, THE BREAST CARE NURSES?

Patient: The breast care nurses are very good as well, they're always willing to listen. I had to go and have the wound drained twice a week when I left the hospital and each time they asked me about my wellbeing and how I was coping, and they were quite prepared to listen, which is nice, and they gave you some advice if you asked for it, they gave you some advice if you didn't ask for it. But it was nice advice, you know, just to take it easy and do your exercises and, yes, I found them all quite good, really quite good. And the thing is, even now that I don't, I haven't got to go back until August to see Miss Wahedna, that's the six-monthly check-up, I can still ring the breast care nurses at any time to ask questions, or even go to see them, they will make an appointment and you can go to see them if you're worried. So, yes, it's, erm, it's a lot better this time: I feel that I've got people there that I can call on which I didn't feel I had the first time.

INT: RIGHT, OK. AND AFTER YOU'D SEEN MISS WAHEDNA AND YOU'D HEARD ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, ERM, WHAT HAPPENED AFTER THAT THEN?

Patient: What, personally or ...?

INT: YEAH, I MEAN, YOU'RE IN THE CONSULTATION, YOU'VE JUST HEARD ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, WHAT HAPPENED IMMEDIATELY THEN?

Patient: Well she made the arrangements for the operation on 3rd February and then I came out with my friend and we went shopping [chuckles].

INT: OH RIGHT. DID YOU GO AND SEE THE BREAST CARE NURSE AFTERWARDS?

Patient: Oh yes, sorry, sorry yes, yes, sorry, sorry, yeah. Then the breast care nurse came for us and she took me in and that's when I asked the questions about having the breast cancer again without, you know, having the double mastectomy. She told me that I, she gave me lots of forms ... you get a package that explains everything, I don't know if you've seen it ...

INT: I HAVEN'T ACTUALLY.

Patient: You haven't?

INT: NO, I HAVEN'T, I'VE SEEN THE ONES THAT THEY GIVE AT THE HALLAMSHIRE BUT THEY'RE ALL A BIT DIFFERENT, AREN'T THEY?

Patient: Yeah.

INT: AH, RIGHT, YEAH.

Patient: That's that one, but this is the best one: this is your actual ...

INT: OH, RIGHT, NOT QUITE A PATIENT-HELD RECORD BUT TREATMENT RECORD, YEAH.

Patient: See it fills you all in and then ... tells you all about it, which I found was very, very good.

INT: MM. ... OH, YOU'VE GOT YOUR EXERCISES HERE AS WELL.

Patient: Yeah, yeah, that's the form ...

INT: [??] YOUR EXERCISE ... AH RIGHT, YOU'VE GOT A CHART HERE ...

Patient: Yeah, I still do them but I can't be bothered to [chuckles] write them down. Then you get those ones, that's when you've finished, you do those at home, you know, for some time. So everything's sort of listed for you and, erm, even the Tamoxafen, they give you a sheet now to explain.

INT: OH, I SEE, RIGHT, I HAVEN'T SEEN THAT, THAT'S INTERESTING.

Patient: See, I had that when I was having it drained, so everything is given to you ...

INT: YEAH, THERE IS, IT'S A NICE LITTLE PACK THAT REALLY.

Patient: Yes, yes, I found it extremely helpful. So, I mean even that one was helpful. So, yes, it's very good now, the things you get. And of course you keep these and you can have a look up and, and they give you that pack, the breast care nurse, and then she made the appointment for me to see the pre-assessment for the operation on the Monday. And then me and my friend went, and we went shopping. So and went and had a cup of coffee and then went shopping and, you know, came back here. I rang Carole and cried to Carole, and she cried, because we're very close, and then, erm, I went over to work and told them at work what had happened and they were very good and gave me lots of support and help and advice. They've been brilliant all the way along actually, all the nurses over there, because, you know, we have, obviously, qualified staff. And I do go over there once a week and sit and talk to the girls and, yes, they're very good, they've been very good.

INT: ERM, WHEN YOU WERE ACTUALLY TALKING ABOUT, TO THE BREAST CARE NURSES AND TO THE CONSULTANT, MISS WAHEDNA, HOW MUCH DID YOU UNDERSTAND OF WHAT WAS BEING TOLD HERE?

Patient: Erm, quite a lot actually.

INT: WAS THERE ANYTHING YOU THINK YOU DIDN'T PARTICULARLY UNDERSTAND?

Patient: No, not really.

INT: WHAT ABOUT THE FIRST TIME ROUND, I MEAN YOU SAID THAT YOU KNOW YOU FEEL AS IF YOU'RE KIND OF SWEEPED ALONG WITH IT, YOU KNOW, THIS IS WHAT

HAPPENS - LOOKING BACK DO YOU THINK THERE WAS ANYTHING YOU DIDN'T PARTICULARLY UNDERSTAND AT THE TIME, OR ...?

Patient: Erm ... it's difficult to say really because it was, the first time you just, your mind is a blank. My GPs helped me a lot the first time: they, I asked them questions more than asking at the hospital because I thought, is this the ... you don't ask questions at the hospital because everybody's rushing around.

INT: YEAH, I SEE.

Patient: And that's what I say, this time everybody seems to have lots more time for me, whereas they didn't the first time, everybody seemed so busy and you didn't like to ask too many questions because you thought you were taking up too much time.

INT: OH, RIGHT, OK. THAT'S INTERESTING. ERM ... WE'VE TALKED ABOUT WHAT TREATMENTS YOU'VE HAD AND YOU'VE SAID YOU SPENT SOME TIME WITH THE BREAST CARE NURSE AFTER SEEING THE DOCTOR, HAVE YOU HAD ANY FURTHER CONTACT WITH THE BREAST CARE NURSES?

Patient: Yes, lots.

INT: AND THAT'S, HAS THAT BEEN MAINLY THROUGH TELEPHONE OR VISITS OR HAVE THERE BEEN BOTH OR ...?

Patient: Well I was going twice a week for the drainage because the breast care nurses do the drainage ... erm, yes and just, you know, to generally sit and talk to them. They don't just drain it and push you out the door: they drain it and then they ask you how you are, any problems, any other problems, if there's anything they can do to help you. Erm, so yes, they do spend time with you.

INT: OK, THAT'S GOOD. AND, JUST LOOKING DOWN MY QUESTIONS, WE'VE TALKED ABOUT SO MUCH, [???) [CHUCKLES] THIS HAPPENS IN INTERVIEWS SOMETIMES, ERM, WHEN YOU WERE THINKING ABOUT THE CONSULTATION THIS TIME, FIRST OF ALL WITH MISS WAHEDNA AND THEN WITH THE BREAST CARE NURSES, WHO DO YOU THINK DID MOST OF THE TALKING AND WHO DID YOU THINK DID MOST OF ASKING OF QUESTIONS?

Patient: What in the ...?

INT: YEAH, IN THE ACTUAL CONSULTATION ROOM, WHO DO YOU THINK WAS DOING MOST OF THE TALKING, WHO DO YOU THINK WAS ASKING MOST OF THE QUESTIONS?

Patient: Erm, I was asking some questions but Miss Wahedna was explaining things, so I suppose really she was, erm, she was the one that did most of the talking.

INT: AND THE BREAST CARE NURSES, WHEN YOU SPENT TIME WITH THEM, WAS THAT SOMETHING SIMILAR OR ...?

Patient: No, no, that was sort of about half and half, you know, sort of half them and half me.

INT: SO WHEN YOU WERE TALKING ABOUT WHAT TREATMENT YOU WERE GONNA HAVE, YOU KNOW YOU SAID YOU GOT ON VERY WELL WITH MISS WAHEDNA, DID YOU FEEL THAT SHE LISTENED TO YOU?

Patient: Yes.

INT: YEAH? AND DO THINK SHE SORT OF UNDERTOOD YOUR NEEDS AND YOUR CONCERNS?

Patient: Yes, yes. Yes, she obviously had the notes from the previous mastectomy and I think she understood why I wanted another mastectomy, and not to take the option of the smaller operation. So she understood what I wanted. And she didn't force me into doing any decisions whatsoever. And once I made the decision she didn't try to change my mind: it was purely my decision, after she had explained the options.

INT: AND THE NURSES? DO YOU FEEL THAT THEY UNDERSTOOD YOUR NEEDS AND CONCERNS AND FEEL THAT THEY LISTENED TO YOU?

Patient: Yes, yes, yeah, very much so.

INT: [???] I'VE INTERVIEWED ALL OF THEM NOW ...

Patient: Sorry?

INT: I'VE INTERVIEWED THEM ALL FOR THIS STUDY, I'VE INTERVIEWED THEM ALL.

Patient: The nurses?

INT: THE NURSE AND THE CONSULTANTS TO GIVE A DIFFERENT, SLIGHTLY DIFFERENT SET OF QUESTIONS [???] AND [???] THEIR PRACTICE IN GENERALLY, REALLY, REALLY GOOD, NICE BUNCH OF PEOPLE TO WORK WITH. THEY'VE BEEN VERY, VERY HELPFUL TO US.

Patient: Yes.

INT: ERM, NOW YOU MENTIONED HERE I SAID, THERE'S THIS QUESTION HERE, 'DID THE BREAST TEAM GIVE YOU ANY KINDS OF TREATMENT OR SUPPORT INFORMATION?' AND YOU SHOWED ME THAT PACK WHICH IS REALLY, REALLY HANDY ... WHO GAVE YOU THAT, WAS IT THE BREAST CARE NURSE?

Patient: The breast care nurse, yeah.

INT: AND THEY GAVE YOU THAT IMMEDIATELY AFTER [???] ??

Patient: You get that immediately after your consultation with the consultant after she told you that, yes, you have got breast cancer, then you see the breast care nurse and she gives you this pack. And she gives you a card with your named nurse on the back, so if you want to you ring that number and you can ask for her, although I've found they're all very good so I don't mind who I

speak to you. So, yes, you get the card with the number of the breast care clinic so you go straight through, you don't have to go through the hospital, which is quite good, I think anyway.

INT: YOU SAY THAT THIS TIME ROUND YOU ASKED MORE QUESTIONS AND YOU KIND OF GOT MORE INFORMATION, APART FROM THE INFORMATION YOU GOT THERE, WHERE ELSE DID YOU FIND INFORMATION FROM?

Patient: Erm, just sort of asking questions of various people, you know, over at work and ...

INT: AND FRIENDS.

Patient: ... yeah, friends, you know, it's ...

INT: AND YOUR FAMILY OF COURSE.

Patient: Yes, yeah, yeah.

INT: YOU SAID YOUR GP WAS VERY HELPFUL AS WELL, DID YOU GET MUCH INFORMATION ABOUT THINGS, THE KINDS OF TREATMENT OPTIONS, FROM YOUR GP?

Patient: No, that was the first time they were very helpful. I didn't, I haven't had too much to do with them this time because I've got the team here so I don't need to go to the GP as well: I go to the breast care clinic. I prefer to ask them because it's their speciality, although the GPs as I say was very good the first time. But they're not obviously specialists, are they? But they're very good.

INT: AND YOU SAID THAT YOU READ A LOT AS WELL AND DO YOU GET MUCH INFORMATION FROM THINGS LIKE BOOKS OR MAGAZINES AND THAT?

Patient: Yes, yes, books, magazines, anything that, if I look in the TV book and there's anything about any cancer, I do tend to watch it, because obviously I'm not that daft that I can't, I don't think that I can't get a different form of cancer. So, yes, I do tend to ... watch programmes and read and ...

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

Patient: It's very good.

INT: MM. DO YOU THINK IT'S MET YOUR EXPECTATIONS AT ALL?

Patient: Sorry?

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

Patient: I think it's better, because I'm thinking back to the first time ...

INT: YEAH, THE FIRST TIME, YEAH.

Patient: ... this time it seems to be a lot better. There's more staff helping, you know, more areas you know, because obviously you can't ring the consultant and ask a question: it's just not done, you don't do it, but there's lots of other people that you can ring up and ask and, yes, they'll see you and they make arrangements for you, they don't say, 'Oh, sorry, ...' you know, but, yes, they're very good.

INT: WELL THAT'S GOOD THEN. THIS MIGHT SOUND A STRANGE QUESTION, BUT WE'VE ASKED THE CONSULTANTS THIS AS WELL, IT CAME UP RIGHT AT THE END THROUGH A COLLEAGUE OF MINE, IF YOU WERE TOLD YOU HAD THE POWER AND THE MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE AT THE CLINIC YOU ATTENDED, WHAT DO YOU THINK THAT WOULD BE?

Patient: [pause] I can't really say. Erm ... maybe to have another couple of more consultants that could do a couple more operations a week. Other than that, no, I think it's a really good team they've got there and a really good clinic, and that's from the consultant down, so the people that look after you when you actually go in for the operation. I found that I was really well looked after. So, no, I don't think there would be anything that I would change at the moment. Except, as I say, maybe to get a couple more people in so that people wouldn't have to wait because the waiting is the worst thing when you've been diagnosed with cancer, the waiting to get something sorted. But, no, other than that, no, I can't think of anything that I would say should be changed.

INT: OK. NOW YOU'VE BEEN THROUGH THIS EXPERIENCE - ACTUALLY YOU'VE BEEN THROUGH IT TWICE - WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS THAT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: ... erm ... well, if you're gonna be all right, which nobody can answer. It's a question that you say, 'Am I gonna die tomorrow?' well nobody knows. It's just, erm, when you go back for your results after the operation and she says, in my particular case she said, 'We've got it, we're almost sure we've got all of it,' and there was no cancer in the lymph glands that she took out, the sample, and then you think, 'Well that's good,' and hopefully I'll have a few more years. And that's all you can really hope for.

INT: THIS WAS THE SECOND TIME?

Patient: Yeah, yeah.

INT: OK. AND WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS THAT SOMEBODY WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPTIONS, THE OPERATIONS, TREATMENT, YOU CAN HAVE?

Patient: The most important thing? Erm, well how it's gonna affect you: do you go back to being, having some normality or is it going to affect you physically or mentally? I mean I know nobody can actually say, but these are the important questions that you need to know, you know, the answers to. So ...

INT: IS THERE ANYTHING ELSE THAT YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY?

Patient: Erm ...

INT: ANYTHING YOU THINK WE'VE MISSED ... OR

Patient: No, I don't think so.

INT: ... ANYTHING YOU THINK IS IMPORTANT YOU'D LIKE TO SAY I HAVEN'T COVERED?

Patient: No, I don't think so. No, I just think, having had cancer, or ... you think to yourself, 'Well I've got cancer in there somewhere,' as I said previously I'm not that daft that I don't think it can come somewhere else, it's a difficult thing to live with ...

INT: MM, YEAH, IT IS.

Patient: ... and it's a difficult thing to know that your body's let you down. I try to live quite rightly by not smoking - yes I have a glass of wine occasionally ...

INT: THAT'S SUPPOSED TO BE GOOD FOR YOU, THAT [CHUCKLES].

Patient: ... yes, yeah. And you think, 'Well, why me?' but then again when you sit down and analyse it, why not? So, yes, you just have to learn to cope with it, that's what I would say, you learn to cope with what's happening. Sometimes you, some days you can feel, erm, yes you can rule the world, and the next day you're down in the dumps and you don't want to do anything. But then I think this ... makes you a slightly better person because you stop and think. It's a thing that you think, 'Well if it can happen to me it can happen to the next person,' so then I should be a bit kinder [chuckles] and not nasty.

INT: I'D BE A BIT NASTY.

Patient: No, but do you know what I mean? It gives you a different outlook.

INT: YEAH, OF COURSE, IT'S BOUND TO.

Patient: And sadly in between the first mastectomy and the second mastectomy my husband got cancer and died, so, yes, it's all around me and I do find days that are not very nice.

INT: NO, OF COURSE.

Patient: But then again, on the other hand, I'm still here to moan about it so I'm winning, aren't I?

INT: WELL, YEAH, THAT'S ONE WAY ...

Patient: And hopefully get back to work in a couple of weeks.

INT: YOU'RE NOT BACK YET THEN?

Patient: No.

INT: BACK IN A COUPLE OF WEEKS' TIME?

Patient: Yeah, yeah. So, erm, go and look after my old people [chuckles] which I enjoy doing very much. I think if you can give something back it's nice, isn't it?

INT: MM, I'VE GOT MY MAM COMING DOWN [???

Patient: Oh, lovely.

INT: SHE'S 77, YOU WOULDN'T THINK IT, I MEAN, SHE GETS ABOUT ALL OVER THE PLACE, BUT SHE'S HAD A LITTLE SCARE JUST RECENTLY, YOU KNOW, SHE HAD A BIT OF HIGH BLOOD PRESSURE AND STUFF AND POUNDING IN HER CHEST AND STUFF, AND SHE'S A BIT OVERWEIGHT AND SHE SMOKES AND STUFF AND I'VE NAGGED HER FOR YEARS ABOUT IT - POLITELY AND KINDLY WHEN I CAN - BUT, YOU KNOW, SHE GOT A BIT OF A SHOCK, AND SHE'S BEEN WORRIED, AND OF COURSE SHE'S UP IN SUNDERLAND, I'M FROM SUNDERLAND ORIGINALLY.

Patient: Oh, right.

INT: SO I'M KIND OF 150 MILES AWAY FROM HER, AND DOING THE JOB I'M DOING IT'S NOT EASY JUST TO SUDDENLY, 'OH, WELL, I'LL GO HOME TONIGHT ...' I CAN'T JUST DO THAT, SO ANYHOW, LUCKILY YESTREDAY SHE SAID, 'OH WELL, EVERYTHING SEEMS FINE, I'VE BEEN BACK TO THE DOCTOR, EVERYTHING'S OK NOW.' SO I SAID, 'AH WELL,' SO I'VE BOOKED HER A TRAIN TICKET ON THE INTERNET AND SENT IT UP TO HER, AND SHE SAID THIS MORNING ON THE MOBILE, SHE SAID, 'AH YEAH, I'VE GOT IT, IT'S REALLY NICE.'

Patient: Ah, lovely.

INT: SO I'LL BE DOING MY BIT OF TLC WHEN SHE COMES DOWN. I THINK WE'RE GOING TO END UP GOING TO WHITBY.

Patient: And tell her to stop smoking. I used to smoke, yeah, I used to smoke. You've switched off have you ... [chuckles]

INT: ACTUALLY I SHOULD DO ...

[End of interview]