

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)  
\*VENUE: High MR unit  
\*DATE:  
\*ID: Patient33  
\*INTERVIEWER: DJW

INT: THANK YOU FOR AGREEING TO BE INTERVIEWED TODAY. I'D LIKE TO START OFF WITH QUESTION 1, WHICH IS CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR YOU UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: What did I know? I know that in young women, say under 50, it's very often much more aggressive and that as women pass that 50 mark and certainly you go post-menopausal it's less aggressive. So I knew that much. I knew that there are a variety of operations that you could have: either a full mastectomy or a lumpectomy; I knew that you could, would probably need radiotherapy, yeah, and I knew about chemotherapy and sampling nodes and ... [???

INT: WHERE DID YOU GET ALL THAT KNOWLEDGE FROM?

Patient: Just from people I know who've had it.

INT: AH, RIGHT, PREVIOUS ...

Patient: Yeah, mostly from friends and family who've had it, yeah.

INT: YOU SAY IT'S IN YOUR FAMILY?

Patient: My sister in law.

INT: YOUR SISTER IN LAW.

Patient: Not, there's no familial ... with me.

INT: RIGHT.

Patient: There's nothing in my side of the family, this is my husband's sister.

INT: RIGHT, OK. AND HOW RECENT WAS THAT?

Patient: She's just had her five year all-clear, so it's five years ago.

INT: OH RIGHT, OK.

Patient: Yeah, and she's young than me, so, so her circumstances were quite different. I had a friend who had it when she was about 30 and she died quite quickly after being diagnosed.

INT: RIGHT, OK. [???] CAN YOU PLEASE TELL ME ABOUT THE TIME WHEN YOU FIRST REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST UP UNTL THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS?

Patient: Right, I think, I didn't realise there was anything the matter until I'd had a routine mammogram just before half-term and when I came back, erm, we went away for a few days and when we came back there was a letter recalling me to the breast unit, and that had happened the previous time three years ago, so I wasn't overly bothered about that. But when I went back into the clinic that day it seemed to me that they were different with me that time than they had been when they'd recalled me the time before, and they'd said there was nothing then. And I think it was when the radiographer was doing the ultrasound that it occurred to me, he was certainly talking about 'Have you felt this lump?' which I had no idea there was anything there, so it was at that point when he said to me, because he was clearly looking for something very specific, in a specific place, that I realised that something clearly was there that wasn't there before. And then they said 'We'd like to do a biopsy now as well,' I think that for me, that was it. Then it was a week later that I actually went back for my results and they actually said that it was positive.

INT: RIGHT, OK. SO YOU WENT THROUGH SCREENING AND THEN YOU WENT ON HOLIDAY, SO, IS THAT RIGHT, YEAH?

Patient: Yeah.

INT: HOW LONG WERE YOU AWAY?

Patient: A few days. So it would be, I think I went on the Tuesday and they said you'll hear from us in two weeks' time, so it would be the Tuesday before half-term and the letter came while we were away, so it would have come within 10 days I would guess, to go back for the second ...

INT: AND HOW LONG WAS IT TILL THE SECOND ONE?

Patient: Erm, they saw me, they saw me that Tuesday, so it would have been two full weeks ...

INT: FOUR WEEKS FROM THE FIRST ...?

Patient: Two full weeks ...

INT: TWO FULL WEEKS ...

Patient: ...from the first time I went for just a routine screening. And then a week later that they actually ...

INT: SO LIKE THREE WEEKS FROMS SCREENING TO HEARING ABOUT YOUR DIAGNOSIS?

Patient: Yes.

INT: SO THAT'S FAIRLY QUICK REALLY.

Patient: It was very quick, yeah.

INT: YEAH, FAIRLY QUICK, YEAH, OK. SO DURING ALL THIS TIME WHAT WAS GOING THROUGH YOUR MIND THEN?

Patient: [chuckles] First of all, because they hadn't confirmed anything, trying really not jump the gun too much but I was, and certainly my husband was ... you know, 'Well you mustn't jump into, you mustn't jump to conclusions, they haven't found anything, and if there is something it's not necessarily positive,' but I think was 95 percent sure in my own head that this was gonna be positive. But trying not to think too far ahead, erm, but knowing that the minute he said, 'Yes, this is positive,' that life was gonna change dramatically from now on, certainly not looking forward to that at all.

INT: AND WHEN THE RADIOGRAPH SAID 'HAVE YOU FELT THIS LUMP' COULD YOU ACTUALLY THEN FEEL IT?

Patient: No, nothing.

INT: COULDN'T FEEL A THING?

Patient: No, and he didn't find it either very easily, he couldn't feel anything, no.

INT: DID THEY SHOW YOU A MAMMOGRAM? WAS IT VERY SMALL?

Patient: They did show me the mammogram but of course I couldn't translate anything from the mammogram, I didn't, they said, 'This is it,' but I think I was a little bit overwhelmed by then because I just felt, it was, erm, it's a tricky one because when I went back to see the consultant about, to get the final results, the question I wanted to know was, was what they were looking at in the same place as they'd found one the time before, 'cos they'd recalled me then and the answer was 'Yes' so ...

INT: OH THIS WAS TWO OR THREE YEARS PREVIOUSLY?

Patient: Three years previously, they recalled me then.

INT: WHAT HAPPENED THEN?

Patient: Well, they'd recalled me and had a look and done another, done another set of x-rays and did an ultrasound and couldn't find it again. Something had come on the first time, they'd recalled, had another look, and decided it was a false positive, I think they call them, don't they?

INT: AH RIGHT, YEAH.

Patient: But it wasn't, they just didn't find it the second time so presumably what was there was very small ...

INT: AH, RIGHT.

Patient: ... and didn't show up.

INT: SO IT WAS IN THE SAME SORT OF PLACE THEY WERE LOOKING FOR BEFORE?

Patient: They said it was, when I asked, they said 'This is the same place as we were looking at last time.' Mm.

INT: AH RIGHT, OK. AND DID, AND YOU MENTIONED, YOU SAID YOU WERE SPEAKING, YOU TALKED TO YOUR HUSBAND ABOUT WHAT YOUR THOUGHTS WERE ...

Patient: Oh yeah.

INT: DID YOU HAVE ANY, TALK ABOUT ANYONE ELSE ABOUT YOUR INITIAL THOUGHTS?

Patient: Not really, no, not at that point, it seemed too much like, assuming too much before the event for no good reason.

INT: AND WHEN YOU STARTED, YOU KNOW, TO THINK IT WAS CANCER, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF SURGERY OR TREATMENT OR ANYTHING?

Patient: No, not until we actually went in to see the consultant on the Tuesday and he confirmed that the tests were positive.

INT: OK. SO CAN YOU ACTUALLY TELL ME WHAT HAPPENED WHEN YOU WENT TO CLINIC THAT DAY AND YOU WERE SORT OF DIAGNOSED?

Patient: Yeah. I can't remember the exact form of words the consultant used, I thought he used the word cancer but maybe he didn't, he just said, you know, 'You've had a second test and it is positive,' or he said some words to that effect, erm, and then he explained, he outlined the different, two different procedures, and explained that I would have to choose, and that I have to say was a real shock, that he was giving me this option between a full mastectomy and a lumpectomy, but without giving me any advice as to which one he thought would be good. He actually said that, 'I will not give you any advice: I have my own opinion but it's up to you,' and it seemed like they wanted - I'm sure they didn't - but it felt like they wanted an answer fairly quickly because they were talking about having surgery within a week. So that came as a real shock, I wasn't expecting it.

INT: THE CHOICE?

Patient: The choice, yeah.

INT: SO WHO ELSE WAS IN THE ROOM WITH YOU [???] ?

Patient: My husband was with me, the consultant was with me and the breast care nurse was with me, and then I think there may have been another nurse in as well.

INT: AND WHO WAS THE CONSULTANT?

Patient: Mr Holliday.

INT: MR HOLLIDAY, YEAH, HOWARD HOLLIDAY.

Patient: Yeah.

INT: ERM, WHAT WERE YOU FEELINGS BEFORE YOU, YOU KNOW, WHEN YOU WERE IN THE CLINIC WAITING TO GO AND GET YOUR DIAGNOSIS?

Patient: Oh I was very anxious, yeah. Yeah. But there's no point discussing stuff that, until you're absolutely sure.

INT: DID YOU HAVE EXPECTATIONS ABOUT WHAT YOU WERE GONNA BE TOLD AND ...?

Patient: Yes, I did, I was ...

INT: APART FROM THE CHOICE?

Patient: Apart from the choice, yeah, I was, I was sure they were going to tell me it was positive.

INT: MM, OK. SO IT WAS, IT WAS MR HOLLIDAY HIMSELF THAT ACTUALLY BROKE THE NEWS TO YOU?

Patient: It was, yeah.

INT: AND, ERM, DID HE USE ANYTHING SUCH AS TOOLS, ANY AIDS, THINGS LIKE MAMMOGRAMS, DIAGRAMS, ANYTHING LIKE THAT? DID HE DRAW ANY DIAGRAMS?

Patient: Do you know, I can't remember now.

INT: NO?

Patient: I, no, I can't remember.

INT: OH, OK.

Patient: He explained the two procedures, not in a lot of detail, just sort of outline, and the consequences afterwards in terms of radiotherapy. They wouldn't discuss chemotherapy with me, I asked about that, but they said, no, it was far too early to discuss anything like that, but certainly the radiotherapy, depending on the lymph node tests.

INT: AND HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENT?

Patient: Er ... well I thought I understood most of what he said to me at the time, yeah.

INT: WAS THERE ANYTHING YOU FOUND DIFFICULT TO UNDERSTAND OR TO TAKE IN?

Patient: Er ... no, no, just the, I think the size of the decision, that I was just, I think really taken back that they ... I think I was shocked that they were offering me a full mastectomy because I'd figured by then, because I'd already asked him was this shadow that they'd found in the same place as they'd found something three years earlier, so I was figuring then it's three years' growth and he, I think he might have told me how big they thought it was on the ultrasound that they'd done, so I knew how big it was and it seemed to me that that wasn't very big for three years' growth, and I was

surprised that, having come up in a routine screening, that they would be offering me a full mastectomy. I think I thought those were, tended to be for people where they'd found a bigger tumour, or it had spread, or maybe there were two tumours, not one. And we weren't talking about that, I thought we were talking about something relatively small that had only come in three years or so, so I was surprised they were offering me that as a ... I think I was just surprised they were offering me that as a treatment.

INT: DID YOU HAVE ANY THOUGHT AT THAT STAGE, WHEN YOU HEARD YOUR DIAGNOSIS AND THEY'D STARTED TALKING ABOUT TREATMENT OPTIONS, ABOUT WHAT TREATMENT YOU MIGHT WANT?

Patient: Yes, I think I made up my mind fairly quickly I think that, since they were telling me that the, after five years there's no difference, whichever treatment I chose to have, after five years there's no difference at the end of that as far as they could tell, it seemed to me that I didn't want anything as radical as a full mastectomy unless they were telling me I actually needed it. So I think I came fairly quickly to that conclusion in my own head, that that wouldn't suit me.

INT: AND DID YOU GET ANY IMPRESSION THAT THERE MIGHR BE ONE TREAMTNET BETTER THAN ANOTHER OR ... ANYTYING AT ALL?

Patient: No, no, they were not giving me anything like that, they were very clear that this was going to be my choice and that they wouldn't push one against the other. They just simply presented all the facts about the two. For example they said, if the lymph nodes were clear and I had a mastectomy, then I wouldn't need radiotherapy; if I chose the lumpectomy I would need, they would want me to have radiotherapy. And that was quite a big decision then, because facing the radiotherapy I'm thinking, well if I'd had a mastectomy and the lymph nodes were clear ... but you don't get that choice really because you're not going to know if the lymph nodes are clear until they've done the operation.

INT: NO, THAT'S RIGHT, YEAH.

Patient: So the radiotherapy really, it's a bonus if everything's clear but you're not gonna know until it's too late.

INT: YEAH, UNTIL YOU'VE HAD THE OPERATION?

Patient: Yeah, yeah.

INT: AND DID YOU SPEND ANY TIME ALONE WITH THE BREAST CARE NURSE AFTER SEEING THE DOCTOR? CAN YOU TELL ME ABOUT THAT?

Patient: Yeah, I can't remember how long I was in with Mr Holliday, but it was probably only 5, 10 minutes maybe and then we went off with the breast care nurse and we sat in another room.

INT: CAN YOU TELL ME A LITTLE ABOUT WHAT HAPPENED THEN?

Patient: She left us alone for a bit, I think, quite deliberately so that we could talk to each other before she came back, and then she went through the whole thing again with all the different options, and said, you know, I didn't have to decide there and then, but I think we had done by then. My

husband had also sort of had time to think about it then. I think we were both clear by the time we left the consultant I didn't want a mastectomy.

INT: OK. AND DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSE AFTER THAT MEETING?

Patient: She's, she came into hospital to visit me after the surgery, and I think she's phoned me once, that's it.

INT: OK, BUT NO EXTRA CONTACT BEFORE YOUR SURGERY?

Patient: No. No, she went away on a course.

INT: OH, OK.

Patient: At some point she was away on a course, so no, I didn't, no.

INT: AND WAS IT MR HOLLIDAY THAT ACTUALLY, AND THE BREAST CARE NURSE, THEY DISCUSSED THE OPERATION YOU WERE GOING TO HAVE ... THAT'S RIGHT, YEAH

Patient: Yeah, so I understood, yeah.

INT: AND DID THE BREAST CARE NURSE USE ANYTHING LIKE MAMMOGRAMS, DIAGRAMS?

Patient: No. I did go up and see my own GP in between to ask her, just some general advice.

INT: AND HOW WAS SHE THEN?

Patient: She ... well I went to see her because I've got a lot of confidence in her and I knew she hadn't got any information about me specifically because it was too quick, so she could only give me very general advice because she didn't know anything specific about what they'd found. But I talked it over with her and one of the things I think that had gone through my head as well is that, having a full breast removed for somebody my size was going to give me problems probably with backache, it would make me very unbalanced. Friends I know who've had a full mastectomy tended to be rather small-chested and I think maybe they've found it, that that was OK for them: I thought that would be a probably not a good plan for me, and she agreed with me.

INT: YEAH, IT DEPENDS, IT ALL DEPENDS ON WHERE THE TUMOUR IS USUALLY. THEY'VE GOT GUIDELINES THAT THEY FOLLOW, SO IF IT'S A LARGE TUMOUR IN A SMALL BREAST THEN THEY WOULD TAKE THE WHOLE BREAST BECAUSE THE COSMETIC APPEARANCE AFTERWARDS WOULD BE TERRIBLE.

Patient: Yeah. I mean actually I never asked them where it was, that's a question I've still to ask. I don't know why?

INT: IS THERE ANY PARTICULAR REASON WHY YOU DIDN'T?

Patient: No, I don't know why I never asked that. I think initially I didn't ask it because I wasn't, I don't think I wanted to know at that point how close to the lymph nodes it might be, because that was

a bit scary waiting for that result, and it felt like this might be quite close and I don't know quite whether that makes a difference, how close the tumour is to the lymph node system or not? But that was a question I didn't want the answer to at that point. I wanted to know I was clear before I asked anything else.

INT: RIGHT, OK. ERM, THROUGHOUT THE WHOLE CONSULTATION PROCESS WITH THE DOCTOR AND WITH THE NURSE, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DID MOST OF THE ACTUAL TALKING?

Patient: Erm ... certainly the consultant when we first sat down and he gave me that information, and then myself and my husband were both asking questions, so I would think in that time period probably slightly more from the consultant because he was, he gave me the information and then he answered the questions, you know, he was very clear ...

INT: RIGHT, SO [??] YEAH?

Patient: Yeah. So he would have said more than we did. With the nurse, probably about equal I would have thought.

INT: AND WHAT SORT OF QUESTIONS DID YOU HAVE, DO YOU REMEMBER?

Patient: Yeah, yeah, mainly about how long was all this going to take because I work full-time and I was trying to figure out in my head what was going to happen. I'm a teacher and so I was a bit, I was really concerned about what was going to happen with my classes. But I never really got any clear answers about how long I'm gonna be off and then, and I'm still not very clear either. And that was a major concern because I went back, I saw the consultant on the Tuesday morning and I went back into school in the afternoon, because then I had to tell people ...

INT: OF COURSE, YEAH.

Patient: ... that I was going to be off like on the Monday, they did the surgery the following Monday. So we didn't have very many days to pick up and try and sort out what was going to happen to all my classes.

INT: IT WAS QUITE A BUSY PERIOD FOR YOU, A TEACHER, THIS TIME OF YEAR.

Patient: Absolutely.

INT: YOU'VE GOT EXAMS COME UP ... IS IT CHILDREN YOU TEACH OR IS IT ...

Patient: No, I teach 11 to 18s ...

INT: AH, RIGHT, SO IT'S SORT OF GCSE STUFF.

Patient: ... so I've got loads of exam classes, yeah. So I was very concerned about that because I'm a physicist, I teach physics and finding someone ...

INT: DO YOU? AH RIGHT.



Patient: ... yeah, so finding somebody to fill in, I knew wasn't gonna be very easy.

INT: NO, NO OF COURSE, SCIENCES ARE DIFFICULT TO FILL IN.

Patient: Yeah. So I knew that was going to be a mega-problem for everybody, and I'd just had a colleague who'd been off since last October with a bad back, he came back on the Mon-, on the Monday as I left on the Friday, so he'd had a long absence and he'd just, he was coming back, I didn't actually see him, and then I went off. And so, and somebody was off as well, so we had a lot of problems with absence within the faculty. So me having a long stretch off I knew was gonna be a problem. So that, the bulk of what I was trying to ask her did seem to revolve about, you know, can you give me any clue about how long I might be off and when I might be able to get back because they need to know to sort out school.

INT: SO, I WANT TO TALK A LITTLE BIT MORE ABOUT TALKING WITH THE DOCTOR. ERM, ...

Patient: My own GP?

INT: NO ...

Patient: The consultant.

INT: YOUR CONSULTANT. WHEN YOU WERE ACTUALLY TALKING ABOUT WHAT OPERATIONS YOU COULD HAVE, DO YOU FEEL THAT THE CONSULTANT, DID YOU FEEL THEY LISTENED TO YOU, THAT THEY UNDERSTOOD YOUR NEEDS, YOUR CONCERNS?

Patient: ... I think, no, I think he was more giving me factual information for me to make a decision on.

INT: AND WHAT ABOUT THE NURSE, DO YOU FEEL THAT THEY LISTENED TO YOU, UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, THINGS LIKE THAT?

Patient: Erm, I think so, but I wasn't getting any clear answers.

INT: ABOUT YOUR ...?

Patient: About, certainly about my concern about how long I was gonna be off, that wasn't at all clear. Erm, but I think by the time I'd seen the nurse, my husband and I had agreed that I didn't want, I wanted a lumpectomy and that, we didn't really pursue it much further really.

INT: AND WHEN DID YOU TELL THEM THAT, YOUR FINAL DECISION?

Patient: We told the consultant as, just before we left the room, and we didn't change our minds after that, so it was very quick.

INT: RIGHT. AND FROM THAT CONSULTATION TO WHEN YOU ACTUALLY HAD THE OPERATION, DID YOU SAY IT WAS A WEEK?

Patient: It was less than a week, I think. He told me on the Tuesday and the operation was the following Monday, so it was just short of a week.

INT: SO FROM WHEN YOU HAD THE SCREENING TO WHEN YOU ACTUALLY HAD THE OPERATION WAS ABOUT A MONTH, WAS IT, PROBABLY?

Patient: Yeah, it must have been, yeah.

INT: THAT'S PRETTY ...

Patient: It's very ...

INT: [???

Patient: Yeah, yeah. That week was a bit of a blur I have to say between when I got the information and when I actually went in and had the, because I was running round at school trying to sort everybody out and ...

INT: YEAH, OF COURSE, IT'LL HAVE PASSED IN NO TIME I BET.

Patient: Yeah.

INT: [???] VERY VERY BUSY. ERM ...

Patient: And people were, people, the other thing to deal with of course is other people's reactions to what you're telling them. Please at school that I work with were very upset, and my family were very upset.

INT: WAS ANYBODY, IS THERE ANYBODY YOU KNOW AT WORK THAT'S HAD THE SAME ILLNESS?

Patient: Not the same, no I had a friend who came to see me at school who'd had a full mastectomy but she'd chosen that option, but we didn't discuss why because she's got a, she's got family problems as well and I didn't know, she doesn't talk about it very much, and I wasn't quite sure why she hasn't talked to me about it yet, maybe she will eventually, but I suspect her reasons for doing what she did were bound up with her family problems rather than anything else.

INT: OK. DID THE BREAST TEAM GIVE YOU ANY CANCER OR TREATMENT SUPPORT INFORMATION? DID THEY GIVE YOU A PACK OR ANYTHING?

Patient: Yes, there's a pink pack somewhere with lots of leaflets in it and ... yes.

INT: OK AND DID THEY GO THROUGH IT WITH YOU OR ...?

Patient: They went through some of it with me, yes, and I asked, they explained, erm, things like how the size of the tumour when they'd figured out how big they thought it was, how the size of it influenced what they might do next, and I think they explained about the Tamoxafen, whether this tumour would turn out to be oestrogen, do they call it oestrogen positive or... [???] the way they phrase it now.

INT: OESTROGEN RECEPTIVE OR SOMETHING LIKE THAT.

Patient: That's it, yeah, so that would make a difference as to whether I would take Tamoxafen afterwards or not. So they talked me through those things as well.

INT: AND THE INFORMATION YOU GOT FROM THERE, THE HOSPITAL, HOW USEFUL DID YOU FIND IT?

Patient: Some of it was quite useful but it was fairly general, erm, yeah, it was fairly generally.

INT: DOES IT INCLUDE THINGS LIKE RADIOTHERAPY AND THINGS LIKE ALL THE DIFFERENT TREATMENTS YOU CAN HAVE, YEAH?

Patient: Yeah, yes.

INT: BUT AT THIS POINT YOU WEREN'T SURE IF YOU WERE GOING TO BE HAVING THAT?

Patient: I think I was sure I was going to have the radiotherapy, nobody had said for, very clearly, whether I'd need chemotherapy. I think that worried me more than the radiotherapy did, yeah.

INT: LET ME SEE IF THERE ANY QUESTIONS I WANT TO ASK IN THIS SECTION ... NO I THINK WE'VE COVERED THAT BIT. I'D LIKE TO MOVE ON A LITTLE BIT, ERM, TO THE ACTUAL OPERATION. SO IT ENDED UP YOU HAD THE LUMPECTOMY, THE WIDE ...

Patient: I had a lumpectomy which is what I'd decided fairly quickly, yeah.

INT: AND, ERM, I THINK YOU'VE TOLD ME A LOT OF WHAT I WANTED TO ASK ANYWAY, YOU'VE DONE VERY WELL [CHUCKLES]. WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD THAT HELPED YOU MAKE THAT DECISION?

Patient: That I was told?

INT: YEAH, OR THAT YOU READ OR, IT DOESN'T HAVE TO BE ...

Patient: No, I think the most important thing was I didn't want anything as radical if I didn't need it, it just seemed to me a massive step to have the whole breast removed if I didn't need to.

INT: YEAH, OF COURSE. DID YOU, YOU KNOW WHEN YOU GOT INFORMATION FROM THE HOSPITAL, DID YOU SEEK ANY OTHER INFORMATION, I MEAN I KNOW YOU WENT TO YOUR GP, ERM, ANY OTHER INFORMATION? DID YOU LOOK ON THE INTERNET OR MAGAZINES ...?

Patient: No, I didn't go on the internet, no. I talked to my sister in law who'd had a lumpectomy done five years ago, so I talked to her at length, but we both realised that, you know, even five years ago, things are slightly out of date already, it's surprising. Talked to a friend who'd had a full mastectomy. But I didn't really change my mind in between. No.

INT: OK. AND SO YOU WENT AHEAD AND THE WIDE LOCAL, THE LUMPECTOMY?

Patient: Yeah, yeah.

INT: AND THEN WHAT HAPPENED JUST AFTER THAT THEN WHEN YOU'D HAD YOUR OPERATION? WHAT WAS THE SEQUENCE OF EVENTS AFTER THAT, BECAUSE YOU'VE OBVIOUSLY BEEN, THEY MUST HAVE TOLD YOU AFTER THAT THAT YOU HAD SOMETHING IN YOUR LYMPHS, DID YOU?

Patient: That's right, sorry, yes. I had the operation on the Monday afternoon, late afternoon, erm, I came out of hospital on the Wednesday. Mr Holliday was on study leave the following week so he managed to get the results through quickly: he rang me to say that he would get the results ... no, he came in and told me and said, like, 'As soon as I get the lymph node system results, I will ring you and let you know because I don't want you to be having to wait for another full week' or longer while he was off, and he rang me on the Friday morning ...

[Interruption in recording]

Patient: ... so he rang me up on the following Friday morning which I think was quite quick, I don't think he would have seen me 'til the following week and said the results had come through and they were all clear, and I went in to see him at the hospital at lunchtime. I think that was right. He either rang me on the Thursday or the Friday and I went him to see him on the lunchtime before his afternoon surgery. And he just told me again the results were clear.

INT: RIGHT, OH THAT'S GOOD NEWS.

Patient: Yes, yeah.

INT: AND THEN, OBVIOUSLY THERE'S THE RADIOTHERAPY, DID YOU DISCUSS THE RADIOTHERAPY THEN AS WELL?

Patient: Erm, he said I would have five or six weeks' worth of radiotherapy and they'd said to me already it would be about five or six weeks after the operation and it was just a question of waiting until the process takes its course while they get ready for you and what-have-you [???]

INT: AND YOU SAY YOU'VE JUST STARTED IT?

Patient: Just started it yesterday, yes, so that was just over five, yeah five weeks.

INT: AND THAT'LL BE AT DERBY, IS THAT RIGHT?

Patient: It's at the DRI, the Royal Infirmary in Derby, there's two hospitals in Derby.

INT: YEAH, THE CITY AND THE ROYAL INFIRMARY.

Patient: Yeah, the breast care unit's at the City, the radiotherapy's all at the Royal Infirmary.

INT: RIGHT. IS THAT GOING TO BE AN EVERYDAY THING, IS IT?

Patient: Every day for five weeks, yes.

INT: EVERY WEEK DAY?

Patient: Every week day, not weekends and bank holidays.

INT: RIGHT, OK. I CAN NEVER REMEMBER IF IT'S WEEK DAYS OR [??] BUT IT'S EVERY WEEK DAY, YEAH.

Patient: It's every week day.

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

Patient: Yeah, the medical care's been absolutely fine, yes. Yeah. I'm not very good, I know, I'd have to be really hard pressed to ring, say, the breast care nurse and ask her anything, I'm not very good at doing that sort of thing, I know I'm not, I sort of would avoid that, but, yes, everyone that I've asked anything has answered me as well as they possible could.

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

Patient: Yeah, yeah.

INT: AND IF YOU WERE TOLD YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SERVICE AT THE GENERAL, AT THE CITY, SORRY, WHAT WOULD IT BE?

Patient: At the City?

INT: MM, THE BREAST SERVICE THAT YOU WENT TO.

Patient: Nothing, no. I think, [chuckles] the only thing that would be nice, and I'm sure for them as well, is if the surroundings were a little bit nicer. The unit itself is very dilapidated and ... that's all. But no, as far as the ...

INT: I KNOW THERE'S A LOT OF BUILDING, CONSTRUCTION WORK GOING ...

Patient: They certainly are, yes, it's a bit of a nightmare actually the City at the minute, yeah, yeah. So par-, practical things like parking and you can't park anywhere, there's nowhere to park, that thing, that sort of thing makes it very difficult.

INT: I KNOW WHEN I WENT THERE A COUPLE OF TIMES I HAD TO PARK RIGHT ACROSS THE OTHER SIDE TO GET TO THE ACTUAL BREAST UNIT AND WALK ALL THE WAY ROUND CARRYING ALL THESE BOXES OF RECRUITMENT MATERIAL AND STUFF.

Patient: Yeah, there's nowhere on the site. You have to park at the far end where the car park is near the, where the scanners are. But, yes, there's nothing at the other end and there's nothing off road either, there's, you can drive for a long way before you can find anywhere to stop and leave the car. But that was all, that's just a physical thing and I'm sure, I know they've got plans to move the whole thing.

INT: THEY HAVE, YEAH, I THINK IT'S GOING TO BE ALL FINISHED IN A COUPLE OF YEARS' TIME PROBABLY, MM.

Patient: Yeah, yeah. Because that sort of surroundings is a bit depressing I have to say.

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

Patient: I think it needs, it needs to be clear, I think, erm, I don't think the word cancer was used, even though I heard it in my own head, and I think they need to be absolutely clear what they're saying to people, and they did regularly ask me to tell them what I thought was going on, which I thought was very good, they were not just saying, 'Do you understand?' because you're going to say yes anyway, but they were asking me to repeat back to them what I thought was going on, and I thought that was excellent that they kept doing that to make sure I did understand what was happening. Because I did get the wrong end of the stick once or twice, simply because too much was coming at me too fast.

INT: IT'S A LOT OF INFORMATION TO TAKE IN, ISN'T IT?

Patient: Yeah, very hard. And even my husband missed some stuff and he was there as a sort of backstop to pick up the stuff I wasn't hearing.

INT: YEAH, IT'S VERY COMMON.

Patient: It does need to be repeated.

INT: YEAH, IT'S VERY COMMON WHEN YOU INTERVIEW PATIENTS, AFTERWARDS THEY SAY, I CAME OUT AND SAID, 'I HAVEN'T A CLUE WHAT THEY SAID,' BECAUSE THEY KIND OF HEAR SO MUCH AND THEN ...

Patient: You shut off after a bit or your mind goes off onto whatever it is that's been said to you first and the rest of it isn't, just isn't getting through.

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

Patient: Erm, I don't think they could have told me anything else. I think it's such a personal thing as to how you feel about whether you want to lose a whole breast or not, if you've got the choice. I don't know what other factors other people might have that would influence them, if they've got, I don't know, say they've got a husband who's also ill with something, maybe they figure the full mastectomy would in the long run be a quicker ... a quicker thing to get over and be right, whereas having a lumpectomy it is turning out to be quite a long procedure, having waited five weeks after the operation there's another five weeks of radiotherapy and then maybe a couple more weeks after that. So I suspect I'm gonna be off a lot longer than if I'd had a mastectomy.

INT: AH, RIGHT, YES, OF COURSE, OBVIOUSLY IF YOU'RE GOING FIVE DAYS A WEEK YOU WON'T BE ABLE TO GET BACK TO WORK.

Patient: No, no. So that, and that really wasn't very clearly either because when I asked them how long might be off, it did seem to be depending on how I responded to the treatment, and what sort of job I did. Some jobs I think may be easier to go back to.

INT: YEAH, THEY WILL BE. ERM, AND YOUR HUSBAND AND FAMILY, I MEAN HOW HAVE THEY BEEN THROUGH IT?

Patient: Brilliant, yeah.

INT: OH THAT'S GOOD. YOU'VE BEEN VERY GOOD, YOU'VE ANSWERED NEARLY ALL, I THINK EVERY QUESTION HAS BEEN DEALT WITH. IS THERE ANYTHING YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY?

Patient: I'm trying to think, apart from the fact that your brain goes to jelly, I can remember when I had a hysterectomy, afterwards it felt like months before my brain would start working properly, and this feels a little bit the same way. That going into another room and can't remember what you've gone for is much more pronounced since the surgery [chuckles] than normal. So I'm doing that a lot more and it is very hard, and I wrote some, I wrote my sixth form reports last week and I really sort of snapped into normality while I did them because I had to concentrate really hard, the rest of the time I'm not, and that doesn't help with knowing what's going on. So when I went for the radiotherapy yesterday and they said, 'Have you had the sheet explaining all the care, the care, and this cream on,' 'Ooh no, I don't remember having that,' but of course I had had one and I'd read it, but that had gone. So, too much happening I think. And you see a lot of different people.

INT: YEAH OF COURSE, THAT'S RIGHT. ERM, I THINK HAVING A LOT OF TIME TO YOURSELF AS WELL, THAT'S A THING.

Patient: Yes, you wind down too much, I've wound down an awful lot, which I know I'm supposed to do because I need to rest and get over it.

INT: OF COURSE YEAH.

Patient: The surgery's taken longer to get over than they'd indicated, it has for me anyway, so, yes, and then you do, you wind right down.

INT: MM, AND YOU'LL WIND UP WHEN YOU GO BACK.

Patient: Yeah.

INT: IT'S IMPORTANT TO PEOPLE, ISN'T IT, WORK? IT'S A FUNNY THING.

Patient: It's very important to me.

INT: YEAH, IT'S A VERY FUNNY THING.

Patient: It's very important to me because I'm getting to that point as well where I'm gonna have to decide soon how much longer I am going to work because it's only another two or three years until I'm retirement age anyway. So I had decided I wanted to carry on longer and then when this happened I thought maybe this is going to really affect quite, more than I thought.

INT: MM, POSSIBLY, [???

Patient: No. And that's had a big impact on me, it does make you feel, you know, as I say I was going along OK here, and then suddenly, Wham! You know.

INT: YEAH, IT'S A BIG SHOCK, ISN'T IT?

Patient: Well it feels a bit like God's pointed his finger at me.

INT: OK, ANYTHING ELSE YOU'D LIKE TO ADD.

Patient: I can't think so.

INT: NO, NEITHER CAN I. I MEAN I THINK WE'VE TRIED TO MAKE IT AS COMPREHENSIVE AS POSSIBLE. ERM ...

Patient: I don't know whether I've actually addressed any of the issues that you ...

INT: YEAH, I MEAN, I'VE GOT LITTLE PROMPTS HERE IN CASE, THERE'S CERTAIN THINGS, YOU KNOW, I'D LIKE TO FIND OUT AND IF A PATIENT DOESN'T MENTION THEM I TEND TO PROMPT THEM, AND THINGS LIKE THAT. BUT YOU'VE KIND OF GONE THROUGH QUITE LOGICALLY REALLY FROM START TO FINISH AND QUITE CONCISELY. SO ...

Patient: I mean I found that, I've personally, because, obviously because of my training, found a lot of the hospital procedures interesting, the actual equipment. I was fascinated by the little thing they stick on your finger which has a little red light in it and can tell your oxygen levels - I thought that was fascinating. And I was very interested in the simulator they put me in, erm, at the hospital when they were measuring me up for the, it's a little, it's a linear accelerator, I didn't realise they used x-rays for the treatment. I always thought they used gamma rays from a cobalt source but they don't any more apparently, they use x-rays. So all that sort of thing's been very interesting ...

INT: OH, THE SCIENCE, [???

Patient: ... for me, because I'm interested in that kind of thing.

INT: YEAH, OF COURSE, YOU WOULD BE.

Patient: Yeah, yes. But [chuckles] so that's helped me along maybe because I'm looking as I'm laying in this machine, thinking ...

INT: HOW DOES THIS WORK?

Patient: What's this thing and why can I see laser lights are coming from and what are they for? Maybe other people might find that very daunting, I don't know, but it was daunting as well but it was also an interesting subject to me.

INT: OH YEAH. NO, I MEAN, I WOULD BE INTERESTED IN THAT SORT OF STUFF ANYWAY, I LIKE SCIENCE AND THAT SORT OF THING. THIS IS AN AREA WHERE OBVIOUSLY



TECHNOLOGY'S MOVING SO FAST THAT'S THE PROBLEM, THERE'S THINGS EVERY WEEK, THERE'S SOMETHING COMING OUT THAT'S A BIT MORE SPECTACULAR THAN THE LAST THING REALLY.

Patient: Yeah.

INT: SO IT'S QUITE INTERESTING MYSELF.

[End of interview]