

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE: 18/06/224

*ID: Patient Patient03

*INTERVIEWER: DJW

INT: First of all thank you for agreeing to be interviewed. I'd like to start with question one which is can you tell me a little bit about what you knew or understood about breast cancer before you realised there was something wrong with your breast?

RESP: It'd happened to someone else, basically.

INT: Yeah.

RESP: And then the reality of when I knew there was something wrong but it was, I didn't think I'd got cancer.

INT: Right.

RESP: Because I'd got a lot of pain and everyone was saying you don't get pain with cancer, erm, so I thought it was more menopausal because I've, I had gone into the menopause really and just put it down to that basically.

INT: OK, yeah. So have you, have you any family history of breast cancer?

RESP: None whatsoever.

INT: None whatsoever, OK. And do you have any friends that have had breast cancer?

RESP: None whatsoever.

*Q1. PLEASE TELL ME ABOUT THE TIME FROM WHEN YOU FIRST REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST TO THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS?

INT: Right, OK then. Um, so how, how did you find out there was something wrong with your breast?

RESP: Well it was quite strange really, um, I went along to my doctors who'd been treating me for the menopause and we'd been trying different things and I don't know if you've heard of the Mirena, I'd had the Mirena fitted to control the periods and we were on the single HRT because I didn't want the combination HRT and the Mirena, we were going along fine and then I developed this severe pain in my breast and it was painful and so I went straight back to her and she took, she took a look and she said, "Dawn, they're going to refer you straight away."

INT: Right.

RESP: And, which she did straight away, I got the appointment within ten days of going to my doctor.

INT: Right.

RESP: Erm, when I got there, Mr Holt the consultant, once I'd given him the symptoms, he says, "I think it is purely hormonal and I don't think we've got anything to worry about." Emotions shown I was relieved hearing it from the professional, it was just hormonal, nothing to worry about, but he said, "We will do the mammogram and we will do the scan." I, my husband came with me, so I thought, "OK, it's just a formality now, just, you know, to get it cleared up." Went in for the mammogram, went in for the scan and, with Dr Shepherd and, erm, I thought, "Oh, I'll just look at this scan and see what's going on," feeling a lot more relieved that Mr Holt the consultant had said he didn't think it was cancer. Mr Shepherd put the erm, started doing the scan and, erm, he did the left breast first and on this scan I could just see this black, black mass. Instinctively, it wasn't right and I said, "What on earth's that?" and he says "We'll come back to that in a minute," so they did the other breasts and I'd got cysts on there and three cysts in the other breast, then he came back to the other breast and he just said, his words were, he says "Prepare yourself for the worst," he says, erm, "there is something there," erm, he says, "and just be prepared." So with that it was just so traumatic from being told in one room it wasn't anything to going into the scan and him saying it was. So anyway they asked me to get back, they fetched Alan over, they asked me to go back and, well, you can imagine, I was just devastated.

INT: Hmm.

RESP: And, erm, Mr Holt then came back to me and he says, "I'm so sorry, Dawn" he says, "I would never have thought it was cancer from, from what you was describing, the pain," he says, "because, it," he was adamant that you do not get pain with breast cancer, and I was in a lot of pain.

INT: Yeah.

RESP: And he said, he then sat me down and said, "What do you want to do?" and with that question I says, "You take it off." I didn't even need to think about it, I says, "You take it off," I says, "I want the breast to go." He says, "Well, we can do," erm, oh I've forgotten the name of it now, where they can just take the lump.

INT: Oh the err, wide local excision or lumpectomy.

RESP: Yeah, lumpectomy, is the, and I says, "No," I says, "I don't want you messing, if you don't get it all, erm, so anyway, I'd agreed there and then from the moment they told me it was cancer I was having the breast off, no question.

INT: Right.

RESP: Erm, and, erm, he said, "Go back and think about it." And I said, "No," I said, "I want the breast off." Erm, so, that's what we planned to do, and they took the biopsy, they took three biopsies as well, and then, at, at that first consultation, erm, but I knew, Mr, Dr Shepherd told me, so I'd sort of, I knew there and then it was cancer, but I mean these guys aren't dealing with this day-in-day-out and not, you know, being able to recognise when something is wrong, are they, I mean, credit due to them, erm, so yeah, I'd got breast cancer from the first consultation and then I went back the seven days it was just a matter of confirming, you know, what I already knew.

INT: Right,

RESP: Which they did, they confirmed it and then you know, we set the date for the mastectomy.

INT: Right.

RESP: And that was it.

INT: OK. Did you, after the first consultation when you'd seen Dr Shepherd and then Mr Holt?

RESP: Mr Holt as well.

INT: Did you see a breast care nurse afterwards?

RESP: Yes, straight away, they erm, it was Mary on the first occasion, erm then they took me into the other room and, as you can imagine it's, it's sort of a word cancer, it's sort of everything.

INT: Yeah, there's heavy connotation with the word.

RESP: Oh, it, really, you know, doesn't happen to me it happens to someone else it doesn't happen to you and, you know, Donna, err, Mary sat down and explained, but at that point things weren't going in.

INT: Yeah.

RESP: Definitely not going in for either of us, it was, there was too much, for me it was just a case of right, I've got cancer, get me out of here. Do you know what I mean? It's, just reactional, so erm, yes she was there, she was, she was very, very nice, very supportive, they're angels those breast nurses, they really are angels. Erm, and, but as I say, nothing went in at that point, I've got breast cancer and the breast was coming off and that was it and the sooner it happened for me, the better and I didn't like the wasted, but then that's me, you know.

INT: Of course.

RESP: Control freak, bang bang bang, let's get it out the way.

INT: Right.

RESP: But, didn't work like that, does it?

INT: Not always! Erm...

RESP: No.

INT: Erm, so you, you're in the consultation, you said your husband went with you, that's right, you saw Mr Holt. Was there a breast care nurse present then, when you saw him that time?

RESP: Yes. Yes.

INT: Anybody else present that time?

RESP: The auxiliary nurse.

INT: Yeah.

RESP: Erm, the clinic nurse, yeah.

INT: Erm, and did they give you any, erm, information at the clinic at that time, any pack or any information to take home an read or anything like that?

RESP: Oh, I've got yards of it here and I don't know when I was given that. Yes, no, not, not at the first one, no.

INT: No.

RESP: Because, bearing in mind I'd just gone in for the first consultation.

INT: So they hadn't confirmed it.

RESP: They hadn't confirmed anything, other than Dr Shepherd had said, "Prepare yourself." He said it was, um, My Holt was absolutely lovely, erm, and then he came back in and, erm, no I wasn't given anything on that one, it was after, the seven days after when they'd got the biopsy results that I was bombarded then with, read this, read this, read this, which is all in here which you can see.

INT: Erm, so, I mean what were your, what were your thoughts and feelings during that week waiting for the confirmations?

RESP: Oh, Jesus, that was, that is the worst time, erm, that is so crucial, I defy any individual to, to get through that without any problem, because you, you, I was told I'd got breast cancer, OK, fine, but where else was it? How had it come anyway? And if I'd got it there, had I got it anywhere else? And your, your, you just go and your, I had great difficulty controlling that during that week.

INT: Yeah.

RESP: You know, I'm going to go back and there going to tell me it's here there and everywhere, I suppose that's quite normal, I don't know, but for me that's, that's what happened.

INT: Yeah, it is, it's a very anxious time, I understand.

RESP: You know, and, and seven days, is it seven days because they need them to culture, I think, I don't know, does it have to be seven days?

INT: I think it's just the number of cancers they're seeing and how long it takes to actually get the results through and stuff and, and they either do it...

RESP: That is a long time.

INT: It's a long seven days, isn't it?

RESP: A long, long time.

INT: Yeah.

RESP: A long, long time. Erm, but, you know, you get through it, as you do, you try and remain positive but, you know, what I told you before we went into this, I'd got that in my mind, I knew, so I suppose I handled it, well I suppose if there is a good way to handle it, we got through it anyway.

INT: Yeah.

RESP: But I was, I was afraid that it was somewhere else.

INT: Yeah of course.

RESP: If you know what I mean, to spread and, I mean, how did it get there in the first bloody place?

INT: Yeah.

RESP: Is it what you eat, is it how you live, is it, no one knows, do they?

INT: No. No, they do have some set of ideas now about how, how it can come around but how it happens in each individual patient is very variable.

RESP: You know.

INT: Yeah, it's err...

RESP: But, the healthiest of people, no one knows what's round the corner, none of us, none of us, and you know, it could happen to anyone, what is it, one in, one in three will either nurse or get cancer of some form so.

INT: That's right, yeah.

RESP: But then I suppose if there's, if you are going to get one then breast cancers probably one of the better ones in a way.

INT: In terms of treatment.

RESP: Treatment and erm, you know life expectancy, that type of thing.

INT: Yeah.

RESP: Because then obviously you then stop, well I did, I made a mistake of reading everything and that was a big mistake, for me.

INT: Our next question was sort of in-between that consultation and the consultation where it was confirmed that you had cancer a week later, I mean did you look you any thing, any information?

RESP: OH, yeah, I bombarded myself and to me that was a mistake because I got myself into a mess then, I'd convinced myself that I'd got inflammatory breast cancer.

INT: Oh yeah.

RESP: Because inflammatory breast cancer is painful and from what I read on the breast cancer erm, website, you know, I'd got that, I'd got that, you know, it doesn't help, and I've learnt now, I don't read anything and I don't listen to anyone because this is me and it's very individual to me, you know, we're not all the same, it's like with chemo, I've had my first chemo and I'm thinking, "I'm a fraud, I feel fine." Do you know what I mean?

INT: Yeah.

RESP: And there was all these stories thrown at me.

INT: Yeah, it's all very individual.

RESP: Do you know what I mean and, and, for me listening to people is bad, erm, do I want support groups, do I want to chat to someone who's gone through it and, well, for me, no.

INT: No, of course.

RESP: Because I'll take, each day is a journey, each change, you know, I'll accept and, get through it, that way, and that's what I've done.

INT: Yeah. Well there's various coping strategies, if that's the one that works for you, that's fine.

RESP: But listening to people and their horrendous stories, I can't cope with it.

INT: I think with, you know, listening to people's stories and that, I mean it is fine to listen to things happening you've just got to remember in the back of your mind that personal experience is exactly that, it's personal, and you might be completely different. Chemo's a classic example where, I have, you know, a consultation because of it, you know, patients, some have had one chemo and it's actually flattened them, you know, you know, all their hair's come out and everything, sort of thing, and then you hear other people who've had like quite strong chemo and they're fine they're just a little bit, they've had no reaction at all, it's the type of chemo, the kind of person they are, their, you know, their type of body they have and all this kind of stuff, it's very, very individualised, so I mean, I think...

RESP: I mean, like my hair, I mean it's not even started, touch wood!

INT: Yeah.

RESP: You know, I've not even started losing it yet and they said that by you second week, well I'm coming up to my next chemo,

INT: Yeah.

RESP: my hair's still there. OK, it might go on the next one but, I'm lucky and I know I'm lucky, but, you know, if this is what it is then, hey, I can through this.

INT: Right, yeah. And erm, in-between that time, between the first consultation and the second one with Mr Holt, did you talk to anyone about your initial thoughts, fears, anxieties, friends, family or anything like that?

RESP: It's been very much a family thing, I've got a very close, I'm very close to my mum, my husband, I've got a sixteen year old daughter, erm, it was more traumatic for her and Alan, because what I think was happening, I wasn't ill, and I wasn't it, yeah I'd got a pain in my breast I was still going to work, I was still doing everything.

INT: Yeah.

RESP: You know so, it's hard, it was hard for everyone because, you know, cancer ooh, it's the word isn't it?

INT: Yeah, of course.

RESP: It's, it's the word but, yeah, I was fit, so, whether that indicated they'd caught it early, um, which I felt they had anyway, which they told me that they had, but then it's all changed after I'd had the operation, but, erm, yeah it was the family, my husband, my mum, just basically family but, erm, the breast care nurses were there if I needed them.

INT: Yeah.

RESP: But, I didn't phone them, as I say I made the mistake of going and reading everything erm, self-diagnosing what I'd got and, you know, which is a bad, bad thing to do, you know, if I, if, any advice I would give to anyone is don't listen to anyone, don't read anything and just go with what's happening to you and what your surgeon's telling you because at the end of the day they don't even know until they've actually got it out.

INT: Yeah.

RESP: And we were still going on maybes, weren't we, you know. We think we've caught it early, it's only one half centimetres big, which is, one and a half centimetres which isn't very big so you're hopeful, you probably won't need chemotherapy.

INT: Right.

RESP: You know, and all that change when they got it out.

*Q2. AND WHAT HAPPENED WHEN YOU WENT TO THE CLINIC AND WERE TOLD YOU HAD BREAST CANCER?

INT: So, can you tell me about the consultation when you went back to hear about the results, second time with Mr Holt?

*Q3. AND WHAT HAPPENED WHILE YOU WERE TALKING ABOUT WHAT TREATMENT YOU COULD HAVE?

RESP: It was Mr Chadwick the second time, they were together. Mr Chadwick said, erm, to be honest I felt Mr Chadwick was trying to get me to have another operation, not the mastectomy.

INT: Right.

RESP: But, to be fair he wasn't, he was making sure I understood what options were available to me, so I sat and I listened and I just said, "I still want a mastectomy."

INT: Right.

RESP: That was very important to me, they weren't messing about and I weren't going backwards and forwards; "take the bloody thing off, I don't need it," you know, back to my medication can, so, that is what I did, but he did say, you know, "you didn't have, have to be, have to have the mastectomy," says, "because you could have this other one, we could get it out this way, that way." I says, "No," I says "I want the breast off." And it's a good job I insisted on that.

INT: Right, yeah. Was he, was he just by himself or was Mr Holt there as well?

RESP: No, the breast nurse was there.

INT: And the breast nurse yeah.

RESP: Was there.

INT: And who was with you again?

RESP: Alan went with us again, yeah. Erm, but we knew by then, we sort of prepared, you know, I'd go cancer and the breast had got to come off, it was just hurry up and get it off and, you know, give me the date for the operation.

INT: Yeah.

RESP: That was how I looked at it.

INT: And was that the consultation where he actually confirmed?

RESP: And he wrote, and when he gave me the date out of the diary and then.

INT: Yeah. How did it feel actually having it confirmed?

RESP: Great.

INT: Yeah?

RESP: But it was too long! I think it was two weeks, it was two weeks I'd got to wait.

INT: Right, oh for the operation?

RESP: Hmm. Admittedly I'd taken my bag that day.

INT: You were ready to go in just then, yeah.

RESP: Yeah, just do it, that was it I just, just do it, just get it off. He says, "We don't do it that quick," and he laughed at be but desperate, not desperate but, I just wanted it out because while it

was in, was it growing, was it going anywhere else and all those sorts of things and they'd only got to miss a little bit, hadn't they, and you know, never questioned that breast was coming off.

INT: Right, OK. And after you'd had the consultation with Mr Chadwick did you see the breast care nurse again?

RESP: Yes.

INT: Yes.

RESP: Yeah we went through, um, they're lovely those nurses, um, and we went through the, what was happening with the mastectomy and I asked for a private room so I could maybe take my tapes with me and meditate.

INT: Yeah.

RESP: That was a bit of a dodgy one because they're very limited with the space they've got in, on the ward but I said look, you know, if I can, please can I have one. Anyway, I did get one, they were able to manage...

INT: Oh right, that's nice of them, you know.

RESP: So I was, I was very, very grateful.

INT: Yeah of course, I mean. [phone rings] Do you want to get that?

.....

INT: YEAH, SO YEAH, YOU WENT TO SEE THE BREAST CARE NURSE AFTERWARDS AND THAT, AND THEN IS THAT WHEN THEY GAVE YOU THE INFORMATION, THE INFORMATION PACK?

Patient: Yeah, they go everything. No, after that, I'm, no, I'm jumping the gun. Yeah, that was it, yes, they gave me ... I didn't read it, I didn't want to read it.

INT: DO YOU THINK HAD ENOUGH FROM ...?

Patient: I didn't want to know anything any more.

INT: OH, RIGHT.

Patient: From the view that, yes, I've got cancer; yes, the breast is coming off; and I'll just go with the journey. Because for me I was getting too much information and it was, it wasn't helping me. You know, my doctor had told me, the consultant had told me what he was going to do, I understood that totally, the breast was coming off, they knew so many centimetres round the tumour as well, how he explained it, but with having all the breast off then we were getting all of it anyway, I'm getting mixed up now. Erm, and then it were just a matter of getting in and getting it done, you know, he explained you'd have a little problem with your arm and what-have-you, but I didn't right.

INT: RIGHT, OH THAT'S GOOD THEN.

Patient: Never had a problem with my arm.

INT: MY NEXT QUESTION WAS HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD ABOUT YOUR CANCER AND YOUR TREATMENT OPTIONS AND THINGS?

Patient: ... How much did I understand? I understood I'd got cancer, erm ...

INT: WAS THERE ANY INFORMATION YOU FELT YOU DIDN'T UNDERSTAND AT ALL OR ... WAS UNCLEAR, OR ANYTHING LIKE THAT?

Patient: No. No. I mean where we're coming from here, they take the medical terms and things like that, I mean I didn't understand any of that.

INT: NO, RIGHT, OK.

Patient: But then I don't need to understand any of that.

INT: WELL NOT IF YOU DON'T FEEL YOU NEED TO AND YOU FEEL, YOU KNOW, YOU UNDERSTOOD ENOUGH TO MAKE YOUR DECISION OF YOUR CHOICE, THAT'S FINE.

Patient: I understood I'd got cancer. I didn't want it in my body, I understood that the breast was coming off, which was an operation, and sew me back up and ...

INT: RIGHT, OK.

Patient: ... that was it for me.

INT: AND, ERM, DID YOU EVER GET AN IMPRESSION FROM ANY OF THE CONSULTANTS OR THE BREAST CARE NURSES, THAT THEY PREFERRED A PARTICULAR TYPE OF TREATMENT?

Patient: Other than Mr Chadwick having really, really having to go into the other alternatives available, erm, no.

[Break in sound file]

Patient: I mean he, I felt Mr Chadwick wanted me to have a different operation, but I didn't want a different operation.

INT: RIGHT, OK.

Patient: But to be fair to him, I suppose he was making sure I did understand that this was available and that was available, but that didn't make no difference to me whatsoever, I don't, yeah, 'You told me, but the breast is coming off,' and I was very, very insistent on that.

INT: RIGHT, OK. ERM, AND AFTER THAT CONSULTATION WHERE YOU'D SEEN MR CHADWICK AND YOU'D HAD, YOU'D SEEN THE BREAST CARE NURSE AFTERWARDS, ERM, IT WAS TWO WEEKS UNTIL YOU HAD THE OPERATION?

Patient: Yeah, 23rd April.

INT: AND DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES IN BETWEEN THAT CONSULTATION AND GOING INTO HOSPITAL?

Patient: No.

INT: NO HOME VISITS, NO CALLS OR ANYTHING?

Patient: Erm, erm ... no. No I didn't get the nurse till I came out of hospital.

INT: AND DID YOU GO FOR A PRE-ASSESSMENT [???] VISIT?

Patient: Yes, YEAH.

INT: HOW DID THAT GO? WHAT HAPPENED THERE?

Patient: She was lovely that nurse there. I went to the pre-assessment day, that was two days before I went in: that was on the Wednesday and I had the operation on the Friday, saw Mr Holt again, saw the nurse there and they gave you the pack and times and, you know, just general, don't ... come in for 8 o'clock and we'll do the operation that morning - I was down for 11 o'clock that morning, and I knew exactly what was happening, you know. Erm ... and saw Mr Holt again and that was it, it was just a formality really. They did my blood, my weight and usual things that I was fit to have the operation.

INT: YEAH.

Patient: Erm, and that was it.

INT: WHEN DID YOU SIGN THE CONSENT FORM FOR TO ACTUALLY HAVE THE OPERATION? DO YOU REMEMBER?

Patient: That day.

INT: THAT DAY FOR THE PRE-ASSESSMENT?

Patient: Yeah.

INT: YEAH, OK.

Patient: Yeah. When I'd had, as Mr Holt put it, we'd got to go back and think about it and what-have-you, and I signed it that day.

INT: MM, OK. ERM, LET'S SEE. THINKING ABOUT THE CONSULTATION NOW WITH MR CHADWICK WHEN YOU ACTUALLY HAD YOUR DIAGNOSIS CONFIRMED, WHO DO YOU THINK DID MOST OF THE TALKING AND WHO DID YOU THINK ASKED MOST OF THE QUESTIONS?

Patient: He did.

INT: DID MOST OF THE TALKING?

Patient: Yes.

INT: YEAH. DO YOU REMEMBER ANY QUESTIONS THAT YOU ASKED?

Patient: I don't think I asked any. [chuckles] I suppose I'm not a very good case study for you because my breast was coming off and no matter what they said, nothing they could do would alter my opinion.

INT: NO, OF COURSE.

Patient: You know, and, erm, I remember him saying something, I can't remember it was, and query sort I said, 'Well shall be think about it?' and I just turned round to [???] and said, 'It's my breast, my body, it's coming off.' You know, and they sort of left it at that. I'm a very determined, plus I'd made my mind up.

INT: YEAH, IT SOUNDS LIKE YOU DID, I MEAN, YOU SOUND EVEN NOW QUITE ... [???]

Patient: I don't regret that decision ...

INT: ... WHAT YOU'VE DONE AND THAT'S FINE.

Patient: ... at all. At all. Erm, you know, but there were alternatives at that point, it was after that, but I'm jumping the gun again, so ...

INT: NO, WELL OK. TELL ME ABOUT WHAT HAPPENED WHEN YOU WENT FOR YOUR OPERATION [???]

Patient: I had the operation, that went well, erm ...

INT: HOW WERE YOU WHEN YOU COME ROUND?

Patient: Fine.

INT: MM, EVERYTHING OK?

Patient: Everything was, you know, just normal how you feel after an operation, you know, a big groggy. Surprised at how much movement I'd got in my arm, he did an amazing job, you know, good scar ...

INT: WHO WAS IT, WAS IT ...

Patient: Mr Holt ...

INT: [???] DID THE SURGERY.

Patient: ... did the surgery.

INT: THEY'RE BOTH GOOD SURGEONS THERE [???]

Patient: Oh they're excellent, I've, you know, great respect for both of them. Both of them, Mr Holt and, you know, I got, I said, 'I'm hungry,' I ate straight away. [chuckles] Erm, and I felt all right, it had happened and, you know, you'd got the drain on and what-have-you, but something that I will bring up when the time is right, erm, you know I said earlier that I would, I asked for a room, in Chesterfield they don't sort of cater for the breast patients in that there isn't a breast ward, it's on the gynae

ward in Chesterfield. Erm, I'm so glad I had that private room because, erm, the other ladies who were in for gynae operations really had a problem with me and my bottle, as in, you know, it filling up with blood and what-have-you, and in there they culture is that you all sit and eat together and interact and what-have-you, those ladies had a problem ...

INT: OH DEAR.

Patient: ... with, well two ladies did, which I respected, which I understood, it upset them, so having the private room and being able to eat in there, you know, was much better from a breast patient point of view rather than a gynae point of view.

INT: RIGHT, OK.

Patient: But to me, I mean, probably they haven't got facilities to do it, but ... it would be better if, if they did have that option of being separate, because you've got the tube and you've got the bottle filling up and some people can and some people, you know, it offended two of the ladies, and I respected that. But, there you go.

INT: AND HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: Two, three days. Friday, came out on the Monday. I'm not a very good patient. [chuckles] I'm a good patient but not, I'm a good patient in that, you know, I don't need caring, you know, having them fuss round me, I was up and dressed and washed and, you know, drip going nicely and 'Let me home.' [chuckles]

INT: AND THEN HOW SOON AFTER THAT DID YOU GO BACK TO GET THE RESULTS OF THE HISTOLOGY, WAS THAT A WEEK OR SO, WAS IT?

Patient: That was a week, and that was when it hit me, erm, it was Mr Holt and he said, erm, he was surprised at how aggressive the cancer was, it was a grade two, and it had spread further than they first thought, which I haven't seen Mr Shepherd to ask, but I'd got pain, a lot of pain, when I went, first went to see him, you know, so the saying that you don't get pain with cancer, had I got two things going on? Although I've never been told this, [???] things going on, he did give me the name of the breast cancer, I've forgotten it now. It wasn't inflammatory, erm, so you will have to ring them up and get the exact name of it, I can't remember. But he said it was more aggressive; it was grade two and the ten lymph nodes they'd taken out, it was all present in all those, so that was scary because then, you know, where else was it, if any? But bless them, Donna, the breast nurse, she'd arrange for the bone scan the very next day, which was amazing that I didn't have to wait - if I'd have had to wait for that, that would have been ...

INT: HORRENDOUS.

Patient: Ugh, you know.

INT: [???

Patient: Being told I hadn't got breast cancer to being told I had got breast cancer, to being told it was quite small, they'd caught it early, wouldn't need chemo, to being told quite aggressive, grade two, and in all the lymph nodes.

INT: YOU'D BEEN THROUGH A ROLLER-COASTER, HADN'T YOU?

Patient: Well, the goalposts kept moving, do you know what I mean. And so Donna arranged for the bone scan, the kidney, what did they do? Bone, kidney and liver ... is that what they do to check?

INT: YEAH.

Patient: And lungs and everything.

INT: YEAH, I THINK THAT'S WHERE IT TENDS TO GO.

Patient: Yeah, well they did, but I was booked, scheduled to have them all done the very next day, which was brilliant, because I didn't have time to think about it.

INT: HAVE YOU HAD THOSE RESULTS?

Patient: Yeah. Got those, well, this is the other, Dr Shepherd, I just love that man. We went back and he did all these tests, I was there the majority of the day, Alan came with me again. I got the all clear on the liver, all clear on the kidneys, all clear ... on the chest x-ray, and then with the bone one you have to take the dye, you have to have the dye, so it goes and you have to wait so long while it goes through. Erm, so while Dr Shepherd was doing the kidneys, liver, whichever he did, he was talking to me, and I said, 'I'm OK,' I said, 'but you keep moving the goalposts,' I said, 'And now I've got to wait for further results,' I says, 'This is really blowing my mind.' You know, 'I need to know today, I'm not leaving the hospital today until I know that every test I've had is clear.' You know, 'You can't keep moving the goalposts like this.'

INT: MM, YEAH.

Patient: Not that they personally were doing it but, do you know where I'm coming from?

INT: ABSOLUTELY, YEAH.

Patient: I'd got to know, I couldn't, I couldn't go on any more. So, Dr Shepherd, he says, 'Dawn,' he said, 'I'll come down at such-and-such a time,' he says, 'and I'll tell you.' Bless him! So we sat and waited - that was horrendous. But I'd sooner wait, sooner have waited the day as we did it than come home because my head would have just been a complete and utter shed. Anyway, he came back down to the Department ...

[Break in sound file]

Patient: ... where they, where you go through the machine, the bone scan, and he went through everything and he said, 'Dawn, you'll all clear.' Oh, relief.

INT: OH THAT'S GOOD NEWS.

Patient: I just hugged him. He's quite dishy actually, Dr Shepherd. [chuckles]

INT: OH WELL [???

Patient: So I just hugged him and hugged Donna, because of course Donna has always been by my side, I mean, she's a psychologist ...

INT: [??] I'VE INTERVIEWED ALL FOUR OF THEM, ERM, THE TWO SURGEONS AND THE TWO NURSES, I'VE INTERVIEWED THEM A WHILE BACK, WHEN WE FIRST STARTED THIS PROJECT, ERM, AND I REALLY LIKED THE FOUR OF THEM, THEY WERE VERY, VERY PROFESSIONAL AND VERY, VERY KIND AND VERY, VERY HELPFUL. MM.

Patient: She's, she's been my, Donna has, she's a psychologist, she sat me down one day, I was having a really bad time, erm, and it was my nurse, district nurse who was coming to see to the wound, because of course I had to infection, didn't I? Which made me really, really poorly. And I was down, I was really, really down, and my district nurse who is equally as supportive, I mean the whole, the whole team, you know, from your district nurse dealing with the wound to your breast cancer nurses is just unbelievable, the support that is there. And then Michelle, my district nurse, rang Donna and said, 'Look, you know, she's not having a very, erm, da-de, good time, da-de-da.' And so when I went in Donna took the time, she said, 'Have you got half an hour?' I says, 'Yeah.' And she sat me down and she spoke to me and I'll never forget her words, you know, 'You have not got cancer. The cancer has been taken out of you.' You know, and she went through everything in detail and ... and counselling - she were wonderful, she really, really, she's amazing, she's amazing. Erm, you know, and it really, really helped, and that was Donna, because you don't get to see the consultants much, I mean, they're very busy people ...

INT: YEAH, OK.

Patient: ... and, and from the ... er, personal side and the psychology side and all that, they sort of don't fit in, in what they do. Do you know what I mean? It's the nurses that pick up either the fall-out, if you like, you know, the fall-out of being operated on, of having cancer - the doctors don't actually see the effect it has on you, the nurses do, and those ...

INT: THIS WHY WE [??] TO INCLUDE THEM IN THIS STUDY.

Patient: ... those nurses are the ones that, for me, that were my strength. I mean, utmost respect for Mr Chadwick and Mr Holt, but if it wasn't for Donna, yeah Mary in the beginning, but Donna was there all the time, do you know what I mean? Probably just as circumstance had it for me it was Donna, you know, for someone else it probably was Mary, you know ...

INT: ABSOLUTELY.

Patient: ... how it works out. But Donna for me, erm, she was the one that got me through this, you know, from knowing what she knows, from her professionalism on how to deal and what to say, do you know, people can say things and it not, it come out and they not mean it that way, but Donna doesn't have that problem. She, it's very hard to describe but she was there for me, she was my strength, you know and we've laughed, we do laugh and, you know, there's a funny side to all this and, but she's been there and you need that. If they weren't there there'd be the biggest hole for a cancer patient, breast cancer patient like me, because you can pick the phone up and say, 'Donna, this is happening today,' 'Quite normal,' you know, and that reassurance, and she's right, it is quite normal. It went, I didn't need it, but just having her there. And what never ceases to amaze me is you can ring that number and there's always one of them that answers it. Now that is phenomenal, isn't it? considering how many patients they have and the varied roles they do, but you will always get one of them. And that is important. Well I found it important, I mean, they've never failed me yet - not that I've rung

them a lot, I haven't, but I have needed to ring them, you know, and you can say things to Donna that you wouldn't dream of saying to your ... well you just wouldn't say to your consultant, would you?

INT: MM, YEAH, THAT'S TRUE.

Patient: Yeah, those are a vital part, crucial, I mean without them, God, I hate to think what ... sorry, I hate to think what would, how I would get through.

INT: AT ONE TIME THEY DIDN'T HAVE THEM.

Patient: Pardon?

INT: AT ONE TIME THEY DIDN'T HAVE THEM, YOU KNOW, THEY'RE A FAIRLY NEW THING REALLY. WHEN I SAY NEW IT'S ABOUT 15 YEARS OR SOMETHING.

Patient: Well, [???] wouldn't work without them. Well, I suppose it would work, you'd get through but, you know, you're not alone and you're not alone.

INT: I THINK THAT'S THE FEELING YOU GET THOUGH NOWADAYS WHEN YOU GO TO THESE PLACES, ESPECIALLY IN BREAST CANCER, BUT I THINK IN ALL CANCERS NOW, YOU DO GET THE FEEL IT'S A TEAM, AND EACH TEAM HAS A PARTICULAR, EACH PART OF THE TEAM HAS A PARTICULAR ROLE. I MEAN YOU'RE QUITE RIGHT ABOUT THE SURGEONS, I MEAN THEY HELP ENORMOUSLY IN THE FACT OF THE JOB THEY DO, YOU KNOW, THEY'VE GOT A BIT OF A DUFF JOB REALLY IN THE FACT THAT THEY'D GOT TO TELL YOU BAD NEWS, IT COMES FROM THEM ALL THE TIME REALLY, YOU KNOW, THEY'RE THE ONES WHO BREAK THE BAD NEWS, WHICH IS NOT A VERY GOOD JOB FOR ANYBODY.

Patient: Mm [???]

INT: BUT AT THE OTHER SIDE OF THINGS THEY'RE GONNA BE DOING THE OPERATION WHICH PROBABLY SAVES YOUR LIFE, SO THEY KIND OF VIEW IN THAT WAY, SO YOU KNOW IT'S SWINGS AND ROUNDABOUTS THERE. AND THE BREAST CARE NURSES, YEAH, THEY HAVE TO PUT UP WITH PROBABLY A LOT OF CRAP AFTERWARDS, BUT AT THE SAME TIME, LIKE YOURSELF, THEY'RE LIKE YOUR FRIEND, YOU KNOW, AND THEY'RE ABLE TO INPUT SO MUCH INTO YOU AND HELP YOU THROUGH, PLUS AT THE TIME IT MIGHT NOT EVEN SEEM LIKE [???] IT'S ON REFLECTION, LOOK BACK AND THINK, 'YEAH, YEAH I REALLY NEEDED THEM, I REALLY NEEDED [???]' YOU KNOW.

Patient: Oh dear, yeah, yeah.

INT: THEY'VE KIND OF UNDERSTOOD AND THEY WERE THERE TO LISTEN TO EVERYTHING I HAD TO SAY AND MAYBE IT JUST DIDN'T APPEAR AT THE TIME. SO IT IS A SORT OF TEAM AND YOU DO GET THAT FEELING, I MEAN WE'RE DOING THREE AREAS IN DEPTH - CHESTERFIELD IS ONE OF THEM, I CAN'T TELL YOU THE OTHER TWO FOR CONFIDENTIAL REASONS - BUT IN ALL THE PROFESSIONALS I'VE INTERVIEWED, NEARLY ALL OF THEM NOW BY ONE I THINK, AND THEY'VE ALWAYS HAD THIS BIG SENSE OF A TEAM SPIRIT AND A TEAM SORT OF OPERATION THERE AND IT'S ...

Patient: At Chesterfield?

INT: AT CHESTERFIELD AND THE OTHER TWO AREAS. YEAH, BRILLIANT, THEY'RE ABSOLUTELY BRILLIANT.

Patient: The whole, it's just. I've been amazed, I mean, I've worked all my life, as you probably have, and you know you've just got on and not had a lot of call to go to hospital, you hear of this happening, that happening, but it's an institution second to none. I mean without that, and what they've done for me ...

INT: MM, YEAH.

Patient: ... you know, I wouldn't even like to go down the private route because I doubt I could have got any better treatment at all, got in quicker, anything. You know, phenomenal, fantastic and, you know, it's, you just can't knock it. I can't knock it.

INT: SO, GOING BACK, YOU'VE GOT ALL YOUR RESULTS AND YOUR TESTS AND STUFF, THEY'RE ALL CLEAR, THAT'S GOOD. WHERE ARE YOU NOW, THEN? YOU'VE STARTED ...

Patient: Where I'm at now is I was given, again, the most gorgeous, er, nurse, erm, oh what [???] .. I was then given options. I met Kay, have you met Kay?

INT: ER ...

Patient: Kay [???].

INT: NO, I DON'T KNOW THAT PERSON, NO.

Patient: Kay [???], Weston Park nurse, and she's a trials nurse, because I was asked if I wanted to take part in trials ...

INT: OH, [???] TRIAL.

Patient: Mm.

INT: OH RIGHT, OK.

Patient: So we got all the bump and lengthy discussions on what the trial involved and everything, and I chose to go on the Tango trial - again it's my way of giving something back.

INT: ABSOLUTELY, YEAH.

Patient: Erm, but I did want to get, I don't know if you know much about the trial, but ...

INT: I DON'T, NO, I DON'T ACTUALLY, NO.

Patient: Well just briefly you either get one extra drug or you get two extra drugs, and I wanted the two extra but I didn't get it, you're randomised.

INT: YES, OF COURSE, YEAH.

Patient: So you can't pick. So I'm on the Tango programme, with [???] and then they gave me Kay [???] ... what a nurse she is! I mean they're angels, you've got Mary, you've got Donna, and now I've got Kay. I've been so blessed with having all three of 'em. Kay is the, erm, trials nurse and, erm, she's gone through everything, erm, and I'm not doing the Tango trial. I've had my first chemo, not last Thursday, the Thursday ... when did I have my first chemo? [chuckles] I don't know where I am, whether I've had two weeks or one weeks, anyway I've had my first chemo at Chesterfield for the basic and I have four chemos there and then I move to Weston Park and then have my [???] for the American Tango programme.

INT: RIGHT. AND WHAT'S THIS, WHAT THE AIM OF THIS TRIAL?

Patient: The aim of the trial is it's in third stage. They go through - you'll know this better than me - they go through three stages. It's gone through stage one and two, it's in its third stage and after this it will get licensed to go onto the market, and it is, it reduces the drugs, the amount of drugs, [???]'s replacing some of the other drugs which they're doing in chemo, which on so far proved to have lesser side effects for people.

INT: OH THAT'S GOT TO BE GOOD, THAT.

Patient: So ... well it's got to be good. I don't ...

[Break in sound file]

Patient: ... extra drug that, you know, in addition to, so, you know, I'm getting something extra and if it is there, if it is gonna come back or, you know, bang, it's gone with this extra drug - hopefully.

[Telephone rings]

INT: OK.

Patient: 10th June I had my first one.

INT: MM, AND YOUR NEXT ONE'S GONNA BE?

Patient: 24th June.

INT: RIGHT, OK.

Patient: Which is a week on Thursday ... yeah.

INT: YEAH, THE FIRST PROJECT IF DID COMING HERE WAS ACTUALLY WITH, LOOKING AT WHY LUNG AND COLORECTAL PATIENTS DO AND DON'T JOIN CLINICAL TRIALS, AND, ERM, THE GUY IN CHARGE OF IT, HE'D JUST DONE THE SAME PROJECT USING BREAST CANCER PATIENTS, SO I DID GET A CHANCE TO GO TO INTERVIEW SOME OF HIS PATIENTS BEFORE I STARTED ON MY INTERVIEWS, ERM, JUST TO FIND OUT WHAT THAT ACTUALLY IS WORKED TOWARDS THESE THINGS AND, YEAH, PEOPLE WHO REFUSED AND PEOPLE WHO AGREED AND ...

Patient: I can't understand and, OK, everybody's entitled to their opinion, but why refuse something that has potential, (1) to help you and (2) to help others.

INT: MM, YEAH.

Patient: Do you know what I mean. I mean it's not going to harm you, I mean they wouldn't let it harm you, you've got as much chance on a trial as you have on the general stuff what is licensed and being used. Do you know what I mean? Well, that was for me, you know, give something back and, you know, be part of it, and if you can help someone else and, plus, I'm getting an extra drug which ...

INT: YOU'LL PROBABLY GET MORE MONITORING I SHOULD IMAGINE AS WELL.

Patient: Yeah, yeah.

INT: YOU'LL GET EXTRA MONITORING SO THAT'LL ALWAYS BE BENEFICIAL FOR YOU.

Patient: Yeah, you know, just pick up the phone and, erm, Dr P-, I can't pronounce his name.

INT: [???

Patient: Yeah.

INT: [???

Patient: [chuckles] I didn't gel with him first off. Frightened me to death, he did.

INT: ANYHOW, LET'S GET THIS ...

Patient: Sorry.

INT: THINKING ABOUT MR HOLT, ERM, WHEN YOU WERE TALKING ABOUT YOUR OPERATION, DIAGNOSIS AND THINGS, DID YOU FEEL HE LISTENED TO YOU, THAT HE UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Oh [???

INT: YES?

Patient: Oh without a question. He really felt for me, and I passionately believe that, because he'd said, you know, 'I don't think it is anything to worry about,' I mean he felt so bad. [chuckles] You know.

INT: AH.

Patient: So bad.

INT: YEAH.

Patient: And he said, 'I'm so sorry.' Well, yeah, erm, he felt, erm, and he's human, you know. I mean he's got a sense of humour. [chuckles] But, yeah, without question, he was lovely.

INT: AND, ERM, LET ME SEE ... [???] ERM, THINKING ABOUT THE OPERATIONS, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED BETWEEN THE OPERATIONS?

Patient: Did I tell you the bit about when I went back after they'd operated, Mr Holt turned round and said, 'Dawn, if you hadn't have chosen mastectomy you'd be in this Friday for one.'

INT: OH, RIGHT, OK.

Patient: So ...

INT: OK. BUT DID YOU ACTUALLY FEEL YOU HAD A CHOICE [???] ?

Patient: Oh I had a choice.

INT: YES, OK.

Patient: My problem was telling them ...

INT: YOU DIDN'T WANT [CHUCKLES]

Patient: ... I don't want a choice.

INT: YOU KNOW WHAT YOU WANT. [???] THINKING ABOUT THE CHOICE YOU MADE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD, THAT YOU WERE, ER, HEARD, YOU READ, OR ANYTHING LIKE THAT, WHAT HELPED YOU MAKE THAT DECISION ABOUT WHAT YOU WANTED TO HAVE?

Patient: What helped me make that decision?

INT: MM.

Patient: Nothing anyone had said, it was my decision, you know, as soon as I was told I had got breast cancer, then you take the breast.

INT: MM, OK, YEAH.

Patient: I don't need it, if I've got a husband that's that shallow then I'm in the wrong marriage, aren't I?

INT: YEAH, WELL ...

Patient: Do you know what I'm saying, though? It wasn't an issue.

INT: YEAH, MM.

Patient: It really wasn't an issue.

INT: RIGHT, OK.

Patient. You know, and, and also, as Mr Holt said, you know, 'We can do major things with reconstruction.' I will go for a reconstruction when all this is over, so, you know, what's the big deal?

INT: RIGHT, OK.

Patient: Do I sound rather ...

INT: NO, NO, NOT AT ALL ACTUALLY, I MEAN I TRY NOT TO BE JUDGEMENTAL IN ANY SORT OF WAY IN THESE THINGS BECAUSE EVERY PERSON IS INDIVIDUAL, YOU KNOW, AND IF THAT DECISION IS RIGHT FOR YOU, THAT IS FINE, THAT'S NO PROBLEM AT ALL. YEAH? YOU SAID, I SAID BEFORE, YOU SOUND QUITE DECISIVE AND QUITE, ERM, YOU KNOW, SINGLE-MINDED ABOUT WHAT YOU WANT, AND THAT'S GOOD, I MEAN, YOU KNOW SOME PEOPLE THEY GET A CHOICE AND THEY FALL APART, THEY DON'T KNOW WHICH ONE, THEY DON'T KNOW WHICH ONE TO CHOOSE, YOU KNOW, THEY EVEN ASK, 'WHY AM I BEING GIVEN A CHOICE? WHAT DO I KNOW?' YOU KNOW ABOUT THESE TREATMENTS. AND IT IS SO INDIVIDUALISTIC BECAUSE SOME PEOPLE, YOU KNOW, THEY'VE HAD A VERY TINY CANCER AND IT WAS THE PERIPHERY OF THE BREAST AND THEY SAY, 'OH JUST TAKE THAT OUT,' SORT OF THING, YOU KNOW, BUT THIS, SOMEBODY, 'NO, I DON'T WANT IT. JUST TAKE IT AWAY FROM ME,' AND THAT'S IT.

Patient: That was me.

INT: AND THAT WAS FINE, YOU KNOW. AND THAT IS IT, IT'S A PURELY PERSONAL PREFERENCE AND THAT'S WHY, YOU KNOW, IN CERTAIN ... SOMETIMES CLINICALLY THEY CAN'T OFFER THAT CHOICE BECAUSE IT'S JUST ...

Patient: Too far.

INT: ... QUITE OBVIOUS, YOU KNOW, IT COULD BE A SMALL BREAST WITH A LARGE TUMOUR OR SOMETHING LIKE THAT, AND IT'S VERY DIFFICULT TO OFFER CHOICE THEN.

Patient: Can you imagine, though, David, you know, you've sort of gone down the route of this lumpectomy and whatever else, and then to be told, you know, 'Can we have you back in to take the breast?' ...

INT: EXACTLY.

Patient: That would have been horrendous, wouldn't it. But again, we come back to what I told you before, it had got to go ...

INT: YEAH, OF COURSE, ABSOLUTELY.

Patient: ... you know, so that was me. And this is my journey. [chuckles]

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

Patient: Oh, I think I've said it all.

INT: YEAH, I THINK YOU HAVE REALLY. I THINK YOU ... DO YOU THINK IT'S MET YOUR EXPECTATIONS?

Patient: Oh, beyond my expectations. I have been amazed that there is so much help and genuine care, to the point where the first week I had my chemo, because I'd been OK, they were ringing me, 'Are you OK?' [chuckles] Bless them.

INT: OH, THAT'S NICE.

Patient: Do you know what I mean? I'm fine, you know, 'Are you sure you're fine?' I'm fine. 'Just ringing to see if you're all right?' Bless them.

INT: OH GOOD.

Patient: You know, but I know if I have a problem I can pick up that phone and I can get Donna, Kay, or Mary, one of them will be there and will tell me. I'm very, very lucky and I really do appreciate all of them, you know, they're quite blasé and 'It's just our job,' but that is not just a job what they do. But they are vital to the machine, if you like.

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

Patient: Not to have to wait seven days from ...

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

Patient: That is the killer.

INT: YEAH, IT'S A LONG TIME, YEAH, I UNDERSTAND.

Patient: Yeah, that is hard. And if I ever came into some money then I would put it in there, and ask them to do something with it to stop that. That is the hardest - I should imagine it's the hardest for any cancer patient.

INT: MM, YEAH.

Patient: You know, but for me that, that was horrendous. That is the only, it's not even a criticism, it's the system, isn't it?

INT: YEAH.

Patient: You know, I'm not just the cancer patient, I mean they're dealing with thousands, aren't they? But it would be better if there was some system that could give you a quicker ... response, you know, that seven days is hard.

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

Patient: ... Give me that question again.

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

Patient: Needs to know? For me it was just is it cancer or isn't it? I don't need to know the medical term of the cancer, there's cancer, it is or it isn't.

INT: RIGHT, OK.

Patient: You know, if it isn't, while if it is, get on with it.

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

Patient: I struggled with this one when I had this ... on here ...

INT: WELL WE ALWAYS LEAVE THE HARD ONES TILL LAST. [CHUCKLES]

Patient: [???] which one is it?

INT: IT'S NUMBER 13.

Patient: Mm. What's important, well, what is important? Whether they're taking it off or ... I can't answer that because for me there was never, I mean I'd got cancer, get rid of the bloody thing.

INT: YEAH, THAT'S

Patient: And I can't answer that.

INT: THAT'S NOT A PROBLEM. NOT A PROBLEM AT ALL. IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED OR ANYTHING IMPORTANT THAT WE HAVEN'T TALKED ABOUT?

Patient: No, I've really enjoyed talking to you.

INT: OH, OK. THANK YOU VERY MUCH. I'VE ENJOYED TALKING TO YOU.

Patient: That was very nice.

INT: O K.

Patient: Interesting.

INT: I'LL TURN OFF NOW.