

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE: 04/10/2004

*ID: Patient63

*INTERVIEWER: DJW

INT: FIRST OF ALL, THANK YOU FOR AGREEING TO BE INTERVIEWED. IT'S VERY KIND OF YOU. 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?

Patient: Right, well I knew about it because my mother unfortunately had it and also my half-sister, we share the same father, not mother.

INT: RIGHT, OK.

Patient: So from that point of view I knew a bit about it. Erm, it's where there's a rogue gene or rogue cells, I understood that. And when there's been articles in the newspaper obviously I've read them because of the family link ...

INT: RIGHT, YES, OF COURSE.

Patient: ... I'd never dreamt that I also [chuckles] would land up with it.

INT: RIGHT, OK. AND WHAT OPERATION DID YOUR MUM HAVE?

Patient: She had, erm, I can't remember exactly what ... I think she had a lump just under her breast and it's, it's 30, almost 30 years, in fact it's 30 years ago. Erm, I think they tried to remove the lump, I don't think they took her lymph nodes away. Whether that wasn't the form in those days I don't know.

INT: RIGHT. I DON'T KNOW, ERM, AND HAVE YOU ANY FRIENDS OR COLLEAGUES THAT HAVE HAD BREAST CANCER?

Patient: No, not close friends.

INT: RIGHT, OK. AND YOUR MUM, WHEN SHE HAD BREAST CANCER, WAS THAT IN LEICESTER OR WAS IT ...?

Patient: That was in Leicester.

INT: RIGHT, OK. AND, ERM, SO CAN YOU JUST SORT OF TELL ME BRIEFLY HOW YOU CAME TO FIND OUT THAT THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: I went for the three-yearly mammogram and had a call back.

INT: RIGHT.

Patient: And that was the first I knew.

INT: WAS THAT A LETTER, WAS IT?

Patient: Yes, it was a letter inviting me to go back.

INT: OK. AND WHEN YOU GOT THAT LETTER, I MEAN, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: Well that, that was the worst time of all.

INT: YEAH?

Patient: From getting the letter to going back because I didn't know which side was in trouble, I didn't know what it was, how bad it was, er, obviously I looked up in, we've got several medical books, and I looked it up on the internet as everybody does, but they were the, those were the dark days, especially about five o'clock in the morning.

INT: RIGHT, YEAH. RIGHT, OK.

Patient: And the added thing was that I knew my son was getting married on December 12th and you start to think, 'Am I going to be around?' and 'What condition am I going to be in?' ...

INT: RIGHT, OK.

Patient: ... for that.

INT: RIGHT, OF COURSE, YEAH.

Patient: So that was the worst bit.

INT: SO DID YOU THINK IT WAS, DID IT CROSS YOUR MIND THAT IT WOULD BE BREAST CANCER?

Patient: I'd felt uneasy about these mammograms, in fact the, Leicester usually let you know within two weeks, and I'd got no sign of anything, but I just, I don't know, my inner sense just told me that, before we went off to Majorca for a holiday, I must get the results. I actually rang up, because they were running a week late, it was three weeks, and I rang up and said, 'Can I just pop and get my result? We're going to Majorca on Friday,' and they said yes, they would be ready on the Thursday afternoon.

INT: RIGHT, OK.

Patient: But it was still a shock to get, yeah.

INT: SO DID YOU ACTUALLY GO FOR THEM, DID YOU?

Patient: I went up and got the, went up and got the letter ...

INT: OH I SEE, RIGHT, OK.

Patient: ... hoping that it would say yes, fine, come back in three years. And it was the letter to say that I'd got to go back for a re-call.

INT: RIGHT, OK. AND HOW SOON WAS THAT THEN THAT YOU GOT THE RECALL?

Patient: It was, erm, I think I had the letter on the Thursday and I think it was the following Wednesday ...

INT: RIGHT, OK.

Patient: ... that my appointment was for. Erm, obviously if the letter had come through the post I wouldn't have heard till the Friday so it would have been less time to worry, but, er, I chose to fetch it on the Thursday afternoon so ...

INT: RIGHT, YEAH, SURE. ERM, AND SO CAN YOU JUST TELL ME WHEN YOU WENT ALONG TO THAT VISIT AFTER YOU GOT THE LETTER?

Patient: Right. When I went for the recall I noticed as soon as I gave my name that there was the letters by my, erm, my appointment time suggested that they were going to give me ultrasound, so by the time I got into see them I knew what to expect as we'd sat in the corridor.

INT: OH RIGHT, WHAT EXACTLY WAS WRITTEN?

Patient: US.

INT: OH I SEE, YEAH, US.

Patient: Erm, and I knew that ultrasound could sometimes, was sometimes better at tracking what it was.

INT: RIGHT, YEAH.

Patient: Erm, so I knew what to, you know, what to expect there. Erm, what was it that you wanted to know, what ...?

INT: JUST TELL, JUST TALK ME THROUGH THAT DAY, THAT'S WHAT, WHAT HAPPENED THAT DAY, YEAH.

Patient: That day, that day. Right. So when I went in to see the radiologist and the doctor, they, they both felt, they could feel absolutely nothing. They showed me the mammograms and they said that it was on my left side and that it looked very, very small, and when they felt they could feel nothing. And that, in itself, was a relief because at least I couldn't blame myself for not ...

INT: YEAH, FINDING IT YOURSELF.

Patient: ... picking it up. And then they did the ultrasound and said, 'Oh yes, it's tiny, really tiny, but there is something there.'

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

Patient: Erm, no I don't because it wasn't the doctor who did the operation, he was on holiday, so it was a lady.

INT: AH RIGHT, OK.

Patient: Which she was, she sort of stepped in because it was his holiday.

INT: OH I SEE, RIGHT, WHAT SHE A CONSULTANT THOUGH?

Patient: Erm, I'm not sure if she was a consultant or a registrar, probably a consultant I would think, but I'm not certain.

INT: OK. THAT'S OK. ERM, AND SO YOU WENT THERE, DID YOU HAVE ANOTHER MAMMOGRAM, AN ULTRASOUND [???

Patient: They did the ultrasound and then they asked if they could take a biopsy.

INT: RIGHT, OK.

Patient: Which of course I said yes to, and they said the results would be ready the following week. And I said, 'right, I want to know the worst case scenario. What do you think in the wor-, you know, if the worse case?' and they said, 'We think that it's a tumour and we think it's probably malignant. It is very, very small ...' and I said, 'Well what does it mean then?' so they said 'It looks as if you'll probably have to have a lumpectomy and the lymph nodes taken away for analysis.'

INT: RIGHT, OK. AND THAT WAS THE DOCTOR THAT SAID THAT, WAS IT?

Patient: That was the doctor, and the radiologist. Yes.

INT: INT: RIGHT, OK. AND DID YOU GO WITH ANYBODY THAT VISIT, DID YOU ...?

Patient: My husband went with me, yes.

INT: YEAH, OK. AND THEN, SO WHAT HAPPENED AFTER YOU SAW THE DOCTORS?

Patient: Well then I had to wait and go back for an appointment the following week.

INT: RIGHT, OK. DID YOU SEE A BREAST CARE NURSE AT ALL THAT VISIT?

Patient: I'd spoken to the breast care nurse, erm, not as a separate appointment, but they were very good at giving out leaflets and they gave their card and said, 'Look if you're the least bit worried, give us a ring. Here's our number and there's a bleep, we have a bleeper, and, you know, do ask any questions that you want to ask.' But luckily I could ask Helen, you see [chuckles] ... my future daughter-in-law ...

INT: YES, SHE'S AN ONCOLOGIST.

Patient: Yes. So that was

INT: IS SHE ACTUALLY AN ONCOLOGIST NOW OR ...?

Patient: Yes she is, yes. Yes. She's not a consultant, she's still a registrar, she hasn't done her exams yet for a consultant. They told me that, erm, it was, because it was very small, if I had to have the operation they probably would actually have to put markers in, wires in, so show exactly where it was.

INT: EXACTLY YEAH, TO GUIDE THE SURGEONS.

Patient: So that in itself was quite comforting because I thought, 'Well if it's that tiny, erm, you know, although it's bad, it could be far worse.'

INT: YEAH, SURE. ERM, SO HOW WERE YOUR FEELINGS AFTER THAT? IM MEAN YOU OBVIOUSLY WENT HOME AFTER THAT, DID YOU?

Patient: Yeah. What, after being told that that's what it could probably be?

INT: YEAH.

Patient: Yes, but if anything it was, there was ... there was almost a feeling of relief that it wasn't even worse, because in those dark days between getting the letter and going back you start with, 'Oh, it's probably the mammogram's not right and they've, I must have moved or something ...' and then you go down and down and down to the very worst things. 'Well maybe I can't feel it because maybe it's so big it's the whole lot,' you know, and

everything in between. During the day time you're fine but at five o'clock in the morning, that's the time ...

INT: YOU'RE LEFT WITH YOUR THOUGHTS, AREN'T YOU?

Patient: ... and it's, it's absolutely ridiculous but, I mean we've got, there's only the two of us now so we've got some spare bedrooms, so I just used to go, wander off and then get in another bed. [chuckles]

INT: OH RIGHT. YEAH, YOU DO GET LEFT IN THE MORNING WITH YOUR THOUGHTS, DON'T YOU? THAT'S THE THING REALLY.

Patient: That's right.

INT: SO YOU HAD THE RESULTS A WEEK LATER, IS THAT RIGHT?

Patient: Yes, in the meantime we said, 'Well we'll go away for a little holiday' and we walked across the car park feeling ... well, yes, at least we know ... [chuckles] what's what.' And said, 'Well where shall we go?' and then we both said, 'Majorca.' [chuckles] so we actually came home and immediately booked a flight for the next morning. And that in itself was good because it took our mind off of thinking about ...

INT: YEAH, SURE.

Patient: ... what was going to happen next.

INT: YEAH, I WAS GOING TO ASK YOU HOW THAT WEEK WAS ACTUALLY?

Patient: Yes, so ... I'd made up my mind by then that I was going to have to have the operation, I knew, well felt that the results were going to come back and it was going to that you've got to have it done. But at least I knew ...

INT: YEAH, YOU KNEW.

Patient: ... what it was and how big it was and what would happen and so forth.

INT: YEAH, SURE.

Patient: And, erm, I must say the Glenfield Hospital are very, very good at giving notes, each time they tell you, they give you the paperwork to show, so that, when you get out you think, 'Oh now what did they say?' it's there ...

INT: RIGHT, OK.

Patient: ... it's written, and I think that's good.

INT: RIGHT. ERM, SO YOU WENT BACK FOR YOUR, YOU HAD YOUR HOLIDAY ..

Patient: Yes.

INT: YOU CAME BACK.

Patient: It was a five-day ... [chuckles]

INT: OH THAT WAS NICE, FIVE DAYS IN SPAIN'S LOVELY.

Patient: So we came back and this time it was the surgeon, he was back from his holiday.

INT: AND WHO WAS THAT, THEN?

Patient: And, erm ... Mr Windle.

INT: MR WINDLE, RIGHT, OK.

Patient: Yes. And, erm, he said more or less what the other consultant had guessed, he actually said, he said, 'I'm sorry, it is malignant, but it is very, very small, erm, you will need to have an operation. I think it would be appropriate for you to have a lumpectomy and we, as the usual course, we will take away some lymph nodes for analysis.'

INT: RIGHT, OK.

Patient: So he didn't actually say, 'Which would you prefer?' but I mean I, he's the professional, he knows ...

INT: YEAH, SURE.

Patient: ... and the fact that it was tiny, I thought, 'Well, you know, he knows that he's doing,' and he of course was the second person who'd said what the course of action would be.

INT: YEAH, MM. AND, ERM, WAS THERE ANY, DID YOU GO WITH ANYBODY TO THAT VISIT? DID YOUR HUSBAND GO?

Patient: Yes, he's tagged along with me. [chuckles]

INT: OK.

Patient: One of the penalties of taking early retirement. [chuckles]

INT: AND, ERM, YOU, WAS THERE ANYBODY ELSE IN THE ROOM WITH YOU, ERM, BREAST CARE NURSE ...?

Patient: Erm, yes, I think there was a breast care nurse in there as well.

INT: ANYBODY ELSE?

Patient: No, just the doctor ... and I think when I saw the first, erm, doctor, when they did the biopsy, I think there was a student in that time ...

INT: RIGHT, OK.

Patient:.. but I think when it was Mr Windle I don't think there was.

INT: RIGHT, OK. AND WHEN HE WAS TALKING TO YOU ABOUT WHAT TREATMENT YOU WERE GONNA HAVE, DID HE AT ALL MENTION ANY OTHER OPERATIONS, LIKE MASTECTOMY?

Patient: No, he didn't at all.

INT: RIGHT, OK.

Patient: No, and I didn't question it because, as I say, he was the second person who'd said that would be the course of it and, er, so I was quite happy to take his word, I mean you've got to trust in them, haven't you?

INT: AND THEN WHAT HAPPENED AFTER, AFTER YOU, HE GAVE YOU YOUR DIAGNOSIS, TALKED ABOUT YOUR TREATMENTS, WHAT HAPPENED AFTER THAT?

Patient: He, I said, 'Well I just would like it to be done as quickly as possible,' and he looked in his diary and he said, 'I think I could probably fit you in next week.'

INT: YEAH.

Patient: He said, 'My list isn't too bad because I've been on holiday,' and so that was great because I felt I was getting to the next ...

INT: YEAH, THE NEXT STAGE.

Patient: ... thing, and then I asked about being treated privately because we are in a private health scheme, but, erm, he said, 'Well I think, I doubt that you'd get in any quicker,' he said, 'And I don't actually do private work.'

INT: RIGHT, OK.

Patient: In the meantime I'd had ... I don't think this ought to be on there ... I'd had my spies out ...

INT: RIGHT, OK. [CHUCKLES]

Patient: Because my future daughter-in-law ...

INT: IT'S ALL CONFIDENTIAL, DON'T WORRY.

Patient: ... right, and also a friend of mine from college days, when we were both training to be teachers, her daughter-in-law, and her son for that matter, are both doctors in Leicester at the hospital, and so I was able to make a few discreet enquiries with both

Helen in Manchester and with Rachel in Leicester about Mr Windle and, you know, what he was like, and he'd got a very, very reputation.

INT: YEAH, SURE.

Patient: So it was as well to stick with him.

INT: RIGHT, YEAH. OK THEN. AND AFTER YOU, DID YOU SEE THE BREAST CARE NURSE AFTER THAT?

Patient: Not as a separate appointment. I spoke to her when she was in the room with Mr Windle and afterwards as well because I asked about, if I wasn't going to go privately, could I have a side room, thinking I'd got to pay for it, which I didn't mind doing.

INT: RIGHT, SURE.

Patient: Erm, 'cos I said I'd prefer a bit of privacy and I would also like my own loo, and so she made enquiries as to whether I could have one. As it turned out they were absolutely free and if they've got them you can have them, as long as somebody doesn't go down with a nasty bug or something. And so, although I spoke to her, it was with regard to that, my creature comforts ...

INT: RIGHT, OK.

Patient: ... rather than anything to do with this.

INT: YEAH, MM. DO YOU REMEMBER WHO THE BREAST CARE NURSE WAS?

Patient: No, I don't.

INT: AH RIGHT, OK. ERM, SO DID YOU NOT GO, DID YOU GO INTO A SEPARATE ROOM AT ALL WITH HER? DID SHE TALK ABOUT TREATMENTS OR DID SHE ... DIAGNOSIS, ANYTHING LIKE THAT, THAT DAY?

Patient: No, I don't ... I ... I can't recall her talking separately. Erm, I have a feeling that when Mr Windle was talking that she also just said a few words.

INT: OH RIGHT, OK.

Patient: But I think she gave me the, the chance if I wanted to to ask any more questions. I think as we were coming out she said, 'Now is there anything else you want to know,' and I said, 'Well, no, not really. I think I've, you know, heard as much detail as I need,' knowing that I could ask Helen in any case. [chuckles]

INT: AND WHEN YOU WERE TALKING WITH MR WINDLE DURING THAT CONSULTATION, WHO DO YOU THINK DID MOST OF THE TALKING, WHO ASKED MOST OF THE QUESTIONS?

Patient: I don't ... I'm not aware that either side were doing ...

INT: RIGHT, OK.

Patient: ... you know, over the top in talking. Any questions I asked he was quite happy to answer, but he was, he was very good at actually answering my, the questions that were in my head before I got to asking them. In fact I think I did say to him, 'Well actually you've answered most of my questions when you've been talking.' He also went through the consent form ...

INT: RIGHT, OK.

Patient: ... I don't know if you've seen the consent form ...

INT: YEAH, I'VE SEEN THEM BEFORE.

Patient: Erm, the consent forms mentions a lot of things which would be on your mind, like the after-effects And the lymph nodes and so forth.

INT: RIGHT, OK, YEAH. DID YOU SIGN THE CONSENT FORM THERE AND THEN OR ...?

Patient: Yes, I did.

INT: RIGHT, OK.

Patient: Yes.

INT: [???] DO IT THEN. ERM, SO YOU DIDN'T SEE THE BREAST CARE NURSE, SO YOU MUST HAVE COME HOME THEN, DID YOU?

Patient: Yes.

INT: YEAH. AND THEN HOW SOON AFTER THAT CONSULTATION DID YOU HAVE YOUR OPERATION?

Patient: That was on the Wednesday, I, the letter came to say that I, to clarify the time and so forth for going in, and I knew I was going to have the operation on a Tuesday, the letter came to say I'd got to be there on the Monday morning ... so that dipped the spirits a bit because I thought, 'My goodness, what am I going to do from Monday morning until Tuesday, stuck in hospital, feeling fine and so on?' so I actually went to the hospital on the Monday morning, they did all the prelim things, erm , ... oh, and on, before I'd left the hospital they'd done blood pressure, they'd taken some blood - mind you they lost it, they had to do it again - and an x-ray, so they'd done those as a preparation. So I went back on the Monday morning and they went through all the other things and then they said, 'Well ...' well we got the room sorted out as well, with my own loss - that was the main thing actually, the loo, it wasn't that I wanted to be antisocial, [???] [chuckles] erm, and by lunchtime the breast nurse had been to talk to me again and had said, you know, 'You will ache and you'll need to do exercises and ...' all the things that, you know, she needs to say.

And then she said, 'Oh you're going to get really bored, erm, do you want me to see if you can go home overnight?' So I got released. [chuckles]

INT: OH RIGHT. GOOD BEHAVIOUR.

Patient: Yes, that's right, it was just like getting the afternoon off from school, you know, 'Wooh.' So I said, so my husband said, 'Oh, do you want to go, shall we take you straight home?' I said, 'No, I want to go to Marks and Spencers,' [chuckles] so ...

INT: BIT OF [???] THERAPY.

Patient: Yes, I know. And I had to promise obviously not to eat and so forth after midnight and I went back the next day at seven.

INT: MM, RIGHT. AND WHAT TIME DID YOU SAY YOU WERE DUE FOR YOUR OPERATION?

Patient: Pardon, sorry?

INT: WHAT TIME WAS YOUR OPERATION ACTUALLY SCHEDULED FOR?

Patient: Erm, I found that it was going to be about lunchtime, it actually got moved to about half past one in the end, but once you're in you don't care.

INT: NO. AND MR WINDLE ACTUALLY DID THE OPERATION, DID HE?

Patient: He did indeed, yes.

INT: YES, THAT'S RIGHT. AND WHAT HAPPENED ON THE MORNING? DID ANY BREAST CARE NURSE COME TO SEE YOU? DID MR WINDLE SEE YOU? THE ANAESTHETIST?

Patient: Erm, the anaesthetist came.

INT: RIGHT, OK.

Patient: Erm ... I can't ... I can't remember if Mr Windle came or not. No, I don't know. He was very good at coming afterwards, I can remember that, erm, but I don't recall beforehand. I'm sure he probably did come but it's all a little bit of a blur.

INT: YEAH, SURE. SO YOU WENT DOWN ABOUT ONE THIRTY FOR THE OPERATION, YOU SAID?

Patient: Yes.

INT: AND, ER, SO IN BETWEEN THAT OPERATION, HAVING THE OPERATION AND THE DIAGNOSIS, YOU HAD YOUR PRE-ASSESSMENT, DIDN'T YOU? IS THAT RIGHT? YOUR PRE-ASSESSMENT THING ON THE MONDAY, WAS IT? DID YOU COME FOR LIKE A PRE-, THEY CALL IT PRE-ASSESSMENT ...

Patient: Is that for the, what, the x-ray and ...

INT: YEAH, I THINK ...

Patient: They did three of them on the day that I saw Mr Windle.

INT: YEAH, THE DIAGNOSIS?

Patient: Yes.

INT: DID, IN BETWEEN THAT AND THE OPERATION, DID YOU GO BACK AGAIN BEFORE ...

Patient: Only on that Monday when I thought I'd got to go actually in to stay ...

INT: RIGHT, OK.

Patient: Erm, but no, not in between.

INT: RIGHT, OK. AND DID YOU ...

Patient: They just, they said on the Wednesday when I'd seen Mr Windle, 'You might have well have these done now and then you've got them out of the way,' which was fine as far as I was concerned.

INT: AND, ERM, DID YOU, IN BETWEEN HEARING YOUR DIAGNOSIS AND THE FIRST TIME YOU SAW MR WINDLE, AND THE DAY OF THE OPERATION THAT YOU WENT IN, DID YOU AT ALL CALL THE BREAST CARE NURSES ..

Patient: No.

INT: DID YOU HAVE ANY CONTACT WITH THEM AT ALL?

Patient: I haven't at all.

INT: RIGHT, OK.

Patient: But again, I mean they were very good, but trying not to plague Helen with lots of questions but I've always known that she's there ...

INT: YEAH, SURE.

Patient: ... if I want to ask anything. I've kept it to the bare minimum. Erm, but I think that probably, it's nice to know that there's somebody you can ask if needs be.

INT: ABSOLUTELY.

Patient: And I did actually see her a few, just after the diagnosis ... or was it just before the diagnosis? ... can't remember, and asked her one or two questions then.

INT: MM. AND WHEN YOU SAW MR WINDLE THE FIRST TIME AT THE DIAGNOSIS, AND IN BETWEEN THAT AND THE OPERATION, DID YOU GO OUT AND LOOK FOR ANY INFORMATION YOURSELF, EITHER FROM THE INTERNET, BOOKS, MAGAZINES, VIDEOS, TALK TO ANY FRIENDS? DID ANYBODY GIVE YOU ANY KIND OF INFORMATION?

Patient: Erm, I certainly, before I had the diagnosis, spent quite a bit of time looking on the internet and looking in books and so forth. Having had the diagnosis and had the operation booked ... if I did it was only a cursory glance, it wasn't ...

INT: RIGHT, OK.

Patient: ... hours spent looking.

INT: MM. AND DID THE HOSPITAL THEMSELVES GIVE YOU ANY INFORMATION, A PACK AND STUFF LIKE THAT, DID THEY GIVE [???

Patient: Yes, yes, a leaflet each time, an that in itself helped, you see.

INT: OH YOU READ THROUGH ALL THAT, DID YOU?

Patient: Oh yes.

INT: YEAH, DID YOU FIND IT USEFUL?

Patient: Yes, extremely useful, and, as I said, my mother had cancer 30 years ago, I don't recall her having that sort of thing, and at the time it would have been excellent to have had it.

INT: MM, RIGHT, YEAH. YEAH, THINGS WERE VERY DIFFERENT THEN, WEREN'T THEY, REALLY?

Patient: I think so, yes. And I've asked Helen and, you know, I said, 'At the Christie do they give out leaflets like this?' and she said, 'Oh yes, they do.' So that's obviously the done thing now, but it, I don't recall my mother having them.'

INT: RIGHT, OK. ERM, SO YOU GOT TO THE OPERATION, THAT'S WHERE WE GOT TO, HOW WERE YOU WHEN YOU CAME ROUND FROM THE OPERATION? HOW WERE YOU FEELING?

Patient: Psychologically OK, 'cos it was done, ached like mad under my arm, and if anything that's been the problem all since, that the nerves, well certainly have been damaged. I think they're gradually coming back into being and so forth, but I was very ...

INT: DID YOU HAVE LIKE EXERCISES TO DO?

Patient: Yes, yes. And I felt very uncomfortable with one of the drains. They put one drain here and one just under, and it was the under one that was very uncomfortable. So, probably felt a little bit sorry for myself, but not, not way down, having had this friend who's got lung and brain, lung cancer and a brain tumour, he's kept so positive, he's the husband of my friend and, you know, that ... I've sort of thought about him and thought, 'Well, right, I must be the same.'

INT: AND HOW LONG WERE YOU IN HOSPITAL THEN AFTER THE OPERATION?

Patient: Erm, I had the operation on the Tuesday and I came out on the Saturday morning. I think I might have got away with coming out on the Friday afternoon but I, I made it quite clear that I'd prefer to stay for another night in the hospital, and a lot of the others said the same, they felt that, you know, with the drains only just coming out - well in fact we were sent home with one drain, but felt happier, you know, to have another night in the hospital.

INT: RIGHT, OK. AND, ERM, HOW SOON AFTER THAT DID YOU GO AND, YOU MUST HAVE GONE TO GET YOUR RESULTS OF YOUR OPERATION?

Patient: Yes.

INT: DID YOU SEE, WAS IT MR WINDLE YOU SAW THEN?

Patient: It was Mr Windle, yes. He ...

INT: CAN YOU TALK ME THROUGH THAT PLEASE?

Patient: You what, sorry?

INT: CAN YOU JUST TALK ME THROUGH THAT VISIT WHEN YOU WENT BACK TO HEAR YOUR RESULTS?

Patient: Yes. He actually had been in several times to see me after the operation and he had said, erm, 'It was very, very small, the area round it looked quite clear and I couldn't

see anything in the lymph nodes, but obviously we've got to wait for the results,' so when I went back to see him I was feeling optimistic and it was exactly as he's said ...

INT: OH RIGHT, OK.

Patient: The area round was clear and the lymph nodes were clear.

INT: RIGHT, OK.

Patient: So, you know, that was good.

INT: RIGHT, OK.

Patient: And that, that must have been about ten days after I left, would it be ... can't remember now, I'll look at the dates afterwards.

INT: ERM, AND SO THEN, WHAT HAPPENS NOW IN TERMS OF, I MEAN ANY KIND OF FOLLOW-UP TREATMENT OR WHAT-HAVE-YOU?

Patient: Well he went through what had happened and talked about the size of the tumour and so forth and said that, he said, 'Your next step now is that I refer you to my colleagues down at Leicester Royal Infirmary, the Oncology Department,' so again I asked him about private treatment 'cos the parking down at Leicester Royal Infirmary is ...

INT: DREADFUL APPARENTLY.

Patient: ... a nightmare. But he said, 'Well it's up to you, and I can refer you privately but I think you probably would find that the treatment down the Infirmary would be as good, erm, as any you would get,' and I also sent my spies out again [chuckles] and, erm, Rachel had sent a message to say, 'I think you'd be better off down at the Infirmary.'

INT: AHA. RIGHT, OK. SO WHEN DID YOU GET THAT UP, HAVE YOU MADE THAT APPOINTMENT, HAVE YOU?

Patient: Yes, yes, oh yes, because I've started the radiotherapy.

INT: YES, YOU'VE STARTED YOUR RADIOTHERAPY, OF COURSE. SO WHAT HAPPENED THEN THEN?

Patient: So I, I was told that, erm, I'd got to go down to the Infirmary so I rang them and asked when the appointment was for because we wanted to go up to see our son in Manchester and also to go to Harrogate for a few days' holiday, and they were very good and said, 'Well I'm just making the appointments: you can either have it on so-and-so or so-and-so,' I think it was September 7th or the 14th, something like that. And I said, 'Oh the 7th then please.' So I was able to go away for a few days and they were most obliging doing that. So I trotted to the infirmary and, erm, he talked through it and gave me another leaflet about, this time about the radiotherapy, and I said, 'Well when do I start and what happens next?' He said, 'Well you need to be marked up?' So I said, 'Well when's that going to happen?' He said, 'Well,' he says, 'What is it, Monday today?' he says, 'There's

a clinic on Wednesday.' He said to the nurse, 'See if you can get Mrs [???] in for the Wednesday clinic?' which I've got it.

INT: OH BRILLIANT.

Patient: So that was quick.

INT: YEAH.

Patient: And then before I left on that day, erm, they gave me the list with all the dates and times for having the radiotherapy and when I asked the lady who gave me it, must have been the receptionist, I said about the starting date, she said, 'Well we like to do it within seven and nine weeks of your having the operation,' she said, 'This is eight weeks,' she said, 'so it's spot-on. It's our, the one we prefer.' Yes.

INT: YEAH. AND, ERM, HOW LONG WILL THE RADIOTHERAPY GO ON FOR? WHAT'S THE [???]

Patient: It's 25 sessions ...

INT: FIVE WEEKS.

Patient: So, yes, it actually goes just over the five weeks because they have two days when they have to service the machine.

INT: OH, RIGHT, OK.

Patient: So I think, erm, next week I've got a day off, [chuckles] and then I think it's the beginning of the November there's another day off.

INT: RIGHT, OK.

Patient: So it's going to stretch just over the five weeks, but it's 25 sessions.

INT: RIGHT, OK THEN. AND YOU'RE HOW FAR THROUGH NOW?

Patient: I've had three so far.

INT: THREE?

Patient: Yes.

INT: THREE SESSIONS, YEAH?

Patient: Yes.

INT: [???]

Patient: Or 12 per cent, I've decided psychologically I always liked maths, so I'm working it out in percentage, so I came out this morning, I thought, 'Ah, that's 12 per cent.' [chuckles]

INT: AND HOW ARE YOU FEELING WITH THAT THEN?

Patient: Er, up to now, touch wood, OK, thank you.

INT: OH GOOD, GOOD.

Patient: Yes.

INT: EXCELLENT. OK. SO I'LL GO BACK TO MY QUESTIONS NOW. [CHUCKLES] WE'VE GONE QUITE A WAY, HAVEN'T WE? RIGHT, ERM ...

Patient: I told you I ramble.

INT: NO, NO, NOT AT ALL, YOU'VE BEEN VERY CLEAR. ERM, WHEN YOU WERE TALKING TO MR WINDLE AND THE BREAST CARE NURSES ABOUT YOUR DIAGNOSIS AND TREATMENT AND THINGS, HOW MUCH DO YOU THINK YOU UNDERSTOOD ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND THE TREATMENT?

Patient: Erm, I'd like to think that I understand quite a lot about it. Erm, I knew that, erm, it was very important to catch it at such an early stage, and I think the fact that he was saying it's very, very small, it would have been six months to a year before you would have felt it, those things in themselves were lifting me up.

INT: YEAH, DID HE SAY ACTUALLY HOW SMALL IT WAS, DID HE GIVE YOU A SIZE?

Patient: He did, yes, erm ...

INT: CAN YOU REMEMBER WHAT HE SAID?

Patient: Now what did he say? Three ... three millimetres maximum would it be?

INT: RIGHT, YEAH.

Patient: I don't know, is that about right.

INT: YEAH.

Patient: So three seems to ring a bell, mm.

INT: AND, ERM, WAS THERE ANYTHING THAT YOU FOUND DIFFICULT TO UNDERSTAND OR TAKE IN?

Patient: No, not really. Not being bigheaded or anything ...

INT: NO, NO, NO [???

Patient: No, erm, I knew that he was a good surgeon, erm, and I knew that he saw this sort of thing every day and so it wasn't for me to delve in and say, 'Oh, why and ...' etc, etc. Interestingly the oncologist, when I saw him, said that he often gets people going in to see him about the radiotherapy and slapping a whole pile of stuff from the internet and saying, 'Why don't you do this, this, this and this?' That's not my scene at all. [chuckles]

INT: RIGHT. YOU DO GET THEM, THE INTERNET JUNKIES, YES.

Patient: Yes, yes, I couldn't believe it when he said it. So ...

INT: AND, ERM, WHERE ARE WE? I'VE GONE THROUGH ALL THEM. THINKING ABOUT THE TIMES YOU SPOKE WITH MR WINDLE, ALL THE TIMES, DO YOU FEEL THAT ... HOW DID YOU GET ON WITH HIM? DID YOU FEEL HE LISTENED?

Patient: He was absolutely fine. He's a really nice man.

INT: YEAH? DID YOU FEEL HE LISTENED TO YOU AND HE UNDERSTOOD YOUR NEEDS, YOUR CONCERNS AND THAT?

Patient: Oh yes, yes.

INT: YEAH. MM. OK. AND DID, YOU SAW THE BREAST CARE NURSE, DID YOU SEE THE SAME ONE EVERY TIME OR WERE THERE DIFFERENT ONES?

Patient: Erm, they te-, we saw a couple of them up in the ward, they came up to visit, erm, and then there was another one I saw on, down at the outpatients, just briefly. I think, perhaps one of the problems is I think they all did, erm, not flexitime, part of the week, you know, shift ...

INT: OH YEAH, PART-TIME SHIFTS.

Patient: Yes, yes, job share.

INT: RIGHT, YEAH.

Patient: Yes, so I think it, there was probably more ...

INT: YEAH, I THINK THEY DO, I THINK THERE IS CERTAIN NURSES DO CERTAIN CLINICS.

Patient: Yes.

INT: WORK WITH CERTAIN CONSULTANTS. ERM, AND WHEN YOU WERE TALKING TO THE BREAST CARE NURSES IN GENERAL, HOW DID YOU GET ON WITH THOSE?

Patient: Fine, in fact for the last session we, a whole group of us got together, she said, 'Do you mind if I talk to you all at the same time?' erm, so we, we ribbed mercilessly, you

know, there was another teacher. [chuckles] WE were saying, 'Well where's your overhead projector? Where's your pin-points? Where's your bullet-points? Where's your so-and-so's.' So you can tell it was a very friendly relationship.

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

Patient: Yes.

INT: YEAH?

Patient: Yes. In fact at one point, erm, one of the nurses, she was talking about how you feel, especially for those who'd had a mastectomy, and she herself, you could see the tears were coming in her eyes as she recounted how some people had found it hard to face their husbands and say, 'This is how I look,' so, erm, she said to us that she loves her job, she loves helping people. I mean it obviously was very close to her that, you know, she wanted to do her best and also she, she knew how people felt, she wasn't cold and, you know, 'Oh well I've not got this,' and walking away. In fact we wondered, we did ask her if she'd had breast cancer and she said, 'No,' but whether somebody close to her has had it ...

INT: MM, POSSIBLY, YEAH.

Patient: ... perhaps with one in particular.

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

Patient: No.

INT: I'VE INTERVIEWED, I THINK ALL THE BREAST CARE NURSES AND SURGEONS DOWN THERE. I MEAN THAT NEVER CAME OUT IN THE INTERVIEW SO I WOULDN'T KNOW REALLY.

Patient: No. It may just be as, after several of us said, 'I wonder if, you know, she's had ... or a narrow escape from it or something.'

INT: AHA. COULD BE, I DON'T KNOW. ERM ... WE'VE ALMOST FINISHED HERE.

Patient: Good, because I've run out of questions on mine.

INT: ERM, LET ME SEE. THINKING ABOUT THE OPERATIONS THAT YOU HAD, YOU KNOW, THE WIDE, THE LUMPECTOMY, WIDE LOCAL EXCISION ONE, YEAH?

Patient: Yeah.

INT: AND THE OPTION OF HAVING A MASTECTOMY, ERM, DO YOU FEEL THAT YOU HAD, DO YOU FEEL THAT YOU HAD A CHOICE BETWEEN THOSE TWO?

Patient: Erm, it was never suggested that I had a mastectomy. It was also never suggested that I would need chemotherapy.

INT: RIGHT, OK.

Patient: Erm, and because it wasn't suggested, and because two people had said lumpectomy, then I left it at that. I had actually looked on the internet beforehand, erm,

..

INT: THIS IS BEFORE YOUR DIAGNOSIS?

Patient: Yes, about lumpectomies and mastectomies and [???] saying that there was no evidence to suggest that in some cases a mastectomy was necessary, it was rather drastic.

INT: YES, RIGHT.

Patient: And you've just got to put your faith in ...

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

Patient: Oh absolutely excellent, all the way through, yes.

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

Patient: I think it ...

INT: DID YOU HAVE ANY EXPECTATIONS?

Patient: I don't want to sound snobbish, but over the years I've had a number of operations: I've had a hysterectomy, had a knee operation, blocked tear duct, mind you that didn't work; I've had an operation on my mouth ... and I've had them done privately. So going with the National Health Service was, you know, a little bit of a worry, shall we say?

INT: RIGHT, YEAH.

Patient: And so ...

INT: WELL THERE'S A LOT OF PRESS AROUND [???]

Patient: Yeah, I mean ...

INT: [???]

Patient: The Glenfield Hospitals, of the three hospital, has got the best reputation, and the breast care unit has got an excellent reputation, and I knew that, but I just wondered what the care would be like, and also the cleanliness for that matter. And it was absolutely super, it was a clean, well-run hospital and it didn't matter whether it was the surgeon, or whether it was a lady cleaning the room, or anybody in between, they were all excellent.

INT: OH, THAT'S EXCELLENT, [???] ERM, SO NOW I'M GONNA ASK YOU, IF YOU HAD ENOUGH, THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE THERE AT THE GLENFIELD, WHAT DO YOU THINK THAT BE?

Patient: To be able to go the next day with the second appointment.

INT: OH RIGHT, OK.

Patient: For them to have the facilities - I know it isn't possible - but that was the worst bit by far.

INT: RIGHT. THIS WAS TO ...

Patient: This was from getting the letter to say 'We need to see you again ...'

INT: RIGHT, YEAH.

Patient: ... to actually going.

INT: YEAH, RIGHT.

Patient: I would have loved to have just ... rung up and say 'Can I come in half an hour?' And I know it isn't possible, but that was the one downside as far as I was concerned. I had too long, erm, to think about it. But then five days is nothing to what some people have to wait. I don't mean necessarily for this but for anything. But, erm, I did find that hard. So, yes, if they'd got enough money to have a doctor down there, ready ... [chuckles] for people like me.

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

Patient: Say that again.

INT: WHAT DO YOU THINK ARE THE MOST IMPORTANT ...

Patient: Oh, I can see it, yes, right.

INT: ... THAT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT FIRSTLY THEIR DIAGNOSIS?

Patient: Er, I think ... I said to them, 'I want to know the worst scenario,' and I think that's important to know. I don't know what they say to others.

INT: RIGHT, OF COURSE, YEAH.

Patient: As far as I'm concerned I think it's important that you should know the worst scenario. Erm, and for the operation well ... it's more or less what I was told I think was fine.

INT: YEAH.

Patient: I haven't got any criticism there at all.

INT: RIGHT, OK. I THINK THAT'S ALL THE QUESTIONS, WE'VE BEEN THROUGH THEM ALL NOW. ERM, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSES? ANYTHING, ANY IMPORTANT POINTS WE HAVEN'T COVERED?

Patient: I can't really think of anything. No, there's nothing that comes to mind really.

INT: OK. IF THAT'S IT THEN, I'LL SWITCH OFF.