

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: Medium MR unit

\*DATE: 19/10/2004

\*ID: Patient Patient14

\*INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED. I WOULD LIKE TO START WITH QUESTION ONE, WHICH IS CAN YOU TELL ME A BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED SOMETHING WAS WRONG WITH YOUR BREAST?

Patient: I've been aware I suppose for a number of years that it was important to, erm, watch for any signs. The doctor has always encouraged me to do that. Erm, but I think my thinking went on parallel lines because for some quite illogical reason I always that was the one thing I wouldn't get.

INT: RIGHT, OK.

Patient: No idea why really. There's nothing in the family at all that I am aware of, so, although I was aware that of course people, women do get breast cancer, erm, and I was doing the routine things one needs to do, I really didn't believe it was something I was going to get. Sounds barmy, but ... [chuckles]

INT: AND HAVE YOU GOT ANY FRIENDS AT ALL OR WORK COLLEAGUES THAT HAVE HAD BREAST CANCER?

Patient: Erm, er, I didn't have until I got it and I discovered how very many other people [chuckles] ...

INT: YEAH, A COMMON PHRASE THAT THEY ALL COME OUT OF THE WOODWORK.

Patient: Yes.

INT: YEAH, A LOT OF PATIENT HAVE SAID THAT.

Patient: Yes.

INT: ERM, RIGHT OK THEN. AND, ERM, SO YOU HAD NO FAMILY HISTORY OF IT AND YOU'VE NEVER HAD BEFORE YOURSELF OF COURSE?

Patient: Well, no, except that my mother's, my mother was orphaned fairly early in life and I wonder whether, I don't know what either of her parents died of ...

INT: RIGHT, OF COURSE.

Patient: ... but you do wonder.

INT: YES. YEAH, OF COURSE.

Patient: Yeah?

INT: RIGHT.

Patient: Erm, but there's, I'm an only child and there's no other cancer in my family, my cousins, my, you know, that I'm aware of.

INT: RIGHT. OK. ERM, AND YOURSELF, AND YOU IN GENERAL, ARE YOU A FIT AND WELL PERSON?

Patient: Mm.

INT: DO YOU VISIT YOUR GP REGULARLY AND THINGS?

Patient: Erm, no, erm, I've had some stress over the past 12 months for which I did need to go the GP. It manifests itself in me with a persistent cough and in the end I needed to go on Ventolin and, 'cos it just appears suddenly, you know, and it was obvious this stress. Erm, but by and large I'm perfectly well.

INT: OK. SO CAN YOU JUST TELL ME NOW HOW YOU ACTUALLY CAME TO FIND OUT THAT YOU HAD BREAST CANCER?

Patient: Yeah. Erm, I had, I was called for a routine mammogram, erm, it must have been the first week in August, erm, and I'd been having them for years so it didn't bother me particularly. The only problem was it was the week before I moved so I almost thought I won't bother to go this time. This is the bit of me that thinks I will never get that, you see. That's that line. And then I did go, erm, and I told them that I was moving and gave them the new address, erm, and so when the call-back came it came here. And to begin with I was completely thrown because, as I say, it was for the same date as the first day of my new job so to speak, there was a big licensing service at church and ... erm, and I thought, 'Well all the way to Chesterfield and ... ooh.' So then I phoned up and asked advice really and they said, 'Well we think you should stay with us at least until we know what's going on, but we'll give you a new appointment,' so I actually went two days after my licensing service. Erm, and they did another x-ray and weren't happy and did an ultrasound and weren't happy and did a biopsy. Erm, and then Doctor, Mr Chadwick said, erm, 'Well we'll have to wait for the results of this but I have to tell you that it's suspicious.'

INT: RIGHT.

Patient: He was very clear, so I went back a week later.

INT: RIGHT, OK.

Patient: So that's the story. [chuckles]

INT: RIGHT, OK. AND, ERM, SO WHEN YOU HEARD THAT, HE SAID IT WAS SUSPICIOUS, I MEAN, WHAT WENT THROUGH YOUR MIND AT THIS POINT WHEN THEY WERE DOING THESE TESTS AND THINGS?

Patient: I was extremely angry ... [chuckles] because of the timing, I was absolutely furious. I was shaking with anger. I thought, 'I have just extricated myself from a very difficult set of circumstances, I have just to come to a new ministry, I cannot believe that this is happening. [chuckles] Erm, so those were the first feelings.'

INT: RIGHT, OF COURSE, YEAH. ERM, AND THAT WEEK IN BETWEEN HEARING THAT, YOU HAD YOUR TESTS AND YOU HEARD IT WAS SUSPICIOUS, UP UNTIL, YOU KNOW, YOU ACTUALLY HEARD YOUR DIAGNOSIS, HOW WERE YOU THAT WEEK? HOW DID THINGS GO?

Patient: Erm, ...

INT: QUITE A BUSY TIME, BY THE SOUNDS OF IT.

Patient: Well, erm, I had some things to sort out here, you see, I had to work out who needed to know, erm, you know, being a public person and just having arrived in a new place, that created its own set of difficulties. So the week was, I had to come to terms with the fact that, although I walked into that hospital feeling perfectly healthy, I was then told I wasn't perfectly healthy, which was a quite difficult sort of ...

INT: IT IS, YEAH.

Patient: ... turnround.

INT: IT'S QUITE A SHOCK FOR SCREENING, THE PEOPLE PICKED UP ON SCREENING.

Patient: Yeah.

INT: YOU KNOW, IF YOU FIND A LUMP YOU'RE SORT OF SUSPICIOUS.

Patient: Absolutely.

INT: BUT ...

Patient: Yes, yeah.

INT: ... WHEN YOU'RE QUITE RIGHT, YEAH.

Patient: To go in thinking, 'Well, I'm fine,' you know, 'I don't feel ill, I don't feel anything wrong at all,' and to be told that ... and I mean the irony in a sense was that, when you go for the, your pre-surgery assessment, I mean and I joked about it, I came back and said to concerned friends, 'Well I'm perfectly healthy apart from the bit of me that's not perfectly healthy.' [chuckles] You know.

INT: RIGHT.

Patient: Erm, but that, the week between, erm, being told it was suspicious and being confirmed, well I suppose I was pretty sure it would be confirmed and so I was coming to terms with what that meant in my life really, erm, and dealing with the anger bit of it. Not what I wanted, not what I intended. [chuckles]

INT: NOT IN THE PLAN, EH?

Patient: Not in my plan.

INT: AND, ERM, DID, IN THAT TIME DID YOU LOOK FOR ANY INFORMATION ABOUT BREAST CANCER OR ANYTHING LIKE THAT?

Patient: Erm, well I did. Erm, in the end, well partly because a friend said to me, a friend who is much more into investigating things than I am I have to say, said, 'I expect you've done all the discovering of this, that and the other,' and I thought to myself, 'Oh no, I haven't.' [chuckles] so then felt challenged to do it, so solemnly went onto the internet and looked up BACUP. BACUP, yes, yeah. Erm, but then I felt it actually didn't help me particularly, erm, because I am squeamish physically. So I actually didn't really want to know how long the incision was going to be ... [chuckles]

INT: OH RIGHT, OK.

Patient: You know ... I ... it sounds awful really but, erm, I read, I read of course everything I was given at Chesterfield and all of that, but I wasn't that keen on any more gory details.

INT: RIGHT, OK. ERM, SO CAN YOU JUST TALK ME NOW THROUGH WHEN YOU WENT BACK TO ACTUALLY HEAR YOUR DIAGNOSIS, WHAT HAPPENED ON THAT DAY WHEN YOU WENT TO SPEAK TO ... WAS IT THE SAME CONSULTANT, MR CHADWICK, WAS IT?

Patient: Yes.

INT: YEAH.

Patient: Erm, well, erm, the first problem was that you have to set off pretty early to get there from here, well you will know of this. Anyway I was there on time, that was fine. Erm ... I can remember him talking me through the whole process and I was taking it in, but I also knew, my body language was like this ... [chuckles] ... we laughed about it, you see, because I was sort of ... the more he talked the more the more I was going ... [chuckles]

INT: RIGHT, YOU WERE VERY CLOSED, YEAH.

Patient: 'Not me thank you,' you know. Erm, and erm, I understood perfectly well, I think, everything he was saying and he said that it was a very small lump, less than a centimetre in diameter, that therefore he thought that a wide local incision [?] would be, would be appropriate at this stage, but he made it quite clear that, erm, it might be that I'd have to have two operations if it wasn't sufficient, erm, but his advice was that, erm, we could go for the wide local excision to begin with. And I was quite clear that I had a choice in that and, erm, and I agreed with him, I would rather take the risk ...

INT: [???

Patient: ... than have a mastectomy straight away. Yeah?

INT: [???] WHEN YOU SAID HE'D ADVISED, DID YOU ASK HIM WHAT HE ADVISED OR ...?

Patient: I don't know if I put it in so many words, but I sort of talked about what I thought I'd heard from him.

INT: OH RIGHT, OK, YEAH.

Patient: Yeah? And we, erm ... I felt, erm, that it was explained to me very clearly and that I had some choice in it, but that I accepted his professional skill in the advice he offered. Yeah? So it felt like a partnership.

INT: RIGHT, OK. ERM, WAS THERE ANYBODY ELSE IN THE ROOM AT THE TIME? DID YOU GO WITH ANYBODY? DID YOU TAKE A FRIEND WITH YOU?

Patient: I did go with somebody but they weren't with me at that point, but as well as Mr Chadwick the two nurses were in the room, Donna and ....

INT: MARY? THE BREAST CARE NURSE?

Patient: Yes.

INT: THEY WERE BOTH THERE, WERE THEY?

Patient: They were, mm.

INT: AND WHEN HE CONFIRMED THAT YOU HAD CANCER, HOW, WHAT WERE YOUR FEELINGS AT THAT POINT? DO YOU REMEMBER?

Patient: ... Erm ... it's very hard to articulate this. Erm, I mean I think, because I'm that sort of person anyway, my body was expressing it as much as anything. My arms were flapping around dramatically, so I was told. [chuckles] As I say, all this was go-, and I said, 'I know perfectly well that I'm demonstrating my anxiety, but I am hearing what you're saying as well,' you know, so, erm, and ... I was fairly upset obviously. After, after Mr Chadwick had finished Donna took me through to the other little room and I was pretty well shaking then: I was upset, yes. You wouldn't not be really. Even though I had known that this was what was going to ... what they were going to say. Erm, and it is something like many things in life that you don't think is going to happen to you until it happens to you. Because we all live like that, you can't, you can't live thinking, 'What if so-and-so happens to me? What if so-and-so happens?' you know, you can't. But when it does, erm, it's a shock obviously.

INT: YEAH, MM. PRIOR TO THE DIAGNOSIS, HAD YOU ANY THOUGHTS ABOUT WHAT YOU, YOU SAID YOU LOOKED ON BACUP FOR INFORMATION, HAD YOU ANY THOUGHTS ABOUT WHAT YOU MIGHT DO IN TERMS OF TREATMENT, IN TERMS OF AN OPERATION? HAD THAT GONE THROUGH YOUR MIND AT ALL?

Patient: Erm, before the consultation?

INT: YEAH, BEFORE IT HAD BEEN CONFIRMED.

Patient: Well I think I wanted, erm, as little surgery as possible.

INT: RIGHT, OK.

Patient: Yes, yes. And I don't regret that, even though I knew it might mean more surgery.

INT: YES, OF COURSE.

Patient: Erm, but, no I don't regret that. I didn't want more than was absolutely necessary.

INT: RIGHT, OK. AND WHILE HE WAS TELLING YOU ABOUT THE CANCER AND THE TREATMENTS THAT YOU COULD HAVE, THE OPERATIONS AND THINGS, ERM, HOW MUCH DO YOU FEEL YOU UNDERSTOOD ABOUT WHAT HE WAS TELLING YOU?

Patient: I think I understood it.

INT: ANYTHING YOU REMEMBER YOU DIDN'T UNDERSTAND OR WAS UNCLEAR AT THE TIME?

Patient: No, I don't think so. He was quite clear that, because, erm, my lump was very close to the nipple, that that actually slightly increased the chances that it might not be successful to have the wide, and I understood that. But as I understood it he said that there was still something like ... it only reduced it by 5 or 10 per cent or something like that. That's what I understood. And so I understood there was an increased risk because of the position of the lump.

INT: RIGHT, YEAH.

Patient: Yeah?

INT: OK.

Patient: But it wasn't a massively increased risk, so it was still, erm, and I understood about the importance of taking the lymph nodes because of them being a filter for whether it was spreading anywhere. Yeah?

INT: YEAH, MM.

Patient: Erm, I think I understood.

INT: YEAH, YEAH. NO, IT SOUNDS LIKE YOU DID.

Patient: Whether that's as good as actually understanding I don't know. [chuckles] I didn't come out thinking, 'Well that was as clear as mud,' you know.

INT: OH RIGHT, YEAH. [CHUCKLES] ERM, AND THEN, DID YOU SPEND SOME TIME WITH THE BREAST CARE NURSE ...

Patient: Yes.

INT: AFTER THAT ... CAN YOU JUST TELL ME WHAT HAPPENED THERE PLEASE?

Patient: Erm, well I think, I found that very helpful in fact because your emotions are suddenly all over the place, erm, and as I was, I know I was wittering about how could it happen just now when I was just trying to start this new and interesting and exciting job, you know, all that, and it was important, it was helpful that I could just come out with all of that to somebody who was not, was not emotionally - she was superb - but, you know, somebody who's detached, it's not personally affecting her. And so that was very helpful, erm, and also because I was able to tell her that I'd got a phobia about anything under my arms, so [chuckles] and she was able to explain precisely what was ...

INT: OK. [???

Patient: [chuckles] [???] psychologist.

INT: WELL YEAH, BECAUSE OBVIOUSLY THE LYMPH NODE OPERATION, DID THAT SORT OF ...?

Patient: That was, upset me more almost.

INT: OH RIGHT, [CHUCKLES] OK, YES.

Patient: Yeah. That was upsetting me more.

INT: YOU SEE I DON'T LIKE NEEDLES, I HATE NEEDLES, I CAN'T STAND THEM. I CAN WATCH ANY OPERATION, I CAN WATCH HORROR MOVIES OR ANYTHING, I DON'T CARE ABOUT THAT, BUT WHEN I GET TO SOME MAD SCIENTIST GIVING SOMEONE AN INJECTION, I'M LIKE .... UGH.

Patient: Yes. Well I always say, I mean, I say if you've got to do it, do it, but don't expect me to look what you're doing, you know. Here's my hand, here's my arm ... [chuckles]

INT: OH YEAH, YEAH, I'M LIKE THAT WHEN I GET AN INJECTION OR ANY KIND OF BLOOD SAMPLE, I HATE IT.

Patient: Yeah, yeah.

INT: YEAH, SO. AND DID SHE, WHEN YOU SPOKE TO THE BREAST CARE NURSE, DID SHE TALK ABOUT ANY OF THE OPERATIONS OR ANY OF THE DIAGNOSIS, DID SHE GO THROUGH ANY OF THAT AGAIN? DO YOU REMEMBER?

Patient: No, because I don't think I particularly needed to.

INT: RIGHT, OK.

Patient: I think, I mean I'd have asked her really. When, when I was with Mr Chadwick and he diagnosed, erm, and told me what needed to be done, he offered me, first of all he offered me the 24th September, if that's the Friday, and I said, 'Well if that's essential I will of course do it, but it's the day before I am marrying my best friend's son, so to speak ...' so I said, 'could it, will it matter if it's not then?' He said, 'No, no, that's absolutely fine, it won't make any difference.' And so, erm, we then selected October the 4th, er, and when I was then talking to Donna afterwards, I was beginning to worry a bit about how long I would be out of action and what that meant in terms of clearing my diary, that was where my mind was. Yeah? What I wouldn't be able to do and what I might reasonably expect to be able to do. Erm, so that was sort of my only other concern then.

INT: RIGHT, OK. SO HOW SOON AFTER THE DIAGNOSIS DID YOU HAVE THE OPERATION? WAS IT ABOUT TWO ... TWO WEEKS?

Patient: Erm, let me just think. I went on the 3rd for my recall, and I went on the 10th to be diagnosed, so that was 10th September, so then I had the operation on the 4th October.

INT: SO THAT'S THREE WEEKS THAT ...?

Patient: Yeah, but I was offered two weeks ...

INT: TWO WEEKS, YEAH.

Patient: ... it was me who ...

INT: YOU WANTED [???

Patient: ... I asked if it would be ... yeah?

INT: RIGHT, OK. AND SORT OF IN BETWEEN YOUR DIAGNOSIS AND YOUR OPERATION, DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES AT ALL?

Patient: I phoned her up, yes.

INT: AH, RIGHT.

Patient: Because I then was thinking, after the operation, there's this date to go back which now is this Friday, and I had been concerned to know whether it would have been last Friday, erm, for reasons which now don't matter but at the time they did ... [chuckles] and so we were talking round, it was still the problems of my diary really. Which sounds awful but actually though it's not because it was commitments to other people, and what I needed to sort out. So I have a conversation with her and she phoned me back and that was helpful.

INT: MM, OK. AND HOW WERE YOU ACTUALLY DURING THOSE THREE WEEKS FROM YOUR DIAGNOSIS TO YOUR OPERATION? WHAT WERE YOUR FEELINGS THEN?

Patient: Erm, apprehensive ... really apprehensive actually, I must underplay it because I've never had an operation, well I've not had an operation for 40-odd years, let's put it that way, probably 50 years, I can't quite remember. When I was, when I was probably about certainly in primary school, probably eight or nine, erm so we are talking 50 years ago, erm, I had most of my milk teeth out and all I can remember is the appalling gas masks they used to put over your faces, and the fact that I was sick for a week afterwards, you see.

INT: MM [???

Patient: So, although I knew perfectly well in my head that it was no longer like that, that's still the driving image and the driving message, you see. So, and for the whole of that time I really couldn't believe that I would be knocked out and not know anything about it. I have this nightmare that I would wake up and know what they were doing. Yeah?

INT: OH RIGHT.

Patient: Yeah? [chuckles]

INT: NO, THAT'S QUITE SCARY, I MEAN.

Patient: Oh, it was very scary, yes, yes.

INT: YEAH, WHEN I WAS YOUNGER I HAD AN AWFUL EXPERIENCE WITH THE DENTIST WHEN I WAS [???] AND I NEVER WENT TILL I WAS 16, AND THAT'S ONLY BECAUSE I NEEDED

FOUR TEETH OUT ABSOLUTELY DESPERATELY, AND I WAS SO TERRIFIED IT WAS GONNA HAPPEN.

Patient: Yes, I didn't go for years. They used to be awful.

INT: I WENT THEN REGULARLY.

Patient: Yes. When you think of the trauma.

INT: OH YEAH, I MEAN, SORT OF, WHEN I WENT IN THERE AND THE DENTIST WAS REALLY GOOD AND AFTER THAT I WENT REGULARLY AND IT'S ONLY THE LAST COUPLE OF YEARS I HAVEN'T BEEN BECAUSE I HAVEN'T FOUND ONE HERE, THAT'S ALL.

Patient: Yeah, yeah. But that, that was actu-, I was very, very frightened about the actual operation.

INT: YEAH.

Patient. And, erm, and I know that sounds silly but that actually was the sort of gut emotional thing about what it would be like.

INT: YEAH, SURE. AND IN THAT TIME, I MEAN, DID YOU SPEAK WITH ANYONE ABOUT YOUR DIAGNOSIS?

Patient: Oh yes. I don't think I could have, I mean living by myself, erm, it's really important, and I know that, to have people to talk to.

INT: ABSOLUTELY.

Patient: Erm, and there are number of close friends who have been superb, yes, yeah.

INT: OK. AND HAVE ANY OF THOSE ACTUALLY HAD CANCER, LIKE BREAST CANCER, BEFORE?

Patient: No, but one of them has just been called back to Chesterfield, she's there tomorrow.

INT: OH, FINGERS CROSS FOR HER.

Patient; And she has got a history of breast cancer. That must actually hurt a lot.

INT: YES, I BET IT HAS.

Patient: Yeah. So, anyway ...[chuckles]

INT: OK, WHERE ARE WE WITH THE QUESTIONS? HERE WE ARE. WHEN YOU WERE TALKING WITH MR CHADWICK ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, DID HE USE ANY VISUAL AIDS OR TOOLS SUCH AS DIAGRAMS ...

Patient: He was drawing, he was drawing pictures. [chuckles]

INT: OH RIGHT, OK.

Patient: Which was fine.

INT: YEAH, DID YOU FIND THOSE HELPFUL IN ANY WAY?

Patient: Yes, yeah. That was very helpful, yeah.

INT: AND WHAT ABOUT THE BREAST CARE NURSES, DID THEY USE ANY KIND OF VISUAL AIDS, DIAGRAMS, ...

Patient: No.

INT: ANY WRITTEN INFORMATION DID THEY GIVE YOU? DID THEY GIVE YOU ANY WRITTEN INFORMATION LIKE THAT?

Patient: I can't remember.

INT: ANY LEAFLETS OR ANYTHING?

Patient: I've got loads of leaflets but who came to them I can't tell you. It might have been them. I mean have got all this ...

INT: YOU END UP WITH QUITE A BIT, DON'T YOU?

Patient: Yes, I've gathered a bundle. This is my Chesterfield bundle, I mean. [chuckles]

INT: ERM, AND THINKING ABOUT THE TIMES THAT YOU WERE TALKING WITH MR CHADWICK, HOW DO YOU FEEL YOU GOT ON WITH HIM?

Patient: I felt, I felt a great deal of confidence in him and probably this is me and perhaps it's being sort of another professional, I sort of handled by having to laugh, you see, and so he said to me, he gave me a piece of paper with some writing on it and I looked at it and I said, 'Am I supposed to be able to read this?' I said, 'Please think I'm a doctor because my handwriting's bad ...' [chuckles] but that helped me you see, we were able to laugh about it. And, erm, and so when, when we settled on October 4th I said, 'Oh well, that's all right, it's a good saint's day.' And I said, 'You must think I'm crackers.' But I felt, erm, sufficient confidence that he would not, he would take this in the right spirit and as a way of handling an awkward ... awkward situation's a bit of a misnomer, but you know what I mean.

INT: YEAH.

Patient: And, erm, and I felt secure that he knew what he was doing and was offering me the best possible advice, so, erm, I wanted to go back to Chesterfield. We did discuss me transferring, but the option of transferring to Stepping Hill rather than going to Chesterfield didn't actually appeal by then because I'd met these nurses who are I think are lovely and very supportive, and the doctors who I felt comfortable with, and that matters I think.

INT: YEAH, YEAH I THINK, YOU'RE RIGHT PROBABLY, A CERTAIN KIND OF FAMILIARITY WITH THINGS.

Patient: Yes.

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

Patient: Mm, mm.

INT: YEAH, OK. AND WHEN YOU WERE SPEAKING WITH THE BREAST CARE NURSE - WAS IT DONNA YOU SAW ALL THE TIME?

Patient: Donna.

INT: YEAH. WAS SHE LIKE YOUR BREAST CARE NURSE?

Patient: Mm.

INT: YEAH. HOW DO YOU FEEL YOU GOT ON WITH DONNA?

Patient: Great. Absolutely great. Yeah.

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

Patient: Oh yes, oh yes, I could say anything to her. Yeah. I had to [???] perfectly well swearing roundly. [chuckles]

INT: REALLY?

Patient: [???] shocking too. This is supposed to be a reverend.

INT: WELL, YEAH, YEAH. [???] SWEAR.

Patient: I forgot this is on tape, but never mind, I'm not ashamed of it.

INT: WELL YOU'RE NOT ACTUALLY SWEARING ON TAPE.

Patient: Well I'm not actually swearing, am I? Only talking about swearing.

INT: ERM, SO, WAS IT MR CHADWICK THAT DID THE OPERATION AS WELL? DO YOU REMEMBER?

Patient: Yes.

INT: YEAH, OK. SO CAN YOU JUST TELL ME NOW WHAT ACTUALLY HAPPENED ON THE DAY OF THE OPERATION, WHEN YOU WENT IN?

Patient: Mm, yeah. Erm, very good friends took me in and ... do you want a blow by blow account?

INT: YEAH. YEAH, GO AHEAD.

Patient: I don't know what you want to know.

INT: JUST TELL ME THE, JUST A THUMBNAIL SKETCH OF THE DAY SORT OF THING, HOW IT WENT AND ...

Patient: Yeah, erm. Well, I, we arrived at half-past eleven, which was when I was told to arrive, and was shown my bed etc and settled down and I wanted to know when the operation would be, and I can't remember who told me, I wasn't told immediately, they said they didn't know immediately. But then they said they thought it would be about three o'clock, by which time I was thinking, 'Why can't I have lunch, then?' I'm a foodie, so nothing put-, even being very scared doesn't put me off my food. And I could smell food and thinking I could eat a nice lunch. And then I think probably round about half twelve Mr Chadwick came round and he said I'd actually go down to theatre at two because they'd had a cancellation, which suited me fine, if you've got to do it, do it as quick as possible, you know. And then I suppose I must have had a pre-med not long after that and so I felt quite calm actually, I mean I wasn't in the state I'd convinced myself I would be in. Erm, and went down to theatre and had the injection and knew nothing else until I was being woken up. So I've discovered that they do knock you out completely. [chuckles] Which was a good bit of learning.

INT: AND HOW WERE YOU WHEN YOU WOKE UP? WERE YOU OK, WERE YOU SICK OR ANYTHING?

Patient: I was fine, I was fine. I didn't have, erm, I never felt sick, I never felt any great pain. I just thought it must have gone extremely well really. Erm, and I went back to the ward and that was it until the morning, by which time I was ready for breakfast.

INT: AND HOW WERE YOU IN HOSPITAL THEN, DO YOU KNOW?

Patient: They ... Mr Holt came round and I was discharged at half-past nine ...

INT: THE NEXT DAY ...?

Patient: ... but didn't actually go till about 11-ish 'cos there were several of us going at once and the poor nurse had to sort of do all the paperwork and take our canulars out and all that stuff.

INT: DID YOU HAVE ANY DRAINS AT ALL? ANY DRAINS ...

Patient: No, I didn't, no.

INT: OH THAT'S GOOD.

Patient: No. So I was discharged fairly quickly.

INT: OH RIGHT, MM. SO THAT WAS LIKE THE NEXT DAY, WASN'T IT, YEAH?

Patient: Yeah.

INT: OH RIGHT. AND SORRY, I NEVER ASKED YOU, DID YOU HAVE A PRE-ASSESSMENT BEFORE THAT?

Patient: Yes.

INT: YES, AND WAS THAT ...?

Patient: The Thursday, erm, yes the Thursday before.

INT: RIGHT, OK. AND WERE THE BREAST CARE NURSES THERE AT ALL?

Patient: Erm, I had been told that she would be but she wasn't, so then I asked to see her, mainly because to me, erm, the continuity of somebody you're familiar with was quite important and Donna was very happy to see me and I just had a bit of chat about it all again, that's all. And, which I found helpful. But that wasn't because I didn't find the people who were dealing with me helpful, I have no complaints about any of them at all. It was just for me, I wanted that reassurance of seeing Donna again.

INT: OK. AND, THINKING ABOUT YOUR, THE OPERATION THAT YOU HAD AND THE DECISION THAT YOU MADE, HOW SOON DO YOU THINK IT TOOK YOU TO MAKE YOUR MIND UP FROM WHEN YOU'D BEEN DIAGNOSED AND HEARD ABOUT YOUR TREATMENT OPTIONS TO ACTUALLY SAYING, 'YES, I'M GOING TO HAVE THIS PARTICULAR OPERATION'?

Patient: Straight away.

INT: STRAIGHT AWAY. MM.

Patient: And I don't regret that.

INT: RIGHT, OK.

Patient: I'm quite clear and, even if I go back on Friday and they say I've got to have a mastectomy, erm, I shan't regret that, at least I've have, you can never know how you're going to be, do you, but I don't think I will.

INT: RIGHT, OK.

Patient: I don't feel at the moment that, erm ... yeah.

INT: AND DO YOU REMEMBER WHEN YOU SIGNED THE CONSENT FORM?

Patient: Just before the operation.

INT: RIGHT, OK. SO THE DAY OF THE OPERATION.

Patient: When Mr Chadwick came round to see me.

INT: OH RIGHT, OK. MM. AND DURING THAT TIME, AFTER YOU'D MADE YOUR MIND UP WHAT SURGERY TO HAVE ...

Patient: Because ... sorry to interrupt you ...

INT: NO, THAT'S FINE.

Patient: ... at that point he was still, as I understand it, checking with me quite carefully that that was still the choice I wanted to make. Yeah.

INT: RIGHT, THAT'S WHAT I WAS JUST GOING TO ASK YOU.

Patient: Sorry.

INT: DID YOU EVER AT ANY POINT CHANGE YOUR MIND OR HAVE SECOND THOUGHTS?

Patient: No.

INT: NO, I WAS GOING TO ASK YOU AFTER THAT DID HE CHECK YOU ... THAT'S OK, THAT'S FINE. LET ME SEE, JUST WANT TO MAKE SURE THAT I'VE ASKED EVERYTHING BEFORE WE MOVE ON ... YEAH. ERM ... IN THE MEAN-, IN BETWEEN YOUR DIAGNOSIS AND YOUR ACTUAL OPERATION, DID YOU LOOK FOR, FIND, OR WERE GIVEN ANY FURTHER INFORMATION ABOUT BREAST CANCER, EITHER FROM A GP, RELATIVES, FRIENDS, NEIGHBOURS, SUPPORT GROUPS, BOOKS, MAGAZINES, VIDEOS ... ANYTHING LIKE THAT?

Patient: OK. Erm, nothing from the GP because I've not met her, which was not her fault, I'm a new patient and I've not made an appointment because I didn't see the point. Erm, there'd been some things in the press: I'm a Guardian reader and there's a Guardian journalist who's been going through precisely the same thing. I found her articles fairly unhelpful actually because they were very, a bit negative I thought.

INT: RIGHT, OK.

Patient: Her article about having the biopsy, if I hadn't already had it, would have put the fear of God in me.

INT: RIGHT, OK. RIGHT.

Patient: I was glad I didn't, hadn't read that before. I mean having a biopsy is not very nice and, as I've said to somebody afterwards, I could think of better ways of spending 20 minutes, [chuckles] but it isn't the end of the world. I mean, it's as nasty as having, it's about as painful in my mind as having an injection when you're having your teeth attended to, but it worse because the vulnerability of where they're doing it.

INT: THIS IS ... YEAH, OF COURSE.

Patient: Yes. But, no, the article, that articles, those articles I didn't find at all helpful. I mean I didn't want to know, I didn't find them encouraging in any way, erm, but there was also an article by Lynn Redgrave, the actress, who's had a mastectomy, erm, and that was very good I thought and was helpful. She didn't cover anything up and, you know, she talked about how she felt about it and in the end how it's almost like the scars of living, you know, you just get on with it basically. And that, and that was a very positive article and I found that helpful.

INT: AND YOU MENTIONED THE INTERNET, DID YOU GO BACK ON THE INTERNET?

Patient: No, no. Erm, I must sound like somebody who has their head in the sand, but I don't think it's that, it's like I don't want too much information about ... why don't I? Well I suppose I feel at the

moment that I've got the information I need to have, erm, and I don't particularly want to explore any more. I mean I know that these, because I said to Mr Chadwick at the interview, I said when he diagnosed me, I said, 'How do we know I haven't got more of these wild cells roaming round my body?' and he was, he said, 'Well, we don't actually know, and that was why we put you on the drugs afterwards and the radiotherapy,' but it's sort of like one step at a time really for me.

INT: OK. AND, ERM, LET ME SEE ... WHAT DO YOU THINK WAS, THINKING ABOUT THE CHOICE THAT YOU MADE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT WERE TOLD OR HEARD OR READ, THAT HELPED YOU MAKE A DECISION TO HAVE THE OPERATION YOU DID?

Patient: I suppose that the fact that a great many people, the percentage of people who have a wide local excision, erm, and that is sufficient, is pretty high. That's what I understood. And ... and Mr Holt said to me after the operation, when he discharged me that the prognosis for people like myself who were diagnosed at screening stage was very good. And I accept that that isn't 100 per cent assurance that it's OK ...

INT: YEAH, OF COURSE.

Patient: ... of course not. I shall go and say, 'You said to me ...' [chuckles] I appreciate that, you know, that that is a reasoned statement, like a best guess. Yeah?

INT: YEAH. YEAH, SURE.

Patient: But that felt OK. And that felt important, that statistic, that for a great many people it is sufficient. And since then I have met or people who are friends who I didn't know ... I had a friend phoned me and said, 'Oh,' she said, 'I had that 16 years ago.' You know. [chuckles]

INT: [???

Patient: There is life after wide local excision, so ...

INT: OH I'M SURE THERE IS. ERM, SO CAN YOU JUST NOW FILL ME IN WHERE YOU ARE? YOU'VE HAD YOUR OPERATION, AND WHAT'S HAPPENED SINCE, WHAT'S BEEN HAPPENING?

Patient: Well I had the operation on the 4th, was discharged on the 5th, erm, and I go back on Friday.

INT: THAT'S FOR THE RESULTS OF THE OPERATION, IS THAT RIGHT?

Patient: Yeah.

INT: YEAH, OK.

Patient: Yeah.

INT: MM. AND HAS HE INDICATED AT ALL WHAT YOU MIGHT HAVE AFTER THAT? I MEAN YOU DID MENTIONED RADIOTHERAPY I THINK.

Patient: Yes, he said that, erm, I would need five weeks of daily radiotherapy and I'll transfer to the Christie for that because going to Sheffield from here is crackers.

INT: YES.

Patient: Yeah.

INT: AND IT'S NOT VERY NICE PARKING THERE EITHER.

Patient: Well, it's just [???] at Christie's, [???]

INT: THAT'S LIKE ROUND THE CORNER, YEAH.

Patient: Yeah. Erm, and I don't know when this will be which is a great irritant to people like me who like to plan their diaries, because I don't know what I've got to block out yet, you see, and I'm hoping it will be after Christmas because that would be so much easier. But I accept that I have no control over that and whatever it is I'll, has to be done. Yeah.

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

Patient: I think the care has been very good. I am very comfortable with that. Erm, I have, I felt, and I said this to my friend, telling her when she told me she was there tomorrow, I said, 'When I went for the second time, erm, no when I went back for the recall, the first time I went to Chesterfield, erm, I felt that I was dealt with with compassion and efficiency, and that actually is what you want in your Health Service. Yeah?

INT: YEAH, IT'S GOOD.

Patient: Never mind anything, any other nonsense they come out with. You need, I was treated as a person, not as a walking disease, [chuckles] I was treated properly and I was treated with understanding of the shock, erm, and very efficiently, and business-like in a proper sort of way, if you see what I mean.

INT: YES, MM, RIGHT.

Patient: I can't fault that. I thought that was very good.

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

Patient: Yes.

INT: YEAH. DID YOU HAVE ANY EXPECTATIONS?

Patient: I was going to say, did I have any expectations? [chuckles]

INT: [???] QUESTION REALLY.

Patient: Well, I mean, I didn't have expectations before then because I didn't know any of this was going to happen, but retrospectively, yes, I, erm, the only thing I would have wished would have been to have gone back last week rather than this week. This three weeks has been a long time.

INT: YEAH, MM, AND HOW HAVE YOU BEEN THROUGH THAT THEN?

Patient: Pardon?

INT: HOW HAVE YOU, HOW HAVE YOU FELT THESE LAST COUPLE OF WEEKS?

Patient: Well it's actually gone quicker than I thought it would, erm, because I've had plenty to do and I have been able to get on reasonably well, but it's the unknown hanging over you.

INT: YEAH, FINDING OUT WHAT THE RESULTS OF THE OPERATION'S GONNA BE?

Patient: Yeah, yeah. Yeah. Erm, but I don't expect that there was anything that could be done about that, I think Mr Chadwick was away or there was something so, you know, I'm not feeling aggrieved, that's just life.

INT: AND YOU MENTIONED I THINK EARLIER YOU SAID YOU WERE SPEAKING TO DONNA ABOUT WHAT YOU COULD AND COULDN'T DO AFTER THE OPERATION, I MEAN HOW, HOW HAS THAT ACTUALLY SHAPED UP?

Patient: Erm, reasonably well really. Erm, I think that the first week I was feeling pretty good, erm, and so I then think I went into my sort of superwoman mode, 'Look I'm OK and I can do this,' and then I did too much, including deciding to take a spade to the garden, which was probably not very sensible. So I then, I then felt not too good.

INT: I'M GOING TO BE NON-JUDGEMENTAL ON THAT ONE. [CHUCKLES] OK.

Patient: Erm, I don't find it easy to do nothing. But on the other hand I'm very fortunate in that some of my work is obviously reading, sitting at the computer, that sort of thing, and my brain seemed to be functioning as well as it ever does, so ...

INT: OH THAT'S GOOD.

Patient: Erm, so, it's been all right. I've been tired, more tired I think, erm, but not sort of wiped out. Erm, so I'm not working at full tilt but I've managed to do quite a bit.

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

Patient: ... Well I've never thought about this so I don't know is the answer, because I'm impressed with the service I received so I could harp on about my little deep objection to every hospital and making a charge in car parks, [???] I think is profoundly wrong. [chuckles] But that's not because I can't pay it, it's because I think it's profoundly wrong. Erm, so that's a money question, if you like. But, erm ... I can't actually imagine anything that money would immediately change. I mean the wards were all right, what, I could sit and re-design wards and do all sorts of things, but, you know, I haven't got any complaints about anything that was there for me.

INT: WELL YOU DON'T HAVE TO CHANGE ANYTHING IF YOU DON'T WANT TO.

Patient: No, no. I mean, erm, I don't know whether it makes any difference less of a wait and whether that is because it needs more staff, I mean, but I thought that I was dealt with pretty promptly, you know, it could have been two weeks from being diagnosed which is pretty good I'd have said. You know, so I haven't got any issues about any of that. I don't think so.

INT: OK.

Patient: If I think of something I'll ...

INT: [???

Patient: [???] before the end of this.

INT: NOW 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'RE GETTING THEIR DIAGNOSIS?

Patient: ... Erm, I think was, I needed to know, was exactly where this lump was, how big it was as clearly as possible - it was very clear in my place, I didn't have any doubts that it was cancerous, by the, you know, by the time I went back there wasn't any doubt about it. Erm, and the importance therefore of knowing whether it had spread and how we discover that, the lymph node thing hopefully. And what he was saying about because of the position there was a greater risk that the lumpectomy wouldn't clearly have dealt with the problem. I needed to understand that, [???] Yeah.

INT: MM. AND I THINK THAT ACTUALLY ANSWERS THE NEXT ONE, I WAS JUST GOING TO SAY, A SIMILAR QUESTION, NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: Erm ... and in the end it's important to know whether the operation is, insofar as any of us can know these things, be successful in dealing with the cancer. So if he had said to me, erm, 'The only way we can deal with this is a mastectomy,' I would have believe that that was ... and that was important, I would have said, 'OK, well this is awful, or I hate it, but that's what's got to happen.' Erm ... one wants to know what the point of the operation is, don't you? Yeah? Erm, and therefore, you know, what I hadn't, what I needed to understand was why, why we needed to have the under-arm bit to take the lymph nodes.

INT: YEAH.

Patient: Yeah?

INT: RIGHT.

Patient: Which I quite understood when he told me. Being somebody without any sort of anatomical expertise at all, I needed to have that explained to me.

INT: RIGHT, OK.

Patient: Yeah.

INT: MM, OK. THE FINAL QUESTION. IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANY POINTS YOU THINK WE'VE MISSED, ANYTHING IMPORTANT WE HAVEN'T COVERED OR ANYTHING?

Patient: Well I shall think of the answer to that when you're halfway back to Sheffield. [chuckles]

INT: THAT'S ALL RIGHT. [???

Patient: I can't immediately think of anything.

INT: THAT'S NO PROBLEM. IS THAT IT THEN? SHALL BE SWITCH OFF? YEAH, OK.