

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: High MR unit
*DATE:
*ID: Patient31
*INTERVIEWER: DJW

INT: THANK YOU VERY MUCH FOR BEING INTERVIEWED. I'D 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 THAT SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, well what I understood about it was, er, when, people usually found a lump if there was going to be a problem, or some kind of, some visual sign that you could feel or see to indicate there was some problem there.

INT: RIGHT.

Patient: Now I didn't realise there was anything wrong with me until the mammogram.

INT: OH SO YOU WERE PICKED UP ON SCREENING, WERE YOU?

Patient: Yes, yes.

INT: YEAH, OK.

Patient: Erm, I mean, what bit, what I knew or understood about it. All I knew it was a woman's worst nightmare and I'd often said, I always worked with women, some people had this problem, and I'd always said if every it happened to me, you'd never see me, I'd go over the horizon, you'd never see me again. And so I drew the short straw. But all I knew about it really was that there was something to see or feel, and the prognosis, you know, could be deadly and it caused people a lot of fear and anguish.

INT: MM, YEAH. DO YOU HAVE SORT OF PERSONAL EXPERIENCE OF IT IN TERMS OF HAVE YOU GOT IT IN YOUR, ANY FAMILY HISTORY OF BREAST CANCER, OR DO YOU KNOW ANY FRIENDS OR RELATIONS, COLLEAGUES, WORK COLLEAGUES, WHO'VE HAD THE SAME THING?

Patient: Well I understand that there's two or three people in the Church community who've had this problem that are all fit and well.

INT: DID YOU KNOW THIS BEFORE YOU YOURSELF HAD BREAST CANCER OR WAS THIS [???]?

Patient: Yes, one lady I did know of that had, she'd had both, a double mastectomy, a young smart woman, and was fine. I had worked with somebody who had the problem and unfortunately she died at a young age. So, you know, I've seen both sides of it.

INT: RIGHT, OK. SO, YOU KNOW, WHEN YOU WENT TO THE SCREENING AND THAT AND THEY SORT OF, AND YOU SORT OF GOT THE FIRST INKLINS, IF YOU LIKE, YOU KNOW, AT SOME POINT THAT THIS MIGHT BE SOMETHING WRONG, WHAT WAS GOING THROUGH YOUR MIND?

Patient: Well [chuckles] right from the beginning, I mean I was on holiday in Malta, came back to a pile of mail, one saying that I'd missed an appointment.

INT: OK.

Patient: So I phoned them and said 'Sorry I've miss it, could we make another one?' 'Yes.' So I went along to the unit and it didn't seem to go very well, it

just didn't seem to go very well. I couldn't, well you obviously what's entailed and so on, I couldn't really seem to get my feet firmly on the floor.

INT: RIGHT, OK.

Patient: Anyway, she said, you know, 'You'll be informed in say a fortnight,' and in less than a week I got a letter. So what was going through my mind was the whole thing had gone to pot, that it wasn't successful, the mammogram, it wasn't clear and we'd got to go through it again.

INT: RIGHT, OK.

Patient: So I went with this in mind.

INT: SO IT WAS A REPEAT MAMMOGRAM YOU WENT FOR WAS IT?

Patient: Well, I was, it's very subtly worded because the letter, the next letter comes from the breast screening unit at Derby City Hospital ...

INT: RIGHT, OK.

Patient: ... and it's telling you that you're invited to take part in Phase II. You're invited to take part in Phase II, so it's like, it indicates that this is just routine, it's just routine. And so I sort of hoped in my mind that this is what it was going to be, it was just a routine thing to clear up the mammogram and get it clear because it must be blurred or something.

[Interruption]

INT: YOU KNOW THE BEST ONE LAST WEEK WE HAD SINGING WINDOW-CLEANERS AND EVERYTHING IN ONE OF THE INTERVIEWS. IT'S TRUE, WE HAD, IT WAS A HOTEL, AND THE LADY SHE SAID, ERM, SHE HAD AN OLD LADY WHO WAS WORKING FOR HER AND SHE WAS DEAF SO SHE KEPT COMING AND ASKING QUESTIONS, SHE HAD TO SOUT AT HER, SORT OF THING, AND THEN WE HAD THESE, THE NEXT [??] THERE WAS THIS BIG WINDOW, AND THE NEXT THING WE KNOW, THERE'S THIS CLOTH RIGHT IN THE WINDOW AND THIS GUY WAS THERE SINGING SORT OF 'RAINDROPS ARE FALLING ON MY HEAD' [CHUCKLES] AND IT'S ALL ON THE TAPE THAT, IT'S FANTASTIC, YEAH. OK SORRY

Patient: Now you've got a deranged dog you can talk about. She only thinks she's missing something that's all it is. She can be a nuisance, we'll see the outcome.

INT: IT SHOULDN'T HAPPEN TO A RESEARCHER BUT IT DOES. OK, SO WE, YOU'D HAD THIS LETTER AND YOU WENT BACK FOR THE SECOND ...

Patient: Yeah, and what was going through my mind that it was all needed sorting, it was a technical error.

INT: AH RIGHT, OK.

Patient: So I got there and I was asked to put the gown on and so on and so forth, and called into this room, and this lady said, 'We're going to do another mammogram.' And I said to her, 'Is there something wrong with the first one, is it blurred?' She said, 'Oh no,' she showed me the thing and said, 'There's something there we've not seen before, we just need to check it out.'

INT: OK, WAS THIS THE RADIOGRAPHER, WAS IT, YES?

Patient: The lady who deals with the mammograms.

INT: YEAH, YEAH, THE RADIOGRAPHER.

Patient: Erm, so she did that and said, 'Wait outside,' so I sat reading this book and I was quite content with myself and I thought, what was going through my mind was, 'This is all a mistake,' you know, I feel slightly sorry for all these ladies around me because, you know, they could have problems, but this isn't relating to me, it's going to be a very simple outcome. And anyway the next thing I was called into the next room, this time I was asked to lie upon a bed, and I was told that, repeated there was something there that needed looking into, and there was this, erm, nurse there with me, who I think is called an x-ray assistant or something, she was wonderful. And the doctor there was explaining everything to me. And so he said, 'The mammogram' you know, 'showed that they needed to look into it a little bit more, and he needed to do an ultrasound, and he told me what it was going to be. And so he did that, and that was fine, and then he said they needed to do this biopsy and they three. And what was going through my mind by this time was, 'Well this is a bit of a surprise to me, I wasn't prepared for this,' was going through my mind. And also what was going through my mind was I was on this bed looking at the ceiling and a most beautiful picture of sunshine and trees and ... it was like, erm, this place in America, what's it called, New England ... oh it was beautiful. Oh. And so that was sort of to take your mind off things. Anyway, so he, at the third attempt he was satisfied. So what was going through my mind then was, 'Well, you know, that's it for now and it's all gonna be resolved.'

INT: RIGHT, OK.

Patient: And then he said, you know, he thanked me and he said would I like to get dressed on and so on, whatever it was, sort myself out, and he was making these notes, and he said, 'We're not going to know the results of these tests just now,' he said, 'So we'd like you to come back next Tuesday.' Erm [chuckles] he said, 'Unfortunately this is another week for you to wait' because it's like a little bit of a waiting game, some people can cope with it and some people can't, and he's obviously dealing with all types of people. I could have been the one in the category that found it difficult to cope for yet another week.

INT: YEAH, OF COURSE.

Patient: But what was going through my mind at that stage was we were due to go on holiday on that date.

INT: AH RIGHT.

Patient: And it was a big one, we were going to Spain, Portugal, Gibraltar, for three months in the caravan.

INT: OH, RIGHT, OK. [???

Patient: And everything was booked. So 'You weren't going on holiday,' he said, I said, 'Well as a matter of fact,' I said, 'We had booked to cross on that day.' He says, 'Are you going far and how long are you going for?' So I told him. He said, 'Mm,' he said, 'Well we would prefer that you could be a week today, you know, because we need to see what the outcome of the doings is.' And this, they were good and said had we got insurance, could we, was it all going to be able to be settled up and so-and-so, so we weren't gonna lose any money. And I said that's all hand, we are insured. Anyway, so, that was it and I was told I could go and he wanted to see me in a week's time. Then I had to go out into the waiting room to tell David, who was ready to go a week from today on his holiday, planned months for. So what was going through my mind then was, 'What is he going to make of it? Is he going to take this worse than me? Is he gonna suspect the worst?' I got, that was a bigger ordeal ...

INT: YEAH, OF COURSE.

Patient: ... than the one before. And so he's sort of laid back and smiling and 'Are we ready?' you know, 'Are we ready?' And I said, 'Look, we're not going anywhere, I've just got to explain things to you.' So I explained things to him and I said, 'Now, look, anything you want to ask, ask now before we leave the hospital, because I can't tell you any more than I've been told, and if you've got more questions you must ask now.' There was one or two little bits of things he went over, just to confirm. And so we came home and he contacted the people and he said, 'Something's cropped, we're not going to be able to travel on that day. It could be we'd wish to travel on the next day.' He said, 'It's a medical thing and we have an appointment on the day we're supposed to travel.' They said, well that was fine. And he said, 'It could well be that we may have to cancel the holiday all together.' They said, 'That's fine, just let us know, just keep us in the picture.' So to cut long story short they were wonderful, the Caravan Club, they didn't want any medical evidence and they just said, 'Blah, blah, blah, all the money will be refunded to your account immediately.'

INT: OH THAT'S ALL RIGHT, ISN'T IT? THAT WAS GOOD OF THEM.

Patient: And I don't think you mentioned cancer at any time, did you?

Husband: No, you see, all we had was the ferry booking, and it's an old site, I'd written, I'd booked a campsite in Seville for actual Easter week because it is a choc-a-block, Seville, because of the parades and everything. So that was the only thing we'd booked and we were able to write and cancel that in time. But the ferry, they were very good, they just said, you know, 'Well we'll re-book it for the following morning, same time.' Er, the only reason we had to do this was because we were taking the dog with us ...

INT: OH OF COURSE, YES.

Husband: She costs more than the flipping caravan [chuckles]. Anyway, no problem. As soon as we got back I rang them up and said, 'Unfortunately, due to this medical problem, you know, we've got to cancel the holiday.'

INT: RIGHT, OK.

Husband: And they wished us all the best, they were very good, she said, 'I'll be two minutes,' came back and she says, 'The money'll be put back into your bank account, that's no problem.'

Patient: Right so the next thing is ...

Husband: And no insurance was necessary at all.

Patient: What ...

INT: YEAH, THAT'S BRILLIANT.

Patient: What was going through my mind at that time, I think, I was getting, I was getting apprehensive and I was beginning to think we had got a problem. And so the following Tuesday we went back - are we still on the question one.

INT: WELL WE'RE KIND OF MOVING SLIGHTLY, IT'S QUESTION TWO, BECAUSE I MEAN SOMETIMES WHEN PATIENTS ARE INTERVIEWED THEY SORT OF, THEY SORT OF MOVE SMOOTHLY AND I JUST IGNORE THE QUESTIONS AND JUST KEEP TALKING. IN BETWEEN THIS, THE SECOND CLINIC, MAMMOGRAM, AND YOU KNOW, WHAT WE'VE JUST BEEN TALKING ABOUT, AND

WHEN YOU WENT TO HEAR YOUR RESULTS, DID YOU TALK ABOUT ANY IDEAS OF WHAT IT MIGHT BE WITH ANYONE ELSE?

Patient: Oh my first thing was to tell all my closest friends ...

INT: OH RIGHT, OK.

Patient: ... that I'd been for this mammogram.

INT: THE SECOND ONE, YEAH.

Patient: And I'd been and had a biopsy and so now I was waiting for the results. Erm, because my feeling was, if it was confirmed as malignant, I really didn't know how I was going to be on the day, and I didn't know whether I was going to be able to tell people it was positive. It seemed to be easier to warn relevant people that it might be than to wait to tell them that it was. I could handle myself, I knew I could handle myself to tell them what had just occurred and what might be, and that's what I did. And the family and everybody who was involved in my life, close people, I let them all know. And life carried on.

Husband: Well the holiday plans we kept them going.

INT: RIGHT, OK.

Husband: So I mean if you've got a caravan and you've got to prepare it for three months' journey,...

Patient: Mm, we did, didn't we?

Husband: ... it kept us busy.

INT: WELL, OK, THAT'S GOOD.

Patient: And doing, yes, yeah, yeah, I remember.

INT: SO WHAT THEN HAPPENED WHEN YOU WENT TO HEAR ABOUT YOUR RESULTS THEN?

Patient: Now what happened when we went to hear about the results, we were just called in and there sat the surgeon, consultant surgeon, because I'd looked on the board at the team: there were two men and a woman.

INT: THAT'S RIGHT, YEAH.

Patient: And I'm very candid me and straightforward and actually I was hoping it would be a man. I prefer a man doctor, a man dentist, it's just something, I think they're more ... you know, a woman wouldn't like to hear me saying this but it's just the way I feel. Anyway when I went in to the room and it was the lady surgeon, then I was a little taken aback, if you like, only because I'd got in my mind I was going to see one of the men. And anyway she said, she was very, very polite and said, 'We've got, the results have come through,' she said, 'We suspected that there may be some malignancy there,' she said, 'We've analysed it and it is.' And she was very direct, very clinical, very efficient. She gave me a minute to think about it and then she got this white piece of paper, which I've still got, and she drew the picture of the breast and where the cancer was and said, 'That's what it is, that's where it is, that's the dimensions of it.' And she was giving me opportunity to, all the way along, to respond or react or whatever. But we didn't say much, and I didn't say much, and then she said, 'Of course surgery is involved and you do have a choice whether, if you have a mastectomy or a lumpectomy.' And she says, 'I don't want to know now,' she says, 'You will be, you will have a pre-op appointment,' she said, 'You can make your

mind up then if you wish to, or you can even tell me on the day of the surgery.' 'cos I said, 'Will you be doing the operation?' She said, 'Yes, it will be me,' and she said, 'Is there anything you want to ask me, anything you want to talk about?' and she said, and this lady, there was a nurse in uniform as a nurse and there was a breast care nurse who was in ordinary gear sat there. And she introduced me to the two of them. She said this lady was the breast care nurse and she would take me along somewhere I would be able to have an in-depth talk with her and she'd explain anything and everything and everything. And she said, 'I will be in the building 'til such-and-such a time in the afternoon, I'm still around 'til that time if you change your mind and you want to speak to me,' and so we were taken from there by the breast care nurse to this room. Now, taken to this room, you see when David had his Hodgkin's disease I was called to a room then because we thought the worst was going to happen, all the family were sent for, and I was shown to this room with a settee, of a lounge arrangement and I thought, 'I don't like this,' you know what I mean? I mean that wasn't criticism about anything it was just this feeling I had, I thought, 'I've seen this before,' and so I was taken in this room where we ... David was with me and we sat on this settee. Anyway she was very good and she gave me all sorts of literature and all about the operation with pictures and all about physiotherapy and the operation and gave me a phone number and anything I wanted to know at any time they were there ... er .. it was just unbelievable, wasn't it?

Husband: Yes.

Patient: Absolutely unbelievable.

Husband: And you were given a date when the operation was going to be ...

Patient: Oh I forgot that.

Husband: And what, when, the pre-med date, everything, even to asking [???

Patient: Yeah, this, this surgeon said, 'Your date, your operation date is fixed for 15th March,' she said, 'We'll be asking you to come in in the morning and the operation will take place later that same morning, and you will be invited to come into the hospital for a pre-med' - whatever they call it, they've a different name for it - 'where you will be, you ECG and blood pressure and all that will be checked out.'

INT: YEAH, PRE-ASSESSMENT, YEAH.

Patient: Pre-assessment. And, erm, so that was it. That covers us right up to being told what all the arrangements were gonna be.

INT: ERM, [???] BEFORE YOU ACTUALLY WENT TO HEAR ABOUT YOUR RESULTS, HAD YOU ACTUALLY THOUGHT IT MIGHT BE A CANCER AT ALL?

Patient: Well, yes, this is why I informed everybody that was close to me, because I was beginning to smell a rat, if you like.

INT: MM, AND DID YOU HAVE ANY THOUGHTS AT ANY TIME THEN ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF TREATMENT, OR WHAT TREATMENT MIGHT BE AVAILABLE?

Patient: Erm, well I knew we'd got surgery, I was obviously, and I was terrified, absolutely terrified. Erm, it's a fear of the unknown, and of course the anaesthetic, it was just a general dread of surgery, if you like. I had a feeling that was in their hands and they were there, not to hurt me or cause any grief, but they were there to, for the very best outcome, you know, that the surgery was successful and the operation would go well. I'd no doubts about that.

INT: AND THEN WHEN YOU WENT INTO THE ACTUAL CONSULTATION TO HEAR ABOUT YOUR RESULTS, WHO, SO THERE WAS THE CLINIC NURSE AND THE BREAST CARE NURSES, THE CONSULTANT AND YOURSELF, WAS THERE ANYBODY ELSE ...

Patient: And David.

INT: DA-, YOU WENT IN AS WELL, DID YOU?

Patient: Oh yes, he's been with me all the time.

INT: AND DID YOU HAVE ANY EXPECTATIONS AT ALL ABOUT WHAT YOU MIGHT BE HEARING, WHAT YOU WERE GOING TO HEAR, WAS THERE ANY EXPECTATIONS AT ALL?

Patient: Well the expectation was that I would be told what form the surgery would take - that was my expectation.

INT: AND WHEN YOU WERE TOLD ABOUT THE DIFFERENT TYPES OF OPERATION, YOU SAID THERE WAS A CHOICE OF MASTECTOMY OR LUMPECTOMY ... WERE YOU FAMILIAR WITH THOSE TERMS, ABOUT WHAT THEY MEANT?

Patient: Yes.

INT: DID THE CONSULTANT SORT OF DESCRIBE WHAT THE OPERATIONS INVOLVED?

Patient: Yes.

INT: OK. AND HOW DO YOU FEEL YOU GOT ON WITH THE DOCTOR, THE CONSULTANT?

Patient: The consultant surgeon?

INT: YEAH.

Patient: Erm, I thought we were a match, I thought we were very direct, we were a similar disposition, you know, we could say and be plain with each other, you know what I mean?

INT: AND WHEN YOU EVENTUALLY WERE TOLD YOUR DIAGNOSIS THAT YOU DID HAVE BREAST CANCER, WHAT WERE YOUR FEELINGS AT THAT POINT?

Patient: Well I was thought like stepping into the unknown really. Er ... it's, because it's all unknown from there on in.

Husband: I think one of things you thought was that it always happened to somebody else.

Patient: Yeah, but, it was unknown territory, and I don't like being on unknown territory, I like to be in control, and I wasn't going to be control, and what was more I'd got to make this decision for myself.

INT: RIGHT, YEAH. SO WHEN YOU HEARD YOU HAD A CHOICE A SURGERY, WHAT WHEN THROUGH YOUR MIND THEN?

Patient: Well I thought, erm, I was on real strange territory, I felt a little bit, erm, like I was alone somehow or another. Not qualified, if you like, to be making this decision myself. And yet knowing at the back of my mind, if I was to have said that, somebody would have come along and said, 'Just don't worry about it,' somebody would have taken it out of my hands. That's the way I felt at the time.

INT: YEAH, RIGHT, OK THEN.

Patient: But knowing that they put it to me that way, I knew the expectation was I was to make the decision myself and I was damn well going to do.

INT: RIGHT, OK.

Patient: But it was like stepping out into the unknown because you're here with this disease, erm, and you don't know which way it's gonna go until after the surgery and so on and so forth, and in the interim you've got this operation that you're absolutely terrified of. So it wasn't, it was a big thing to take on, obviously.

INT: YEAH, OF COURSE, IT WILL BE.

Patient: But I was aware that everybody was there to help me. Everybody was sort of on my side.

INT: YES, YEAH. AND WHEN YOU WERE TALKING ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT WITH THE CONSULTANT, DID YOU UNDERSTAND EVERYTHING THAT WAS BEING SAID TO YOU?

Patient: Yes I did, but if I hadn't have done she'd have told me, she'd have explained it all again. I got the impression that it was sort of being laid on the line to me, it was being delivered in a certain way: it was certainly being put to me very directly - no beating about the bush. I did get that feeling.

INT: MM, I'VE INTERVIEWED THE CONSULTANTS THERE, THEY DO HAVE THAT KIND OF PHILOSOPHY, SORT OF THEY DON'T LIKE TO SORT OF MINCE WORDS, THEY SORT OF ...

Patient: That's it.

INT: THEY LIKE TO SAY IT'S A BREAST CANCER, THEY DON'T LIKE TO SAY IT'S LUMPS, TUMOURS, OR ANYTHING ELSE, BECAUSE THEY CAN ALL BE MISINTERPRETED. BUT A CANCER'S A CANCER'S A CANCER REALLY.

Patient: yeah.

INT: DID YOU HAVE ANY THOUGHTS AT THAT POINT, WHEN SHE MENTIONED ABOUT THE TWO TREATMENTS, ANY INITIAL THOUGHTS ABOUT WHICH TREATMENT YOU'D THINK YOU'D PREFER?

Patient: Well, yes, I was thinking from one to the other, erm, and thinking, 'My God, what a decision this has got to be,' but knowing I'd got this fortnight, because the operation was gonna be a fortnight hence. And being told two or three times I didn't have to make a decision there and then, I could leave it right 'til the morning of the operation, which helped. So I didn't panic, I didn't panic because I knew I'd got this, I was going to come home, and there's no place like home for thinking things through without any pressure.

INT: THAT'S TRUE, YEAH. DID YOU GET IMPRESSION FROM ANYONE THERE AT THE CLINIC THAT THERE MIGHT BE ONE TREATMENT OVER ANOTHER?

Patient: I got the impression that nobody was going to tell me that, answer that question.

INT: OK, THAT'S GOOD.

Patient: They were absolutely rigid that nobody was going to tell me one was better than the other. They kept giving me these things like 'Statistics show that nobody lives longer having one or the other.'

INT: WHETHER THEY'VE HAD ONE ... THAT'S RIGHT, THAT'S GOOD. AND THEN YOU SPENT SOME TIME WITH THE BREAST CARE NURSE AFTER SEEING THE DOCTOR.

Patient: Yes, yes, in this lounge.

INT: YES, I'VE DONE ALL MY INTERVIEWS IN THERE SO FAR WITH THE BREAST CARE NURSES, SO I KNOW WHAT'S LIKE.

Patient: It's only because I'd had the experience with David, and that's where you go when you're given the bad news, you see.

INT: YES OF COURSE.

Husband: And treatment.

INT: RIGHT.

Husband: When you're on the chemotherapy and you go into this wonderful lounge, where you can have a cup of coffee, but later on the morning you'd have this drip come and you've got

Patient: Yeah, it wasn't that lounge, David.

Husband: Well ...

Patient: No, it wasn't, you went into the day room for the chemotherapy treatment. I'm talking about the small lounge where there's just a small settee. David knows what I mean, don't you?

INT: YES, YEAH, I'VE BEEN THERE BEFORE. SO WHEN YOU WERE IN THERE WITH YOURSELF, WHAT, YOU MENTIONED THEY GAVE YOU A PACK AND STUFF LIKE THAT?

Patient: Yeah, do you want to see it?

INT: NO, NO. I'VE SEEN, I'VE SEEN THEM BEFORE.

Patient: Yeah, there was everything, absolutely everything you could think of. All about hospital procedure, anaesthetics, what the operation means, a diagram of the breast and all about it and ... just everything you could imagine you'd want to know. What to take into the hospital and ...

INT: YEAH, AND YOUR CONSULTANT ACTUALLY DREW YOU DIAGRAM AS WELL?

Patient: Yes, I've still got it.

INT: AND DID YOU, DID THEY USE ANY OTHER WHAT WE CALL TOOLS? MAMMOGRAMS, PICTURES ...

Patient: Yes, she'd got like a measurement thing and showed us how big it was.

INT: OH, RIGHT, OK. WHAT WOULD THAT BE CALLED?

Husband: 7 mm.

Patient: What was it called, this tool, do you know? It was like a pair of tweezers really.

Husband: Like, yeah, callipers.

Patient: Callipers.

INT: CALIPERS, OH RIGHT, OK, YEAH. AND ... LET ME JUST GO THROUGH THIS BECAUSE YOU'VE MOVED ON QUITE QUICKLY HERE ... ERM, ...

Husband: She was very good at explaining to me as well ...

INT: SHE'S VERY, VERY CONCERNED ...

Husband: You know, as a lay person.

INT: ERM, CAN YOU TELL ME A BIT ABOUT THE TIME YOU WERE TO THE DOCTOR AND WHEN YOU WERE TALKING ABOUT THE OPERATION ...

Patient: Do you mean the surgeon?

INT: THE SURGEON, YEAH. WHEN YOU WERE TALKING ABOUT THE OPERATION AND STUFF LIKE THAT, ERM, DO YOU FEEL THAT THE SURGEON WAS LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Oh, definitely, definitely. No pussy-footing about but if I'd had a question she would have given me a direct answer immediately, immediately. I wasn't forthcoming with questions because [chuckles] I really didn't know, you know, which way I was gonna go at that time. It was all becoming, sort of all the unknown to me.

INT: AND HOW DID YOU FIND TALKING TO THE BREAST CARE NURSE?

Patient: Well I did, I did get the sense at one stage that, erm, because I am hypersensitive, because I've worked with people myself in the social services, you know, interviewing people, and at one time she, we had a long silence and I'd said to her, you know, 'Are you waiting for me to say something?' [chuckles] you know, because, I think half the technique is, obviously, people are given time to get their thoughts and give answers and they're gonna cry if they want to and do all this kind of thing, you know. But apart from that she was excellent, she was just coming up with all that was needed on the practical side, or chatting about all this information and what it meant and she'd be there, there was a team of five of them. She would give me this card with the phone number, if she couldn't get back to me that day somebody would get back to me the next day. Erm, anything about anything at all, they were there to help, that's what they were there for.

INT: OH THAT'S GOOD THEN. AND THE INFORMATION PACK THAT YOU RECEIVED, DID YOU READ THROUGH IT AND THAT WHEN YOU GOT HOME?

Patient: Yeah, ooh yeah.

INT: YEAH? AND HOW USEFUL DID YOU FIND IT?

Patient: Very useful, very useful. The aspect I didn't like was this aftercare thing. After, post-operative, post-operative, coming round from the operation all these tubes, and I asked them, 'Please don't tell me because I don't want to know,' because following that, oh I was, no that was late on, later on. I didn't want to know too much about it. And I don't think this breast care nurse did discuss that but she gave me the booklet on it, and it was all about the drains and, I mean I know what it is now, but I didn't know at the time, it was all the unknown, you know, and it makes me nervous.

INT: YEAH, I THINK THAT'S RIGHT. ERM, SO FROM WHEN YOU WENT FOR YOUR FIRST MAMMOGRAM AND THEY PICKED SOMETHING UP THAT WAS OBVIOUSLY WRONG TO WHEN YOU HAD YOUR OPERATION, HOW LONG DO YOU THINK THAT WAS? WHAT, FOUR, FIVE WEEKS WAS IT?

Patient: Erm, well I went on the, wait a minute, it was two and a half weeks, wasn't it, from the diagnosis to the operation.

Husband: Yes.

Patient: And it had been a week before that they'd done the biopsy. So what's that?

Husband: Three, three and a half weeks.

INT: AND A WEEK BEFORE THAT WHEN YOU HAD THE FIRST MAMMOGRAM.

Patient: Yes.

INT: YEAH, SO IT'S LIKE FOUR AND A HALF WEEKS ...

Patient: From beginning to end, isn't that fantastic?

INT: MM, YEAH, IT'S ABOUT FOUR OR FIVE WEEKS, YES, I THINK IT'S QUITE, I THINK IT'S QUITE NORMAL THAT ACTUALLY. YEAH.

Husband: I just thought it was fantastic.

INT: MM. LET'S SEE, WHERE ARE WE NOW? SO, CONSIDERING YOUR DECISION, WHEN DID YOU ACTUALLY MAKE THE DECISION THEN WHAT FINAL TREATMENT YOU WERE GONNA HAVE?

Patient: Well I think right from the beginning, although, you know, it came as a bombshell and I was thinking I'm going into the unknown and I felt not sort of qualified medically, not knowing which was the best medically, and nobody wanted to tell me, in fact they were adamant they weren't going to guide me ...

INT: YEAH, OF COURSE.

Patient: Erm, I had to think, well, what's relevant is following the operation, how am I going to be then? What's the situation going to be following a lumpectomy or a mastectomy? I wake up and I've had one or the other. Now I thought, 'If I wake up and I've had a lumpectomy, at least I'm still whole, erm, you know, I've had a bit of an operation and it'll take, it'll be a quicker recovery, and that's probably all that's required, and it's probably just a storm in a teacup,' you know, because it was, it was the size of a nail or something, a fingernail. So there was that aspect to it. Or I could have the mastectomy, which is a much bigger operation, but feel that the problem's gone, it's not going to recur in the breast tissue because it's not there any more. And I thought, well of all the millions of emotions I'm going to feel after the operation, the one I couldn't stand would be to have the lumpectomy and it come back in the same side. It would, I just couldn't cope with that.

INT: RIGHT, OK.

Patient: And that's what decided to me. And I talked to people, friends ...

INT: YEAGH, I WAS GOING TO ASK A QUESTION ON THIS.

Patient: Yeah, I talked to my friends about it, and I said, 'Now don't feel any responsibility, it's not going to be what you say that's going to influence me, but I was just interested,' and most of my close friends said they would have a

lumpectomy, and, which I thought was interesting, but, er, David's cousin, she'd had a mastectomy and, erm, she was fit and well and fine, she made a good recovery. I'd heard of Clare Raynor, who'd had a double mastectomy - I don't know whether you knew that.

INT: YEAH, AND I THINK KOO STARK'S HAD ONE AS WELL.

Patient: Oh has she ...

INT: YES, YES, SHE'S HAD ...

Patient: And people make a wonderful recovery and I thought, 'Yeah, that's the one I'm gonna go for,' and I don't think I ever really wavered.

INT: AFTER THAT, YEAH. HOW SOON DO YOU THINK YOU MADE THAT DECISION THEN?

Patient: I think as soon as I really came away from the hospital, digested the situation, began to get on my own ground, and be able to think clearly and slowly, I think from the beginning it was going to be a mastectomy and I never wavered and I don't regret it.

INT: RIGHT, OK.

Patient: Would that be correct, would you say?

Husband: Oh yes, yes. The decision and whatever it was, that was what you were going for and that's what, and you've come through it with flying colours.

INT: SO, YOU CHOSE MASTECTOMY AND SO WHEN DID YOU TELL THE DOCTOR THAT YOU, THE MORNING YOU WENT IN FOR SURGERY OR BEFORE?

Patient: When I went for the, what did you call it again?

INT: PRE-ASSESSMENT.

Patient: Pre-assessment.

INT: RIGHT OK.

Patient: Now ... go on, you ask me the questions.

INT: OH WELL I WAS JUST GONNA SAY, YOU KNOW, CAN YOU TELL NOW FROM WHAT HAPPENED AT PRE-ASSESSMENT THROUGH TO POST-OPERATION.

Patient: Yeah. So when we got to the pre-assessment I went for this ECG and, erm, and then I was, went to see a nurse who took various questions, and then I, she agreed reluctantly that I could tape it, the interview, and then I saw a young lady doctor and she took blood, which she didn't get, she made an attempt but I had to have it taken later. And she was asking me a thousand questions and examining me from head to foot, no problems. And she even asked me how many pillows I like ... how many pillows did I sleep with. And I couldn't over that, that was fantastic.

INT: OH THAT'S NICE, ISN'T IT?

Patient: And she was so lovely. And so that was, er questions, and then what else happened after that, on the pre-assessment? That was it, wasn't it? The ECG and then the nurse asked me a lot of questions, then the doctor tried to take the blood, took my blood pressure, and filled in reams of questions about general health.

Husband: Mm, [???] the first time, she did get it eventually, she had two goes at it if you remember.

Patient: Yeah, but on the ward, on the day of the operation, they had to take it again.

Husband: Oh yeah.

Patient: Yeah. So I think as about it, wasn't it? And everybody was, er, it took longer than we thought. Did it take over two hours?

Husband: Yes, because you were a bit, there was no hold-ups but by the time you've had an ECG and then gone back, seen a nurse, then you go and see the doctor, it takes time.

INT: OF COURSE YEAH.

Patient: I thought, I saw a physiotherapist ...

Husband: Yes.

Patient: ... and she took me again to this room with the settee, and she'd got this young student with her, which was all by-the-by, but she was telling me all about these exercises that I would be doing and why I would be doing then. And so we went through them, and she was telling me, she says, 'Now, when you come round from the operation ...' I said, 'Excuse me, would you not go into that please?' I said, 'I've just, I'm ready to face this operation and I just want to present myself and say let's go for it. Now when I recover [chuckles] then whatever will be will be.' She said, 'OK, that's fine,' she says, 'It's up to you, whatever you wish,' she says, 'I'll make a note,' she says, 'and I'll come and speak to you on the ward following the operation.' And so we went through these exercises and just, she gave me a book to read about it, and said she'd see me at a later date, you know, and she'd probably come on the ward and we'd see her around and that kind of thing. And all that took I think over two hours. It all went very well.

INT: RIGHT, OK, THAT'S GOOD THEN. AND UNTIL THAT POINT WHEN YOU WENT FROM YOUR DIAG-, WHEN YOU GOT YOUR DIAGNOSIS, THAT CONSULTATION TO THE PRE-ASSESSMENT, DID YOU HAVE ANY CONTACT WITH THE BREAST CARE NURSE AT ALL?

Patient: No.

INT: NO TELEPHONE CALLS, HOME VISITS, ANYTHING LIKE THAT?

Patient: No, no.

INT: OK. AND THEN OF COURSE YOU WENT IN FOR YOUR OPERATION, SO WHAT HAPPENED THEN THEN?

Patient: Now just a moment, David, I'm just thinking when did I see the girl who brought me that prayer?

Husband: That was the meeting, that was then. She came to see you on the ward afterwards and brought you it.

Patient: Yeah, I know, but what did she come to me, ...1

Husband: [???]

Patient: ... what did she come to me in the room for?

Husband: She came in and she was going to tell you about the exercise and after-care ...

Patient: No, no, no, no, I've got it now. The physiotherapist showed me the exercises, then this breast care nurse came in, different from the one who sat at the doings ...

INT: AYE, OK.

Patient: ... when I was given the diagnosis, and she came for me to sign or complete a form of all the details for consent.

INT: RIGHT, FOR THE OPERATION?

Patient: Yeah, but I don't think I was to sign it until the day of the operation.

INT: THAT'S RIGHT, YEAH.

Patient: That's what she came in for, and we were just having a ...

Husband: And that, she'd gone through all the things on that list with you and discussed everything on this list and you signed for her, you know, that you had received all this information.

Patient: Yeah, and it was like a lead-in to the surgery and the ... but when we were in this room waiting for her to come in, we were having a set-to because he was messing about with this coffee-maker. And I said, 'Oh for goodness sake don't throw it all over the place,' and I was really having a set-to with him, and whilst I was doing that I was turning round, there was this little prayer in a frame, and I thought, 'Ooh, that is beautiful,' and I was reading it. 'Ooh, this is beautiful,' and I'd heard the door go and I thought this young woman had gone out, but she'd come in and shut the door behind her, and she stood there listening to this rowing, you see. I said, 'I didn't know you're stood there, I wouldn't have been saying these things if I knew you were there.' Anyway, I said, 'I do like this,' she said she'd got it in Ireland in a place called 'The Gardens' in Ireland in the south, I can't think anyway, and she said, 'Would you like me to get you a copy?' I said, 'Oh, I'd love that.' She says, 'I'll run a copy off,' and, er, anyway the thing was concluded and we went our separate ways and I'd forgotten about it. And then on the morning of the surgery she came in with it, she gave it to me. Terrace Court Gardens or something, some place in Ireland she'd got it. She was an Irish girl.

Husband: Palace Court.

Patient: Palace Court Gardens, that's it.

INT: AND SO YOU WENT IN FOR THE OPERATION, AND THEN WHAT WHEN YOU ACTUALLY HAD THE OPERATION, AND CAME ROUND?

Patient: Yeah, well what happened then was we were supposed to phone at 7 o'clock and be on the ward at half past. We live in Ilkeston and the hospital's in Derby. David was beside himself because of getting through the traffic and getting me there. And I said, 'For goodness sake, calm down,' this was me. Now I've got to tell you in the interim that we belong to the Catholic Church, it could have been any church, any religion, and we just choose to be Catholic. And the people were absolutely marvellous and everybody was praying and lighting candles, it's a wonder the Church didn't burn down. I had 64 get well cards and

I thought, I thought, 'Well everybody's doing their bit for me, all I've got to do is present myself for the job.'

INT: THAT MUST FEEL VERY, SOUNDS LIKE YOU'RE VERY WELL SUPPORTED THROUGH ALL OF THIS

Husband: It was calm as [???

Patient: Absolutely.

INT: YEAH, BRILLIANT.

Patient: Couldn't have been better supported. So I said to David, 'Oh for goodness sake calm down, what I'll do, I'll take the mobile, we'll get moving through Derby and I'll phone en route' So this is what I did, rang the ward, 'Oh yes, yes,' she says, 'the bed's ready, blah, blah, blah.' So off we go and, well, I was just shown where my bed was ...

Husband: Oh, they were so friendly, so cheerful [???

Patient: And everybody, of course, the ladies we were all in the same boat, all trying to be normal and all very mmmmm, and anyway in due course the, ah this nurse came, I'd got my daughter, the one I've been telling you about, who, she's also a qualified podiatrist, and I said, 'Naomi come and do my feet before the operation,' massage the feet, you know, how it is, there's a name for it.

INT: PEDICURE?

Patient: That's it, and I said while you're at it pain my toenails, I just felt like being the devil, you know. So she painted my toenails. So the first thing that happened is this varnish had to be removed, you see. And so we had a laugh about that. And the nurse puts this bracelet on and they're very sort of reassuring and lovely. And then the anaesthetist came and I said, 'My word,' I said, 'Are you the last person I'm going to see before I go to sleep and the first person I'm going to see when I wake up?' He says, 'Ooh,' he says, 'this is wonderful way to start my working week.' Quite handsome he was in this here pinstriped suit.

INT: REALLY?

Patient: So I had a bit of a laugh about that. And then, he was very reassuring, very relaxed, and then in due course Miss Wahedna comes around.

INT: MISS WAHEDNA, YEAH.

Patient: Yeah, looking very smart, smart, very smart, in her day clothes, you know. And she says, 'I understand you've had some words with my anaesthetist, and we was in an uproar, everybody was just laughing their heads off, it was wonderful. And in the meantime this young woman had come in with this prayer for me, I couldn't for asked for more. And I jumped the gun a little bit because when we went for the pre-assessment, I said that I'd opted for the mastectomy and they'd got me down for a lumpectomy.

INT: RIGHT, OK, HOW DID THAT HAPPEN?

Patient: And phone calls were made from the person I was speaking to to the breast care nurse saying, 'Anita A- is down for, has chosen a mastectomy and you've got her down for a lumpectomy.' So I've just remembered this, so when we went in and spoke to this young woman with the prayer and all the rest of it, erm, I said 'I understand you've got me down for a lumpectomy,' and she said,

'Yes.' I says, 'Was it you that the nurse was ringing to change the details?' she says, 'It was, yes.' She says 'And this surprised me,' she says, 'because the size of your tumour is the size of my fingernail.' I says, 'Were you assuming then that I was going to have a lumpectomy?' this surprised me, and apparently notes had been made. So when the surgeon came round on the day of the operation I said, I said 'It seems that when I came in for the pre-assessment,' I said, 'That notes had been made that I was going to have a lumpectomy and not a mastectomy,' and she said, well, she did put 'plus-plus' or something, I don't know whether this is some sort of coding ...

INT: [???

Patient: ... down by something or other, and I think she had assumed that I was going to have a lumpectomy.

INT: INTERESTING.

Patient: Mm. But that didn't alter my wishes at all, I mean there was no contradicting going on whatsoever, this was just small-talk.

INT: OH RIGHT, OK.

Patient: It was just what I, what my wishes were. But it did surprise me that it had gone down on the notes before I'd made a decision.

INT: [???

Husband: I think they thought you would be, you know, be wanting that. I mean [???

Patient: Yeah, it was an assumption.

Husband: Yeah.

Patient: It was an assumption. I'm not casting aspersions, but I was surprised it got onto paper before I'd decided.

INT: AND AFTER YOUR OPERATION, HOW DID YOU FEEL THEN WHEN YOU CAME ROUND?

Patient: Absolutely, well whacked out, I mean I slept most of the day, but when I began to wake up, wonderful. When my family came I was eating boiled beef and carrots, and I'd said to the daughter who's the nurse, I said, the day of the operation, 'If you'll stay with your Dad tonight and go back to Yorkshire the following the day, but before you go back home just pop into the hospital and see I've got what I want, will you?' because I thought I was going to be absolutely [???] I didn't think I was gonna be able to use this arm, whether I was gonna be recovered from the anaesthetic. I'd got this at the back of my mind it was a tremendous operation this mastectomy, and when they came I was sitting up eating boiled beef and carrots and I'd been across the ward to the toilet.

Husband: You were lifting your arm off and taking things off your cupboard.

Patient: So I said, 'Well I don't need you Naomi, thank you, you can go home now, isn't it wonderful?' and we were all rejoicing and it was marvellous. I'd got this, the drain, two drains and two bottles, which were a nuisance. They were just a nuisance because if you went anywhere you'd got to remember to pick them up and carry them. But, er, I can't say I was in a lot of pain. Erm, that night the nurse came and said, 'Now, look,' she said, 'if you want anything at all, be it painkillers, a cup of tea, just somebody to talk to, if you want anything at all, you let us know because that's what we're here for.' And

everybody was so wonderful, and, er, I can't even remember getting out of this gown into a nightie so it couldn't have been stressful.

INT: MM, YEAH. AND SINCE THEN HOW HAVE YOU BEEN?

Patient: On top of the world. Now we did have a bit of blip that I had an infection. Well, to start from the beginning when we came home we had to ring the hospital every morning at 8 o'clock. Now this is where people need somebody with them, those living alone probably might find it a bit difficult to cope with. But David was able to read the bottle and make the phone call for me, talk to the nurse and make some sense of it.

INT: RIGHT, WAS THIS SOMETHING LIKE THE DRAIN, YOU MEAN?

Patient: Yes.

INT: YEAH, THE DRAIN.

Patient: And so this went on for eight days, every morning getting out of bed at 8 o'clock and having to measure the bottle and talk to the nurse at the other end, so he was able to do that.

Husband: Getting up at 8 o'clock [chuckles].

Patient: But I was ready to get it out because it was becoming a nuisance, that's the best way I can describe it. And on the day we had a little bit of a discussion about it because she said, 'Well it's reading actually on the line, neither above or below,' she said, 'You're neither one thing nor the other,' and I says, 'Well ...' She says, [???] It's being talked about now, some people say it should be left in until it goes down to a certain reading and other people are saying it should come out so many days after and no longer. And so I found this a little bit more decision making, I found a little stressful, so I said to her, 'What would my surgeon be saying? My surgeon, what decision would she be making?' She said, 'She would say take it out.' I said, 'Well can I come along then please and will you take it out.' And I went and they're absolutely incredibly wonderful. They were going, 'Have you had this done before?' which I had already one taken out. So she says 'I'm going to ask you to ...' to cough was it? Swallow and cough, or something or other.

Husband: Take a breath and cough.

Patient: That's it, so by the time I'd done that it was out. And they were marvellous. I signed this paper to say I'd been in and what had happened, I'd been discharged, and, erm, and then after that I was doing fine and then I sensed we'd got a bit of an infection. So I thought, 'Well do I go back ...' oh, it came at the weekend, it came on the Friday night, and the breast care nurses have fixed hours. Although the nurse who took the drain out told me I could contact them on the, in this pre-assessment unit, any time of day or night. And I thought, 'Well do I do that or do I consult the GP?' Now I could decide and make the decision to consult the G P because we'd already had the district nurses involved, they - oh, they came three times, the district nurses.

INT: THIS IS AFTER YOUR OPERATION.

Patient: Yeah, just to check things over and change the dressing. Now the first one says, 'You are an inspiration,' and the second one said, 'It's been a privilege to meet you.' I'm loving this, talking about myself. Am I boring you?

INT: [???]

Patient: So we were in contact with the surgery because we'd had the nurses come in. And so I thought, 'I'll contact the GP.' So I rang the receptionist and sometimes it can make you poorly trying to make an appointment, it's dreadful. But anyway I said who I was, and I said I'd just had this mastectomy and I thought I'd got an infection. She says, 'Just come along straight away,' and they even asked me did I want a lady doctor because it was a man doctor on call. And they were so wonderful. And so he looked at it and he gave me a massive dose of antibiotics. He said he wasn't unduly concerned, there was a bit of infection there but we'd get rid of it with these antibiotics and codeine sulphate for the pain.

INT: RIGHT, MM.

Patient: And he wanted to see me in a fortnight. Well by the time the fortnight was up, we'd been caravanning and all sorts. I felt so wonderful that I nearly cancelled it. But anyway I did go back in deference to him to say 'Thanks for your help, it's been wonderful, and we're cured.' Anyway he had a look at it and he said, 'That's absolutely wonderful, the wound, it's healing beautifully,' he says, 'But under your arm,' he says, 'I think you'll find your surgeon will want to do something with that.' I says, 'What do you mean?' I says, 'Not another operation?' He said, 'I don't know,' he said, 'It's possible they may want to do something about it,' he said, 'It's like a tuck,' he says, 'When you have your operation,' he says, 'You lay like the ...' he had a name for it, some lady Diva or something, you've got your arm up here and ...

Husband: Is it Venus?

INT: OH RIGHT, YEAH.

Patient: And he says, 'Until you lower your arm they don't really know how the land lays with the stitching of the wound,' and what's happened with mine, I've got some loose skin under my arm.

INT: OH RIGHT, OK.

Patient: And I said, 'Well, look here,' I said, 'I wasn't in favour at all.' He says, 'Well, the choice is yours if it's not bothering you, you know, that's it.' And I sort of said, 'Well I don't swim, I don't want to wear a swimsuit and I don't wear ball gowns, so as things are going at the moment I can't see the necessity for it.' But we'll see as we go along.

INT: OK.

Patient: And I've felt physically in myself incredibly fit and well.

INT: OH THAT'S GOOD.

Patient: I've felt a bit also that I've had an obligation to put a bright face on things, although it's not been difficult ...

INT: NO, OF COURSE.

Patient: ... because I realise it's a woman's worst nightmare and I've had such strange reactions you wouldn't believe it. I've had people walk by me like that ...; I've had people walk by who've just ignore me as I wasn't there; I had a most weird telephone call from a man - I know who the man was and I've never addressed him with him and I never will, it was a most sick phone call, what must have gone through his mind; and I realise that some of the time other people are having more of a problem with this than I am.

INT: ABSOLUTELY, THAT'S QUITE CLEAR.

Patient: Because it could be either be them or one of their loved ones. Now the lady next door, she's going to the same unit this afternoon, she's 84 and they've just got her on Tamoxafen, and she's been terrified to have the surgery. Now I've been putting a bright face on it, which as I say hasn't been difficult because I do feel well, and it's helped her no end because she's going this afternoon and we suspect, there's been new nighties and slippers and towels and things, we suspect that she's getting round to having this surgery herself, being brave enough to do it.

INT: OH THAT'S GOOD NEWS. YEAH, I MEAN, I'VE INTERVIEWED OTHER PATIENTS, NOT WITH BREAST CANCER BUT WITH LUNG AND COLORECTAL CANCER, AND I'VE HEARD A FEW STORIES. I MEAN ONE WOMAN IN PARTICULAR SAID THAT, YOU KNOW, SHE WAS A YOUNGISH SORT OF WOMAN, IN HER THIRTIES, AND SHE HAD BREAST, NOT BREAST CANCER, LUNG CANCER, AND SHE SAID THAT, LIKE, SHE LOST HER FRIENDS FOR LIKE SO MANY MONTHS, NO-ONE BOTHERED WITH HER, NO-ONE CALLED, NO-ONE STOPPED HER IN THE STREET, AND THIS, THAT AND THE OTHER, AND THEN, YOU KNOW, SHE WAS GIVEN LIKE THE ALL CLEAR AFTERWARDS, AFTER HAVING THIS TREATMENT, AND THEY ALL CAME BACK AGAIN. IT WAS LIKE THEY COULDN'T DEAL WITH THAT.

Patient: Now I've got a brother that we were rather estranged my family, it's brought my family together.

INT: RATHER THAN [???

Patient: But David's got two sisters and they don't know how to deal with it. One I've never heard a thing from her. The other one sent me flowers, but she's just disappeared since.

INT: I THINK PEOPLE FIND IT HARDER TO DEAL WITH. THEY DELA WITH IT IN THEIR OWN WAY.

Patient: Do you know, I'm beginning to realise that some people are having more of a problem with it than I am.

INT: MM, YEAH. I THINK IT'S PARTLY BECAUSE IT'S SUCH AN EVOCATIVE WORD. THAT WORD CANCER EVOKES SO MANY DIFFERENT ...

Patient: Yeah, terrible.

Husband: Terrified.

INT: IT MEANS, YEAH, TERROR [???] YEAH.

Patient: Well the only way I can describe when I, before the operation and we were getting closer and closer to this operation, and I'd all sorts of emotions. One day I wanted to walk down by the river: we went down to the Cromford near Matlock, and it was frozen over and the birds were sliding along the ice. I don't forget these things, you know, because it was poignant at the time. Another time we'd just got to get in the car and go to Matlock, not Matlock, Skegness, fish and chips. And, er, but as time came on and it got nearer to the operation, if I sat and thought my mind was black with terror.

INT: AH OF COURSE, IT WOULD BE.

Patient: And, erm, the girls were here, two daughters, and they were talking about when I was in, because they both live away, 'Get Dad to do this with the mobile phone letting ...' I said, 'Don't complicate him with the mobile phone, he's got enough on.' And anyway I went out to get it to see how we stood with

the battery and all the rest of it, and I was just casually seeing if there was any messages, I hardly ever use it, and there was this one from this man and it was absolutely just unbelievable. And, as I say, when your mind's black with terror anyway and you read something like that, it's a weird reaction.

Husband: He'd sent it as a joke, to brighten her up, but it had [???

Patient: The opposite effect, the opposite effect.

INT: YEAH, WELL, I MEAN, OBVIOUSLY SOME, YOU CAN'T ALWAYS JOKE WHEN YOU'VE GOT SUCH A ... BECAUSE YOU DON'T KNOW HOW PEOPLE ARE GOING TO TAKE THAT.

Husband: To be fair to this fellow, he, he's had a lot of suffering in his life.

INT: AH RIGHT, OK.

Husband. And he still has to have injections every fortnight, you know, transfusions, and will do for the rest of his life. So I can, I know he's a funny fellow, he picks on, makes a joke out of some weird things [chuckles] ...

Patient: Yeah, but anyway, it just wasn't the time. But I think the point I'm making is I have found it easy to cope with it, so far. Erm, and felt very, very well in myself, physically fit, and I've been aware that, you know, I've been able to sort of reassure a lot of people who are very apprehensive about these things. You know, you can sense that they're going to sort of make sure they have the mammogram and all the rest of it and, you know, check themselves out, as it were.

INT: APART FROM THE INFORMATION THAT YOU RECEIVED FROM THE HOSPITAL THAT THE BREAST CARE NURSES GAVE YOU, DID YOU LOOK FOR ANY INFORMATION ANYWHERE ELSE? DID YOU HAVE FRIENDS OR RELATIVES SEND TO YOU MAGAZINES OR VIDEOS OR ...

Patient: Oh, one girl brought me this, yes. 'Your Life in Your Hands.' Are you familiar with that?

INT: NO, I'M NOT ACTUALLY, [???

Patient: Oh, it's written by a professor and she's dealt with it, has cured herself through diet and so on.

INT: MM, YEAH. [???] OH RIGHT, THAT'S INTERESTING. AND YOU'RE JUST OBVIOUSLY STARTING TO READ THIS NOW, ARE YOU?

Patient: Well I'm not an easy reader, I intended to but I've read a little bit and put it down. It's called 'Your Life in Your Hands' Professor Jane Plant. So, and the girl who bought me this is a very dire sufferer of Parkinson's Disease ...

INT: OH RIGHT.

Patient: ... but she's not gonna let this thing beat her and yesterday she did a wing walk on an aeroplane at one of the local airports to raise money for Parkinson's Disease. She runs the show, she's like the secretary, you know. Goes round helping people, talking to people, and this girl doesn't bring you flowers, 'I'm going to bring you this book and you're to read it, it's gonna help you.'

INT: REGARDING THE DECISION THAT YOU MADE FOR WHAT TREATMENT TO HAVE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU HEARD OR READ THAT HELPED YOU COME TO THE DECISION THAT YOU DID TO HAVE A MASTECTOMY?

Patient: Well it was my own thoughts, you know, it was me myself. I mean I was being told all along the line, 'It's you,' and having been put in that forum whereby I was going to have to decide, I stood up on my own two feet and said, 'Right, I will.' And I looked at it from my own point of view, from every which way, and I thought the best way to approach this is how am I going to feel when the operation is over, depending upon which one I chose. And that's how I tackled it, and I think I've explained to you how I came to the decision.

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

Patient: Absolutely incredibly first-class.

INT: I PROBABLY COULD HAVE GUESSED THAT FROM THE [??] YOU THINK IT'S MET YOUR EXPECTATIONS THEN?

Patient: Oh, absolutely, I've been absolutely amazed. Erm, there's probably one aspect I might have wanted to know a little bit more about but I could understand probably why it wasn't explained, because I didn't want to know too much about after the operation. But had I known that, and about the recovery, that on the first day I was going to be able to take myself off to the toilet and be independent and brush my hair and be independent, and all the facilities were there to be independent, I could go into the toilet where there was a sink and everything, hand basin, and have the privacy, I could lock the door, and these things are important to people ...

INT: YEAH, OF COURSE.

Patient: ... and that would have taken a load off my mind if I'd have known that. But we've got to bear in mind that I did say to the young lady 'Don't tell me what I'm gonna look when I come round, I don't want to know about tubes,' that's what was frightening me because I'm terrified of hospitals and surgery.

INT: AND THE FACT IS ALSO NOT EVERYBODY WOULD HAVE THAT EXPERIENCE. SOME PEOPLE HAVE ACTUALLY BEEN QUITE ... YOU KNOW.

Patient: The average were like myself, make marvellous recovery, you know, and coming out on, we only had two nights in the hospital.

INT: YEAH, THEY DON'T KEEP YOU IN LONG NOW.

Patient: No. I mean we were told, what was it, four to seven?

Husband: Yeah.

Patient: And I came, I only had two nights and came home.

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

Patient: To have a toilet adjacent to all the facilities were you were having the biopsies and the ultrasound. People were sitting there in their gowns and there were quite elderly ladies there, very sensitive and nervous, and of course that's the time when you want the toilet, when you don't know what's going to happen to you next, and you're all vulnerable. And we had to go out into the waiting room where there was, you know, the husbands and people, because husbands weren't allowed in with us at that stage, go out into the waiting room to use the public toilet. Now that probably sounds futile, I don't know, but it's one thing that stuck in my mind.

INT: MM, OK. AND ...

Patient: Is there anything else I would change if I'd got the money and what?

INT: IF YOU HAD THE MONEY AND THE POWER TO CHANGE ONE THING AT THE UNIT. OR THE SERVICE I SHOULD SAY, NOT JUST THE UNIT, THE SERVICE THAT YOU WENT THROUGH.

Patient: Well, obviously, I mean ... mind I was going to say the procedure being shortened, it took five weeks.

Husband: That's not [???] that's [???]

Patient: No, but I'm being asked a question. Now I think possibly, when I'd gone through the biopsy and the ultrasound and all that, if I could have been told say, wait half an hour, what it is, be told on that day ...

INT: YES, SO YOU DIDN'T HAVE TO WAIT THAT WEEK FOR THE RESULTS.

Patient: Yeah.

INT: YEAH.

Patient: But I mean that's, I don't know whether that's held up because of lack of staff or the technical side of things, I don't know, but that would have been helpful. Now to be waiting two and a half weeks for the surgery, I've got mixed feelings about that because one is, well get it over with as soon as we can, but the other half is getting your mind accustomed to it, getting to realise what it's going to mean to you making this decision in your own time without being stressed. So I'm a little, you know, two ways of thinking about that, but, er, the one about going through all the tests and things and being told on that day would have been helpful instead of waiting a week. Erm ...

Husband: [???] can they?

Patient: I suppose ...

Husband: [???]

Patient: Well I've got the power and the money ...

Husband: Yeah, yeah, all right, yes.

Patient: ... and I'm being asked a question.

Husband: I understand, yeah.

Patient: So I think, you know, tightening up the waiting time between going for the ... I mean in real terms it's wonderful ...

INT: OH YES, OF COURSE.

Patient: ... but if we're talking about a perfect world where I've got the power and the money, that's what I would say to you.

INT: YEAH, OF COURSE, YEAH, RIGHT, OK.

Patient: Now things standing as they are I would still like to mention about that toilet inside where all the ladies are in their gowns and going through all this procedure, if they could have a toilet just there instead of having to go

out into the waiting room where everybody's sitting and you're in your gown.
Have I answered your question?

INT: YES, PERFECTLY. 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: Well I think they need to know exactly ... where it is, what it is, how big it is. They need to be able to get some picture in their mind, some real, erm, information to get hold of, you know, and, er, they need the thing explained slowly and properly, and people to give any answers that may be required. In fact, you know, everything that happened. It all happened as I would wish it to happen.

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

Patient: Now, you mean about the type of operation?

INT: THE KINDS OF OPERATIONS YOU CAN HAVE, YEAH.

Patient: You mean just as opposed to a lumpectomy, mastectomy, one or the other?

INT: YEAH, THE TWO, YOU HAD A CHOICE BETWEEN THE TWO OPERATIONS THAT YOU COULD HAVE.

Patient: Well I mean, it's ... well really a lot of it is for the person themselves to decide how they feel about it, it's very personal, it's a very, very personal thing. And to help them make the decision there are such things as recovery time, you know, how big the operation is, what's entailed with removing the lymph glands and so on, the type of thing they explained to you. I mean some people couldn't just tolerate a big operation and the recovery time. But one person'd be guided by it being simple, a lumpectomy and stitches and get it over with quickly and a quick recovery, and take the chance that it might recur, you know?

INT: ERM, OH, I THINK THAT'S, I THINK THAT'S EVERYTHING. IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED?

Patient: Is there anything you want, that I've missed.

Husband: I [??] one pointer ...

INT: YEAH.

Husband: If a lady has a lumpectomy they have got to have radiotherapy as well.

Patient: No, they don't.

Husband: That's five weeks, every day for five weeks. Now ...

Patient: No, they don't David, this lady I'm in touch hasn't had to have either. It's an individual thing. Now when I went and they gave me my diagnosis, the lady did say usually along with a lumpectomy will go radium and, the radium, 25 sessions of radium.

INT: YEAH, IT'S FAIRLY USUAL, NOT ALWAYS THOUGH, NOT ALWAYS.

Patient: No, but when you go back seven days after the surgery she'll tell you then what's, what treatment is ahead of you. For me it was just Tamoxafen.

INT: YEAH, MM.

Patient: She said, 'It's 100 per cent successful, there was no cancer in the lymph glands, the surgery did the rest, I'm just asking you to take Tamoxafen from now on,' and explained, and I had a big sheet of what Tamoxafen was all about and what it meant, and so on and so forth.

INT: AND YOU WERE GONNA SAY ...

Husband: Well that was the only addition I would send to, you know, that, if a woman s facing a lumpectomy, she's also quite ...

INT: POTENTIALLY FACING ...

Husband: ... positively ... positively, there's a good chance she'll have to have this five weeks of treatment which ...

Patient: Which could affect her judgement.

Husband: ... radiotherapy can affect in many different ways, different, you know. ...

INT: WAYS OF MAKING DECISIONS [???

Husband: Yeah, can do damage as well as cure.

INT: AH RIGHT, YEAH.

Husband: Do you know what I mean, it's not just a simple thing that you have, it's something to be thought about.

Patient: You mean to say that could affect a woman making a decision about what operation.

Husband: It can do, yes, yes.

Patient: Yes, that's a good point.

INT: MM, THAT IS, YEAH, THAT'S A GOOD POINT. AND I'VE GOT A COUPLE OF LADIES I'VE INTERVIEWED WHO ARE GOING THROUGH RADIOTHERAPY AND THEY SAY THAT, YOU KNOW, THAT WHEN THEY WERE TOLD ABOUT THE OPERATION THEY SAID, 'WELL I COULD GET THE OPERATION, THAT'S NO PROBLEM, BUT IT WAS THE RADIOTHERAPY AFTERWARDS, [???] THE WAY TO GO ROUND, SO, YOU KNOW, YOU'RE QUITE RIGHT. ANYTYING ELSE?

Patient: No, I can't think of anything.

[End of interview]