

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: High MR unit

*DATE:

*ID: Patient25

*INTERVIEWER: KC

INT: SO JUST TAKE ME THROUGH BEFORE THAT YOU ACTUALLY KNEW YOU'D GOT THIS PROBLEM.

Patient: I didn't know, I didn't know anything about it, I had no indication in any way, I'd always had a reversed nipple on the left but I went for a mammogram, a routine mammogram, on the 5th January and I was called back, and the letter just said, 'The screening's a two-part process and some ladies do get called back,' and I just thought, because I'd had had surgery eight years ago for something totally unconnected with breast cancer, I'd had a sympathectomy [?], but the incision was made through in two areas on the top and at the side of my right breast, I just thought that it was a thickening of scar tissue or something that they had found and that that's all it would be. So I went to this, erm, second mammogram, I didn't even tell anyone, my daughter noticed it on the calendar and insisted on coming with me, so that was in January.

INT: SO THAT WAS IN JANUARY AND THEN YOU WENT FOR YOUR MAMMOGRAM TWO WEEKS LATER WAS IT?

Patient: About two weeks later, I think it was the 5th when I went for the first one and I was called back for the second one on the 20th, yeah. Erm, I went in, my daughter sat in the waiting room and I went in to where they take the x-rays and I had, erm, the radiographer, not the consultant radiographer but the ordinary radiographer, so the ordinary radiographer said, 'Oh we've got to take some more pictures.'

INT: THIS WAS THE RADIOGRAPHER NOT THE RADIOLOGIST?

Patient: Yes, the radiographer, yes, she said, 'Oh I've got to take some more pictures and there's a problem with the left breast,' and I was quite shocked at that because I was convinced that it would have been the scar tissue on the right one, so that was my first indication, 'Oh, that's odd ...' and warning bells rang but only a little bit, because I've never, ever in all my life checked my breasts for lumps, ever, it's just something I haven't done, I don't know why, I just haven't. And, erm, so she said, 'We need to take some more pictures and we need to take a couple of close-ups,' which she did. And I came out of there with a gown on and I went in to, straight in to see the radiologist, who was in a different room with a breast care nurse.

INT: THIS WAS THE FIRST TIME YOU'D SEEN THE RADIOLOGIT AND THE BREAST CARE NURSE?

Patient: Yeah, yeah. I didn't know she was a breast care nurse, I didn't know there were such things as breast care nurses, but she was, I know now she was a breast care nurse because I've seen her several times since.

INT: DID SHE INTRODUCE HERSELF AT ALL AS A BREAST CARE NURSE OR WAS IT JUST, DID SHE NOT INTRODUCE HERSELF?

Patient: I can't remember, I really can't remember. Erm, the only reason I know she was a breast care nurse is because I've seen her in clinic, she's not my breast care nurse but I've seen her in clinic and she is also the lady that deals with the prostheses, which, subsequently I came to know her through that. So, er, I went in to see the Radiologist, Dr Turnbull, and she said that 'There's a problem area here, can you see it?' and I couldn't, not really.

INT: THIS WAS ON THE X-RAY? SHE SHOWED YOU THE X-RAY?

Patient: On the x-ray she showed me the x-ray and she said, 'This is the one from three years ago, this is the one we've taken today, and this is the close-up that we've taken today. Now can you see ...?' you know, quite a, you know, white, it looked white, like a white shadowy ...' Erm, I couldn't really see a great deal of difference but anyway she said that she would like to do an ultrasound scan, so she did the ultrasound scan and she said, 'Ooh, yes, look, can you see on here, and it's within the same area and I can't feel it,' she said, 'so you wouldn't have been able to feel it, so don't feel bad about not noticing it yourself.'

INT: DID YOU ASK AT THAT POINT WHAT SHE THOUGHT IT MIGHT BE?

Patient: No.

INT: DID YOU HAVE SOME IDEA IT MIGHT BE, OR WHAT WERE YOU THINKING AT THAT POINT?

Patient: I don't really know what I was thinking, to be honest, I was just so ... it was a fuss about nothing because my sister had had a lump in her breast as big as a pea for 20 years and she had refused treatment of it because she said she doesn't want them poking needles in and doing, it's there and it's not, doesn't seem to be doing anything or going anywhere, erm, she said if it was cancer it would grow and she'd be aware of it, but, you know, she - and I just thought at that, my sister came straight to mind and, although my sister is 13 years younger than me, I do tend to follow her guidance somehow in a lot of ways. She, I'm very impetuous and I'm very, erm ... she weighs things up and she thinks about things and she invariably makes the right decision on lots of things, and I tend not to because I'm too fast, I want things done yesterday, and so it instantly came to mind about her lump and how she'd dealt with, and I just thought, 'Oh mine'll be the same,' if I thought anything. So then Dr Turnbull said she'd like to do a biopsy, a core biopsy, and I said, well I knew a biopsy was taking a piece of tissue, and she said she wanted to take a piece of tissue, it would be analysed and I would be called back next week and she'd tell me what it was. And I said, 'No, I don't so,' and they both looked a bit shocked and she said, 'Do you mind me asking why?' and I said, 'Well I have a friend who died in 1973 who had a lump ...' I must admit at this point I don't know any, I didn't know, when she said she wanted to take a biopsy, I think in my own mind I'd got it in my mind that what she meant was a lumpectomy, like take a piece, and I wasn't quite sure, and she did talk me through the process, she said, 'We'll give you a local anaesthetic in your breast and I'll put the machine in, it's like a needle, and you feel a bit of a thump and it makes a noise a bit like when you have your ears pierced, and it just with.' And I said, 'No, I don't think so,' and I told her why and they seemed quite surprised. So it was suggested, you know, I think the nurse, it was the nurse that said, 'Have you brought anyone with you?' I said, 'Yes my daughter's in the waiting room,' 'Would you like your daughter to come in?' I said, 'Well, not really, I didn't really, well I suppose she can do,' so my daughter came in and they talked her through, I asked the radiographer just to talk her through it the same as she'd talked me through it, and my daughter sort of said, 'Ooh well, you know, you've got no choice, you've got to have, you've got

to let them take a sample, how can you not?' I said, 'Well ...' and I don't think I'd ever told my daughter about my sister's lump, and I told Karen, I said, 'Well, you know, Auntie Helen's got a lump and she's had it 20 years and it's never grown, she's never had anything done, and she's still here,' I said, 'But look at Kathleen, Kathleen had a lump,' I know now she had a lumpectomy and two years later it had gone into her lungs and she died and, you know, it was very sad, she was only 43, she'd got young children. Erm, so Karen said, 'Oh well I think, you know, really do think you ought to have it done,' and I felt a bit angry, I felt I'd been bulldozed, you know, backed into a corner, and I was a bit annoyed.

INT: WERE YOU ANNOYED, WHAT, WITH THE BREAST CARE NURSE AND THE RADIOLOGIST? I MEAN WHEN YOU SAID, 'OK, I DON'T THINK I WANT THIS,' DID THEY, I MEAN, WERE THEY PUSHY, WERE THEY ...

Patient: Yes.

INT: I MEAN HOW DID THEY PUSH YOU, WERE THEY SORT OF SAYING, 'WELL YOU NEED TO HAVE THIS ...' I MEAN HOW, WERE THEY PUSHY?

Patient: I just felt that, erm, it was expected of me. I felt that it was expected of me because the facility is there to find out about things, and she did say technology's moved forward, which I know it has, and all to the good, erm, I think I was probably very, I don't know when I say I was mixed up, because I don't think I felt all that bothered, it was like as if it wasn't happening to me.

INT: AND WHY SHOULD IT, YOU KNOW, TWO WEEKS BEFORE YOU'D GONE FOR YOUR SCREENING THINKING EVERYTHING'D BE ALL RIGHT ...

Patient: Everything was fine.

INT: ... TWO WEEKS LATER YOU'RE IN A POSITION WHERE THEY'RE TELLING YOU YOU NEED A BIOPSY, SO THAT'S QUITE UNDERSTANDABLE, ISN'T IT?

Patient: It is, and as I say my sister had chosen not to have needles stuck in and have bits took out, drawn out, and I thought, 'Well she's still here, you know, perhaps I ought to say no.' So I did. And I think in my heart of hearts what I was thinking of saying was, erm, 'Well I'm gonna go home and talk to Helen about it, talk to my sister about it,' because she is 13 years younger than me but in a lot of ways a lot more knowledgeable, she's a lot more [???] than me, she's got 'A' levels and I haven't got any but that doesn't mean I don't know things because I do, erm, but, you know, I value her opinion, and I wanted, I felt as if I wanted to talk to somebody about it.

INT: MM, SOMEBODY THAT YOU COULD TRUST, YOU COULD [???]

Patient: Anyway I felt backed into a corner where I couldn't say no to having this biopsy, so I agreed to have the biopsy there and then, and she said we'll give you a local anaesthetic, your daughter can stay in here with you. So I just thought, 'Oh well, what the heck, you know, get it over and done with.' ... So I had this biopsy and (a) it was a lot, a lot more painful than had been led to expect, which annoyed me. I don't mind, if I'm having a procedure done, I expect people to be honest with me. If it's going to take 2 minutes I expect to be told it will take 2 minutes; if it will take 30 seconds, that's what I expect. If I'm told it won't hurt, I don't expect it to hurt. If I'm told it will sting or it might feel like something cold or ..., you know, I expect to be told the truth. And what she told me was that she '... will give me a local anaesthetic, and a local anaesthetic will hurt more than, because you'll feel

the sting and the coldness of the local anaesthetic as it goes in, but that will numb the area where I take the biopsy from so that you won't feel it. You will feel a pressure as I'm pressing down but it won't hurt and you'll feel, you will hear or feel or both a click, something like when you have your ears pierced.' So I'd sort of got it in my mind what to expect, and I lay there and the doctor, I lay on my right side and the doctor was, she did it under ultra, she used the ultrasound gown [?] while she was doing it, so that she could locate the exact position, and the breast care nurse was there and Karen was there, my daughter, and I had the local anaesthetic and it was just like an injection, I mean, you know, you expect that. But then she said, 'It will only take 30 seconds,' and it didn't, it took about 2-3 minutes and I remember thinking at the time, 'Liars! Should have told me it was going to take this long,' and I felt like I wanted to cry because I was angry, very, very angry that they hadn't been up-front with me because I'm a very up-front person and I'm straight John Bull with people and I expect them to be the same with me, and I was bloody annoyed that they hadn't. But I didn't move, I didn't flinch, I know I was brave, that my Dad always said 'I'm a brave little bugger' [laughs] erm, and my daughter said afterwards she was proud of me, er, and they put, they did it and they put a dressing on it, and she had to press for quite a long time, the breast care nurse, and I don't know whether that was to stop it bleeding or quite what, but anyway, that was done and I came out of there, very, very sore, and I was told, 'Well just take some paracetamols, when the local anaesthetic wears off it might be a bit painful, and if you take some paracetamol or something.' Well if I can just briefly tell you about the operation that I had eight years ago, it was a routine operation, albeit one that isn't done very often, and it was to stop my hands from sweating, it was called a florascopic sympathectomy [?]. Something went wrong during surgery and it left me with nerve damage which has left me in the excruciating pain, girdle pain all the way around my rib area, into my back, into the shoulder blade area, both scapulas are affected. I'm having treatment, I'm having physiotherapy for it now down in London, but the reason I'm telling you this is because everything that I've had wrong with me since that operation, the pain seems to be ten times worse than it was before I had the operation. So it's possible that this hurt more than they thought it would because of the operation I had eight years ago.

INT: BUT IT HURTS, AND THAT'S THE ONLY, YOU KNOW ... IT HURTS.

Patient: Yes, and I was told it wouldn't.

INT: YEAH, I MEAN THAT'S ...

Patient: And I was angry, and when I came out from seeing Dr Turnbull and I was with my daughter and I went into the changing room to get changed, my daughter came in with me and I had a dressing on the side of my, side of my breast, and I started to cry. And my daughter cried and she put her arms round me and said, 'Come on, you'll be all right,' you know. And I came home, I think we may have gone and had a cup of coffee in the hospital and then we came home. And it was a very busy time in my private life because my son, who'd been living with me with his two children for 18 months, had been offered a house local, a council house locally and he was planning, you know, we were getting ready for him to sort of move and one thing and another and we'd got - I'd forgotten that we'd got the keys, we must have had the keys, yes because we signed the tenancy agreement on the 16th, so we were going down to his house, it was just a tip and we were decorating and just emulsioneing. It's quite sad really because the whole house is being demolished in September so we didn't want to spend an awful lot of money on it because it's being completely demolished in September and re-built ...

INT: BUT YOU WANTED IT ...

Patient: But we wanted it clean and fresh for him. So, it was a case of, you know, cheapest white emulsion and just all hands ...

INT: TO THE DECK.

Patient: ... to the deck, and get stuck in and get it done.

INT: SO THIS WAS IN THE WEEK BEFORE YOU WENT BACK FOR YOUR RESULTS?

Patient: Well, yes, the week before I went back for my result. Erm, the whole family sort of mollycoddled me but, having said that, I was totally shocked at the bruising and the pain that I was in following the biopsy. I could not believe it, the bruise was as big as a, easily as big as an orange, the bruise was that big, and it was black, it was a very big, you could tell, you know like if you just bump yourself and it goes slightly purple and a bit yellowy, but, no, this was black and it looked, it looked awful, and it was so very, very painful. And I was due to go, the following day I was due to go for some physiotherapy down in London and he is a specialist in neuro-dynamics and he, erm, works on my back, on the spinal chord and the nerves around, the [??] nerve, and he, and I knew that I would not be able to bear, because of the pain in my breast, I wouldn't be able to lie on my tummy and let him do this. So I rang him up and told him and he said, 'Oh, no, no, no, you mustn't come down.' So that week I was feeling fragile, feeling ... even then ... it's a fuss about nothing.

INT: YOU DIDN'T AT THAT POINT THINK IT MIGHT BE CANCER?

Patient: No.

INT: AT ALL, DIDN'T THINK ...?

PATIENT: Erm, I suppose if I'm honest it must have entered my mind, but as fast as it entered my mind I put it to the back of my mind, thinking, 'No, it can't be ... they're making a fuss about nothing.'

INT: AGAIN THINKING ABOUT YOUR SISTER AND ...

Patient: Yes. And again feeling very angry and aggrieved that I was in pain, I'd had this done, I didn't really want it done, why had I had it done? Why hadn't I said no, why hadn't I stuck to my guns? Why hadn't I, you know, said no and stamped my authority, because I am assertive, I mean I do get, I do get action, if I think something should be done or not done, you know, I do, I am an assertive person. And I do it nicely, I'm not rude with it, but I was annoyed with myself almost for allowing it to happen. Erm, it was a dreadful week because I knew that my daughter was worried sick and I could sense that, and I, it was not talked about and that's unusual for us because we talk about anything and everything. She 40 [?] so, you know, it's not like she's an 18-year-old that you can't talk to, but we just didn't, and I think it was because I'd convinced myself in my own mind that there was nothing to worry about, and I think she had convinced herself ...

INT: IT PROBABLY WAS.

Patient: ... it could be. And I'm a [??] and, you know. Anyway ...

INT: LATER ON IN THAT WEEK ...

Patient: So it was exactly a week ...

INT: A WEEK AFTER THE BIOPSY.

Patient: I went for the biopsy on the 20th and I went back on the 27th and it's quite funny [chuckles] because I can remember thinking to myself, 'I've got to get back in the driving seat here and I've got to be in control of this.' So I'd made my mind up before I went that, if they asked me to get undressed, I was going to say no, because there was no need to because I was going to go and see the consultant for a result of a test which I'd already had, and if she wanted me undressed then I'd get undressed in her office, but I was not going to be told to get undressed as a matter of routine, because everybody does, to save the surgeon from waiting. And it was like, I'd almost worked myself up into this, erm, I'd geared myself up into top notch, gear, to almost have a go at, with them.

INT: YOU WERE PREARPING YOURSELF?

Patient: I was preparing myself, and I was quite shocked when I got in there and I was called through immediately. I mean I'm never late for appointments and I got there, you know, five minutes early, and quite often hospital appointments have been noted for being kept waiting [???] you know, 10, 15, 20 minutes, half an hour ... 2 minutes, and I was called straight through, and my daughter came with me, and we went in, straight in to see the consultant, not the radiologist.

INT: YOU DIDN'T SEE THE RADIOLOGIST [???]

Patient: I didn't see the radiologist again.

INT: IT WAS A NEW CONSULTANT?

Patient: It was a new consultant, breast consultant, a lady, Miss Wahedna, and she did have, I think she had a student with her, I don't think it was a nurse, there might have been a nurse as well but I believe she had a student and she asked me if I minded the student being there and I said no. And she put my back up immediately by saying, 'Why do you think you have been called here?' And I said, 'Well I was told that screening is a two-part process, I'd been called back for part two last week, and I had it pointed out to me that there may be a problem, had a biopsy, and I'm here for the result. That's why I think I've been brought back.' But I felt, she didn't put me at ease. I expected her to be doing the talking, I didn't expect to be greeted with a question like, 'Why do you think you've been brought back here?'... just didn't expect that, and I was annoyed, you know.

INT: WAS YOUR DAUGHTER WITH YOU AT THAT ...

Patient: Yes.

INT: SHE WAS, WENT IN WITH YOU AS WELL?

Patient: Oh, yes, my daughter sat at the side of me. And ..

INT: SO HOW DID IT PROGRESS FROM THERE?

Patient: And then she just said when I told her what I thought and I sort of shrugged my shoulders as if to say, 'Well if I'm right and if I'm wrong, you know, you tell me,' sort of thing. And she said, 'Well I

do have to tell you that it is cancer and we can offer you a lumpectomy or a mastectomy,' and I said, 'Right,' and I can remember being aware of my daughter at the side of me, and I didn't look at her because I knew that if I looked at her she would cry and I would cry, so I was being very matter-of-fact and taking control of the situation and like, 'Right,' erm, 'So what's the difference?' 'Well, a lumpectomy or wide local excision ...' is that what ...

INT: MM.

Patient: '... a wide local excision is where we take the lump and leave a clear margin, leave a clear margin. What quite often happens, or usually does happen is that if you choose the lumpectomy, it is followed by six weeks of radiotherapy. If it's in the lymph nodes that might have to be preceded by chemotherapy as well, but we wouldn't know until after the surgery. The other alternative would be for a mastectomy in which all the breast tissue is removed and then there would be no need for radiotherapy but, even with a mastectomy, if it was found that you had cancer cells in lymph nodes, then you would have to have chemotherapy.' And I said, 'Right, well, I've already made my mind up, I'm going for a mastectomy.'

INT: CAN YOU, BEFORE YOU GO ON FROM THAT POINT, WHAT WAS GOING THROUGH YOUR MIND THEN? IMMEDIATELY YOU SAID, 'I KNOW IMMEDIATELY I'LL HAVE A MASTECTOMY,' TELL ME WHAT YOU WERE THINKING ABOUT THEN.

Patient: I was thinking, if I'd got cancer I wanted it out, I want it off. It's in a place that can be chopped off. It's like if you've got gangrene in your toe, you don't have your toe off you have foot off, you know, you pre-empt it spreading by going for the most radical first, so why mess about taking a piece out which may or may not get it all, because then it might grow, like it did in the case of my friend. If they take a lump and they haven't got it all, she did say some ladies that have a lumpectomy and we don't get a clear margin have to come back in and either have another lumpectomy or even a mastectomy. So I then said, 'Why can't you, why can't I sign the form for both, let you, decide to do a lumpectomy and if you do have a clear margin leave it at that, and ...' oh in the meantime, I've just remember, I asked her how big the cancer was and she said 17 mms which is about that big. And I said, 'Right, so that is sort of, from top to bottom and side to side, but how deep does it go?' and she said, 'That we won't know until ...' you know if you can imagine it being a grape it could be a grape ledged on your breast there or it could be with just a small bit showing and ...

INT: THEY JUST DON'T KNOW, YES.

Patient: You just don't. I'd already asked her what size it was and she'd told me, and I'd made my mind up that I wanted, I was going to have a mastectomy rather than the lumpectomy, but I did say to her 'Can you let me sign both papers and then do either or, you know, try the lumpectomy and then if it's not got a clear margin then go for the mastectomy, and if I sign to say ...' 'Oh no, no, no, no, you've got to decide, it's your decision, but you've got to ...' and then something else she said, 'You've got to make sure that you are making the right decision for the right reasons.' And I said, 'Well I don't what you mean.' So she then said, 'Why do you want a mastectomy?' And I don't know why, because it wasn't because it was in order of importance, it was just the first thing that came into my mind, and I said, 'Well I don't want to be coming back every day for radiotherapy for six week' because I had got at that time my son and his two children here, we knew that my son and one child was going to go, but we knew that the other one, aged 12, was going to stay here and live with me. And, you know, I take my duty as a surrogate parent seriously and I thought, you know, it's time-consuming, I've got to give the time up to go down to the hospital every day, I've got to have this treatment, but I think it was

because I knew people that had had it and they said how tired and how weary - well I have that anyway because of the pain that I'm always in, and I just didn't feel able, I just didn't feel that, you know. So, and she said, 'Oh that's totally the wrong reason.' And I said, 'Well it isn't the only reason,' I said, 'The main reason is that if I've got cancer there I want it out, end of story, not chip away at it until you've got it all: straight down the middle, off, done with.' 'Oh, that's the right reason.'

INT: AND HOW DID YOU FEEL ABOUT THAT?

Patient: I felt angry that she'd made me decide. I felt very, very angry that they'd made me decide.

INT: ARE YOU SAYING THEN THAT YOUU WOULD HAVE PREFERRED HER TO HAVE SAID, 'I THINK IT'S BEST FOR YOU TO HAVE A MASTECTOMY' OR 'I THINK IT'S BEST FOR YOU TO HAVE A LUMPECTOMY.'

Patient: Yes, yes.

INT: WOULD YOU HAVE PREFERRED THAT?

Patient: She did imply that she thought it was better that I had a lumpectomy because what she said was, 'The ... statistics show that the outcome in terms of whether people live or die, the prognosis, is the same with ladies that have had a lumpectomy followed by chemotherapy and/or radiotherapy, there's the same rate of survival as there is with people who, ladies who choose to have the mastectomy right at the very beginning.' And I just felt that, (a) I didn't, (a) I'd got cancer and I wanted it gone and that was the end of it, (b) for selfish reasons and practical reasons, I didn't want to be going down every day for six weeks for radiotherapy.

INT: I DON'T THINK IT'S A SELFISH REASON, BECAUSE I MEAN WHEN YOU'VE GOT YOUR SON THERE AND YOUR GRANDSON AND THAT, IT'S MORE FOR PERSONAL REASONS [???] ...

Patient: Of course it is, you've got to sort of weight up what your lifestyle is like, erm, I didn't want to run the risk of having to have two operations, that was the major, major issue for me because I'd thought in my own mind that if I'd had a lumpectomy and for whatever reason it didn't have a clear margin and then I had to go back for a further lumpectomy or a mastectomy, I would be so much weaker, what would happen if the cancer had suddenly started to escalate and grow in that period of time, because I do know that when cancers are disturbed it seems to speed up the speed with which the cells multiply, so it does grow faster, and it's no good them saying, 'No, it doesn't,' but it jolly well does, I know people that it's happened to.

INT: LIKE YOUR FRIEND AND THE INFLUENCES LIKE THAT?

Patient: That's it. So I was very, erm, I didn't feel comfortable with her, and I didn't feel 100 per cent comfortable with what she'd said about any of it.

INT: CAN YOU EXPLAIN THAT A BIT MORE? WAS IT WHAT, YOU SAID IT WAS LIKE ONE YOU DIDN'T LIKE THE FACT THAT YOU HAD THE CHOICE, YOU WOULD PREFER TO OBVIOUSLY HAVE HAD HER OPINION, YOU DIN'T, OBVOUSLY, YOU DIN'T LIKE THE, RIGHT AT THE BEGINNING OF THE CONSULTATION ...

Patient: Yes. I was going to say, but she seemed to imply, although it wasn't said, she might just as well have said it because her actions and her general demeanour said it for her, 'You've only got a little tiny cancer,' I mean she didn't actually say this but this was what came across as unspoken from her, 'You've only got a little tiny cancer, erm, what the hell are you messing about at going for a mastectomy when you could have a lumpectomy and ...' she just gave me the impression that she didn't think I ought to have gone for the radical option, she made me feel that I was blowing it up out of all proportion and that I, perhaps martyr-y, I don't know, I don't know what she thought, but I felt uncomfortable with how she made me feel ...

INT: ABOUT THE DECISION YOU MADE.

Patient: ... about the decision I'd made.

INT: AFTER SHE'D GIVEN YOU THE CHOICE?

Patient: After she'd given me the choice. So ...

INT: DID SHE SHOW YOU ANY, WAS THERE ANY DIAGRAMS, OR, ...?

Patient: Yes, she drew, erm, she had a piece of paper and she drew the breast and the cancer and the wide margin and, I mean, common-sense, you know, I mean I knew, she didn't have to draw a diagram, I would have, erm ...

INT: WAS IT HELPFUL?

Patient: Not really, no. I felt she was patronising me, because it was only like a matchstick man type diagram, if you know what I mean, very basic.

INT: DID YOUR DAUGHTER, YOU KNOW, AT THAT POINT, DID YOUR DAUGHTER HAVE ANY INFLUENCE OVER ...?

Patient: No.

INT: YOU SAID, 'THAT'S WHAT I WANT, THESE ARE THE REASONS, I WANT THE CANCER OUT AND YOU'RE THINKING OF THE FACT THAT OF HAVING TO COME BACK AND YOUR SON AND GRANDSON, YOU KNOW, AND FOR YOU, THAT'S WHAT YOU WANTED?

Patient: Yeah, that's what I wanted. And that was the decision I'd made. Erm, we came out ..

INT: DID SHE, AS THAT POINT, BEFORE YOU CAME OUT ... SORRY I KEEP STOPPING YOU ...

Patient: No, no, no, that's OK?

INT: BEFORE SHE CAME OUT, BEFORE YOU CAME OUT DID SHE, HOW LONG DID THE CONSULTATION END?

Patient: Oh ... and then she said, erm, 'Right, I can get you in on Monday, the 2nd.

INT: WHICH WAS HOW MANY?

Patient: Six days later.

INT: SIX DAYS AFTER. AND HOW DID YOU FEEL ABOUT THAT.

Patient: Bloody Hell! [chuckles] That's quick.

INT: DID IT FEEL ALL A BIT TOO QUICK, I MEAN OBVOIUSLY YOU'D GONE FROM A WEEK, YOU GO FOR YOUR SCREEING, THEN YOU'VE HAD A WEEK LATER, TWO WEEKS LATER THEN YOU WERE AT THE SCREENING CLINIC, THEN A WEEK AFTER THAT YOU WERE AT THE ...?

Patient: It was a shock but at the same time relief that it could be done with, it was a whole mixture of everything, and I think I said, when she said, 'Oh I can fit you in on Monday,' this was on Tuesday, the 27th January, 'I can fit you in on Monday the 2nd February,' and it was like, 'Oh, my goodness ...' and I think my daughter might have said something along of the lines of 'Ooh, goodness, that's not long.' And then I think she said, 'Well you can have longer if you want,' and I said, 'No, no, that's fine.'

INT: DID AT ANY POINT THE CONSULTANT SAY TO YOU, ERM, YOU KNOW, YOU HAVE GOT THESE CHOICES AND, HAVE I GOT IT RIGHT ...?

Patient: The choice she didn't give me, which I think she should have done, and it didn't dawn on me until afterwards, was the fact that I could have nothing done, and that was a choice she didn't give me. One thing that I really do want to make a point of really that something I omitted to ask her, which is unforgivable in the circumstances, which I'm gonna tell you about, when I had this surgery eight years ago, erm, it was never an issue that something had gone wrong, er, it's apparently something, it's a risk involved in the surgery that I had, what was an issue was that I'd gone in to see the consultant, at eight years ago, armed with a shopping list - I'd been to see my GP that same day and I'd asked the GP all these questions and he starting laughing, he said it looked like a shopping list my, you know, which it did, and he said, 'I can't answer these questions, what you need to do is go and see the consultant,' and I was due to go in for surgery three or four days later, and he said, 'My advice is go down to the clinic now, present yourself, tell them what you've asked me, take your list and they'll probably fit you in with it,' which is exactly what happened. Now I didn't ask, I asked what I thought were the right questions about the surgery, I didn't realise that there weren't all the right questions, and he maintains because there was a subsequent court case because I haven't been warned pre-operatively of the risks involved. And he stood in court and said he had warned me and I stood in court and said he hadn't, which he didn't. And I'd got all the documentary evidence which showed that he hadn't because I'd got, I'd even got my original list which was tucked inside my diary, and I took that to court as evidence, and he still denied in court, and I felt very, very bitter and very, very angry and let down, because, whilst he did not deny that something had gone wrong which had resulted in nerve damage, but that was part and parcel of the risks involved in this particular type of surgery. And I made my mind up that I would never, ever have surgery again, elective surgery for anything ever again. And I totally forgot all that, and yet, I mean that's what, I think that's what shock does to you, it makes, you know, and I didn't ask her if there were any risks involved, but she didn't tell me whether there were any risks involved.

INT: AND DO YOU THINK THAT ESSENTIALLY YOU WERE IN QUITE A BIT OF SHOCK THAT IT WAS SUCH A SHORT TIME?

Patient: I think it was, yes. I mean looking back now in hindsight, I mean, you know, if we'd all got the benefit hindsight, you know, but we haven't and, you know, it was shock, I thought about it three or four days later, 'Why didn't I ask her,' in fact I don't think I even thought about it until after the surgery, you know, because what, everything just happened so quickly, and I was booked in to have this surgery done on the Monday, I was told to be there at 7.30 in the morning, after six days.

INT: YOU KNOW IN THAT PROCESS OF, DID THE CONSULTANT, ERM, OH I'M GONNA TO ASK YOU WHAT HAPPENED AFTER YOU'D, DID YU SEE THE BREAST CARE NURSE AFTERWARDS, BUT FIRST BEFORE I ASK THAT, DID YOU, WERE YOU GIVEN AN OPPORTUNITY TO CHANGE YOUR MIND, DID SHE WAY, WHAT ...

Patient: She did say, 'If you want to talk to me about any of this, if you feel that you haven't got enough information, if you want to come back and see me ...'

INT: BEFORE MONDAY?

Patient: Yes.

INT: SIX DAYS AFTER.

Patient: Yeah, she said, 'If you do decide to the surgery done on Monday, erm, you will ...' er, what did she say, 'If you do have the surgery done on Monday, erm ...' no I can't remember now what I was going to say.

INT: SHE GAVE YOU THE, SO SHE GAVE YOU THE CHOICE OF ACTUALLY COME BACK TO TALK TO HER.

Patient: To come back to talk, that was it, 'If you do have the surgery on Monday, you'll have to come in ...' this was on the Tuesday, 'If you do come in next Monday you'll have to come in on Thursday to have bloods taken and various tests done, ECG,' you know, full clinical assessment I would imagine, '... and you can come back and see me on the Thursday,' that's what I was going to say, 'You can come back and see me on Thursday.' So that was all arranged, that's what we did. I agreed to have the surgery ../

INT: DID YOU AT THIS CONSULTATION THEN, OBVOIUSLY [???] ALL THESE THING [???] DID YOU GO THROUGH THEN TO SEE THE BREAST CARE NOT? WAS THAT NOT OFFERED TO YOU? AT WHAT POINT DID YOU SEE HER?

Patient: Yes, yes. I was offered, we were taken through to see the breast care nurse.

INT: WAS THAT STRAIGHT AFTER SEEING THE CONSULTANT?

Patient: Yes.

INT: AND DID YOU TAKE THAT UP OR NOT?

Patient: Oh yes, oh yes, I went straight through with my daughter. I was shown in to the, like a lovely sitting room, erm, pale pink furnishings, carpet, lovely comfortable settee, pictures on the wall, I can't remember if there was soft music playing but it wouldn't have surprised me [laughs] it was that, a very

relaxing ... they'd obviously made a great effort to put people that had just been recently diagnosed at ease. And I just burst into tears.

INT: BUT THE BREAST CARE NURSE HADN'T BEEN WITH YOU IN THAT CONSULTATION?

Patient: No.

INT: THAT WAS THE FIRST TIME YOU'D SEEN THE BREAST CARE NURSE?

Patient: Yes, I was, she came when I was shown in, I was taken by the .. I can't remember, it must have been one of the nurses, probably one of the clinic breast nurses, er, up to the breast unit, and I was shown into this room with my daughter, I think I was asked if I would like a cup of a coffee or a drink, told to help myself, then they went out and just left my daughter and me alone and I remember we both started to cry, and I said, 'Well that's it, then, isn't it. Off it

[End of side A]

INT: WHERE HAD WE GOT TO? I THINK WE'D GOT TO, SO YOU WENT INTO THIS ROOM AND THEY LEFT YOU IN THIS BREAST, YOU WENT TO THE BREAST CARE CLINIC ...

Patient: That's it, and my daughter and I were in their on our own.

INT: ON YOUR OWN. DID YOU, WHAT DID YOUR DAUGHTER SAY, DID SHE INFLUENCE YOU IN ANY WAY, OR HOW, OR DID YOU STILL FEEL VERY SURE THAT THAT'S, YOU WANTED TO HAVE THE MASTECTOMY AND THAT'S WHERE YOU WERE GOING?

Patient: I don't ... I can't really remember. I know we cried and I really can't remember but I know at some point, I don't know whether it was on that day or not, but the conversation, erm, you know, was 'Well you did make your mind up instantly, don't you think you've been a bit hasty?' is I think what she said, and I said, 'No, if I've got cancer let's get it sorted and let's, you know ...' and that was that.

INT: SO THEN THE BREAST CARE ...

Patient: Then the breast care nurse, a lady came in, very pleasant, a lady called Jill, introduced herself and said, 'I am going to be your breast care nurse.' Erm, she handed me that ... folder full of papers and told me to go away and read it, erm, told me to come back on Thursday, two days later, for ECG, told me where to go and the order in which I'd got to go and do things. I can't remember if I went down to physiotherapy, I think I did, I think I had to go down to physiotherapy on that appointment.

INT: [??] BACK AGAIN, I'M SORRY I KEEP [??]

Patient: No, you know what you want to ask me.

INT: WELL I'M SLOWING YOU DOWN BECAUSE YOU KNOW IT ALL, SORT OF THING, BECAUSE ALL THESE THINGS YOU'RE [??], YOU KNOW, ARE REALLY IMPORTANT THINGS, YOU KNOW, SO DID THE BREAST CARE NURSE, DID SHE GO THOROUGH THE MASTECTOMY WITH YOU AND WHAT, OR THE CHOICES [??]

Patient: Yes, she went through those.

INT: DID SHE? AND DID SHE, YOU KNOW, [???

Patient: She put it a lot, she put it a lot better, the way she put it to me, it seemed, whether it was because I felt that I disliked the surgeon and it was different because it was coming from someone other than the surgeon, may have been that. I think her general, the way she was, she seemed to take a real interest. The information she gave me was the same basically about the, what she say was that if I chose to have the lumpectomy I would have to have something, I forget what it's called now, a marker which involved going down to the radiology department prior to surgery, having an ultrasound scan or a mammogram or something, and having a needle marker put into place and taped into place so it would like be a needle put into the lump - haven't you heard of any of this?

INT: YEAH, I'VE HEARD OF IT, BUT, YEAH.

Patient: And it would be left there and then when she operated she'd know exactly that she'd got the right bit, and that was yet another reason - the consultant didn't tell me, that was the breast care nurse that told me that - because I said, 'Can I make my mind up on the day?' and she said, 'No, because we need to book the radiology department,' you know, 'Someone will need to come in and do that and if you go in for a mastectomy you will probably, Miss Wahedna usually does all her mastectomy ladies first so that she can do the lumpectomies later in the day when they've been to radiology and had the needle marker put in.

INT: SO DID THAT MAKE YOU UNDERSTAND MORE, YOU KNOW, WHEN YOU'RE GOING BACK TO WHAT YOU SAID ABOUT THE FACT THAT YOU ASKED IF YOU COULD ACTUALLY SIGN TWO CONSENT FORMS?

Patient: Yes.

INT: DID THAT MAKE YOU UNDERSTAND THEN THE REASON WHY ...

Patient: Why I perhaps couldn't, yes, yes, but it also made me think I'd made the right choice because I've got such a fear of needles, it's unbelievable, I mean I try and be very brave when I've got to have blood tests and injections ...

INT: I'M A BIT LIKE THAT ...

Patient: I'm a bit cowardly, yes.

INT: WHEN YOU WERE TELLING ME ABOUT NEEDLES IN YOUR BREAST, I THINK IT ...

Patient: Yes, I must admit I'm, you know ...

INT: I DON'T THINK IT'S COWARDLY,

Patient: Well they cringe, yes.

INT: I THINK MOST PEOPLE WOULD FEEL LIKE THAT.

Patient: Yes, cringe-worthy when you see what they're gonna do.

INT: SO DID THAT BREAST CARE NURSE CONFIRM WHAT YOU ACTUALLY WANTED TO DO, THEN? DID YOU FEEL HAPPIER ONCE YOU'D SEEN THE BREAST CARE NURSE?

Patient: Yes, well yes and no: yes I felt happier because I felt more comfortable talking to her because I felt she cared, but there was something not quite right, I didn't know what, and it wasn't until we came out that my daughter said, 'I didn't like that consultant and I want you to have a second opinion. I don't agree with a lot of what she said ...' this was what my daughter said, 'I don't like the way she spoke to you, I don't like the way I felt she bullied you. I could tell you were on the verge of tears more than once, and I was angry with her for doing that.'

INT: WHEN YOU SAY YOU FELT THAT SHE BULLIED YOU ... I'M TRYING TO JUST GET A HANDLE ON IT, I'M TRYING TO IMAGINE THAT I WAS THERE, SHE GAVE YOU THE CHOICE OF THE ONE OR THE OTHER AND SHE DIDN'T, YOU STILL FELT THAT SHE COULDN'T UNDERSTAND WHY YOU'D GOT TO GO FOR THE MASTECTOMY, SO ACTUALLY YOU FELT THAT THERE WAS A LITTLE BIT OF PRESSURE TO HAVE THE LUMPECTOMY ... IS THAT WHAT YOU'RE SAYING?

Patient: Yes, yes. That was right.

INT: THAT ... SORRY, YOU CARRY ON.

Patient: No, I did feel that she was, wanted me to have the lumpectomy but couldn't actually say because she'd given me the choice.

INT: YES, I UNDERSTAND [???

Patient: So having given me the choice he couldn't then, but I felt that they're the surgeons, they're the experts, so why can't they say, 'This is what we're going to do ...' because at the end of the day we're people, we're lay people, we don't know how they go about these things - if we make a suggestion and it can't be like we would like it to be, then fair enough, the surgeons tell us why and, you know, when she explained about the, when the breast care nurse explained about the needle marker, that highlighted to me the possibility of, well, yes, you know, you do need to go through the right procedures at the right time, you know, but it still didn't alter the fact that I could have had a nee-, in my own mind I thought I could have had a needle marker put in, I could have gone down for a lumpectomy and, if she decided that, you know, for whatever reason, that a mastectomy would have been best, then why couldn't she have just done the mastectomy? I couldn't understand why that wasn't feasible, and I still can't, I still can't in my own mind rationalise how they can make people - well I can, in hindsight, again, I think in my own mind that it's because, if they were to take a breast off and then it was later found that the cancer was only as big as your thumbnail or your fingernail, they might have ladies suing them and saying, 'Well you could have just taken the lump out, it was no bigger than a pea and I've lost my whole breast.' By the same token you could also have ladies that have had a lumpectomy, that went on to develop cancer, and they could be sued because the surgeon didn't take the whole thing off, the whole breast off, or the whole cancer away. So, you know, I can now in hindsight see why they make us make the decision, but I still don't think that it's right: I think that they're the expert and we are 99 times out of 100 guided by what they say and what they suggest, and I think that they should make decisions and not be afraid of subsequent litigation. I suppose that's easy for me to say because I'm somebody that did [???] the hospital ...

INT: NO, [???

Patient: But that's ...

INT: I UNDERSTAND WHAT YOU'RE SAYING WITH THAT. ERM, AND THIS, I DO UNDERSTAND WHAT YOU'RE SAYING I THINK WITH THAT. ERM, IF WE GO BACK THEN TO THE BREAST CARE NURSE, THE BREAST CARE NURSE, [???] SO YOU WENT TO SEE THE BREAST CARE NURSE [???] DO YOU THINK THE NURSE HAD A PARTICULAR TREATMENT IN MIND OR DO YOU THINK SHE WAS VERY MUCH GUIDED BY WHAT YOU WANTED?

Patient: Ooh well that would be difficult to say. She put across in no uncertain terms the same views as the consultant but at the same time did say that what I dec-, I'd got to make the choice and what I decided, you know, was fine. And she did point out the prognosis was the same whatever ...

INT: [???

Patient: I did to her at one point, 'If it was you what would you do?' and she declined to answer.

INT: SO SHE WAS STILL LEAVING YOU WITH THAT CHOICE, WASN'T SHE, TOTALLY?

Patient: She declined to answer when I asked her that.

INT: THAT'S INTERESTING. AND SHE GAVE YOU YOUR PACKAGE ...?

Patient: She gave my package ...

INT: ... WITH INFORMATION AND THAT KIND OF THING.

Patient: ... and told me to go away and read it.

INT: RIGHT. AND THEN YOU WERE COMING BACK ON THE THURSDAY?

Patient: I went back on the Thursday. She opened some of the literature, went, I can't remember now what it was - she didn't really talk a great deal about it, it was, most of what she talked about was the procedure that was leading up, she talked about what would be done when I came for the ECG and, erm, you know, when I came in for my operation. Something that really, really upset me was that it was a mixed ward, and I was told this, and I think it's absolutely diabolical that, erm, ladies with this type of surgery are subjected to being in a mixed, on a mixed ward, because it's a visible operation, it's not something you have done, you know, you have your appendix took out, you have a scar on your tummy which is covered by a dressing and subsequently covered by a nightie, no-one really knows what you've gone in, you could be in there for anything. When you've had a mastectomy it's a visible, you know, people know what you've had done, you're walking round lopsided; you're walking round with drains hanging out of you with a little carrier bag with bottles in, you know, and I just think it's wrong, totally wrong that you are in a mixed ward.

INT: AND THAT'S, ACTUALLY THAT WAS ONE OF THE LAST QUESTIONS THAT I WAS GOING TO ASK YOU, WHICH I MIGHT AS WELL ASK YOU NOW SEEING AS YOU'VE GONE ON TO THAT, NOW THAT YOU'VE BEEN THROUGH THE EXPERIENCE THAT YOU'VE BEEN THROUGH,

THAT'S OBVIOUSLY ONE THING THAT YOU THEN POTENTIALLY WOULD SAY THAT WOULDBE ROOM FOR IMPROVEMENT.

Patient: Ooh, my goodness, too right.

INT: I MEAN WHAT OTHER THING - I MEAN YOU COULD GO BACK ON YOURSELF.

Patient: There's lot, there's lots actually, I mean, you know, erm, I mean how far do you want me to actually ...?

INT: WELL IF, WELL I TELL YOU WHAT WE'LL TALK ABOUT, WE'LL TALK ABOUT IF YOU COULD CHANGE SOMETHING ABOUT THE SERVICE FIRST OF ALL, WHAT WOULD IT BE? YOU'VE SAID THAT, IT WOULDN'T BE ON A ...

Patient: Well it would be on a women on-, women ... thing.

INT: ONLY WARD.

Patient: Yes.

INT: WHAT OTHER THINGS IN THE PROCESS THAT YOU'VE TOLD ME ABOUT ...

Patient: I haven't told you about one process, that's something that's happened the day I came home regarding whether I wanted to look at, look at the scar really, and this was obviously after surgery, but there's a vast room for improvement there in the way the nursing, nursing staff on the ward are trained to deal with people, not - I mean the ward, it all revolved round the fact that the ward was a Monday to Friday ward. I went in at half past seven on a Monday, I wasn't ready to be discharged on the Friday, but I was discharged because the ward closed, and I thought that was scandalous. So I think there's room for improvement there.

INT: [???

Patient: Erm, you know, I mean I can go onto that. Do you want me to sort of ...

INT: YES, SHALL BE JUST. YEAH LET'S, WE'LL CARRY ON WHERE WE ARE THEN WE CAN GO ON TO THE [???] WHICH IS IMPROVEMENTS AND THINGS LIKE THAT. BUT, OK, SO YOU'RE WITH THE NURSE AND YOU FELT THAT SHE UNDERSTOOD YOUR NEEDS AND CONCERNS.[???

Patient: Yeah.

INT: IN BETWEEN THEN YOUR, DID THE BREAST CARE NURSE SEE YOU AGAIN?

Patient: Yes, I went back to her on the Thursday, two days later, I went to all the various departments for various things, and I went back to see her - again I think it, don't ask me why, the only thing I can say is I think it was because I wanted to be in control of something - I felt that everything was spinning out of my control. There were so many decisions that had been made and going to be made and ... and when I walked in she said, 'Oh, have you read your books, have you read the paperwork?' and I said, 'No.' Now I had Tuesday night and Wednesday night in which to read that paperwork and twice I got it out and I just stuffed it all back in. And I didn't read it (a) because I

wasn't ready and (b) most importantly because I didn't want to. Whether I was ostrich, burying my head in the sand, I don't know, but, er, I told her that I hadn't read the brochures and when she asked me why I said, 'Because I don't want to,' and she said, 'Well I really think you should.' And I said, 'Yes, but you're not me, and I don't want to read them at the moment. I might read them before I come in for surgery, but then again I might not.' I realised afterwards that that book lists all the risk, but I think it's wrong that I didn't read that book until after I'd had the surgery, so I wasn't aware of the risks, and I would have thought with what happened to me eight years ago - me of all people - the first question I should have asked any surgeon, with any operation, should be 'What are the risks involved? Are there any risks?'

INT: AND THE SURGEON DIDN'T BRING THAT UP [???

Patient: No, no, the surgeon didn't bring it up and I think she should have done. And, whether it was the shock because it all happened so quick, I can't imagine why I didn't say anything, but I didn't, and it wasn't until I'd had the surgery and I was in hospital, that I sat and read some of the, some of it. And it was all there in black and white. And again I felt, I was sort of like 'Oh! [???] [???] and I couldn't believe that I hadn't done that. So, no, I came, I went back to see the breast care nurse on the Thursday ...

INT: WAS THERE ANY WAVERING IN YOUR MIND OR WERE YOU STILL VERY [???

Patient: No, I was still very much [???] now funnily enough ...

INT: WERE YOU INFLUENCED BY ANYTHING? LIKE WERE YOU INFLUENCED BY, YOU KNOW, I WAS, THAT WAS GOING TO BE MY VERY FIRST QUESTION ABOUT, YOU KNOW, WHAT YOU ACTUALLY SEE, YOU KNOW, DID YOU HAVE A LOOK ON THE, YOU KNOW, INTERNET, MAGAZINES ...

Patient: No, I didn't want to know.

INT: RIGHT.

Patient: No, my daughter came down, erm, the next day, that night, and the next day, erm, with about 50 pages of stuff off the internet and in the end I had to say to her, 'Please stop because I don't want to know, I really don't want ...' I felt as if I was being bombarded by science and options and choices, and something that was really strange, erm, I've got four children - I've got three sons and my daughter - and I've also got a grown-up grandson who, he doesn't live with me now but he did live with me, he lived with me from when he was 12 up till he was 18 and he's 20 now, or he'll be 20 next week. And I asked my sons, three sons and my grown-up grandson, it was sort of talked about, you know, when we got home. It was like, 'Oh, no, Mum's got cancer, she's either got to have the lump out or the breast off,' and, you know, and 'Which do you think she ought to do?' And the strange thing was that all the men, oh and my sister's husband as well, so that was five, without any hesitation, 'Have the breast off, mastectomy, no question about it, don't even think about any other option, Mum, just get rid.'

INT: [???] INTERESTING, BUT IF THEY'D SAID TO YOU, 'HAVE A LUMPECTOMY,' HOW WOULD YOU HAVE FELT IF THEY'D ALL SAID, 'HAVE A LUMPECTOMY,' WOULD YOU HAVE STILL FELT YOU WANTED THAT MASTECTOMY?

Patient: Yes, yes. Now the thing was, my sister and my daughter, females, both said, 'I think you ought to have the lumpectomy.'

INT: THAT'S INTERESTING BECAUSE OF LIKE YOUR SISTER AND YOU WERE SAYING HOW MUCH, RIGHT AT THE BEGINNING OF THIS INTERVIEW YOU WERE SAYING HOW MUCH SHE INFLUENCES YOU AND YOU VALUE HER OPINION, THAT'S INTERESTING THAT YOU STILL FELT YOU WANTED TO HAVE A MASTECTOMY.

Patient: Yes, and I think the reason was what the consultant had defined as the right reason, although there was lots of things that came to it like not wanting to go every day for radiotherapy, the main reason that I wanted a mastectomy was, if I've got cancer in my breast, I don't want my breast - end of story. I would sooner have me without a breast and alive than run the risk of, you know, the alternative. So it was really strange that the two most important female sin my life, my daughter and my sister, both said that they thought I ought to have the lumpectomy until I said to them categorically, 'I'm having a mastectomy, there's no question about it, I've made my mind up, please don't try and influence me any more. My mind, I made my mind up straight away,' even my daughter said, 'Well you made your mind up within 30 seconds,' and after I'd made it quite clear that I didn't want the pressure of them thinking I ought to have something different to what I'd decided, they both said that the only reason that they had thought that I should have the lumpectomy was because they both were protective of me and they both thought that it would be less traumatic. But ... deep down they both admitted that they were glad that I'd chosen the mastectomy and they both said that I was braver than them because they wouldn't have done. And I thought, ah, you know, I could like see the reasoning behind all of that, it was like they were protective of me, they didn't want me to be disfigured, they thought perhaps I wouldn't cope with it, they thought perhaps ...

INT: THINKING ABOUT YOU AND YOUR FEELINGS.

Patient: They were thinking about me and my feelings.

INT: YEAH, THEY WERE.

Patient: And, you know, they thought that they were advising me what was best for me. But when I told them that I was having a mastectomy, deep down they were glad, and they've both said since that it's given them the strength that if ever they had to make the same choice they might be influenced by what I've had done, it might give them the strength to make the right decision.

INT: IT'S PROBABLY ABOUT-TURN A BIT WITH YOUR SISTER NOW, SHE'S ACTUALLY, YOU'VE ALWAYS ADMIRERED HER FOR THAT AND NOW SHE'S LOOKING AT WHERE YOU ARE.

Patient: She, she has got another problem, you know, she may have ovarian cancer, we don't know yet.

INT: OH GOD.

Patient: But we're just waiting on various tests coming back this week.

INT: OH GOSH, SO IF YOU'VE NOT GOT ONE THING IT'S ANOTHER, ISN'T IT?

Patient: [???

INT: SO YOU HAD, WERE YOU, SO DID YOU FEEL ALL THE WAY UP TO THAT, WHEN YOU HAD YOUR SURGERY ON THAT MONDAY THAT YOU COULD HAVE CHANGED YOUR MIND AT ANY POINT?

Patient: Yes, yes. I, I, erm ... I knew I could change my mind. I knew I wasn't going go.

INT: BUT YOU KNEW YOU HAD THE OPTION TO [???

Patient: But I knew that if I wanted to I could just say, 'Right, that's it,' and in fact, erm, something else that was important to me, erm, I wouldn't exactly say I suffer from claustrophobia to a degree where it's a major problem for me, it isn't, but I don't like closed spaces much. I, sometimes if the bus is full and the only seat is right at the back I go right to the back of the bus, and then when I'm at the back of the bus I think, 'Oh my God, what am I doing here? I really don't like being here, I really do not like it,' and I have to force myself to sort of, 'Right, take some deep breaths, calm down, just look out the window, you'll be home in 10 minutes, [???' and I sort of get myself into, worked up into a bit of a tizz over it. When I went into hospice I was shown to my bed at 7.30 in the morning and if I was to tell you that there was enough room for a chair and then the next bed one each side, it was absolutely unbelievable, and I sat on the bed and the clerk, nursing clerk came in and just asked a few questions regarding, I can't remember now what it was, probably ... she had my name and address and things, I can't remember what it was. Erm, but clerking issues rather than nursing issues. Then the anaesthetist came and he was lovely, and I told him that I was very frightened and that, which I was, I'm terrified of surgery, I told him that am always violently sick. I said, 'And I don't just mean being a bit nauseous, I mean being sick all day,' and I laughed and I said, 'Oh something else as well, just in case I forget, I've got dentures and I'll tell you now they're the last thing that come out when I have surgery and they're the first thing that goes back in when I open my eyes,' [laughter] and he started to laugh. He saw the funny side, saw the funny side to that. And, erm, and then he went and I had doctors and nurses and there was a lot of activity because everybody, it was Monday morning, the ward opens at 7 o'clock and this was 7.30, so everybody just like arrives and there were curtains being drawn while people were being spoken to by a consultants and one thing and another, and I just sat there and I just started to cry and my daughter knew instantly, and she said, 'Mum, just sit still, I'm going to go and sort something out for you.' I didn't say anything about what was bothering me but my daughter knew and she went to the nursing staff and she said, 'You know, my Mum is ...' and I could have quite easily, I think if they hadn't moved me into a private room, I think I would have just [???' and walked out because I felt ... I just did not like it. I've missed something out ... shall I go ... I'll finish telling you about this ... anyway they put me into a private room and it was marvellous, you know, because, I know everybody can't have a private room but again I do think that they should not cram the beds ...

INT: NO, THAT IS VERY ...

Patient: It was so close as to be untrue.

INT: YEAH. I MUST ADMIT WHEN MY SON WAS IN HOSPITAL IT WAS THE SAME THING AND I, I FELT IT AND I DIDN'T LIKE IT, I FELT I WAS SAT NEXT TO HIM AND THEN THERE WAS A BED LITERALLY THERE, YOU KNOW, I FELT LIKE JUST [???' AWAY.

Patient: Yes, because, you know, you value your privacy and curtain, you know, people can't see what's happening but they can hear when they're so ...

INT: WELL THEY CAN HEAR EVERYTHING, CAN'T THEY?

Patient: Yes, there's no privacy whatsoever and there should be. No, something I'd forgotten to tell you about was that, erm, in between the Tuesday when I was diagnosed with cancer and the Thursday when I went back to see the breast care nurse, my daughter and I - well my daughter, it was my daughter's instance, she said, 'I don't feel happy, I want you to have a second opinion,' and she rang the Nuffield Private Hospital and she spoke to one of the doctors there, Mr Sibbering, and Mr Sibbering had actually said to her that he had helped make the decision on what treatment I was to be offered. He was part of the breast team, there are three doctors, three consultants ... not doctors, three consultant who all liaise with each other and he said, you know, 'There's no point in you paying money to come and see me at the Nuffield because I have already been involved in the decision-making regarding your Mum,' so, you know, that was, and when we went on the Thursday we were surprised, taken aback, and a little bit shocked that the breast care nurse knew that we'd rung Mr Sibbering. So much for patient confidentiality.

INT: WHAT DID, AND WHAT WAS YOUR[?] RESPONSE TO THAT THEN?

Patient: Erm, well when it became known, we, I think we said, my daughter said, 'Ooh I've rung the Nuffield,' 'Ooh yes, you've spoken to Mr Sibbering ...' and, you know, I was quite shocked that they already knew about it and I didn't see the consultant from the Tuesday when I was diagnosed, I didn't see her again on the Thursday because I'd, she said there was, I only needed to go and see her if I changed my mind about what operation I was going to have or if I needed to talk to her about anything. Well I didn't, I felt that my mind was made up, I was having a mastectomy, there was no point in wasting her time, her clinic's busy enough anyway. So I didn't bother going to see her, but when I, when she came to see me the morning of the surgery, she upset me, she took me to task on two issues which I don't think she should have done - one was, erm, I, 'Where did you get to on Thursday? I waited and waited and waited and waited ..' and I said, 'Well I'm sorry I wasn't aware that you were waiting for me.' 'Well I told you that you could come back and see me.' I says, 'Yes, but I was under the impression that I was only to come and see you if I'd changed my mind about what surgery I'd decided to have, and I hadn't changed my mind,' I said, 'But I didn't think I'd kept you waiting because I thought you were in clinic anyway.' 'Well, yes I was, but that's beside the point. And I also hear that you've ... what's all this about a second opinion?' And I said, 'Well, I just wanted to be sure I was doing the right thing,' but I was very annoyed that she knew about it.

INT: AND PERHAPS NOT THE BEST OF TIMES TO BRING IT UP WITH YOU, THE MORNING OF YOUR SURGERY.

Patient: I felt obliged to stand up and shake her hand because I felt she was shirty and off-hand with me on the day of the consultation, she was more than a little rude, I felt, taking me to task, her timing was crap, you know, the morning of surgery, I was on the verge of tears, I'd only just gone into this room, and she breezed in and she said, 'Right, I'll see you in 20 minutes, you're first on the list.' So, and then the man was there, the nurse was 'There's your gown and everything,' and then the man was there with the trolley and [chuckles] and I was on my way.

INT: THIS ... LOOKING BACK NOW THEN AT THE CARE YOU RECEIVED FROM, RIGHT FROM THE BEGINNING TO WHEN YOU HAD THE MASTECTOMY, HOW DO YOU FEEL GENERALLY ABOUT THE CARE YOU RECEIVED, YOU KNOW, IT WAS MANAGED? DID IT MEET YOUR EXPECTATIONS OR NOT?

Patient: It's very difficult because people in shock ... often, they're expectations are all haywire, you know. Erm, when you're in shock you perhaps say things and do things, thing things that you wouldn't normally, and as I say my feelings changed, you know, I mean in hindsight now I'm glad I didn't have, I'm glad it all happened so quick because I didn't have time to worry, I didn't have time to change my mind, I didn't have time to pussyfoot about and sort of, you know, hum and hah, because that would have prolonged the agony for everybody and meant a lot of work for the people who are busy enough arranging schedules and fitting people in for surgery, you know, if I'd have, if on the day of surgery I'd said, 'Well I'm not stopping here and having this done, I'm going,' some other poor lady that's got cancer might have been able to have been operated on a day earlier, you know, there's all these things to consider.

INT: WOULD YOU HAVE LIKED MORE TIME AT THE TIME?

Patient: No, they did offer me more time. When she said, when the surgeon said on the Tuesday, erm, you know, 'I can fit you in on Monday, the 2nd,' and I said, 'Ooh, that's quick,' and she said, 'Well if you want longer, you know, I can give you longer,' and I said, 'No, I'd sooner ...' Can you see what I mean though about you changing your mind, you change your mind from one minute to the next let alone in two or three days?

INT: SO WAS THAT A GOOD THING ABOUT THE FACT THAT SHE, THAT SHE DID GIVE YOU THAT OPPORTUNITY TO CHANGE, TO HAVE A BIT LONGER TO THINK ABOUT IT ...

Patient: Yes, it was good.

INT: ... OR YOU COULD HAVE IT DONE ON THAT MONDAY OR MAYBE A FEW WEEKS ON, OR WHATEVER?

Patient: Yeah, yeah, no I think it was good that the facility is there to have it done quickly for people that want it, but they also give you the opportunity to take your time. I mean I was speaking to a lady who I've met since down in London at a place called The Haven which is a place ...

INT: [???

Patient: ... you know it. And, erm, and had breast surgery, she had a lumpectomy 14 years ago and the lump's come back and she's debating now whether to have another lumpectomy or have a mastectomy. And she's still debating and it's like eight weeks. It's like 'What're you waiting [???], you know, why don't you go and have it done?' And she said, 'Well I'm going away ...' I bumped into her funnily enough in London [???] she said, 'I'm going down to my holiday home in France in May and I'll probably have it done in June or July.' So I met her in March and I just can't see the logic, but then that's her choice. This is where choice, patient choice. It's obviously what she wants.

INT: IF YOU COULD CHANGE ANYTHING ABOUT THE SERVICE, THE CARE THAT, THE MANAGEMENT YOU RECEIVED, WHAT WOULD IT BE?

Patient: I would say it would be nice for the experts to make a decision and tell you what they think you should have, and not give you a choice. Having said that, again in hindsight, if I had been told that I was to have the lumpectomy I would have had a lumpectomy and I would have had to have had that followed with radiotherapy and I wouldn't have questioned it because I would have been told 'This is

what is going to happen.' I would have been none the wiser about, if you like, how quick and easy mastectomy is compared to it, because that wouldn't have entered into it.

INT: [???

Patient: So ... you know, it's a difficult one. I don't know. I really don't know.

INT: YOU SAID ABOUT THE MIXED WARDS, THAT WOULD BE [???] IMPROVED.

Patient: Oh yes, that would be a big improvement.

INT: AND WHAT ABOUT THE, YOU KNOW, THE GOING FROM THE, ERM, THE FACT THAT YOU HAD ALL, A WEEK TO WAIT BETWEEN WHEN YOU HAD THE ULTRASOUND AND THE BIOPSY TO THE ... CAN BE THAT BE CHANGED OR, YOU KNOW, ARE YOU QUITE HAPPY WITH THAT, THEN YOU WENT TO BREAST CARE NURSE AFTERWARDS OR ...

Patient: No, I think, I think a week is about right because, I mean it was a very busy, traumatic week because my son was moving house that mean, I mean I was diagnosed on the Tuesday, I spent all day Thursday at hospital having tests done, my son moved house on Saturday and I was in hospital on Monday, and I was in until the Friday. No, I think it's nice to know that the speed with which they can get you in for something like this, it's reassuring.

INT: SO THAT'S GOOD .

Patient: That's a positive.

INT: WHAT OTHER POSITIVES, THEN, WOULD YOU THINK OUT OF THE CARE THAT STAND OUT IN YOUR MIND AS BEING GOOD SERVICE, A GOOD SERVICE [???

Patient: Well I think it's nice that you have a breast care nurse, erm, that's sort of allocated to you, and they're all very nice.

INT: DID YOU SEE THE BREAST CARE NURSE ON THE WARD?

Patient: No, she didn't come to see me.

INT: SO YOU SAW HER AT THE ...?

Patient: I saw her at the clinic. The only time I've seen her is when I've put myself out to see her, she has never come to see me, she didn't come once.

INT: SO THAT'S YOU ...

Patient: And that, I actually, I forget the question I needed to ask, but I saw a breast care nurse going to somebody else, so I knew she was a breast care nurse, and I called her over and I wanted to ask her something, I can't remember now what it was, and I remember at the time feeling slightly annoyed that it wasn't my breast care nurse, that I'd had to ask somebody who I'd not spoken to before.

INT: SO THAT COULD BE A POSITIVE, ER THAT COULD BE SOMETHING THAT COULD BE IMPROVED ...

Patient: That ... improved.

INT: THE BREAST CARE NURSE, AS WELL AS SEIENG YOU ON THAT THURSDAY, COULD HAVE SEEN YOU WHILE YOU WER IN THE HOSPITAL?

Patient: Yeah. I was also under the impression that physiotherapists were going to come up to the ward and no-one came anywhere near, erm, and I mean I think that the only, only reason I have got such a good range of movement is because of my perseverance. I mean I was doing exercises within an hour of waking up from surgery.

INT: WHICH IS SELF-MOTIVATION?

Patient: Oh yes.

INT: BUT YOU COULD HAVE DONE WITH THE PHYSIOS COMING ON THAT WARD AS WELL?

Patient: Yes. I felt, I felt so proud of myself, I wanted to show her, and she wasn't there, and I felt a little bit let down by that. But a point, something I would like to talk about which had a real, real impact on me. My best friend had a mastectomy 17 years ago and I spoke to her the night before I went down for surgery and she said something that made me, it really upset me actually. She said that, even now, when she has a bath she covers herself up with a flannel, she can't bear to look at it. And I thought that was very sad. And I thought, 'Well that won't happen to me because I shall look it and I'll get used to it. I wouldn't let something like that happen to me.' But then when I'd had the surgery and I was in the most excruciating pain, again I think that is par for the course with the other problem with the nerve damage, when I mentioned to the nursing staff they were very sympathetic, erm, gave me pain relief, offered lots of different sorts, but said quite often ladies are number there, they've no nerve endings, so you shouldn't really be in pain. But I am, you know, what you should be and what is are two different things.

INT: THAT'S AS YOU ARE, YOU KNOW.

Patient: Yes. But I did feel that the pain was emanating from the drains that were in. Now one drain came out and I was left with one drain in. One drain was taken out on the Thursday, four days after, three days after surgery, four days after surgery, and I was told that - whether it's true or not I don't know - bigger breasted ladies quite often, you fill up with fluid because if there's something that was there that isn't there, the body's way of trying to deal with that is to fill it with fluid. So, because I am quite chesty, I had got quite a lot of fluid and I was told that you would not be expected to go home unless you were draining 30ml or less in the previous 24 hours. Now on the, they'd taken one drain out on the Thursday and the following morning they measured my drain and it had drained 70ml from the previous day, which was quite a lot. Then the consultant came to see me and said, 'Oh you're all right to go home today.' Now I didn't feel happy coming home on the Friday, (a) because I was in, still in so much pain, (b) I didn't want to come home with a drain in because I thought, you know, what if it, what if I turn over and it comes down, what if ... a hundred and one things could go wrong. And last but not least I didn't think it was nice for my grandson who lives with me. So I said, 'No, I'd rather stop in if you don't mind.' 'Well you can't, the ward closes.' So I said, 'Well you'll have to move me to a different ward,' and it didn't go down very well and they said no, they couldn't do that, there

was no reason why I couldn't go home with the drain in. I point blank refused to go home with the drain in. They then said, 'Well we'll take your drain out,' so I said, 'Well I thought you can't take a drain out unless it's draining 30ml or less, mine drained 70, what I don't want to happen is for the drain to be taken out and then when I get home find that I get a seroma, which has got to be drained. If I can avoid that by leaving the drain in another two or three days and stopping in hospital over the weekend, then that's what I'd prefer to do.' And that wasn't an option: that was not an option, and I was told that my drain would be taken out and I would be going home. My daughter rang the hospital, spoke to the nursing staff to find out, it was lunchtime, to see whether I'd be going home or not and the nursing staff said, 'Oh, we're not sure yet, erm, we're waiting, she's going to have her other drain out and then I think she's probably coming home this afternoon, she'll be coming home after dinner.' And my daughter said, 'I'm a little bit concerned that Mum has looked at her scar,' because they'd taken the, they'd taken the dressing off when they took the first drain out but then they'd put a lighter dressing on, so I hadn't looked at it, and again, exactly the same as it was with the brochures, I didn't look because I didn't want to, and I felt I was in control, I think that's what it was. That's the only rational reason that I felt I didn't want to be pressured to looking at it, I don't know whether I wanted to look at it ...

[End of side B]

Patient ... I didn't know whether I wanted to cry, I didn't know whether I wanted to be myself or if I wanted somebody with me, I didn't know whether I wanted to be at home or if I wanted to look at it in hospital - erm, I didn't really, I hadn't given it a lot of thought other than I wasn't ready to look at it. So my daughter said to the nursing staff, unbeknown to me, 'I'm a little bit concerned that Mum hasn't looked at her scar.' 'Ooh, she has,' [???] 'think she has.' So one of the nurses came down and in front of everybody at the top of her voice, said, 'Have you looked at your scar yet?' I said, 'No, there's a dressing on it.' 'Well, when they took the first dressing off and put the ...' she said, 'Let's have a look,' and she came and had a look, and she could see it was just a lightweight white dressing as opposed to the green surgical dressing, and she said, 'Have you, did you look at it when they changed it?' and I said 'No.' She said, 'Why?' I said, 'Because I didn't bloody want to.' And she like looked and she said, 'Well I think you should before you go home.' I said, 'Ooh, I might not even go home.' And I was beginning to get angry, she was, she was reducing me feeling like, I don't know how she made me feel, she made me feel a combination of angry - I was hostile towards her because I felt she was pushing me too fast[?]. She says, 'Well I've got your daughter on the phone and your daughter's worried that you haven't looked at your scar. So, what we're going to do is take you into the treatment room in 10 minutes, we're going to take your drain out, take your dressing down and have a look at your scar before you go home. OK?' I said, 'No,' I said, 'You go back,' I said, 'and you tell my daughter that I'll look at the scar when I'm good and ready,' I said, 'and I won't be backed into a corner by you, her, or anybody else.' I said, 'So there. And I remember I got my paper and I picked my paper up. I said, 'Right? Understood?' And I went like that ... and I picked my paper up and I was crying my eyes out and a girl opposite who'd had a gall bladder operation the night before, who was terribly, terribly sick the night before and I think I got up twice in the night and went, her buzzer wasn't working and I went down and fetched the nurse for her. And she came over, she must have known, she'd heard, and she actually said, 'I cannot believe what I have, I can't believe what I have just heard. How dare she speak to you like that? How dare she?' she said, 'in front of ...' And I'd just got tears rolling down my face. I says, 'Yeah, well,' I said, 'They'll find out,' I said, 'when they get me in that treatment room,' I said, 'because I won't look until I'm ready,' I said, 'and they can't open my bloody eyes for me.' And I was so angry about it and worked up. Anyway my daughter came [chuckles] she started laughing. She said, 'Ooh you're a [???] monkey you are,' and I said, 'Well, I don't feel that I'm ready.' And she said, 'Ooh, Mum ...' and she like, we had a cry, and she put her arm round me and we had a cuddle and I said,

'I'll look at it when I'm ready, I'll look at it when I'm ready.' Anyway they came to fetch me to take me to have the drain took out. Erm, the first drain I had took out was excruciatingly painful, it felt like they'd yanked it from halfway across me, almost from where my breast bone was, it felt like they'd pulled it right the way across and scratched something, it was so painful. Anyway I went in and I was expecting the second one to be a bad, so I was dreading it, and she said, 'Right,' she said, 'I'll undo, take the stitch out,' she said, 'and if you want me to stop when I'm taking the drain out just put your hand up and I'll stop.' And anyway she, and it just came out, just easy, it was so easy. I didn't feel a thing, didn't feel a thing. She turned her back, she got all the wires and everything and the bottles with the fluid in, and she turned her back on me and went to put it in the bin. My daughter didn't come in with us, by the way, there was two nurses. And I was concerned as well, something else, that the nurse that took the second drain out was a nurse in blue, who I think is a qualified nurse. The nurse that took the first one out the day before, they were both in grey, and I don't think they are nursing staff.

INT: OH I'M NOT THAT [???] I DON'T KNOW MYSELF, I DON'T KNOW WHAT [???] IN DERBY.

Patient: And ... no, well I was concerned, because it hurt so much, it was so sore while she was doing it and afterwards that, I was concerned that somebody who was unqualified was doing a qualified task ...

INT: [??]

Patient: You know? So that was, anyway she turned her back and put this thing in the bin and I looked down and I said, 'Right, I'm just letting you know that I've looked at my scar, I've seen it,' I said, 'And what's more I've looked at it when I'm good and ready, not when I was told to.' And I felt that I'd put myself back in control. Having said that I was really, really angry because I wasn't ready to look at that time. And I felt that I'd been bulldozed and bullied into that by the nursing staff, and I think the nursing staff should take more notice of how patients feel and I think that, if I, under the circumstances, if I'd have said - which I did - 'I'm not ready to look at my scar, I don't feel well enough to go home, I don't want to go home with the drain in, I want to stop in hospital in the weekend, and I don't care whether the ward's closing.' There was another nu-, there was another lady who was in hospital who was a nurse, she stayed in, she had her surgery the day after me on the Tuesday she had a mastectomy, she'd had one mastectomy ten years ago, she had the other breast off, and, erm, she stayed in for another week. She was moved to a different ward and she said it was lovely, they were all ladies, it wasn't a mixed ward. And I felt very angry and let down by that.

INT: MM.

Patient: And bitter, you know, I sort of, I feel like I want to go back to the hospital and tell them where they went wrong. And what they can do to put it right. And that this shouldn't happen, and that shouldn't happen. I should never have gone home on that day. So the nursing staff knew my concerns about going home too soon and they agreed to put the district nurse, to get a district nurse to come and see me. I came home on the Friday, the district nurse would come on the Saturday. So ...

INT: WAS IT EVER SUGGESTED THAT BREAST CARE COMES TO SEE YOU?

Patient: No, it wasn't. No, that ... they did say, it was pointed out that they have a facility there where, if there's a surgical problem, say like if I'd started to bleed from the wound or something drastic had happened, I could go back to the City Hospital to their Surgical Assessment Unit, I think it is, and I think it's open 24 hours a day or it's manned, the telephone's manned. So I did feel

reassured that if there was a problem I could have gone straight back, but that didn't alter the fact that I don't think I should have come home, that was the middle and both ends of it. But, erm ... as I say, I came home on that day, on the Friday, felt very tearful, er, I went up into the bathroom and I looked at the scar and I couldn't believe the bruising and the scar and the swelling - I think it was the swelling and the bruising, it was just the whole breast area was black and it was such a huge swelling which I've still got, I mean, [???

INT: [???

Patient: Yeah.

INT: IT'S NOT, I THINK PROBABLY IT'S MORE, IT'S MORE, YOU KNOW YOU CAN PROBABLY SEE IT AND FEEL IT MORE THAN I CAN SEE IT.

Patient: But it hurts when I put my arm down.

INT: YES.

Patient: So, anyway, and then I found out, I can't remember whether it was the night before, whether it was the day I came home, that evening, or whether it was the following morning, but ... no, it was, it was the same day because I rang the hospital back. Er, I think the district nurse rang me to say she'd be coming in to see me on Monday, and this was Friday afternoon, within five minutes of coming home from hospital. And I rang the hospital back and I spoke to the nurse that had discharged me, who'd arranged, and I was crying, and I said, 'I really feel that I've been shunted out of hospital far too soon. I've been shunted home, offered a full facility back-up plan which immediately is falling down around me because she's rung from the district to say she's not coming in till Monday.' And the nurse at the hospital said, 'Leave it with me, I'll get back to you.' She must have made arrangements and she rang me back and she said, 'They will come tomorrow.' The nurse came in on the Saturday morning, I think it was two nurses came in on the Saturday, they didn't stay very long, I think it was two, they weren't from my surgery, they were like on a rota ...

INT: ROTATION OR SOMETHING, YES.

Patient: Erm, and they were very nice and there was no problem, er, everything was fine. I had a home help, they arranged for somebody to come and help me prepare a meal and, you know, do anything that needed doing: it was hovering that I couldn't do. My grandson gets that now. Erm, anyway, the next day, on the Monday, erm, the nurse came and she poured some Avon - I've just got this thing from about, if they come from one house and they haven't washed their hands, you know, I know someone that had that MRSA, and it is a frightening, frightening thing. And I saw her squeeze this green stuff on her hands and rub it in, like that, and she said, 'Right, let's ...' and I said, 'Oh, excuse me, can you wash your hands please?' And she said, 'Oh no I've just done, I've just ... er, you know, it's far better than having my hands in water.' I said, 'Well I'm sorry, I can't help what's best for your hands, I want what's best for me and I insist that before you look at me you wash your hands.' And she tutted, she went 'Tut,' and went into the bathroom and that immediately put my back up. Immediately. Because I thought it was so unprofessional, you know, how can an antibacterial hand gel be better than soap and water in that sort of situation?

INT: YEAH, I UNDERSTAND HOW IT WOULD GET YOUR BACK UP, I DO.

Patient: You know, and I felt so protective of my scar because I've had so much that's gone wrong in the past, I just didn't want to take any chances with it. And I insisted that she washed her hands, and she was really, really cross about it, and she just looked, 'Oh yes, yes, well everything's healing nicely. I've no need to come and see you again,' and that was it. Then I think it was into the second day a man came and I needed help to wash my hair and it was a man, so I said, 'Oh I'm sorry,' and I burst into tears. So I just felt that he back-up service could ...

INT: IT LET YOU DOWN, THAT COULD HAVE BEEN IMPROVED.

Patient: ... it could have been improved. I didn't want a man. When you've had, you know, when you've had breast surgery and you need help with washing your hair or having a bath, who wants a strange man? Not me. So I felt that that could have been improved. And, erm ...

INT: I MEAN LOOKING BACK NOW THOROUGH YOUR EXPERIENCE, WHAT, I'LL ASK TWO QUESTIONS HERE, ONE IS ABOUT WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS THAT SOMEBODY WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS, AND THEN I WANT TO MOVE ON TO SAY ABOUT THE OPERATION THAT THEY HAD. SO IT'S ABOUT THE DIAGNOSIS FIRST. WHAT DO THEY NEED TO KNOW?

Patient: They need to know they can change their mind, they need to know that they can ask questions, and they need truthful answers, you know, I'm going back to being told that it wouldn't hurt when it did, and things like that. Because when you are told something and it doesn't happen, or it's different to what you're led to expect, it makes you begin to question what else isn't right, you know, did, was it only 17cms [sic], what if it was bigger?, what if it was smaller?, you know, you question all sorts of things. And with regard to the actual operation I think it's nice to know that they're, the speed with which they can get things done. Again, it's far better to be offered surgery within a week and say, 'Well, no, I'm sorry, I need a month to decide,' than it is for them to say, 'Well you're coming next month for your surgery,' and then to spend a whole month thinking, 'What if this cancer's growing?' you know. So I think they've got it the right way round.

INT: YOU SAY ABOUT CHOICE, I JUST WANT TO BE CLEAR ABOUT WHAT I GO AWAY WITH. YOU KNOW YOU SAID OBVIOUSLY ONE THING YOU NEED TO KNOW ABOUT YOUR DIAGNOSIS IS THAT YOU'VE GOT A CHOICE, AND I'M JUST SAYING ABOUT, ARE YOU SAYING ... YOU KNOW THAT YOU SAID, I'M JUST GOING BACK IN THE INTERVIEW WHERE YOU SAID THAT ACTUALLY YOU WOULD HAVE LIKED THE CONSULTANT TO HAVE TOLD YOU ...

Patient: Yes.

INT: SO THAT WAS, THAT WAS IN SOME WAYS YOU'RE SAYING THAT YOU DON'T, YOU WOULDN'T WANT A CHOICE.

Patient: Yes.

INT: I'M JUST TRYING TO UNDERSTAND THAT A LITTLE BIT MORE.

Patient: I don't, this is, this is what I meant when I said how I've changed my mind as things have progressed, so it's difficult now to give a defined answer, whereas if you'd interviewed me at the time I could have told you how I was feeling.

INT: SO OVER TIME YOUR FEELINGS HAVE CHANGED?

Patient. Changed, yes.

INT: YEAH.

Patient: You see initially I was angry that I was given a choice, I felt let down by the service, I thought they should make the choice, they're the experts. But now I'm glad that I had the choice because I've made the choice and I've got to live with it. And I am quite sure that I made the right choice. Well I know that I made the right choice for me because, erm, if I'd had a lumpectomy ... I mean I still worry now, what if cancer's still there, even though the breast's gone. My best friend who I referred to who had, she had a mastectomy 17 years ago and 10 years later she was offered, she decided she wanted reconstructive surgery and one week before she was due to go in for the reconstruction she found a pea-sized lump on the chest wall, and, er, it was taken very seriously and it was cancer and it had come back. She had to have further surgery and she never did go ahead with the reconstruction. But she made me realise that there are risks concerning reconstruction that are not always obvious. Now no-one's even mentioned reconstructive surgery to me: if they had I would have said no, I don't want it, but no-one's even mentioned it. But ... all the ladies that have had reconstructive surgery, if my friend had had reconstruction, she wouldn't have noticed that lump, and then it could have killed her because it would have grown undetected because it would have been, you know, on the inside if you like with the breast on the outside.

INT: I UNDERSTAND WHAT YOU MEAN. I MEAN I SUPPOSE THAT, I MEAN I THINK THAT, THAT GOES A LITTLE BIT BACK TO WHAT I WAS GOING TO SAY ABOUT WHAT YOU UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU FOUND OUT YOURSELF YOU'D GOT CANCER.

Patient: I didn't know anything about it, I [???] it existed, I didn't know anything about it. I mean I had mammograms to detect it at an early stages and I knew that, I'd heard of lumpectomies because that's what my friend Kathleen had, and I knew that there mastectomies because that's what Sheila had, but I didn't really, I never ever checked my breast, so I just didn't really take much notice. I think I just thought, 'It'll never happen to me,' and it was a real shock ...

INT: [???]

Patient: ... when it did. Yeah.

INT: AND ALSO THAT LEADS ME ON TO ONE LAST THING. I'M SORRY, IT'S TAKEN A LONG TIME THIS AND I'M SORRY ABOUT THAT, YOU MENTIONED, THIS IS QUITE INTERESTING BECAUSE SOMEBODY ELSE MENTIONED IT AS WELL, IT WAS THE FACT OF YOU WEARING A GOWN, AND TOLD ME RIGHT NEAR THE BEGINNING OF THE INTERVIEW THAT ACTUALLY YOU WENT TO SEE THE RADIOLOGIST, AND YOU WERE WEARING YOUR GOWN, YOU'D GOT THAT, NOT DIAGNOSIS, BUT THAT YOU REALISED SOMETHING WAS WRONG. AND THEN YOU SAID THE NEXT TIME YOU SAW THAT, YOU WERE READY TO NOT [???]

Patient: I wasn't gonna wear a gown.

INT: IS THERE SOMETHING ABOUT THAT? I MEAN IS THERE SOMETHING ABOUT RECEIVING INFORMATION AND YOU FEELING IN CONTROL OF THINGS ACTUALLY IN YOUR CLOTHES, YOU DON'T WANT TO BE IN A GOWN. I MEAN ... OR NOT.

Patient: I don't know. Now it's strange you should say that because I got up at 4 o'clock this morning to get dressed because it was thundering and lightning and that is something I do. I feel in control if I am dressed. I feel vulnerable when I'm in my nightie, and if there's a thunderstorm in the middle of the night I get up and I get dressed and then I just get a lightweight cover and throw over, I've got a blanket, just one blanket that I throw over, and I lay on top of the bed in my clothes with just the blanket.

INT: SO FOR YOU THEN PERHAPS, YOU ACKNOWLEDGE THAT PERHAPS THAT COULD HAVE BEEN, [??] YOU [??] WANTED TO FEEL VULNERABLE YOU WANTED TO FEEL IN CONTROL OF THE SITUATION?

Patient: In control, yeah,

INT: YEAH, THAT'S VERY INTERESTING.

Patient: And I wanted, I wanted to be able, yeah, in control.

INT: YEAH, THAT IS VERY INTERESTING.

Patient: And I'm not a control freak. A lot of people ...

INT: NO, NO, YOU'VE SAID IT THROUGH THE INTERVIEW AND I CAN SEE EXACTLY WHEN YOU'VE SAID, THE MOMENT YOU'VE SAID IT, EXACTLY WHAT YOU MEAN. IT'S NOT ABOUT A CONTROL FREAK ...

Patient: No.

INT: ... IT'S ABOUT BEING, YOU KNOW, THAT YOU FEEL .L..

Patient: In control. There's so much, regarding breast cancer, there's so much that seems out of your control, you know, you don't have any say in the matter to a point.

INT: I UNDERSTAND [??]

Patient: You know? Even when it comes down to silly things like having meals at set times. I mean I know the importance of having breakfast, dinner ... breakfast, lunch, tea, dinner whatever in the right order, throughout the day, but it doesn't alter the fact, if you wake up in the middle of the night and you're at home you can come down and have a cup of coffee and a biscuit, or you can have a snack, you know, and you're in control, and you feel in control. You feel so vulnerable when you're in hospital ...

INT: YEAH I UNDERSTAND THAT.

Patient: ... you know, I can remember, going back to when I had surgery before, erm, I was on morphine, it was the day after, it was the day, I'd had the surgery and it was during the night, you know like the following, I had surgery in the morning, I'd gone right through the day and it was in the

middle of the night and I'd had morphine and it had made me violently sick and, you know, I felt that I just needed something to take the pain away, just anything. And I said, 'Can I have some paracodol, some co-codamol?' and she said 'No, you can have some, you know, at six o'clock' and this was sort of like four o'clock, and I said, 'But, you know, I need them.' And, I know I shouldn't have done, but the minute she'd gone I got out of bed and got two out of my handbag and took them. I knew I wasn't being silly because I knew that it wouldn't interfere with what I'd already had. I'd had the morphine at ten o'clock.

INT: I UNDERSTAND WHAT YOU'RE SAYING.

Patient: You know, so there was ample time had elapsed, this was four o'clock in the morning, she came in at six and she said, 'Ooh you can have your co-codamol, shall I get your co-codamol?' I said, 'forget it, I've already had 'em,' and she was cross but so what? And that's what I say, being in control and it makes you feel that you've got some order - well it makes me feel that I've got some order back in my life.

INT: MM I REALLY DO UNDERSTAND IT. I THINK YOU'VE COVERED EXTENSIVELY AND JUST SO WELL YOUR EXPERIENCE, YOU KNOW, AND I THANK YOU FOR THAT, YOU KNOW, YOU REALLY HAVE, YOU'VE TAKEN ME THROUGH IT. I MEAN IT'S BEEN SUCH, FOR ME, AN EASY INTERVIEW BECAUSE YOU HAVE, YOU'VE GONE THROUGH THE PROCESS SO, SO WELL, I THINK. IS THERE ANYTHING ELSE THAT YOU'D LIKE TO ADD ABOUT WHAT WE'VE BEEN TALKING ABOUT TODAY? AND IS THERE ANYTHING YOU WANT ME, I MEAN, IS THERE ANYTHING YOU WANT ME TO TAKE AWAY TODAY OF ACTUALLY KNOWING THAT IT'S THE MOST IMPORTANT THING FROM YOUR POINT OF VIEW AND THE REASON THAT ACTUALLY YOU WANTED TO TAKE PART IN THE INTERVIEW?

Patient: Erm, well, I think the reason I took part in the interview was because I felt that, if I could do anything that would help someone else, I'm all for that. Erm ... and that's about it basically. I mean ...

INT: DO YOU THINK THAT WE'VE COVERED THAT YOU THOUGHT WE WERE GOING TO TALK ABOUT, [???

Patient: Oh yes, yes. I was gonna say, I feel that I have had the opportunity to discuss all the issues that I wasn't happy with and, whilst I would not, erm, I've got no intention of complaining to the hospital about any of the issues that I didn't feel were quite right, erm, whereas eight years ago I did and I mean it ended up in a court case, but that was totally different. And nothing like that is going to happen and I know that, you know, it's a different kettle of fish altogether, but I feel that we've discussed everything, and I feel almost as if, erm, I've got a lot of things off my chest, if you like, by talking to you about it all. So it's, you know, it's been helpful to me.

INT: WELL I FEEL VERY PRIVILEGED FOR YOU TO HEAR ABOUT IT ALL AND I MEAN IT HUMBLER YOU ACTUALLY LISTENING TO IT ALL, YOU KNOW, THE EXPERIENCES PEOPLE HAVE. SO I MEAN I'M GLAD THAT IT MADE YOU FEEL LIKE THAT AND THAT ...

Patient: Yeah. How many people have been involved in the ...

[End of interview]