

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE: 05/7/2004

*ID: Patient54

*INTERVIEWER: DJW

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

Patient: Erm, I knew quite a lot about breast cancer because my Mum died of breast cancer.

INT: RIGHT, OK.

Patient: Well she initially had breast cancer, unfortunately she, erm, didn't sort of, she was 71 when she discovered that she'd got a lump, which was quite enormous at the time, so when she was, erm, diagnosed, basically it was just a question of Tamoxafen, there was no question of an operation or anything, from that point of view, erm, so I'd always been aware, you know, to check my breasts, and I was on HRT anyway so I was actually checked every six months by my GP. Erm, but, er, and I obviously had regular mammograms from my when my Mum died, knowing full well. But, having said all of that, I had no sign of it whatsoever, there was no lump, bump, nothing at all. So I went for the mammogram and obviously I was recalled.

INT: RIGHT.

Patient: So, erm, it did come as a bit of a shock, I must admit, because I'd got no outward signs at all, physical signs.

INT: AND HOW LONG AGO WAS IT YOUR MUM HAD BREAST CANCER?

Patient: Erm, she died eight years ago. She had breast cancer originally, they shrunk the tumour quite dramatically actually over three years, but then, erm, she had metastases which they found in her back and ankles I think and things.

INT: RIGHT, OK. YEAH, IT DOES GO INTO THE SPINE.

Patient: Yeah. So it was, she had a backache, went to the doctors, took her for a private consultation, she had a scan and died within five weeks of all of that. So it was quite dramatic at the time. Erm, so, as I say, it just went on from there really. But I'd never thought about it myself, it's never concerned me that I would have it, although I think it's something now, at some stage, I will try delicately to discuss with my own daughter.

INT: RIGHT, OK.

Patient: She's 30 now. So, because, you know, if it wasn't for a mammogram ...

INT: YEAH, OF COURSE.

Patient: You know.

INT: YEAH.

Patient: She, I was told it would have taken at least two years for anything to have been detected without the mammogram. So I can only urge anyone ...

INT: YEAH, OF COURSE. AND WHAT ABOUT ANY FRIENDS THAT HAVE HAD BREAST CANCER OVER THE YEARS, DO YOU KNOW ANY FRIENDS, COLLEAGUES, ANYTHING LIKE THAT?

Patient: As I say, not friends as such, but certainly people related to people that I know. And the two that I have already mentioned, erm, both of which have had exactly the same operation as I have and have just been discharged after five years within the last three or four months.

INT: YEAH.

Patient: Both very successfully, and having said all of that, there's another friend of a friend, if you like, that had breast cancer eight years ago, she actually lives in Canada, and she had total mastectomy and has since had reconstruction and, you know, with her everything seems to be fine. So, on the other hand many, many years ago there was another friend that had breast cancer and obviously it went into the lymph nodes and she eventually died. So you get both sides of the coin I think really, and you have to accept that, you know, some can and some can't.

INT: AND YOU SAID YOU GOT PICKED UP ON THE MAMMOGRAM, IS THAT RIGHT?

Patient: Mm, mm.

INT: CAN YOU JUST TELL ME ABOUT HOW THAT ACTUALLY CAME ABOUT, HOW IT HAPPENED?

Patient: Erm, the mammogram was taken in, erm, the end of May. Normal routine mammogram that I'd gone for on a regular basis in Loughborough. I had a notice three weeks later that I was going to be recalled, the letter was very, erm, nicely put, trying not to sort of concern you. Having said that it is a little bit of a concern. Erm, it was to be a week later, which was in fact three weeks ago today that I actually went for a recall mammogram.

INT: AND THAT WAS AT THE GLENFIELD?

Patient: That was at the Glenfield Breast ...

INT: MM, THE FIRST ONE WAS IN LOUGHBOROUGH, DID YOU SAY?

Patient: Yes, it was the mobile unit ...

INT: OH RIGHT.

Patient: ... that they bring to Loughborough every so often. Erm, so I went along to Glenfield, the mammogram was taken again. It did, the letter did warn you that you might have to have an

ultrascan or tests if it was necessary. So when I was called into the ultrascan room I knew full well that something was amiss, I mean it was obvious. Erm, they did a scan and they did a biopsy. Erm, the following Monday I went back for the results and obviously was told that the area was cancerous and a week later I was having the operation. So within three weeks ...

INT: THAT WAS QUICK, WASN'T IT?

Patient: ... three weeks today, I've actually been analysed, had the op and out. So the system I can't fault at all.

INT: RIGHT, OK. WHEN YOU WENT FOR, WHEN YOU FIRST GOT THE LETTER TO SAY GO BACK FOR ANOTHER MAMMOGRAM, I MEAN WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: I can't think initially I was too concerned. I spoke to, obviously spoke to my husband about it, and I spoke to my GP about it, purely because he was a friend, not because, erm, I mean if he'd just been out GP I wouldn't have rung and said, 'I need to talk to you, I've had this letter.' Erm, he was quite good, he did reassure me that quite a lot of ladies in the area had been recalled, but did say that, you know, a certain percentage they were going to find that there was something, but the majority they didn't. So at this stage there was no point in the, in being too concerned. Everything seemed quite positive. I had nothing to feel, also he felt if there was a problem then it couldn't be a massive problem. But on the other hand he was quite - he's really good, he'll talk to you and, so I felt a little bit about it, better about it. And I've just remembered actually, my cousin-in-law was here at the time, she lives in Sweden, and she'd actually had, and I'd forgotten, breast cancer and had similar, you know, circumstances, and she reassured me, she said, 'You know, whatever happens you've got to be positive about it.' So I can't think that the day I walked into the breast cancer unit at Glenfield I was too concerned: I don't think at that time my brain had actually told me that something could be wrong. And even having the scan and the, erm, the biopsy - because at that point they still don't know whether it's positive or negative - erm, the staff were excellent. I had somebody with me the whole time either having the mammogram or the breast cancer nurses was with me, no, I was never left at any point on my own.

INT: OH THAT'S GOOD.

Patient: When I went in for the scan there was the breast cancer, there was a doctor, there was the girl taking the ultrascan - everybody was so caring and, you know, the reassurance was there, so I don't, I didn't feel vulnerable at that stage at all. And even when I went back in to see the doctor who then said, 'Look, you know we really can't analyse it at this stage, it could be, you know, it could be something, it could be nothing, and until we've done the biopsy test we can't tell you,' erm, and at that point I did ask her what, you know, what could happen, because being a positive person I wanted to know. I said, 'What could be the worst scenario?' So she said, 'Well the worst scenario is that it could be a cancerous tumour and that we have to remove it, but again, at this stage, you know ...' So I was still fairly positive about things. Erm, and at that stage we didn't tell anyone: didn't tell the family or anything, because it seemed a bit pointless ..

INT: YEAH, OF COURSE, [???

Patient: But we only had to wait a week, I mean the following Monday I went back in and actually saw Miss Stotter and, erm, initially, erm, I think I was a bit wary of what she was going to say. Erm, having said that, she's a very forthright lady ... wonderful ... she's just been a godsend really because she doesn't mince her words and yet she's very careful about she says this - it sounds weird really - and she actually said, you know, that, erm, she didn't sound sorry or, you know, whatever, it's, you know, 'You have breast cancer,' and it still, it doesn't hit you as such, it doesn't, I don't think, 'Gosh I've got a life-threatening problem here.' But then she went on to say, erm, this is what will happen, this is your options, what could happen, what couldn't happen and so on and so forth. And, erm, but she kept saying to me, erm, 'There's something bothering you, what is it?' and subconsciously I didn't know there was anything bothering me, and, erm, so I said, 'Nothing, I'm fine.' So she went on and then said, 'Now tell me what's bothering you,' and, erm - it's still quite emotional actually - 'cos I burst out crying and she gives me the tissues and she said, 'What's the matter?' I said, 'Well there's only ...' it sounds pathetic now, I said, 'There's only two operations in my life that's ever bothered me, one is having a brain tumour - I don't know why - and one is having a mastectomy.' And so she smiled, so she said, 'Well don't you think any of us would be concerned if, you know, if those were the operations we had to face?' So after that things became quite positive and she went through again the wide excision or the mastectomy, erm, and what would happen, how it would happen, and then she said, erm, 'I want you to go ...' oh, actually we went then into the other room with the breast cancer nurse and discussed everything again, any questions, any doubt whatever. And then I went back to see her and she said, erm, ... or was that the Thursday? I went back on the Thursday and saw the ... I'm sorry I'm a bit confused. No, she told me on the Monday about it, and then she said, 'I want you to go home now,' and she said 'I want you to consider your options, think about it, erm, and then come back on Thursday and we'll discuss it.' So I went back on Thursday and she said, erm, I had seen the breast cancer nurse on the Monday and the Thursday, and she said, 'have you made your decision?' and so I said ... 'Are you telling ...' I said, 'cos you've obviously gone through things really well with me,' I said, erm, 'the wide excision operation and the mastectomy,' I said, 'If you're telling me that the mastectomy will save my life, then obviously I have no option. If you're telling me that the wide excision one could be just as successful in my particular case, erm, then obviously that's the one I will do.' So she said, 'I'm leaving it entirely up to you.' So she made me make my own decision because deep down, somebody once said to me, 'Your mind makes your mind up before you know it,' over any decision in life, and my mind had already made that up. If the operation that I chose, erm, would save my life, then I would accept anything, but I knew that what, in my case, this one was going to be helpfully as successful as the other. And so I said I'd go for that one. So, erm, so she said, 'Right.' So again we go back and see the breast care, you go through it all with her again. Nothing's left to guessing, erm, you know, you go through time and time again, any questions, any procedures, anything you need to know, and even, they give you the consent form to sit down there, really discuss it with, because obviously John was with me in all this. Erm, so nothing was left to chance: nothing was maybes or perhaps's or 'Are you absolutely certain?' And when we went back and she said, 'Are you really certain about this?' and I said, 'Yes, I'm absolutely positive certain.' And so then we made a date for the following Tuesday.

INT: RIGHT.

Patient: So it was all very positive at the end. Erm, I certainly didn't lose sleepless nights over deciding which operation because in my book that was the one that was going to suit me. Erm, and as it's turned out it's hopefully been very successful. But ... I think you have to listen to what your consultant says, and I have to, I think you have to see beyond what they're saying.

They will put the pros and cons and the fors and against, but I think somewhere by the way they're saying it comes a positive reaction from it. I also did have a long chat with, erm, Peter Cannon ...

INT: YEAH, YOUR GP.

Patient: ... again, only, not because he was my GP, but because he'd actually worked ...

INT: AT NOTTINGHAM.

Patient: ... in a breast cancer unit.

INT: YEAH, AT NOTTINGHAM.

Patient: If he'd have been my normal GP I would not have considered it because the professionals, the breast care nurses, are there to do that job. And they, I only got from him what I would have got from them. Erm, but they reinforced it anyway.

INT: YEAH. SO WHAT DID PETER SAY THEN? WHEN YOU SPOKE WITH HIM, WHAT DID YOU TALK ABOUT?

Patient: Erm, he basically told me, 'cos I wanted ... I'm a very upfront person, I can face anything if I know what I'm dealing with, and that's the honest ... erm, so I said I wanted to know what the operation entailed, what the consequences could be, what the worst scenario could be, and he told me quite truthfully. But, on the other hand, he did say that there were lots of positive signs in my case. I mean I did ask her how big the area was and at that point it was approximately 8 millimetres and he told me that, you know, a really concern would be anything above 2 centimetres and this sort of thing. So, again, he was doing what Miss Stotter was doing, they were reassuring me on one hand that all the positive signs were there, but on the other hand still making me aware that Mother Nature's Mother Nature [chuckles] and really and truly, until it all happens, you don't know what it's gonna do.

INT: YEAH, OF COURSE.

Patient: So ... I went in I think with very positive feelings about things. On the other hand I think subconsciously you don't realise, you know, what the worries are, and your brain acts quite stupidly at times. Erm, although my mother had the breast cancer, and this is what Peter tried to reassure me, 'cos he treated my mother - I mean, this is the whole ...

INT: OH RIGHT, OK, YEAH.

Patient: ... scenario of it - erm, he assured me that I couldn't compare my situation with hers, which helped, because I couldn't. Obviously at the point of my Mum's being diagnosed, the only thing they could do was palliate it: there wasn't even an operation, there was no options to that. Erm, so that, that sort of helped, but my father also died of cancer. Erm, he had Hodgkin's lymphoma and he, he's not my biological father, he was my stepfather but he'd been my father since I was 18 months old because my father was killed during the war, erm, and so there was no related part there - it's not from your father anyway, is it? Erm, but he again, although he'd been ill for quite some months with a cough and whatever, he had Hodgkin's lymphoma and, erm,

he again died within six weeks of being diagnosed. And so then I was thinking, and this is very real really, thinking, 'Right, so I've got breast cancer and, you know, my lymph ...' - this is why it was so important to me - 'my lymph nodes could be affected, which means it could be anywhere,' and my brain ran riot. But the nice thing is I've got a very supportive husband who is medically trained, erm - he didn't tell me at the time but apparently he'd got sheets and sheets and sheets off the internet of different scenarios and what we could do and where we could go if it was and whatever, which he didn't discuss with me at the time, but all he did was, erm, if I felt sort of a bit down about things, I'd sit and talk to him and tell him what was worrying me and then he'd either poo-hoo it and say, 'I've never heard of such rubbish in my life,' or he'd talk it through with me. So I think in all honesty I have had the best back-up team in the world, you know, from a husband to a GP to, I mean the breast cancer unit itself, I just think is ... and the ward I was on, the nurses, the care - in fact I'm going to write a letter because I don't know how else to express to them all that, you know, what they do is just incredible.

INT: YEAH, THAT CERTAINLY SOUNDS THAT YOU'VE HAD A LOT OF SUPPORT, WITHOUT A DOUBT.

Patient: I have. I have, I've been very, very lucky.

INT: YOU'VE HAD SOME PRETTY SOUND ADVICE ALL THE WAY ALONG THE LINE REALLY.

Patient: Yes. I mean we haven't sort of openly dis-, openly told that many people, erm, it's not something I wanted to discuss with anybody, but on the other hand I feel, I was talking to my son today and I just feel that sometimes now perhaps, if I knew that somebody was in the same situation, I would be happy to give them a little bit of back-up somehow. Fortunately, you know, mine's fairly positive, but, er, I still think it's necessary to hear these things.

INT: YEAH, OF COURSE.

Patient: Because you'll think you all the only one out there, and when you've, you know, see that there's so many women, it's just amazing, absolutely amazing. Sorry, I'm [???

INT: NO, YOU'VE GIVEN ME NEARLY ALL THE INFORMATION WE NEED REALLY. [CHUCKLES] ERM, JUST GONNA GO OVER A FEW POINTS, GOING BACK TO WHEN YOU WENT FOR YOUR MAMMOGRAM FIRST AT GLENFIELD, YOU SAID THE BREAST CARE NURSE WAS WITH YOU ALL THE WAY AND THAT, WHILE YOU WERE GETTING ALL YOUR TESTS, DID ANYONE GIVE YOU, ERM, AN IDEA OF WHAT MIGHT BE WRONG OR, DURING THE TESTS?

Patient: The radiographer, erm, when I had it taken again, she said, erm, that, er, there was a shadow on the x-ray, erm, this could have been caused by the equipment, it could have been caused by the developing, erm, or it could have just been by tissues overlapping. Those were the positive points, but on the other hand she said obviously there could be a small area of concern. So again it was putting lots of positive things there, but on the other hand not building you up to think everything was going to be wonderful.

INT: YEAH, OF COURSE. MM.

Patient: And the letter itself did say that it might be necessary to do other tests, so your brain is already ...

INT: PREPARED.

Patient: ... erm, geared up to thinking, 'OK ...' I knew when the breast care nurse came to take me down to another room where you would normally see the doctor to be told it was fine or not and, as I say, it had ultrascan on the door, so you know when you go through the door that that's the next step. But then, as I say, there was, there was actually four of them in the room: there was a student, I presume a student doctor, there was the doctor that took the scan - she was lovely - and then, erm, the breast care doctor and a breast care nurse. And they were all so, as I say, they were just lovely. They, any, you know, 'Are you OK?' 'Are you comfortable?' and every step of the way told you exactly what they were doing.

INT: THEN YOU SAID AFTER ALL YOUR SCANS YOU WENT TO SEE A CONSULTANT, WAS THAT, OR A DOCTOR, IS THAT RIGHT?

Patient: Er, yes, when they'd done the scan and the biopsy you went to see - and I can't - Doctor, was it Dr Reed? It was a short name. I'm sorry, time's gone so quickly, erm, ...

INT: WHAT DID SHE LOOK LIKE?

Patient: Erm, quite a tall lady, erm ... 50s ...

INT: EATON?

Patient: Yes.

INT: ELIZABETH EATON.

Patient: Yes, yes. Yeah, I knew it was a short name but I couldn't think, yes. 'Cos I've got Dr Peat at, 'cos obviously she's the next one, yes, and she was lovely. And, erm, she was very wary what she said at first, but then I just asked her straight out, I said, 'I need to know.' I said, 'I want to know what the worst scenario could be,' and she was, she was very nice, she told me. Which again was positives and lots of positives.

INT: DID SHE AT ALL AT ANY TIME DISCUSS TREATMENT OPTIONS? I CAN'T REMEMBER NOW.

Patient: No.

INT: NO.

Patient: No, she didn't.

INT: THEN YOU SAW THE BREAST CARE NURSE AFTERWARDS, THAT'S RIGHT.

Patient: Erm, no, I didn't see the breast care nurse after that. That was the end of the session really.

INT: RIGHT, OK.

Patient: Then I had to come home for a week and wait for the results, and then I went back on the following Monday, and that's when I was seen by ...

INT: MISS STOTTER.

Patient: ... Miss Stotter. Erm, the breast care nurse again came and got me from the waiting room, she took us both in, John and myself, she sat in the room alongside another nurse, erm, who obviously works permanently on the clinic, and Miss Stotter, so there was three of them there again. And, erm, all supporting me, and then I think I went, then I think we went into the little patchwork room, the little room where you sit and had a long chat with her, the breast care nurse, again, about questions and procedures. Erm ... and then obviously we went home. Then we were back on the Thursday and this is when a decision was asked for.

INT: IN BETWEEN SEEING DR EATON AND THE FIRST TIME YOU SAW MISS STOTTER, ERM, DID YOU DISCUSS, ERM, WHAT IT MIGHT, WHAT THE OUTCOME MIGHT BE WITH ANYBODY?

Patient: No, no-one at all.

INT: NONE AT ALL, RIGHT.

Patient: No, no.

INT: DID YOU LOOK FOR ANY FURTHER INFORMATION AND THINGS?

Patient: I didn't, John obviously did.

INT: RIGHT. YES, BUT HE DIDN'T TELL YOU AT THE TIME.

Patient: No. No, he didn't tell me at the time. All he kept saying was, 'Look, whatever it takes, we'll make sure that you, you know, we'll take it to whatever steps,' so I suppose he was looking at the worst scenarios. I'm not sure that at that stage I was.

INT: DID YOU HAVE ANY THOUGHTS AT THAT POINT ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF AN OPERATION OR ANYTHING LIKE THAT, IF IT CAME BACK AS CANCER?

Patient: Erm ... I don't think I did. Erm, I think, I think in honesty my mind went into limbo. It was a question of, well I've had the tests, I've got to wait for the results before we move on from that. Erm, as I said, I mean I'd talked about it with John but not to any degree really. We just, that week just seemed to be endless I think, if I was [???] ...

INT: YEAH, [???]

Patient: But, having said that, again, I was fortunate or whatever because I went on the Monday, erm, the Wednesday we went to Ascot for the day which we do each year, with Peter

Cannon and his wife actually, then on the Thursday I was back in London for a river cruise with the Guild, 'cos we're members of the Freedom of the City of London, so the whole week was taken up really, and the weekend was busy - I can't remember what we did - and he kept me busy, so I really didn't have time, there was so many things to sort out and I do work and stuff. So, erm, I didn't really, if I was honest, have time to even think about it.

INT: RIGHT.

Patient: And I didn't think about it until the Monday morning ...

INT: RIGHT, OK.

Patient: ... when I knew I was going in the afternoon. [chuckles]

INT: SO WHEN YOU WENT IN TO SEE MISS STOTTER FOR THE FIRST TIME, ERM, YOU SAID THAT THE NURSE CAME AND COLLECTED YOU AND YOU WENT IN WITH YOUR HUSBAND, AND THERE WAS A BREAST CARE NURSE THERE AND ANOTHER NURSE ...

Patient: Yes, there was.

INT: ... SO WHAT HAPPENED AFTER, IMMEDIATELY AFTER THAT THEN? I MEAN, SORT OF, HOW DID SHE JUST BEGIN, IF YOU LIKE, WHAT DID SHE SAY TO YOU?

Patient: Erm, I sat down ... and I can't remember what her first words were, a greeting of some sort. I think may, I think if I was honest, the only thing that really stands out, and it was very shortly after I sat down, she might have just said, 'We've got your tests back,' or I don't really know, erm, she said, erm, 'You have breast cancer,' ... maybe I'm exaggerating, it didn't come out maybe like that, but maybe that's the only thing that stuck in my subconscious, you know, 'You have breast cancer,' it's a very bold statement.

INT: YES, OF COURSE.

Patient: And I remember saying, 'Right, right, OK. So what do I do now [???]?' Erm, but then she went on to stress that it was ... oh no, she didn't, she asked me, I remember now, she asked me what Doc-, that was the first thing she asked me, I remember now, what Doctor Eaton had said to me the week before. And I said that she'd, erm, I told her what she'd said basically and that, you know, I would get the results today. And she, right, and that's when she said, 'You have breast cancer.' and so then she went on to say that, I did say that they'd had an aw-, they'd had a job to find a bump or anything and the scan had been difficult and I'd have to have three lots of biopsy because again it was difficult to find. And she said, 'Well, the reason that it was difficult to find was that it was so small.' She said, 'It's just a very tiny area, erm, which could be removed,' and then she went through both operations. She said, in fact I think she said, 'I've got a funny feeling that she said the mastectomy first, not the other one, I might be wrong - erm, it's only three weeks ago but there's been so much water under the bridge - erm, but she went into full flow about the wide excision and what I would have to have and went on to say, and then it would, it was more or less certain I'd have to have radiotherapy and, erm, possibly Tamoxafen, which I didn't realise was a hormone drug, which again she explained to me. Erm, and then, erm, as I say, so she went through all that with me then. Erm, and then obviously we went the bit where I had the little cry, and then I apologised and said, 'I'm fine now,' and she chatted

a bit more. Erm, and then obviously I was left to come home and think about my decision, but the big decision then of course was we'd have to tell the family. I mean we've got five children between us: I've got two John's got three, we've been married 20 years now. So I felt duty bound, although it was very emotional, to go and tell the children directly from the hospital, erm, which we did. We rang my daughter: we got my daughter to go home from work and my son to join her and we told them there and then. And then I think John actually rang ... no, we didn't, we went and told the other physically because we felt that was fair. And only told, not even a handful of friends, I think, our three closest friends - one because we were supposed to be going to Dublin with them the weekend I was gonna be in hospital [chuckles] and the other two because they are my close friends and, as I say, they've been very supportive. So ... so we haven't had a lot of, erm, I didn't want a lot of hassle and whatever.

INT: YEAH, OF COURSE. AND WHEN MISS STOTTER WAS TALKING YOUR DIAGNOSIS AND ABOUT THE TREATMENT OPTIONS, DID SHE USE ANY VISUAL AIDS SUCH MAMMOGRAMS ...

Patient: No.

INT: ... DID SHE DRAW YOU DIAGRAMS ...

Patient: No.

INT: ANY [???] OF ANY KIND LIKE THAT?

Patient: No, nothing.

INT: NOTHING AT ALL? OK. RIGHT. AND, ERM, HOW DID YOU FEEL THAT YOU GOT ON WITH THE, WITH MISS STOTTER?

Patient: Perfectly.

INT: YEAH. DO YOU FEEL THAT SHE LISTENED TO YOUR NEEDS AND CONCERNS?

Patient: Yes, I do.

INT: YEAH.

Patient: And I, erm, yes, because she was astute enough to pick up that something was bothering me, whereas I don't think a lot of people would have done. I mean, erm, anyone would be upset if they're told they've got breast cancer ...

INT: ABSOLUTELY, YEAH.

Patient: ... there didn't need to be an underlying reason, but she needed for me to say it and, erm, and she said it twice. So, erm, yes, I do think she does. You know, she's a very strong person I'm sure, but on the other hand I'm sure she's, well she is obviously a very caring person, and she cares about her patients. But very straight to the point, and I think that's so nec-, well with me she was, but maybe that's because that's how I wanted it. So maybe any consultant or doctor has to listen to their, you know, to their patient's needs. You know, if somebody goes in

and falls apart they don't necessarily want to hear, you know, what the worst scenario could be, do they? I don't think.

INT: AND THE BREAST CARE NURSE, HOW DID YOU GET ON WITH HER?

Patient: She's lovely, Jane. Yes, absolutely wonder-, in fact there was three breast care nurses, there was two Janes I think and a Sue - again I ...

INT: SUE [???

Patient: ... as I say, I saw so many of the ... is there, there is a Sue, isn't there?

INT: YES, SUE [???] AND THERE'S TWO JANES, THERE'S REYNOLDS AND [???

Patient: It was Sue that I, that was with me when I had my biopsy I am sure, and the two Janes, the Jane with the long, blonde hair, is that ... erm ...

INT: [???], TALLISH GIRL.

Patient: Yes.

INT: SHE'S [???

Patient: Yes, a lovely, lovely girl. She was the one that was around with me most of the time.

INT: YEAH.

Patient: But the other Jane did come and see me in the ward as well, and in fact one of them was in every day at some point.

INT: OH THAT'S GOOD.

Patient: And, er, very, erm, all my questions were answered. I think the written information is just incredible. You were given a leaflet ...

INT: YEAH, I WAS GOING TO ASK YOU ABOUT THAT THEN, HOW USEFUL DID YOU FIND THAT? DID YOU [???

Patient: Very, very useful. It's very much in layman's terms, obviously you were given them on seroma, lymphoma, erm, the operation itself and ..

INT: WHAT, BOTH TYPES OF OPERATIONS COVER, YOU KNOW, LIKE, WAS IT MASTECTOMY AND ...?

Patient: No.

INT: ... OR WAS IT WIDE LOCAL?

Patient: ... No, I think it was just the wide one, because I think that's the one I'd chosen. I think that was given to me, erm ...

INT: THE SECOND VISIT?

Patient: .. the second visit, [chuckles] yeah. Erm, and then obviously in hospital the one on exercises, then the one on seromas and lymphoma, that was after that I think. Erm, I've since been given one on the radiotherapy, erm, but nicely written, nice, easy to, very easy to read, erm, anybody I feel could understand them.

INT: RIGHT, OK.

Patient: So ...

INT: AND, ERM, WHEN YOU WERE TALKING ABOUT YOUR DIAGNOSIS AND TREATMENT OPTIONS, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENT?

Patient: Everything I think.

INT: MM, YEAH?

Patient: Again, it was in very layman's terms, there was nothing, erm, medical about it in a sense, you know. I was told that the area, how big the area was, because I asked [chuckles] again, you know, how said, 'How big's the area?' and, erm, that was cancerous and that would be removed, erm, and an area around that was gonna be removed, which makes sense. Erm, the only thing that was different was that initially I was told I would probably have two incisions, one to the breast and one to the lymph nodes. Erm, the bonus was that I didn't, I've only got one, and apparently, erm, the nurse did say that, you know, 'If Miss Stotter can do this she does.' Obviously mine was in the upper right quadrant so it was an ideal situation to have all of it removed in one incision.

INT: YES, OK.

Patient: So that was very nice, and that was the only bit of information that was slightly different from what I'd been told.

INT: RIGHT, OK. AND WAS THERE ANYTHING YOU THINK YOU DIDN'T UNDERSTAND, OR FOUND HARD TO UNDERSTAND?

Patient: No.

INT: OK.

Patient: I think, I have to be honest, though, erm, as I said to you before, erm, we are sort of a medical background, you know, I've got lots of medical background to me as of friends, erm, I've been into hospital for a few major operations and I think I've learned over time, so I don't think I would be perhaps as, erm, perhaps a lady that hadn't had any of these .. I was going to say advantages ... it's not really an advantage, [chuckles] but, erm, could feel the same, so I think

you'd have to be asking someone that had not, you know, had their questions answered earlier in different forms. So ...

INT: ERM, DID YOU EVER GET AN IMPRESSION AT ANY POINT, ERM, FROM EITHER MISS EATON OR MISS STOTTER OR ANY OF THE BREAST CARE NURSES THAT ANY OF THEM HAD A PREFERENCE FOR A PARTICULAR TYPE OF OPERATION?

Patient: No.

INT: NONE AT ALL?

Patient: No. No, I didn't.

INT: RIGHT, OK.

Patient: No, I didn't. Erm, I ... as I said, I'd discussing it with Miss Stotter, and that's the only one I really discussed the operation with in any form, was that I kept sort of saying about the mastectomy or the other one and, erm, she more or less said, 'You have to make the decision,' and I said to her, 'But you're the professional,' and she said, 'But it's your body.' And then all I wanted to ascertain from her was that the, erm, the wide excision one would, erm, benefit me personally ...

INT: RIGHT, OK.

Patient: ... but again, although I think, I think maybe she leant slightly towards that one because she knew from my, from me as a person, it could work. Erm ...

INT: WHAT MADE YOU THINK THAT?

Patient: I don't know, I don't know.

INT: A FEELING?

Patient: I don't know. There was nothing that, again, because she still insisted I made the decision for myself. Each time, 'Are you sure?' 'Is that what you want?' Erm, and all I could say, well, you know, 'This, the excision one, the wide excision one, is that going to work for me?' and she said, 'Yes.' On the other hand then I'm saying, well, you know, 'Is a mastectomy gonna save my life?' so I think it was, it was, but at the end of the day there wasn't really a decision to be made. I just felt towards that one but that might have just been me as a person.

INT: AND THE BREAST CARE NURSES, DID YOU SPEAK WITH THOSE ABOUT THE OPERATIONS?

Patient: Only the excision one because, as I say, the decision had already been made.

INT: RIGHT, YOU DIDN'T SEE A BREAST CARE NURSE ON THE MONDAY, DID YOU? WHEN SHE ASKED YOU TO GO HOME ... DID YOU SEE A BREAST CARE NURSE AFTER YOU SAW MISS STOTTER THE FIRST TIME?

Patient: Yes ... do you know, I'm not sure. I know we had a long session with Jane, but that was on the Thursday because my appointment was at twenty to two and we didn't leave the hospital until about quarter to four. And most of that time had been spent with Jane in the little, little room, chatting over different things and signing the consent forms, erm ... I really can't remember actually. I might, she might have, I think that's ... I'm sure we'd been in that room before, so I'm sure we did go in on the Monday after I'd seen Miss Stotter and she went, because she must have given me the, erm, some paperwork. I really can't remember, I'm sorry.

INT: NO, THAT'S OK. AND IN BETWEEN THE FIRST MEETING WITH MISS STOTTER AND THE SECOND MEETING WHERE YOU'D MADE THE DECISION, DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSE OR THE TEAM OR ANYTHING?

Patient: No.

INT: OK.

Patient: No, I didn't. I ...

INT: AND ... SORRY?

Patient: No, I didn't, I actually, as I said, told the family and then just went back on the Thursday.

INT: AND, YEAH, SO YOU TOLD THE FAMILY AFTER THAT MEETING ON THE MONDAY?

Patient: Mm.

INT: THE FIRST TIME. AND I MEAN HOW DID YOUR FAMILY TAKE IT.

Patient: [chuckles] Erm, I think they, well my daughter, erm ... because my Mum had obviously, she immediately, that was it, you know, cancer ... morphine ... any of these names to her are, you know, 'That it, you've had it.' So, erm, and my son was quite upset, but you have to sort of then try and say to them, 'Look, please don't compare, give it a chance.' Initially I broke down obviously but I said to John, 'I have to tell them,' so ... excuse me ...

INT: NO, THAT'S OK, TAKE YOUR TIME.

Patient: Erm which I did. And I thought there's only one way to do it and that was just say it.

INT: MM, YEAH, JUST COME OUT WITH STRAIGHT AWAY. MM.

Patient: But of course being summonsed as they were ... they knew something was wrong. Erm ... so anyway, I just, we sat there and I just said it. I said, 'I've got breast cancer,' er ... but then we talked about it and, erm, tried to be fairly positive about it. We told them exactly what, as much as we knew what was going to happen and that I was going back on the Thursday and it would be decided when it was all gonna happen. So, I think, er, they both took it quite hard, but on the other hand ..

INT: YEAH, OF COURSE. [???

Patient: ... erm, they coped with it, and they've coped with it since, er, you know, they've been really good. Erm, and I'm sure that, you know, both of them in the background have been quite devastated ...

INT: YEAH, OF COURSE.

Patient: ... but they've never been, and they've, you know, they've supported me every inch of the way - as have the other three I have to hasten to add, which are my stepchildren if you like. They've been just as supportive and wonderful, as I say, and, erm, obviously when we got the news last Thursday, er, everybody celebrated which was quite nice. So ... yeah.

INT: AND YOU ALSO HAD SUPPORT WITH PETER, IS THAT RIGHT?

Patient: Sorry?

INT: IN BETWEEN SEEING MISS STOTTER THE FIRST TIME AND THE SECOND TIME, DID YOU SPEAK WITH PETER?

Patient: No.

INT: NO, IT WAS AFTER WAS IT?

Patient: I, John actually, erm ... ooh, wait a minute, I'm telling a lie. Yes, I did. John actually went and told him on the Tuesday morning, we'd learnt on the Monday, erm, obviously Monday ... no, I'm telling lies, I'm telling lies completely ... sorry.

INT: THAT'S OK. TAKE YOUR TIME.

Patient: We didn't tell Peter until Miss Stotter had confirmed to me that I had it, so the Monday that I went back for the repeat mammogram, he knew I was going but I didn't speak to him again ...

INT: UNTIL AFTER YOU'D [???

Patient: ... until after I'd got the results.

INT: THAT WAS THE FOLLOWING MONDAY, YEAH?

Patient: The following Monday we told the family and John rang him and he came straight over ...

INT: DID HE? OH THAT'S NICE.

Patient: ... that Monday night, and spent an hour and a half, that's, you know, telling me all about what with answering all my questions ...

INT: RIGHT, OK.

Patient: ... because I found I was so upset obviously when I left the, erm, clinic, I really couldn't ask questions, I didn't ...

INT: NO, IT'S VERY DIFFICULT.

Patient: ... it's, all that was concerning me was telling the family at that point, not what was happening to me, that was irrelevant, erm, and so he sort of, you know, went through it all again, an hour and a half.

INT: IT KIND OF DROPS, IT STOPS YOU DEAD IN YOUR TRACKS, DOESN'T IT?

Patient: Yes, it did, it did. It's, and it wasn't for me, I don't think, in all honesty it wasn't for me, all I knew is I had to tell the family and how they would react to it, you know, I'm thinking ... that's what worried me most, not for myself. Erm, you know, and how are they gonna cope with it? But, as I say, initially they were very upset but, er ... once the realisation set in I think we all cope with anything because you have to, don't you?

INT: YEAH, YOU'VE GOT TO GET ON WITH IT.

Patient: You get on with it, don't you?

INT: YOU GET ON WITH LIFE, MM.

Patient: That's absolutely right.

INT: YEAH, OF COURSE.

Patient: And, erm, so, er, yeah they've been brilliant.

INT: ERM, LET ME SEE, WHERE ARE WE? WE'VE MOVED ON QUITE A BIT NOW. ERM, HOW LONG DID YOU, FROM HEARING THAT YOU HAD A DIAGNOSIS OF BREAST CANCER, HOW LONG DID IT TAKE YOU TO MAKE UP YOUR MIND WHAT OPERATION YOU WERE GONNA HAVE?

Patient: Erm, from the Monday to the Thursday I suppose: I think I made my mind up there and then.

INT: WHEN YOU HEARD THE DIAGNOSIS DO YOU MEAN OR ...?

Patient: Yeah.

INT: RIGHT, OK.

Patient: And she said what the options were. I think I knew there and then.

INT: YOU KNEW THEN REALLY, YEAH, OK.

Patient: Subconsciously anyway. Erm, I don't think, I don't think I had a choice really, I don't think, erm, I'll be really honest, I mean, as I said to you earlier, my, one of my biggest fears in life for some reason or other is having a mastectomy.

INT: RIGHT, OK.

Patient: On the other hand, if it's gonna save my life ...

INT: YES, OF COURSE.

Patient: ... then it wouldn't bother me. Erm, I was given an option of having mastectomy or an operation that would be just as successful - maybe that was my interpretation because maybe that's what I wanted to know - erm, so I think I'd immediately made my mind up that if that operation was going to be successful for me, then there wasn't an option.

INT: RIGHT, OK.

Patient: But if I'd have been told, as you've just said, 'It's a mastectomy or nothing,' I wouldn't have hesitated - or even if I'd been told, 'You can have the lesser of the two **but** there was a possibility that ... you know, it can recur, blah blah blah ...' I still wouldn't have, I would have then gone for the mastectomy.

INT: RIGHT, OK.

Patient: So, but because talking it over it seemed to me that it was a fairly positive option, as it has proved to be, erm, and for that I'm grateful, but, erm, it's more by luck than judgement I think probably.

INT: AND AT ANY POINT DID YOU EVER CHANGE YOUR MIND ABOUT WHAT SURGERY YOU WERE GONNA HAVE?

Patient: No.

INT: ONCE YOU'D MADE YOUR MIND UP THAT WAS IT?

Patient: Mm.

INT: ERM, WHERE ARE WE? ERM, SO, WE'VE GOT AS FAR I THINK AS YOU TELLING ME THAT YOU'D MAKE YOUR DECISION, YOU'D SEEN THE BREAST CARE NURSE, YOU WENT BACK THE FOLLOWING MONDAY FOR THE OPERATION? IS THAT RIGHT?

Patient: Tuesday.

INT: TUESDAY, SORRY. CAN YOU JUST TELL ME WHAT HAPPENED WHEN YOU WENT IN FOR THE OPERATION?

Patient: Erm, well I had to be there at 8 o'clock in the morning and the operation was going to be in the afternoon. Erm, the pleasant surprise was that I had this beautiful room [chuckles] quite, again, more by, it was just the luck of the draw, the, I don't know if you know the ward 23a but

it has two bays of 6 beds, plus two side wards, or three side wards I think. I happened to end up in a side ward, beautiful room, my own bathroom, erm, big windows, the sun streaming in, whereas the other one was quite dark. So I thought, 'Gosh,' you know, 'I've fallen on my feet.' Erm, obviously that was, that was pleasant, although I'm sure being in the bays is just as pleasant, it was just that I think, you know, having this nice big ... and your own bathroom I think was nice, although it would have been just as well in the ward I suppose. And, erm, and from the minute I got there at 8 o'clock, Angela, was on duty, erm, she was in and out like a, you know, making sure I was all right. Then obviously you've got lots of, lots of nurses with lots of questions about lots of different things [chuckles] or the same thing over again, which was good really because it kept you completely busy, erm, took your mind off ... although as I say the operation really didn't bother me, and that is the honest ... I was not bothered about an operation, anaesthetic and thing. We were fortunate that, erm, Sue Taylor is an anaesthetist at Glenfield, John had actually worked at Glenfield, and she lives just up the road from here and so she came down to say hello. I also saw her in theatre but she didn't do my operation because she does Dr Windle, is it, another consultant?

INT: OH YEAH, RICHARD WINDLE, YEAH.

Patient: Erm, so that was nice, that made it more friendly. Again, quite a few of the members of staff actually recognised John as his, as they're patients or whatever [chuckles] it was quite funny really. Erm, and then one of, erm, Miss Stotter's associates, I don't know what position he was, came and had a long chat with me. He was going to assist in the operation.

INT: OH, RIGHT, OK.

Patient: A really guy who'd come from ...

INT: WAS THIS A SPECIALIST REGISTRAR OR SOMETHING?

Patient: He came from, he'd being doing cardiac at, erm ... oh, Brompton Hosp[ital in London.

INT: OH RIGHT.

Patient: Erm, oriental ...

INT: CHAND?

Patient: It could be. I can't remember. Really, really smiley, very, very pleasant, he came and sat and had a long chat. Erm, and then the anaesthetist came and, again, sat with us for quite some time and chatter about different things. So the whole morning was really taken up by people in and out.

INT: YEAH.

Patient: Erm, I was supposed to have had the operation, I think I second or third on the list, but in fact they changed the list and so my operation was scheduled then for half past one, which was quite nice, but in fact I went down at quarter past one. And, again, the ...

INT: WAS IT MISS STOTTER THAT CARRIED OUT THE OPERATION?

Patient: Yes.

INT: YES, THAT'S RIGHT, YEAH.

Patient: Well, I'm saying yes, I believe so. I, that was another question that I did ask her, erm, because obviously she's got such a wonderful reputation, Peter knew of her reputation. the two ladies that I'd spoken had, she'd done their operation, and I said to her, I did have, she said, 'Have you any questions?' - this was before, on the Thursday - and I said, 'Yes, there's just one,' I said, 'You know, I've heard such, you know, good reports about ... and I feel so confident in you, are you going to do my operation?' and she said that it's a team that does it ...'

INT: SHE ALWAYS SAYS THAT.

Patient: Yeah, she said, 'well it's a team that does the operation ...

INT: [???

Patient: ... 'So ...' but then she said, 'Unless I get pneumonia that day, the probability is yes.'

INT: YEAH, SHE'S VERY, SHE IS VERY, VERY PROUD OF HER TEAM. MM.

Patient: Yeah, she did say that, and, erm, so I did, I gleaned from, she never actually said, 'I personally did it,' I gleaned from what was said that, yes, she did do it. Erm, one of her registrars did pop one day and just said, 'Hello,' purely because he was a friend of Sue Taylor's, which was [???]. And so ...

INT: AND WHEN YOU CAME ROUND FROM THE OPERATION HOW WERE YOU? WERE YOU ALL RIGHT?

Patient: Fine, erm, I must have come round fairly quickly I think and I had the operation at half past one, I believe I was down for a couple of hours or so, erm, two, two and a half hours, erm, and I got back into the room, I remember being popped back into bed, and obviously John stayed with me until about eight o'clock at night and I, I remember having a drink of water and drifting in and out of sleep, as you do after an op, erm, but I felt fine, I didn't feel sick, I didn't feel, erm, obviously they were checking my, erm, blood pressure and so on and did that a couple of times during the night.

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

Patient: I went in on the Tuesday, I came out on the Saturday afternoon.

INT: RIGHT, SO FOUR, FOUR OR FIVE DAYS.

Patient: Yeah. That was choice. I could have, they basically said, 'You can stay as long as you wish,' erm, so I came home with one drain. The breast drain they took out, I think that was on Thursday, and then by Saturday, erm, they said, you know, 'The choice is yours, you can either go home with the drain and monitor it and ring in each day, or you can stay.' And I have to be

really, really honest, I found it very difficult to make a choice. I was comfortable there, I was well looked after, it was, the girls were so lovely ...

INT: YOU'D SETTLED YOURSELF IN THERE.

Patient: ... erm, most of them were doing this Run for Life on the Sunday.

INT: WAS THE FOOD NICE?

Patient: Mm?

INT: WAS THE FOOD NICE?

Patient: Erm, this is on record, isn't it?

INT: SAY WHAT YOU LIKE, IT'S ALL CONFIDENTIAL.

Patient: It could be better. [chuckles] Not really, the first day, my first day after the operation, because you sort of what other people have ordered and not been, erm, and not [???] it was sandwiches, all day sandwiches because the choice was, the hot food was, I think it was shepherd's pie, which I don't like anyway, so it was purely me that didn't [???], so the sandwiches, so they weren't too bad. Erm, I can't say it was brilliant. Having said all of that, the omelettes I can absolutely say were wonderful. I had an omelette one day, that was lovely, and the bread and butter pudding they do beautifully, but, erm, I know one day she did take my soup away and that was before I said anything, she said, 'Ooh, you can't eat that,' it was a bit solidified [chuckles] it was a little bit like solidified jelly. So, so no, it wasn't brilliant. But I think, you know, it can't be easy. The trouble is that you get this wonderful menu that you choose from and it sounds absolutely wonderful, and when it comes it's not quite what it's supposed to be.

INT: MM, I THINK IT'S SO MASS PRODUCED I MEAN ...

Patient: Well what they do is, they cook it all, you see, and push it into these heated trolleys and then they heat it up when it arrives on the ward, which I found out when I went back to get my drain out, so how can, it's cooked and then just pre-heated, so it's going to be dried up round the edges and ... anyway, I survived.

INT: ERM, YEAH. SO, AND THEN YOU CAME HOME ON THE SATURDAY, AND THEN WHEN DID YOU SEE, DID YOU GO BACK TO SEE MISS STOTTER? YOU WILL HAVE [???]

Patient: No, I went back on the Tuesday to get my drain out.

INT: OH, RIGHT, OK.

Patient: I rang in and ... it has to come out seven days anyway.

INT: THAT'S RIGHT, YEAH.

Patient: So I went back, got my drain out, and then I went back last Thursday.

INT: TO SEE MISS STOTTER, YEAH?

Patient: Yes, yes.

INT: MM, AND THAT'S WHEN YOU GOT THE GOOD NEWS WAS ...

Patient: Yeah. I walked in and she said, 'You look well,' so I said, 'Yes, I've been on holiday, didn't you know?' So she smiled, so she said, 'Well I've got some really good news for you,' and immediately she said it, she doesn't, 'I've got some really good news for you,' she said. So that put me at ease to start with 'cos I have to be honest it's the only day really that I've gone to the breast cancer unit, really not knowing, not knowing what to expect, and I was absolutely petrified.

INT: I CAN IMAGINE, YEAH.

Patient: Mm, really, really petrified.

INT: BUT YOU GOT GOOD NEWS.

Patient: Absolutely, yeah. So I said to her, 'Can I cry now?' so she said, 'You can if you want, here's some tissues.' [chuckles] So I said, no, so I waited till I got outside and cried. But that was just because I was overwhelmed with joy.

INT: WAS JOHN THERE AS WELL, WAS HE?

Patient: Yes, yes, he was with me every inch of the way.

INT: ERM, OK. A COUPLE OF QUESTIONS TO FINISH OFF WITH. ERM, WHAT WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU HEARD OR THAT YOU READ OR WHATEVER THAT HELPED YOU MAKE A DECISION WHAT, TO HAVE THE WIDE LOCAL EXCISION?

Patient: It was what I heard.

INT: WHICH WAS?

Patient: What I was told, I suppose. Erm, and because it was explained to me in a very positive way that was the most important thing. I hadn't read about it, I didn't know anything about it. Erm, Dr Eaton had explained in simple terms what the operation was, erm, but when Miss Stotter went through it again, to me, again, as I said to you before, maybe because it's what I wanted to hear, but it was so positive, there wasn't a question, well you know, there could be a problem, it was a very positive statement of terms of how it was going to be and what the results would be. Well obviously you can't say what the exact results are going to be, so it was the way that it was relayed to me personally, but I still wonder if it's because I wanted to hear.

INT: RIGHT, OK. AND NOW YOU'VE GOT FIVE WEEKS' RADIOTHERAPY?

Patient: Yes.

INT: DO YOU KNOW WHEN THAT STARTS?

Patient: Erm, I don't.

INT: OH, YOU SEE DR PEAT, DON'T YOU?

Patient: Yes.

INT: THAT'S RIGHT.

Patient: I saw Miss Stotter on Tues-, on Thursday, they, Jane, the breast care nurse, said that, er, I would possibly get an appointment with Dr Peat in two weeks, but the radiotherapy starts very soon after that. So I can only assume it'll be in about three weeks' time.

INT: AND THAT'LL BE AT THE ROYAL, WON'T IT?

Patient: Yes. They were hoping that Dr Peat would see me at the, at Glenfield, just as an initial consultation.

INT: BUT I MEAN THE RADIOTHERAPY'LL BE AT ...

Patient: The radiotherapy's all at the Royal and she did explain that it would be every day for five days of the week, erm, but sometimes, if a bank holiday comes into the middle of it or anything it does extend the time, so she said it's normally five weeks but if you allow six weeks it'll cover it.

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

Patient: Impeccable. I could not, this is why I feel it's, I've got, we have to, I have to write, because I can't believe the first visit with Miss Stotter, we have got private medical insurance, my, the majority of my operations apart from the one on my hand have all been done in the private sector, erm, and we did mention on my first visit when she first told us that we have private medical insurance, you know, is it of any help? Thinking ... and she said, 'Not at all,' and she was absolutely right. I ... I couldn't think that anything, I couldn't have been given more support, more care, more professionalism, better attention than I've had. I mean three weeks from start to finish, with all these professionals - the breast cancer unit's been open I believe now six years, these girls have all got so much professionalism, erm, they've got so much at the back of them. You go in there, they know their patients, - or patients that have come back for, you know, check-ups years la-, a year later. Erm, and that's what it's all about. And the, ward 23A, again, exactly the same. The girls were so caring, they've been there such a long time. I mean one of the girls that, one of the staff nurses, I mean she'd been there since it's opening. And this is, this is what it obviously is all about. And I don't think in the private sector you would get that. I truly believe that you cannot get the care and attention, erm, and the high standard in a private sector that you do get - believe it or not - in an NHS hospital when you have breast cancer. I wouldn't have wanted to have been anywhere else.

INT: MM. ERM, IF YOU WERE TOLD YOU COULD, YOU HAD THE POWER AND MONEY TO CHANGE SOMETHING ABOUT THE SERVICE AT GLENFIELD, THE BREAST CARE SERVICE, WHAT DO YOU THINK IT WOULD BE?

Patient: ... Well because I've said what I've said, I suppose ...

INT: [???

Patient: I can't, yeah, there's nothing really. Erm ... I think if I had money to change things then what I would do, I would go and ask them what they feel would improve ... the service itself to me ...

INT: THEM, THE PROFESSIONALS?

Patient: Yes.,

INT: YES.

Patient: ... I would ask, I would ask the consultants, I would ask the radiographers, I would ask the breast care ... breast care nurses especially. Erm, I'm sure that money needs to be put in there, erm, but I think the reasons would have to come from them, erm, because the unit, I think, works so well because they all work as a team. I was gonna say, 'enjoy what they're doing.' They can't possibly enjoy what they're doing in a sense of, you know, because it's, they're working with life and death each day. Erm, but they do such a fantastic job, but I'm sure they could do with a lot more money ploughing into it. But I think that, from my point of view, it couldn't come from me, it would have to come from them because only they would know, you know, where bits and pieces are needed, even if it's equipment, if it's more staff, erm, because they work so hard in there. I mean they never stop. The ward they don't stop, you know, I've never seen such dedicated people. They don't sit around.

INT: MM, I THINK THEY SEE ABOUT 50 WOMEN A WEEK, NOT ALL WITH BREAST CANCER, BUT ABOUT 50-ODD I THINK THEY SEE A WEEK.

Patient: I can believe that.

INT: YEAH, IT'S QUITE A BIG UNIT.

Patient: So this is what I say ...

INT: IT'S A BIG CATCHMENT AREA.

Patient: I mean even the, even the cleaner on the ward, I've never seen anybody clean anywhere like it. We said to her, the bed goes up, she cleans the knobs underneath ... it's, er, you know, and that's someone that they're trying to sort of put onto another ward. Erm, why when you've got such a dedicated person? It's ... they're all, so, yes, that's where I would, I wish I had that amount of money because I would certainly dedicate it to that unit. I think it could be of great assistance, but how ... maybe they need more staff, maybe they wouldn't have to work quite so hard. Anyway ...

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

Patient: I think the most important thing really isn't ... well perhaps it is to do with diagnosis, the first thing is that, erm, all women should be encouraged to have mammograms. That I think is, has got to be, for me, the most important thing. Erm ... and the most important thing about ...

INT: WHEN YOU SAY ALL WOMEN, I MEAN, IT'S CURRENTLY BETWEEN ...

Patient: ... fifty and sixty ...

INT: FIFTY AND SEVENTY.

Patient: Is it fifty and seventy?

INT: IT'S BEEN EXTENDED TO SEVENTY NOW.

Patient: Erm, I mean I don't know enough about mammograms and how they become of use. I certainly know that, I think, is it something like 30, below 40 they're not really of any diagnose, they're not diagnostically viable, are they? There's something to do with new tissue ... I don't really know, I've not really read enough about it.

INT: [???

Patient: I certainly will, but I think from whatever age medically, erm, is optionable, [?] I think people should definitely, and should go. I mean they were telling us in the unit that, you know, some people don't even attend for the mammogram because, but I think, but then perhaps some people are just feared of the unknown, I don't know. Erm, the diagnosis for me, again, is, erm, I think it's important for me personally to know what you're facing. Erm, I'm not sure how I'd handle that, but I think it's unfair to basically beat around the bush, they never did. I think it's nice to know what you've got, I think it's nice to know what, what you're facing. Erm ... fortunately, you know, as I say, I've been quite lucky, but, er ... but I think even, you know, if it, if it was something a little bit nastier than that, then I think you need to know the truth. But that's me, but I think there's perhaps lots of women that wouldn't think that.

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

Patient: I think they need to know whether or not ... I think with the wide excision, I think they have to be convinced in their own mind that it could solve problems for them. I think, I think it would be nice if people could say, 'Look, your only option is a mastectomy, that anything less than that is gonna be a risk,' then let them make the choice. Erm, so I think possibly that's the only way you can look at it. For me a mastectomy, yeah, if it's gonna save your life, no option at all, but if you're given options then I think that the person has to be convinced that the other one, you know, is fairly positive for them. Nothing is positive in life so I don't say 100 per cent positive. You can't say for the operation I had, somebody couldn't say to me, 'Well, yes, it's 100 per cent positive, it's all going to work out wonderful and fine.' You don't know that. But if, on the other hand, they say, you know, it's iffy enough to say 'Well maybe, maybe not, but the

other one is a definite,' then you go for the definite, don't you? You can't mess about with your life.

INT: IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED? ANYTHING YOU'VE FORGOTTEN? ANY IMPORTANT POINTS WE HAVEN'T COVERED?

Patient: I don't think so really.

INT: NO. I THINK WE'VE GOT QUITE A BIT OF IT DOWN REALLY.

Patient: I think so. I do tend to rabbit on I'm afraid.

INT: THAT'S OK, THAT'S FINE.

Patient: Erm ... no, I don't think there is actually. I, as I say, I can only stress that in my particular case my treatment and everything else has just been 100 per cent perfect, from day one when it was diagnosed, you know. So, you know, what more can you say?

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