

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: Low MR unit

\*DATE:

\*ID: Patient62

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 THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: I thought it couldn't happen to somebody of my age, to be honest, that's the first thing I'd say, because all the people that I'd known who'd got breast cancer were all in their 60s or 70s, and I didn't know anybody of my age. And, erm, and I also thought that if you got it that it was like a death sentence, any cancer was a death sentence, that's what I thought. I didn't realise that, you know, they could treat it and there's quite a good success survival rate, etc etc. So I didn't know a lot really apart from the fact that I just didn't think it was, it could happen - I don't know why I thought that - I just didn't think that I was the sort of age group. And also I was under the false impression that it sort of happened - I thought it happened to women that were post-menopause.

INT: RIGHT, OK.

Patient: And I'm not, you see. And I'd heard that that was, you know, I'd heard a time. I'd also heard that if you've got it in the family you could get it, and there's nobody in my family with breast cancer. I've also heard that, you know, if you were on HRT you've got more chance of getting it. And I didn't fit into any of those categories at all, you know, I've always kept myself fit and healthy and whatever. So I just thought that I was, it just couldn't happen to me. So I didn't know very much about the disease because I didn't think it would happen to someone of my age.

INT: YEAH, MM. AND YOU SAY THERE'S NO MEMBERS OF YOUR FAMILY HAVE GOT BREAST CANCER?

Patient: No.

INT: ERM, WHAT ABOUT ANY FRIENDS OR WORK COLLEAGUES WHO'VE HAD IT?

Patient: No. The only people I know, there's a lady two doors down who's had a lump removed and she's in her 60s. I know a lady of 85 who's had breast cancer. But none of my friends, I mean most of my friends are my sort of age. No, I don't, I didn't, since I've had the cancer, I just can't believe how many people there are of my age that have got it. Erm, so, it's because I never thought it was something I needed to know about, you know, I just didn't really know an awful lot about it really.

INT: MM, OK. ERM, SO CAN YOU JUST TELL ME BRIEFLY HOW YOU ACTUALLY CAME TO FIND OUT THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Well I've always self-examined, every month I've sort of self-examined, and it was a week, it was in May and it was a week after I'd had one of my dogs put to sleep, and I was lying in bed and I was self-examining, and I just thought, 'Shit.' It was like, I thought, 'This isn't right, this is like a

lump,' and it was like under my nipple and it felt really hard and, erm, well it completely freaked me out and I didn't sleep at all that night.

INT: MM, I CAN IMAGINE.

Patient: And what I did was, the next morning I got straight onto the phone to my GP and I said, 'I want to see a lady doctor.' Well, and they said there was no lady doctors in today. I said, 'Right, I want to see a man doctor and I'm coming down now.' And I came down and I've got to say the GP was fantastic, and he straight away referred me to the Glenfield Breast Clinic, and within 10 days I was there. So I actually found it through checking myself.

INT: MM, YEAH.

Patient: Thank God I did really.

INT: YEAH. AND SO YOU WENT TO GLENFIELD. CAN YOU JUST TELL ME NOW WHAT HAPPENED WHEN YOU WENT FOR YOUR FIRST VISIT TO GLENFIELD?

Patient: Erm, I saw a doctor called Mr Goach [?] who in the end wasn't my, he's one of the registrars who works with Mr Windle, and he examined me and he sort of said, 'Well it feels like it's a cyst,' ... that's what he said, he says, 'But I want you to have an ultrasound and I want you to have a mammogram.' So I had the ultrasound and that didn't show anything at all. I had the mastec-, the mammogram and they said to me that they'd seen that little white dot on the mammogram, which could be a sign that it could be cancer. And they said ...

INT: DID THEY ACTUALLY SORT OF SAY THAT AT THE TIME, DID THEY?

Patient: Yeah. I'll tell you a little bit about Mr Goach at the end of this.

INT: [CHUCKLES] OH RIGHT, OK.

Patient: Erm, and then, so what they did was, I had a core biopsy.

INT: THIS IS ON THE SAME DAY, IS IT?

Patient: That was on the same day. Well by now I didn't know what the hell was going on at all, and the breast care nurse, erm, who was looking after me, she said to me, she said, 'You don't know what's going on here, do you?' I said, 'No,' I said, 'My head's completely, I just don't understand what's happening,' 'cos it was being explained to me in very medical terms rather than ...

INT: RIGHT, OK.

Patient: ... sort of personal, and a little bit of sympathy, if you like. So before I had my core biopsy, she arranged for me to speak to one of the, you know, the trained breast care nurses there, who sat down with me and explained to me what was happening. And, erm, and I've got to say I felt a little bit better after that.

INT: OH, OK.

Patient: So I went and had my core biopsy, which was absolutely excruciating, and they said to me, 'Right, we want you to come back in half an hour, 'cos sometimes we can tell in half an hour whether it's malignant or benign.' So I trundled off, came back in half an hour and Mr Goach walked in ... and I had somebody with me ... with a smile on his face, and he said to me, 'Well I can't tell you this week whether it's cancer or not, you'll have to come back next Friday.'

INT: RIGHT.

Patient: Well ... as you can imagine, that completely blew my head.

INT: YEAH, OF COURSE.

Patient: So, to cut a long story short, I broke down in front of him and the breast care nurse spent about an hour with me and that hence why I no longer saw Mr Goach.

INT: RIGHT.

Patient: I was referred to Mr Windle, who was the consultant anyway.

INT: YES, YEAH.

Patient: And I've got to say, totally, completely different man, fantastic bloke, you know, really nice. So my first experience was very bad. I understand that what I went through was like the correct procedure and, you know, and everyone was trying to do their best for me, but what made it worse was the way I was spoken to ...

INT: YEAH, YEAH [???

Patient: ... and how it wasn't, I didn't really know what was going on, but the breast care nurses put that right.

INT: RIGHT, OK.

Patient: So I went away and I had an appointment to go back the next week, erm, for the result of my core biopsy.

INT: OK. SO IN BETWEEN THE TIME OF FINDING THE LUMP AND WHEN YOU WENT TO SEE YOUR GP, UNTIL YOU SORT OF WENT TO SEE, THE FIRST VISIT TO GLENFIELD, I MEAN WHAT WAS GOING THROUGH YOUR MIND AT THIS POINT?

Patient: Well I was on the internet constantly.

INT: I SEE, RIGHT, OK.

Patient: Erm, I've got to say that really depressed me because a lot of, certainly the American websites are quite, quite bad.

INT: [???

Patient: No, you know.

INT: YEAH, I KNOW IT'S [???] NOW BUT ...

Patient: It's too late, I mean I've stopped doing it now, but, erm ... I just sort of, I just thought, felt the worst really, you know, it was the worst week of my life, and I made the decision that I wasn't gonna tell my mum until I knew which way it was because she suffers with a bad heart so I thought, 'I won't tell her.' In fact I didn't tell any, I didn't tell anybody, erm, apart from the friend who'd gone with me to the breast, to the centre. So I just spent all of my time on the internet, finding out things and, well, if I'd have believed everything that I'd read I think I would have probably committed suicide before I got to [???] because it was very depressing.

INT: CAN YOU THINK, I MEAN, YOU WERE LOOKING THINGS LIKE CANCER AND THAT, [???]

Patient: Oh God, yeah. I was looking, I was looking at the cancer and I was looking at, I mean, every single website, and now as I understand it is the younger you are the more likely you are to have a faster growing cancer anyway, so that was like a negative it. Oh I was looking at what Tamoxafen was and, you know, whether to have my whole breast off ... oh, I'd got myself, you know, the worst possible [???] scenario in my head really.

INT: YEAH, THERE'S SO MUCH INFORMATION OUT THERE AS WELL ...

Patient: Yeah. I mean I didn't ask people, I wasn't at that point trying to find out, but I just did it all off the internet. And I've learnt ... I think I know too much now.

INT: RIGHT, OK.

Patient: And, if I could advise anybody, I would certainly say don't look at the American sites because they are quite depressing. There's, I did find a couple of good sites. The BBC do a very good site. So I did, and Cancer BACUP do quite a good site.

INT: YEAH, [???]

Patient: Yeah. So I did find a couple, but the trouble is, when you find a lot of negative things, it doesn't matter what the other sites say, that just ... I mean there was one night when I was up till five in the morning looking at it. So it was a, it was quite a hard time really ... a very long week.

INT: YEAH, I BET IT WAS. ERM, DID ANYONE GO WITH YOU TO THE FIRST VISIT TO THE [???]

Patient: Yeah, I had a friend with me, yeah.

INT: RIGHT, OK.

Patient: Oh, yeah, I couldn't have done it on my own.

INT: YEAH, MM. ERM, SO YOU SAW MR GOACH AND YOU GOT YOUR RESULTS ... OH, YOU DIDN'T GET YOUR RESULTS, YOU GOT TOLD YOU HAD TO COME BACK THE FOLLOWING FRIDAY?

Patient: Yeah.

INT: ERM, SO TELL ME WHAT HAPPENED THAT, I MEAN, HOW WAS THAT WEEK, YOU HADN'T HAD THE ANSWER YET, HAD YOU SO ...

Patient: Well, it was just ... it was just horrendous. I mean I went to work but towards the end of the week I just took time off, I couldn't cope with work.

INT: MM.

Patient: Erm, 'cos I teach the law you see, so my head was just complete ... erm, but then ... do you want me to talk through when I went back for my result?

INT: YEAH, YES, PLEASE DO.

Patient: I went back for my result and I walked into the room and I saw a different doctor that I'd never seen before, really nice man, and he said to me, 'Your core biopsy was negative, nothing wrong with it.' It was, like, came back as normal breast tissue. And I remember saying to him, 'Oh, I haven't got cancer, then?' And he just said, 'We're not happy with the result, we think there was something wrong with the core biopsy and we want you to have another one.'

INT: OH RIGHT.

Patient: So ...

INT: AND YOU DIDN'T FIND THE FIRST ONE VERY NICE, DID YOU?

Patient: No. So the lady, Dr Denton, who does the core biopsies, she's a lovely lady, really nice - well they all were, they were all really nice - and I had to go and see her and because I was so badly bruised from the first one she gave me the option of waiting a couple of weeks or waiting a week and going back to have the ... I said, 'No, just do it.' But, so she did it again and she took a little bit more this time because the first time I had the core biopsy they took two samples, and this time she took three, and she was quite happy that she'd got, got enough. So, well, my breast at that point was just so sore, it was so sore. And that's all that happened that day. And I then had to wait another week to go back for the result. And when I went back for my result I saw, that's the first time I saw Mr Windle, and he said that the rea-, he said that when they'd, erm, that the second core biopsy still showed there was nothing wrong.

INT: OH RIGHT.

Patient: So, by now, my lump in my mind, I felt it was slightly growing, it was getting a bit bigger. Now I don't know whether that was just me being paranoid or pessimistic, but I said to him, I said, and it was starting to hurt me as well, but again I didn't know whether that was the core biopsy, so I asked him if he would remove it, and he said he would. And, luckily, he managed to get me in, erm, four days after that Friday, so on the following Tuesday I went into the Glenfield to have the lump removed. But of course by now in my head I'd been told, I mean I was only, as far as I was concerned I was only having it removed because it was starting to hurt me, that, you know, because I was told the two core biopsies had come back fine, I just thought, 'Well it's fine.'

INT: RIGHT, OK.

Patient: So he removed the lump and he came to see me afterwards and I said to him, I said, 'What do you think, what did it look like?' He said, 'Oh, it looked benign.' So, he says, 'But I need to see you next week,' because obviously they send it off to be checked and everything. Erm, so I went, so for the week I was waiting to go and see him I'd got it into my head, I've had two core biopsies that say I'm fine, he said it looks ...

INT: RIGHT, OK.

Patient: ... benign, and when I went back for the result, I went into the room and he said, ...

INT: IS THIS MR WINDLE? YEAH?

Patient: Yeah. So this was like my third visit to see them, and I lay down on the couch, 'cos I thought he'd just come in and say, 'Oh yeah, it was benign, fine.' I lay down on the couch and he started to feel under my arm. And I said to my mate, and he said, he felt under my arm and then he felt my breast again and he just said to me, 'Put your clothes on and I want to come in and talk to you.' I said to my friend, 'There's something wrong here, because he's never, ever felt under my arm before.' I mean I now know he was feeling for the lymph nodes. And I thought, I just filled with tears streaming down my face, and, erm, he just came in and said it was malignant, but he said the reason why the core biopsies didn't show anything was because the malignant cells were round the edge, and the core biopsy had gone in the middle.

INT: AH, RIGHT, SO, YEAH.

Patient: So when it had pulled out the, it hadn't actually touched any of the malignant bits.

INT: YEAH.

Patient: And of course, when he took the lump out, yeah, 95 per cent of the lump was benign, but there was just that bit round the edge that was the malignant stuff. Well, you can imagine ... if I hadn't have been given that, because initially when I found the lump I told myself it was cancer, I was convinced it was cancer; then - I'm not blaming anybody for this at all - but because of the result I'd got leading up to the operation and the comment that was made after the lump was removed, I was then 99 per cent sure it was gonna be OK. And then to be told it wasn't, it was like up and down ...

INT: YEAH, OF COURSE.

Patient: ... with my emotions.

INT: YES.

Patient: It would have been far better, and I've talked this through with the breast care nurse afterwards, and she said that, well her words were that, 'You shouldn't have been told it was benign, it looked benign,' because, you know, you can't always tell with the naked eye whether it's benign or what. So, I know it was done for the best intentions, but emotionally it screwed me up really, you know. Sort of, I would rather have been told all the way along, 'Look, Sue, we just don't know,' ...

INT: RIGHT, OK.

Patient: You know, 'It could be either.' And that would be, not fine, but that would have been easier for me to cope with rather than give, I've had some hope and then it was taken away really.

INT: MM, OK.

Patient: So that was the first operation.

INT: AND YOU HAD ACTUALLY REQUESTED THAT OPERATION?

Patient: I asked him to remove it. And thank goodness I did.

INT: YEAH, EXACTLY. AND WHEN HE, WHEN YOU WENT BACK FOR YOUR RESULTS THE FIRST TIME AND YOU SAW MR WINDLE, HE DID THE EXAMINATION AND THEN HE ASKED YOU TO COME IN THE ROOM, SO HOW DID HE, HOW DID HE, CAN YOU REMEMBER THE WORDS HE USED TO EXPLAIN WHAT IT WAS, THE RESULTS WERE?

Patient: What, you mean after he felt under my arm and then ...?

INT: YEAH.

Patient: He just sat down with me and he said, 'I'm really sorry,' he says, 'But some of the, you know, the edge was malignant.' And he said it a lo-, you know, you can't fault him the way he told me, you know, it was done in a really nice way, and he just said, 'I really, really wish I could give you like good news.' Erm, I felt he was really concerned about it, you know, genuinely concerned. But no, completely different to my experience with Mr Goach, completely different. Restored my faith a lot really.

INT: RIGHT, YEAH.

Patient: And I had a breast care nurse in with me and after he'd given me the results, 'cos he, 'cos when he gave me the result he said, 'I want to go in again and get a better margin,' he said because the fact that the cells were on the edge, he said, 'I need to get a better margin.'

INT: RIGHT, OK.

Patient: And the breast care nurse explained that to me, what that meant. So I was quite happy that I understood what ...

INT: DID YOU GO IN A SEPARATE ROOM WITH THE BREAST CARE NURSE, DID YOU?

Patient: After Mr Windle'd left.

INT: YEAH? CAN YOU REMEMBER WHO THE BREAST CARE NURSE WAS?

Patient: Erm, that was Maureen.

INT: YES, MAUREEN, YEAH.

Patient: The main two I've had dealings with is Maureen and Sue.

INT: SUE [???]?

Patient: Yeah.

INT: YEAH.

Patient: They're the two. Maureen probably a little bit more. Certainly on my third time with the, when I had the mastectomy, I saw her a lot more, but I've not really had any dealings so much with the others, just with those, those were the main two. So I was obviously really, really upset but at least I knew, I just kept saying, 'Thank God I asked him to remove it.'

INT: MM, YEAH.

Patient: Because when he first said to me, when it came with the core biopsy, when the two core biopsies came back negative, he did say he wanted to see me again in six months, so he obviously in his mind thought ...

INT: YEAH.

Patient: ... things weren't 100 per cent, but I suppose call it intuition, I just felt that something wasn't quite right and I wanted it removing.

INT: YEAH, SURE.

Patient: You know, I didn't want that reminder every time that it was there, it was hurting me.

INT: AND WHEN HE, WHEN MR WINDLE HAD DIAGNOSED IT AND YOU WENT TO SEE MAUREEN, DO YOU REMEMBER WHAT YOU TALKED ABOUT WITH MAUREEN?

Patient: Whether to have the whole breast off or not.

INT: RIGHT, OK. DID YOU DISCUSS THAT WITH MR WINDLE AS WELL OR ...?

Patient: That came later.

INT: OH RIGHT, OK.

Patient: Because what happened was, Mr Windle was going on holiday.

INT: RIGHT, OK.

Patient: He gave me the results on the Friday and on the Monday, on the next day he was going off for three weeks, and he actually gave me the option of having the wider margin done with another surgeon, and I said, 'No, I'd like you to do it.' So while we were there we arranged for my second operation to be three weeks later when he, like the week he came back from holiday, and that's when my conversation with him ended. And then I went into another room with Maureen and we just talked about whether I should have, because I kept saying 'I want the whole breast off, I want the whole breast off.' And she sort of listened to me and she said, 'Look, it's your decision, Sue, but go away and think about it.' Which I did. I even went to my own GP and talked to him about it. Because in this time I'd found out that the cancer I'd got was grade three, and I understand now what grade three means, but nobody had explained that to me. Because I asked, I'd asked Mr Windle, 'Was it aggressive?' and he said, 'Yes.' And I now know that, you know, grade three's like the most aggressive and that most people of my age seem to get this grade three. But I went to my GP and asked him to explain to me what grade three meant. And I talked it through with him about whether I should have the mastectomy or whether I should have the wider margin, and he sort of just gave me the sort of, a balanced view really of, 'Well, this is the benefits of this, and this is the benefits of that, but it's obviously down to you.' So after thinking long and hard and then going on the internet again to find out what grade three meant, erm, I went, I rang up the breast care nurses the week before my operation was due, and I made an appointment to go and speak to Mr Windle the day before my operation to talk through with him about, relative about having the whole thing off, because I'd decided by then I wanted the whole thing off. I didn't want to take the risk of having a wide margin because it'd been explained to me that, if they still weren't happy with the wider margin, I'd have to have the whole thing off anyway.

INT: RIGHT, YEAH.

Patient: So, because it was a grade three and I knew it was 2 cm, then I just thought, 'Right, just take the whole thing off.' So I went to see him the day before my operation, Mr Windle, and I felt - and this is quite important to me really - I felt I was talked out of the mastectomy.

INT: RIGHT, OK. WHAT MADE YOU FEEL THAT THEN?

Patient: Because, whereas my GP had given, had listened to what I had to say and gave me the pluses and minuses of going either way, Mr Windle said to me, and I'll never forget these words, he said, 'I don't like doing mastectomies,' he said, 'I'm confident I can get a wide margin even though ...' 'cos I said to him, 'Look, I know I'm a grade three,' I said, 'So, you know ...' He said, 'I'm quite happy,' he said, 'I'm quite confident 'cos you've caught it early,' erm, and he said, 'I'm quite happy that I can get a

wider margin.' So the way he was talking, he didn't give me any, there was no sort of discussion really on having my whole breast off, all the discussion was on him saying about me having this wide margin. And every time I brought up the subject of having the whole breast off, I felt that, because Mr Windle didn't want to do it and he was happy that, he wasn't really listening to what I was saying.

INT: RIGHT, OK.

Patient: So, rather than us having a balanced conversation, it was all weighted on having a wider margin. So, and he had another doctor with him, he had a, erm, a student, you know, a trainee doctor with him.

INT: YEAH, OK.

Patient: So there was me and the two doctors in there. And although she didn't get involved in the conversation, there wasn't a breast care nurse in with me and I just ... I feel that I sort of ... went with what he said, rather than what - 'cos I'd gone in there, I'd gone in there to tell him I wanted a mastectomy.

INT: YEAH, SURE.

Patient: And to rip up the consent form and sign another one.

INT: RIGHT, OK. SO YOU'D DONE A CONSENT FORM?

Patient: Yeah, I'd done the consent form for the ... but I was told all the way through that that could be, like, that can be ripped up half an hour before the operation. So I'd gone in to do one thing and I'd come out - and even when I came out I still wasn't 100 per cent that I'd done the right thing.

INT: RIGHT, OK. DID YOU SEE THE BREAST CARE NURSE AFTERWARDS?

Patient: No.

INT: OK.

Patient: Erm, I suppose because they'd, like, it wasn't a proper appointment, they'd like pushed me in and I'd gone in ...

INT: YEAH, OK.

Patient: So he hadn't got a lot of time, and I understand that. So I came out and so he went ahead with the operation as it was originally agreed for him to do the wider margin and to take out level one of the lymph nodes, erm, because he didn't think that, he said, 'If there is any lymph node involved,' he said, 'it's very minor.' Erm, so he did that and then I was in hospital for about five days and I came out and I had, got my results again a week later, and he said, he said, 'I'm not happy I've got the wide margin.' He said, 'If I'd have gone 1 cm more I would have got it.' Well ...

INT: SO WHAT WERE YOUR THOUGHTS AT THAT POINT THEN?

Patient: I was really angry ... really angry. I didn't tell him I was. I just, I just thought, I just kept saying to myself, 'Why didn't I go with my gut feeling to begin with? Why did you talk me out of it.' And he was nice about it, he said, 'Look, I'm really sorry, Sue,' because the reason why, because what he thought, when he gave me my results and he said 'If I'd have gone for another centimetre I'd have got the wide margin,' he thought, he drew me a little diagram on a piece of paper, and he was quite confident that maybe I've got like little dots of cancer sort of all over, 'cos he said there was like little spurs going off and ... so he thought it was important that I had the whole breast off really quickly. So, oh, and there was one lymph node involvement, which was the one nearest the breast, so obviously that's not good but it could have been a lot worse, so I wasn't ... So he, I was, so while I was there we made an appointment for me to back into hospital four days later ...

INT: TO HAVE THE MASTECTOMY?

Patient: ... to have the mastectomy. He gave me the option of having the chemo first and then going back to have the breast off, or having the breast off and then having the chemo. Well, I just wanted it off. I didn't want the thought of going through ... 'cos the chemo's what's bothering me more than the operation so I didn't want to go through the chemo and then have to go through having an operation again. I just wanted a ... and also, because of what he said about he thought there might be, like, dots everywhere, I thought, 'Well, get it off me then,' you know, 'Just take it away.' So I had the mastectomy - by now I was quite low, I've got to say. I'd started off reasonably positive and by then I was really, really cheesed off. So I had the mastectomy and I'd got, well in my mind it was good news about the mastectomy, because when he, when I got the results, he said, 'No, there wasn't any, it was all confined to the middle bit,' he said there was no, you know ... So I said, 'So you're quite happy then that you've got it all?' and he said, 'Yeah, I'm happy I've got it all,' he said, 'It was all confined to the middle and if I'd have got another centimetre I'd have got [???]

INT: OK.

Patient: So that's why I've had three operations.

INT: YEAH, ONE ... THE FIRST ONE WAS YOUR CHOICE, [???]

Patient: Oh yeah.

INT: THE SECOND ONE WAS THE WIDE LOCAL, AND THEN THE MASTECTOMY.

Patient: So if I'd have had my time again, I would have, I really wished I'd have stuck to my guns.

INT: RIGHT, OK.

Patient: And, erm, if I could give any doctor any feedback, it's like, 'Listen to what your patient's saying really and, you know, you might think, "Well, the best thing is this," but listen to why they don't want to go with that and sort of ...' Rather than it be a discussion between us, I felt it was a one-sided discussion, that's the best way I can describe it really. And because there was two doctors in the room and I didn't have a nurse in with me ...

INT: YEAH - YOU HAD NO PATIENT ADVOCATE THERE TYPE OF THING?

Patient: Yeah, yeah, you know. Erm, because when I had a breast care nurse with me before, we were all involved in the conversation so I felt I had my support with me, but because I ... I just felt a little bit, not intimidated, because he's not an intimidating man, I just ...

INT: DID HE SAY WHY HE DIDN'T LIKE DOING MASTECTOMIES?

Patient: He said he doesn't like doing them on women of my age.

INT: RIGHT.

Patient: Erm, because I'm 44 and that's what he said, he said it really upsets him to have to do a mastectomy on women, younger women. And certainly, because obviously speak in hospitals, and the other women who were in my ward on the three times that I'd gone in, there were some surgeons where everybody seemed to have a mastectomy; and then there was other surgeons, Mr Windle being one of them, where they were all the wide, the wider ...

INT: EXCISIONS, YEAH.

Patient: Yeah. So, obviously different surgeons have, different ways really. And as it's turned out in the end, you know, what, the three operations haven't been detrimental to my health or anything like that. I just felt that I was put through an operation I didn't need to be put through.

INT: YEAH, AND IT'S KNOCKED YOUR SPIRIT A BIT REALLY, I SUPPOSE?

Patient: Yeah. I mean I'm still positive, don't get me wrong, you know, I'm still positive and, you know, I've asked Mr Windle, you know, 'Have I got a good chance of beating this?' and he said yes, you know, and I've asked the chemo people who said yes, so I am positive but at the time it was quite stressful.

INT: YEAH, I'M SURE IT WAS. WELL, THE QUESTIONS HAVE GONE OUT THE WINDOW ...  
[CHUCKLES] [???] QUESTION TWO AND THAT WAS [???] OK.

Patient: Sorry I went on ...

INT: NO, NO, THE THING IS YOU'VE ANSWERED MOST, MOST OF THE QUESTIONS I WAS GONNA ASK ANYWAY, SO ...

Patient: I'm quite glad that you're here actually because that's quite important feedback. That's the biggest feedback I could give any doctor.

INT: YEAH.

Patient: I mean, it's just this thing really about, I think a woman knows her own body, don't they? I mean even when I first found the lump, my initial thought was, 'I want to have the whole breast off.' I know that probably wasn't realistic at the time. And even now part of me wishes I'd had the other breast off, even though there's not cancer in, 'cos I've got it into my head that cancer's gonna come in there. Do you know what I mean?

INT: YEAH.

Patient: Whether that's feasible or not I don't know but, you know, well, at the end of the day it's only a bit of flesh, isn't it? So ...

INT: WHEN YOU MENTIONED, DO YOU THINK ANY OF THE STUFF YOU READ ON THE INTERNET INFLUENCE YOU IN ANY WAY ABOUT WHERE YOU WERE THINKING ABOUT WHAT SURGERY TO HAVE, ANYTHING YOU READ THERE?

Patient: Only that, only when I understood what grade three was. Erm, and the fact that all of the sites, didn't matter which one I went on, were all very clear that the younger you are the faster potentially it grows, and, I mean, I've got my, I've got like a little support group now of people I've met in the hospital. All the women of roughly my age or younger, all of us were grade three. I was, I'd actually got the least lymph nodes involved, because most, some of them, I've got one friend who had over 20 lymph nodes involved - now I know that's really bad. But we're all, we've all ended up at the same place: we've all ended up now having mastectomies, and most of them have gone through what I've gone through, they had to have the wider margin that didn't work so they've had the mastectomy.

INT: YEAH.

Patient: Erm, you know, so, and all of them said, 'I wish we'd have just gone for the mastectomy in the first place.'

INT: RIGHT, OK.

Patient: And I know there's the other side of the coin, that, yes, if Mr Windle had have got the clear margin, I could have save my breast, I understand that.

INT: YEAH, SURE.

Patient: But it was gonna be deformed any, he explained to me that, 'cos he had to take quite a bit out, that it wasn't gonna look right, and I just, in my mind I just think if it's not there it can't come back in there. Do you know what I mean?

INT: YEAH.

Patient: And the prosthesis that they give you are so good, you know, and I've already been told I can have reconstruction in 12 months, so, do you know what I mean? So it's only, you're only sort of not having a breast for 12 months, do you know what I mean, it's not like - if that's the route you want to go down, I mean not all women have a ...

INT: YEAH, OF COURSE, YEAH.

Patient: So it's not like you're gonna be without a breast for the rest of your life. It's a temporary thing. But, you know, the benefits of, mentally, outweigh that, I think.

INT: WHEN, SO WHEN WERE YOU ASKED TO TAKE PART IN THIS, THEN, JUST AS A POINT OF INTEREST?

Patient: What, this project?

INT: THE STUDY, YEAH.

Patient: I'd got, I'd come out of the hospital having had the mastectomy and it landed on my doorstep about two days later.

INT: OH RIGHT, OK. AND YOU SAID SOME FRIENDS [???] DO YOU KNOW ANYBODY ELSE WHO'S DOING THIS? DO YOU KEEP IN CONTACT WITH THEM?

Patient: Yeah, but I'm the only person that's ...

INT: RIGHT, OK.

Patient: ... that's doing it.

INT: I JUST WANT TO KNOW IF THERE WAS ANYBODY ELSE.

Patient: Not that I'm aware of, no. They've certainly not mentioned it.

INT: OK. ERM, OK ... THINKING ABOUT THE TIME YOU SPENT WITH ME WINDLE, WHEN HE WAS DESCRIBING TO YOUR DIAGNOSIS AND THE OPERATIONS AND THINGS LIKE THAT, DID HE EVER USED ANY KIND OF VISUAL AIDS OR TOOLS? YOU MENTIONED A DIAGRAM I THINK, DID HE USE ANYTHING ELSE?

Patient: He drew, he drew, he drew an armpit and he drew, like, the lymph nodes and explained to me what he'd done and which one was, got the cancer in and the fact that the others were clear. He explained all that, and he did, you know, a couple of times he did a drawing of a breast and sort of explained what he was gonna do. So, yeah, he did really. And he didn't use any language that I didn't understand or ...

INT: RIGHT, OK.

Patient: ... or whatever. You see by now I'd been on the internet and I did know too much and, in hindsight, there's things I wish I didn't know. Do you know what I mean? Like, erm, I wish I'd just left it as, 'Yes, it's aggressive.' I wish I didn't know it was a grade three, but my GP told me anyway so, you know, I would have found out, but I wish, part of me wishes that ...

INT: YEAH, I THINK INFORMATION'S A TWO-EDGED SWORD, SOMETIMES IT EMPOWERS YOU BUT SOMETIMES IT FRIGHTENS AS WELL.

Patient: Yeah. I mean I know women that have rung up the breast cancer place and have asked what their survival rate is, you know, they've explained down the phone, 'This is what I've got, this is what I've had,' and the people on the other end of the phone have said, 'Well, are you sure you really want to know?' and they've said yes. Now I don't want to go down, I don't want that information, thank you, you know. Erm, but, yeah, I mean, some women have even gone further than I have to try and find out.

INT: ERM ... JUST LOOKING AT THE QUESTIONS TO MAKE SURE I'VE GOT EVERYTHING. ERM ... THINKING ABOUT THE TIMES YOU SPENT WITH THE BREAST CARE NURSE, HOW DID YOU GET ON WITH THE BREAST CARE NURSES?

Patient: Oh, they were brilliant, absolutely brilliant.

INT: DID YOU FEEL THAT THEY WERE LISTENING, UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, DO YOU THINK?

Patient: Yeah, I mean, I don't think I could have got through it really. And what I did was, when I had the mastectomy, and I sort of looked at it for the first time, I got quite upset, so, and I asked for the breast care nurse to come and see me, and I just said, 'Right, I want you to stand there,' and I just like got, you know, took my top off and said, 'What do you think?' And that really helped me talked through it and it was like a real emotional support for me. Oh, I can't, I can't criticise them at all. They've been absolutely fantastic. And that, they have like a help-line that you can ring any time of day, and I've used that a couple of times and they always get back to you really quick if, you know, the phone's, you know, if, like, there's nobody there or whatever. No, all of them, all of them have been really good.

INT: MM. AND THINKING ABOUT THE TIMES YOU SPENT WITH MR WINDLE, HOW DO YOU FEEL YOU GOT ON WITH HIM?

Patient: I got on really ... I got on, I got on with him really well, and I found that he explained things. He's like, he's a really gentle man, he's a real ... and he hates giving you bad news, but he does it in a nice way. Erm, my only - and I obviously think he's, you know, I can't criticise his surgical skills 'cos I think he's a fantastic surgeon - there was just that one issue about not really listening to the fact I kept saying 'I want a mastectomy'. That was the only thing. Erm, and I've talked this through with the breast care nurse and she did say that she was going to speak to him about it. But everything, no, a lovely man and always came round to see me in the ward, you know, really nice. Yeah - I don't regret having him as my surgeon at all. I would, you know ... there was just that one, one thing. I mean I've got there in the end, I just could have got there a bit quicker really.

INT: YEAH, RIGHT OK. AND DID THE BREAST TEAM GIVE YOU ANY WRITTEN INFORMATION, SUPPORT INFORMATION, YES?

Patient: Yeah. Yeah, I had it on, before I went into hospital I had, like, all the sheets on what the operation was about. When I, before I went in to have the mastectomy, erm, they actually got a prosthesis out and showed me, you know, what it did and explained to me about all the different bras and swimming costumes you can have and ... oh, yeah. There was nothing I didn't know or didn't get information on. So, yeah, that was really good, that was really a good part of it.

INT: MM, OK. AND DID YOU AT THE INFORMATION AND STUFF AND DID YOU FIND IT USEFUL IN ANY WAY?

Patient: Yeah. I've got to say that, after talking to Mr Windle, he'd gone through most of it anyway.

INT: RIGHT, OK.

Patient: Erm ... but I mean I've had some stuff on the chemotherapy and that's quite heavy reading. The leaflets that they gave me, yeah, there was a bout seromas and stuff like that, it was really, really good, no problem.

INT: AND, ERM ... AND YOU MENTIONED A LOT ABOUT BEING ON THE INTERNET, DIDN'T YOU? YOU GOT INFORMATION OFF THE INTERNET. IN ALL THIS TIME, YOU KNOW, DID YOU LOOK FOR ANY INFORMATION OR WERE GIVEN ANY INFORMATION FROM ANYWHERE ELSE, SUCH AS RELATIVES, FRIENDS, SUPPORT GROUPS, BOOKS, MAGAZINES, ANYTHING LIKE THAT? VIDEOS ... ANYTHING?

Patient: I found myself reading everything in the newspapers on breast cancer. Erm, I mean I've got SKY tele and I was going on to all the health channels and trying to find stuff on that, but there wasn't a lot. But what I started to do was, I'd sort of obviously started meeting people by going to the breast care centre quite a lot, and so I was starting to talk more to people. So the information I was getting was from other women that had had breast cancer.

INT: RIGHT, OK.

Patient: But I didn't, I didn't go and try and find any books or ...

INT: RIGHT, OK.

Patient: And I stopped going on the internet.

INT: MM. AND WHAT ABOUT, ERM, YOUR FAMILY AND FRIENDS AND THAT, WHEN DID YOU BREAK THE NEWS TO THEM?

Patient: I told my Mum after I'd had the, erm, first core biopsy, and I told my friends when I found out that it was malignant round the edge.

INT: RIGHT, OK.

Patient: And, erm, one positive thing that's come out of all this is that I've got more friends than I thought I had, you know, so ... no, no, my friends have been really, really good.

INT: MM, OK. AND YOUR MUM, HOW'S SHE?

Patient: Erm, very stressed. She's on beta-blockers for her heart.

INT: OH YEAH.

Patient: And she's very thin anyway and she's, well she looks like a walking skeleton at the minute. I think she'll be glad when I have my first chemo, she's coming with me tomorrow.

INT: OH RIGHT.

Patient: And I want her to sit with me while I'm having it so she can see that I'm OK, 'cos she's obviously heard horror stories about it. And I just want her to see that I'm OK and whatever, so, I think she'll be glad when it's, you know, all the treatments have finished. And I'm going for a check-up with Mr Windle in February and I think, you know, if he says everything's OK then I think she'll be a bit better then.

INT: YEAH, SURE. ERM ... THINKING BACK TO, YOU KNOW, THE OPERATIONS THAT YOU'VE HAD AND YOU TALKED ABOUT THE WIDE LOCAL EXCISIONS AND THE MASTECTOMY, ERM, I MEAN WHAT DO YOU THINK WERE THE MOST IMPORTANT THINGS THAT YOU HEARD OR TOLD WERE THAT HELPED YOU MAKE A DECISION ABOUT WHAT TREATMENT THAT YOU DECIDED YOU WANTED? I KNOW INITIALLY YOU SAID YOU WERE TALKED OUT OF IT, BUT WHAT WAS THE IMPORTANT THING THAT YOU'D MADE YOUR MIND UP ABOUT TO TRY AND HAVE A MASTECTOMY?

Patient: Because it was grade three.

INT: GRADE THREE, OK.

Patient: And because, even, there was like a three-week gap between having the first op to the second and you think negatively all the time and I was just convinced in that three weeks it was gonna like go the size of a tomato. I mean I know that's stupid, but I just thought, I just thought, 'I'll have my breast off and then I'm not gonna be thinking all the while, "Is it there again? Is it coming back again? Just take the whole thing off.'" Because I've not got kids, you know, and losing my breast, it's not really a massive deal to me. Yes, I got upset the first time I saw it, but, you know, I mean I had friends round the other day and I even took my prosthesis out and showed them it, you know, so it's really, it's not that big an issue. The biggest issue for me is that, whatever was there has gone. Erm, so ... it was when I found out my age and the fact that it was aggressive, I just thought, 'Just take it away.'

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

Patient: Fantastic.

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

Patient: Oh God, yeah. I mean you hear horror stories, don't you, about the national health and you see all these things about dirty hospitals, and Glenfield, the ward, it's, I mean the nurses, the ward, erm, well I thought it was spotless. The nurses were fantastic, erm, I mean the longest I've had to wait for anything was seven days, you know. I mean the operations I was getting in within two or three days, I mean, 'cos when I first found out I actually said to them, 'Should I go private? Will I get it done quicker?' and she said no, and that's right, you know, I wouldn't even dream ...

INT: IT MIGHT EVEN BE THE SAME SURGEONS.

Patient: Well, yeah, exactly, although Mr Windle doesn't do private work, but, I mean, I can't speak, I don't know what happens in the National Health in other areas, but much, much better than I ever thought. By far exceeded my expectations.

INT: WAS THERE ANY PART THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: Yeah. What I've explained to you about Mr Goach right at the beginning and, just the issue with Mr Windle with the mastectomy. But apart from that ... no.

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

Patient: ... that's a hard question.

INT: SAVE THE HARD ONES TILL LAST.

Patient: ... to have the, everything confined to one unit. The breast care centre, where you have all your tests and everything, is like a really nice, up-to-date, modern building, and it would have been nice to have had the wards and the theatres and everything in the same place. But you had to go into like the main part of the hospital and, although we were having a lot of contact with the breast care nurses, it would have been, I mean there was a couple of times when we had men in the ward when, you know, the weekend when there was beds free. It would have been nice to have had, like, a women's only ... just totally dedicated to breast care, all confined within the same building. That would have been ... I mean I remember one day there was a man getting, I just looked, happened to look to my right, and he was stood there with nothing on, putting his gown on [chuckles] you know. And, like, and obviously the women are walking round in all states of dress and undress, some with two breasts, some with none and ... it was just a bit embarrassing at times. So, to have had it all within the same unit.

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

Patient: I think they need, I think, I found out I was a grade three from my GP. I would have liked to have been told by the people at Glenfield. So maybe a little bit more information, erm, 'cos I felt that I've had to go and find some of it myself.

INT: RIGHT, YAH.

Patient: I mean I decided that I wanted a mastectomy because I went off and found out information. It would have been nice to have had a little bit more explained, because, I mean I understand now through talking to different doctors that, if they had got the wider margin, really there's not a lot of difference in sort of survival rate whether you have that or have the whole breast off. Now I didn't know that at the time. Erm, so just a bit more ... I sometimes think that they were, not frightened to tell me, but didn't want to give me all the bad news. Erm, but I mean I found out anyway, but only 'cos I had to really push and probe and ... so just a bit more information really. So the first when I'd gone I'd have liked them to have said, 'Right, Sue, we've found a lump, it's malignant, it's a grade three which means it's fast-growing, these are your options.'

INT: RIGHT, YEAH.

Patient: And that would have been fine.

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

Patient: ... .. You see I found out all, this is a hard question for me because I found out by looking on the internet, erm, because as far as I'm aware the only two operations is, well, three, is to have the lump removed or to have a lumpectomy or to have the mastectomy.

INT: RIGHT, OK.

Patient: Erm, and I knew that anyway, I knew that through looking ... now not everybody's got internet, have they? Not everybody's got that information, so ... it's quite a hard question really, because I did know what each of the operations involved.

INT: RIGHT, OK.

Patient: Erm ... I certainly, I mean I was given leaflets that explained what a lumpectomy was, I was given leaflets that explained what a mastectomy was, so I actually think, for me, that it was explained.

INT: RIGHT, OK.

Patient: So that's quite ... quite a hard question for me to answer really.

INT: THAT'S OK. ERM, RIGHT THEN, JUST BEFORE FINISH, I'LL HAVE A QUICK CHECK TO MAKE SURE WE HAVE COVERED ...

Patient: Do they normally last this long? [chuckles]

INT: [??] YEAH, 50 MINUTES, 40 MINUTES, THAT'S ALL RIGHT. ER, I THINK THAT'S, I THINK THAT'S ALL WE'VE BEEN THROUGH. YOU SPOKE AN AWFUL LOT AT THE BEGINNING AND YOU COVERED A LOT OF QUESTIONS WHICH KIND OF, [??] BACK-TRACK ON. I THINK THE LAST QUESTION IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE'VE BEEN TALKING TODAY? ANYTHING YOU THINK WE'VE MISSED, ANYTHING YOU THINK WE HAVEN'T COVERED, OR YOU THINK'S IMPORTANT [??]

Patient: No.

INT: NO? SURE?

Patient: Yeah.

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

Patient: OK.

[End of interview]