

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE:

*ID: Patient12

INTERVIEWER: DJW

INT: FIRST OF ALL THANKS FOR AGREEING TO BE INTERVIEWED. LET ME 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: Well, when my Mum was 72 she had a mastectomy but prior to that for several years she'd been saying 'I've been to the doctor and told him I've got this lump in my breast,' and for somebody of my Mum's age group for them to go even to a doctor and let them look at their body was not like it is now: it was very, very personal and private, so she was very brave to have done that - this is 22 years ago, you know. And she went along and the doctor said to her, patted her on the head, because she was only five foot nothing, said, 'Go away Mrs [???], it's just your age.' Well she'd go and she'd stew a little bit longer and then she changed surgeries and she went to another doctor. 'Go away, it's your age,' and she went to about four different surgeries. Finally she ended up at Saltergate Health Centre and she says, 'I saw this big, black man and he said, "Oh, Mrs [???] why ever didn't you seek help before? You are definitely going to lose your breast, you've got cancer."' She says, 'Thank you very much, you're the first person that's listened to me.' Well she had her breast removed at Scarsdale Hospital, that was on Newbould Road, and I went in to see her and she was so proud that she'd finally been listened to, she bared her chest and said, 'Just look at this, it's gone, my cancer's gone,' and they'd run a tacking stitch through it, gathered it up so it was all tucks and folds, and when she got home she had to wash in between each crease with a cotton bud because she hadn't got a flat scar and it was, I think hers was her left, she'd got it from the centre of her chest all the way across in one go, to right across underneath her arm.

INT: YEAH, IT WAS QUITE RADICAL IN THOSE DAYS.

Patient: And it was, she was mutilated.

INT: YEAH, OF COURSE.

Patient: Two years later I'd got lumps in my right breast and under my right arm, but that side is quite lumpy anyway. Now when they tell you to feel yourself you don't really know what you're feeling for, you don't know what is normal that's already there, so you're a little bit in the dark, but I went along and ... to the doctor, and they said, 'Oh it's nothing ...

Patient's husband [?]: I'm sorry if it's a little bit too black for you, I don't know how you like it, whether it's light or dark.

INT: IT'S FINE, IT'S OK. NO WORRIES, THANK YOU VERY MUCH. THANK YOU.

Patient: He can only carry them once at a time because of his arthritis.

INT: OH RIGHT.

Patient: I went along to the doctor, 'Oh, it's nothing to worry about,' so I left it a bit longer and then I went back again and said, 'Can you check me these lumps out, I'm still not very happy about them.' 'It's nothing to worry about, it's nothing at all,' and this went on, and I thought, 'This is my Mum all over again.' Finally I had bleeding from the nipple and back to the doctor,

and he said, 'Well,' he says, 'It's not urgent, it's nothing,' he says, 'but if you insist I'll refer you to the hospital but I'm going to tell them that it's not urgent.' Well several weeks later I had a letter, got an appointment with Mr Lambert, went along to see Mr Lambert and he says, 'I want to analyse the blood.' 'What blood?' I said, 'The doctor said it wasn't urgent, there's no blood there now.' He says, 'Every lump is urgent, you should have been referred.' Anyway at that time - I'm going back now to 1985 - er, and it was nearer the nipple than this one is, my latest one, I had to sign a consent form to say that, if they found anything untoward whilst I was under anaesthetic, they could remove the whole breast.

INT: MM, MM.

Patient: I was absolutely distraught because all I could see was my Mum's scar, all gather up, erm, and I thought, 'I don't want to look like that. I'm still young enough ...' we used to go on holiday abroad twice a year, bikinis, skimpy sun tops and things, and I thought, 'There's no way, this will ruin my life,' and they said, 'well, we'll take you along to talk to one of the patients that's already had a mast- ...' I said, 'Look, no amount of talking,' I says, 'I've got my Mum at home that's, I've seen, etc, no amount of talking to anybody else is going to comfort me.' Erm, anyway, I knew I'd no choice, I signed the consent form. Soon as I came to out of the anaesthetic I felt straight away, yes, my breast was still there. They analysed the lump because they used to take the full lump out then, and they'd taken one of four out from high underneath my armpit.

INT: OH, THE LYMPH NODES.

Patient: Not all of them ... well, no, I don't think it could have been the lymph nodes because this operation is right down here, that one was right up underneath the armpit.

INT: RIGHT.

Patient: Anyway, er, everything was all right, it obviously wasn't cancer, it was benign, whatever. So, in other words, I got away with it that time, I came through with flying colours, all I've got is two scars. Well I was fanatical about examining myself, every night in bed, couldn't go to sleep, so you're feeling ... yes, the lumps are still ... are they any bigger? And it absolutely took over my life and I thought, 'Joan, you've got to stop this. Don't feel them at all.'

INT: RIGHT, YEAH.

Patient: 'Trust to luck that everything's, is all right, they were all right.' So I stopped examining myself for years and years and years to get over it, because it just ruined my life. And then, erm, it's only quite recently that I thought, 'You'd better start feeling again.' So I felt and it was always the right side, because it's lumpy anyway, I never bothered much about the left side at all. And then I thought, 'There's something here. No, it's nothing, it's only small, it can't be, you know, it's just ... is it something or is it just lumpy tissue anyway?' As I say, you don't really know what you're feeling for. With my right hand I couldn't feel it, with my right hand, my left hand it used to go straight to it because as it's bent it was right underneath my fingers and high up, right up here, and I could feel it. Well I'd got this appointment with the doctor already because I'd had three attacks of asthma between November and March, and I'd got to go back for the results of a spirometry test and for a review on my prescription.

INT: THIS IS YOUR GP, YEAH?

Patient: This is my GP. So I went along to see Dr Cooper and we went through what the appointment was for and I said, 'While I'm here, I think I've got ...' I says, 'No, I don't think I've got, I've got a lump.' 'Right, go behind the screen and take your top things off.' So I did and she came and she says, 'Point to where it is.' So I found it with my left hand, I said, 'It's here.' So she felt it and she says, 'Oh, it's very small, I'm sure it's only a cyst, but because you have told me about it I have to refer you. Er, the appointment ...'

INT: IT'S AMAZING THE DIFFERENCE IN PRACTICE, ISN'T IT?

Patient: 'The appointment will come through,' she says, 'within a fortnight.' Well I think it was about two days off, the appointment came through for something like another ten days ahead, so from that point things are stepping up and moving along quite quickly and when I went along, I went to the hospital by myself, thinking, 'He's going to tell me off, I'm wasting his time, it's only a cyst, I shouldn't be here, I'm fanatical again, I'm going through all this again.' Well when I went in to see him he said, 'Right, what will happen, you'll go in and you'll have a mammogram, then you'll have an ultrasound, and if it's necessary they will then do a biopsy, but it's done under local anaesthetic so it won't hurt.' So I trot off into, went and had my mammogram, sat and waited, went in and had the ultrasound and she said, this female doctor said, 'would you like to look?' I said, 'Oh yes,' I'm very interested in medicine, I watch all the hospital programmes, I watch 'Trauma' the real-life London one, I've very interested, I'm not morbid, I just love anything to do with medicine. So she says, 'Oh no,' she says, 'Close you eyes, the machine isn't working,' and I closed my eyes and I thought, 'Well if it's not working, why have I got to close my eyes? There's something wrong here.' So I closed my eyes and she says, 'I'd felt the cold, I'd had the ultrasounds and she said, 'You're going to hear something that sounds like a staple gun, but it won't hurt.' Well I heard this sound, because she's practising and it's, I thought, 'It sounds more like a nail gun than a stapler to me.' Anyway she, I felt something sharp go in and I could feel going right, so I'm sort of squirming a little bit but trying not to move, and I thought, 'It does hurt.' She did a couple and I felt them both, and she says, 'Just one more,' so I thought, 'Thank goodness for that.' Felt that one as well. 'Just one more ...' felt that one as well. 'Just one more ...' I said, 'Look, you keep saying just one more, how many more?' 'Just one more.' The fifth one I didn't feel: that's the only one I didn't feel, so all the others had been outside the local anaesthetic. Went back out again and she says, 'Right, you'll now be going back in to see Mr Chadwick, the Consultant.' Went in to see him, as I walked through the door, met by this beautiful big smile that he always has on his face, and I said to him, 'I don't like you very much,' [chuckles] because he said it wouldn't hurt and it did. But he knew how I meant it, I wasn't being nasty, I just thought, 'Ooh, you know, how could you say that?' Erm, so then he said, erm, I would have to wait for the result of the biopsies etc, but all I could remember was, all of a sudden, this screen went up, this brick wall. It was as if it was sort of glass bricks and I could sort of see through them but I was protected, and all I remember him saying was, 'Yes ... abnormalities ... are you prepared to have the treatment?' Now this is on the first consultation.

INT: RIGHT.

Patient: And everything else just went, you know, I didn't grasp anything other than those three things, and then I remember saying, 'Whatever it takes ...' because if you've got cancer it's no good saying, 'Oh no, I'm not going to have any treatment.' You want rid, it's an invasion and you want it out. 'Yes, whatever it takes.' Well then I went home and they'd made me, or they'd made me an appointment to go back just over a week later I think it was, and during that time I'm thinking, 'Yes ... abnormalities ... are you prepared to have the treatment?' I'd been given a little bit of information but now I wanted more. It

was enough to make me afraid so that was when the tears started, 'But it's only supposed to be a cyst,' and 'I wasn't wasting his time after all,' you know, I thought, 'Cancer, I've got ... my Mum, my Mum ... this scar, this scar.' So that week or whatever it was was the longest I think that I've ever had to wait because being told that little bit, I wanted to know 'What's coming? What am I in for?' you know. So when I went back the following week which was supposed to be for the results of the biopsy but he'd already been able to tell from, presumably from the ultrasound I would imagine, and, erm, that was then when he started talking about, erm, what was going to happen, that because it's small, erm, 'As far as I'm aware there is enough healthy ti- ...' Oh, the choices, the choices. Erm, 'You can either go for the full mastectomy where you know everything has gone, lose the whole breast and take the whole lot away or you can have the lumpectomy where we take away ...' and he drew me, I've got a diagram on a sheet, 'This is the lump which is only small and it's well placed because it's high. If it was nearer to the nipple then it's a different story, but there's lots of what appears to be healthy tissue around it and underneath to be able to be sure that we get every cell, because we cannot leave one cell because that would then grow and spread.' Now I'd taken a friend with me on this occasion, who is a retired nurse, and my husband went as well, but she went sort of for anything I didn't grasp she would pick up on and be able to explain to me later. Erm, now I gave him chance to finish what he was saying but in my head I was saying, 'Which would be your choice?' but before I could get the words out she jumped in and said, 'Well, what would be your choice? What would you advise?' and he said, 'Well, in this case lumpectomy,' and I said, 'Oh good, because that is what I would prefer. I do not want to lose my breast if I haven't got to.' Erm, he said that there were no guarantees, obviously, that it can come back, rear its head somewhere else, and also it would depend on whether or not it had spread to the lymph nodes, so that I would be put in for surgery for the lumpectomy which we'd both agreed upon, but they'd take the lymph nodes to see whether it had travelled to there. Erm, I can't remember but I would imagine it was also at that time, because I think I only had those two appointments then, that, following surgery, there would then be a choice of two drugs, er, and in my case radiotherapy but for the full course of five days a week for five weeks. And I said, 'So I'm not going to lose my hair I've taken all my life to try and grow to chemo?' and he says, 'No, I don't think you're going to have chemo, just radiotherapy.' Well then, er, the appointment came through very quickly - we're talking sort of from about the end of May when I first found the lump and went to see him until, when did I go in? on 26th June surgery, which in my opinion is very, very quickly.

INT: PROBABLY SIX WEEKS [???

Patient: Very, very quickly. Everything moved really quickly. Erm ... there was something else I just thought of that I was going to say and it's again. Anyway, it'll probably come back in a bit.

INT: NO, DON'T WORRY, WE'RE GONNA RECAP OBVIOUSLY AT SOME POINT ANYWAY, JUST YOU TELL ME THE STORY.

Patient: Yes, is there anything else that you want, instead of letting me sort of spout on, is there anything else ... am I digressing or ...?

INT: NO, NO, YOU'RE DOING VERY WELL AT THE MOMENT, I MEAN, SORT OF, I MEAN, WHAT I'LL DO IS, I THINK WE'LL HEAR YOUR STORY AND THEN WE'LL RECAP OVER THE POINTS AND [???

Patient: Yeah. Well I'm trying to remember but, erm, it's so much to take on board, because once you hear the big 'C' word, lots of people are afraid to speak to you about it. In fact what I haven't told you is my Mum had breast cancer, which she lived another eight years and then died of heart attacks

because she'd got angina as well, so, although she'd had a bad start, a very bad experience because they just didn't want to know, she survived it, and she was so pleased that having her breast removed wasn't a worry, getting them to listen to her was her big worry.

INT: MM, SOUNDS LIKE IT.

Patient; And, although she was a short, big-busted woman, erm, it never bothered her that she was then lopsided. In fact she always used to say when we were kids and I was growing up, I always used to say, 'Oh, I've really got to breathe in to make mine a 30" chest, why can't I be like you, Mum?' She says, 'Oh, I wish I hadn't got so much,' she says, 'It's awful,' she says, 'I've no waistline,' she sort of said, from her bust she then became hips because when you're short you've not got much frame, whereas I've always been tall. I mean I used to look down on my Mum because I was 5'6 at the age of about 13. And she'd say, 'Oh I wish I could get rid of some of this,' so when I went into hospital to see her after she'd had the mastectomy I said to her, 'Trust you, Mum,' I says, 'You never do things by halves, do you?' I says, 'You said you wanted to lose some of your boobs but you should have told them ... a bit off each side, not all one and not the other,' and of course she took it the way I meant it, and this was all part of the healing process. She just laughed, erm, and to her it wasn't a major thing that she'd lost her breast, it was the best thing. Now when I was discussing it with Mr Chadwick about me, yes it is breast cancer, I didn't hear the 'C' word which he probably used: as I say, all I heard was, 'Yes ... abnormalities ... and are you prepared to have the treatment?' and nothing else. But I think that is nature's way of protecting you. This, this wall is unbelievable, you just see this wall rise and you feel enclosed inside it, nothing's going to hurt you and you just don't hear everything that's being said. I suppose that's to relieve the shock, I don't know. Anyway ... erm, he said what would I prefer to have, and I said, 'Well I don't want to end up looking like my Mum. I know I'm 69 years old but up here I'm not, and I still want my body intact.' Erm, I'd stood in front of a mirror when I was having, after I'd had a shower and did that ... and I just burst into tears. I thought, no, I can't, I cannot cope with one, I've got to keep it. But it comes from here, you know, it's not ... it's not what you've got, it's not what people say to you, it's your own inner feelings and my head was saying, 'I can't lose it, I can't lose it.' Not unless I'd no alternative.

INT: OF COURSE, YEAH.

Patient: But whilst I was being given a choice, I'd got to keep it.

INT: YEAH, MM.

Patient: I've a friend of mine that's offered to take me to Weston Park on occasions for treatment, she had a mass down the side of her left breast and when she went along and they didn't listen to her straight away, it took three attempts for her to get somebody to listen to her, but she thought she'd got breast cancer, which she had. And they said, 'Yes, you have.' She said, 'Oh take it away, take the lot, be sure you've got it,' so mentally she was ready for that. I wasn't. We're all individuals ...

INT: ABSOLUTELY, YEAH.

Patient: ... and to me all I can see ... I know you shouldn't go by what happened 22 years ago, I know medicine's different, I know surgery's different ... but the scar is still there ...

INT: EXACTLY.

Patient: ... and I did not want to look like that. I mean the lumps I had out in 1985, they are straight lumps, they're very, you can hardly see the scars, but the mastectomy that my Mum had was horrific. And it wasn't for me ... unless I hadn't got a choice. I mean I'm not stupid: life is more important than anything that's more cosmetic, but I was given the choice and up to now everything seems to be going well, but I know there aren't any guarantees.

INT: NO, OF COURSE.

Patient: Erm, anyway, 14 months after my Mum died of a heart attack not cancer, erm, my Dad died of cancer. Erm, his - we never mentioned the 'C' word - I used to go and see him every day after work and my sister was caring for him, he was at home living by himself obviously because my Mum had died, and he was happy and cheerful and he said, 'Well, why not me? Look at today's paper ...' and the heart-throb of the time from Crossroads, this tall, dark, handsome guy had died at the age of something like 49 of cancer, and my Dad said, 'Well, why not me?'

INT: WAS HE THE MANAGER, DAVID SOMEBODY?

Patient: Yes, gorgeous hunk. Well he died. Well at that, that was just a few days before, that was just a few days before my Dad died. Er, and he'd got this huge lump, it was as if he'd got a baby coming out of the side of his stomach, this big lump, and he used to massage it with Ralgex and things for the pain, but my Dad, he'd been crippled with arthritis for years and years and years as a result of World War II and my Dad never, ever complained of pain or of having cancer or anything, but you could see the pain in his eyes.

INT: YEAH, OF COURSE.

Patient: You know, but he never, ever complained. And I just thought, 'Well, if only I could be half as brave as him, to go through what he did, and lived on his own, ...' Anyway, during the last fortnight of his life they said, 'Well what about coming up to Ashgate Hospice as a day patient, you know, just to sort of get you out a bit and we'd like to check your medication?' Well he went one day and I called to see him that night. 'How've you gone on?' because he said, 'No, I don't want to [???] they'll ask about your Mum' and it was too painful.

INT: YEAH.

Patient: ... This isn't for me, this is ... my Mum died while we were on holiday on Rhodes, and I never even got back in time for the funeral - we couldn't get a flight back. So, although it's 14 years ago ...

INT: IT NEVER LEAVES YOU, DOES IT?

Patient: I never said goodbye.

INT: NO, [???]

Patient: Anyway, I went to see him this night and he'd been up to Ashgate Hospice, and I said, 'How did you get on, Dad?' 'Oh, he says, there was this old guy there,' he says, 'and I had him tears.' I says, 'Oh dear, Dad, did you talk about cancer?' He says, 'No,' he says, 'we were talking about everything we got up to during the War,' he says, 'and he laughed and he laughed and he laughed until tears were coming down his cheeks.' Well this was one week and he'd just been for this one day, and I thought, good, you know, 'He's settled in.' He was a very sociable man, my Dad. He went again the following week, he went on the Wednesday and they hadn't got a bed for him, and he says, 'Well, you know I'm coming, I'm supposed to be coming just to check my medication, etc.' Anyway, they didn't turn him away, they took him in. And they were supposed to be going

on a picnic to Chatsworth Park, Chatsworth House, on the Friday, 26th June. He died at 4 o'clock in the morning on Friday, the 26th ... so I'd got both parents who had cancer, but apparently because of my age, it isn't genetic, it's just one of those things, because obviously I've got children as well, but, erm, it doesn't look as if it's genetic, it's just one of those things. I know we've all got cancer lurking and it can either come out at some time or might not, but when you find out you've got cancer yourself you immediately think, 'I'm more at risk because of my Mum and because of my Dad,' ... but that's not the case. As I say, I'd done very, very well right until last night, I've been very positive because first of all I thought, 'Oh dear, I ordered the new car two days ago, I'd better cancel it.' This was when Mr Chadwick said yes, etc, etc. 'Ah, better cancel the car,' and then I thought, 'Why? You're not gonna die. It's already said it's not life-threatening. You're not gonna die. You're gonna have this car.' So I then turned and I thought, 'Right. You got my Mum but you didn't kill her. You got my Dad and you killed him, but you're not gonna get me, and you're not gonna kill me, I'm going to fight.' I had a lot of support. I've prayed. I've been prayed for. I've been cushioned. I've never had even to drive as far as the Royal Hospital, even when I've said, 'I'm going to be all right.' 'No, you are not going on your own, this is when you need somebody with you,' etc, etc. I've been really, really well-supported and I've been in excellent spirits and I know, right from the word go, I've said, 'I'm gonna come through this. Don't worry, I am fine. I'm not ill, I don't feel ill. I am absolutely fine.' I feel a fraud that I'm getting all this attention, 'cos I don't think I warrant it, it's not an illness. [chuckles] There's lot of people out there much worse than I am. Erm, I just live a day at a time, I don't look ahead, I don't think, 'Oh dear, what if ...?' 'Oh dear, I've got to have this. Oh dear ...' I just don't think 'Oh dear'. I just think today's today, I'm trying to rush about and get things done and I seem very, very slow, which I think is all part of getting over the surgery. Erm, but I'm not down in the dumps. Erm, I think I'm very, very lucky, the way that things are going, even right up to there was a possibility that if this test proved negative I might have to go for chemo. When I was explaining it to anybody over the telephone, because the phone never stops, I said, 'Well, there might be a little blip, I might have to have chemo after all but we don't know that yet until we get this result.' But chemo, a blip, and that's really the way that I've thought of it. Well I haven't got to have the chemo so I'm keeping onto the track that was first drawn for me, 'You'll have surgery, you'll have drugs, and you'll also have radiotherapy.' And that is the way that it's going.

INT: RIGHT, YEAH.

Patient: So ... as far as I've been concerned, right up to [chuckles] going to oncology yesterday, you know, I'm very, very lucky, everything's going according to plan. And I'm quite happy with that.

INT: CAN WE JUST RECAP OVER A FEW POINTS?

Patient: Yes, of course.

INT: ERM, WHEN YOU WENT FOR YOUR ORIGINAL, YOUR FIRST MAMMOGRAM, WHEN YOU SAW MR CHADWICK AND HAD YOUR BIOPSIES AND THINGS, WHEN YOU, DID YOU SEE ANYBODY AFTER MR CHADWICK? DID YOU SEE A BREAST CARE NURSE?

Patient: The breast care nurse, when I first went in to see Mr Chadwick before I'd had the mammogram, the ultrasound, etc, I was aware that there was sort of somebody hovering at the back of the room. Then when I'd gone through the mammogram, the ultrasound, the biopsies, and I went back in to see Mr Chadwick, this person I was still aware was there, and Mr Chadwick then said, 'This is Mary Buxton, she is the breast cancer care nurse, da-de-da-de-da ...' Well of course, after I'd gone through these three tests and he said this, yeah, well

all I'm aware of him saying is this 'Yes ... abnormalities ... are you prepared to have the treatment?' obviously I was in shock, which is why this wall came up.

INT: YES.

Patient: ... which is why this wall came up, and, erm, 'But you'll come and see me next week,' they gave me the appointment, I was ushered out of the room by this shadow from the back and she said, 'Would you like to pop into a little room at the side here for a minute?' and I said, 'Oh, yes, please,' because obviously I was fighting back the tears.

INT: YEAH, OF COURSE.

Patient: And I just went in and sat down in a wing chair and I can't remember what she said, but I sort of within, oh, a minute, two minutes, I'd recovered myself and thought, 'Don't worry, we'll fight,' you know, so I quickly changed from 'Oh dear, it's not a cyst,' to 'It's cancer' to 'I'm gonna come through this. And that's been my attitude right from the word go. I am going to get through this. I'm gonna fight. It's not gonna get me.'

INT: AND WHEN YOU WERE IN THERE WITH MARY, WHAT DID YOU TALK ABOUT, DO YOU REMEMBER?

Patient: Well on that first occasion I really can't remember because of the shock that had just been issued. But we were only there minutes, very, very short time, but she did give me a card and she did say, 'Any problems at all, anything you want to talk about, please ring at any time.' So I'd been given the option. But I quickly recovered myself and didn't feel the need. I was quite content to wait for the next step, because by then I was in, erm, fight mode: 'This is my life and I'm going to be in control of it, not cancer. I'm not gonna let it.' So by then I was in charge of myself and I didn't feel that I needed to ring Mary. But what I did, because, erm, I'd already spoken to this friend who's a retired nurse and she also used to care for cancer patients, I didn't want word to get out in the village because, although I suppose I'd accepted what Mr Chadwick had told me, I'd still got this, 'What if it's a cyst? And everybody's ringing up and everybody saying "Are you all right?" and all the rest,' I thought, 'I've got all this sympathy, what if it turns out to be a cyst after all? I'm going to feel such an idiot, they'll think I've been having them on.' So I said to my husband, 'Come on, we're going to pack up, we're going off to the caravan for a few days.' So we went away to the caravan on the Friday, my next appointment with Mr Chadwick, the consultant, was the following Thursday, so I said, 'If we go on Friday and come back Tuesday, that'll give me chance to do my washing on the Wednesday and then go and see Mr Chadwick on the Thursday.' So I'd got it all planned, you know, we'll go away for a few days, stop people asking and everything, let me come to terms with what I'd been told. Because for three days I'd get up in the morning and I'd think, 'Have I dreamt it? I've only got a cyst, have I dreamt this?' And then I'd think, 'I haven't, because I remember this and I remember this ...' but you cannot believe yourself and, although everybody means well, you can't cope with it.

INT: YEAH.

Patient: Because as soon as they talk to you the tears come and you're fighting desperately not, because to me it's a weakness and I didn't want to cry, I wanted to be strong. And all the support they were giving me was coming too soon: I'd got to learn to accept that, yes, this is happening, you're not dreaming. So we shot off to the caravan where we just went about the normal things that we do when we go over there anyway. Off to Boston one day and off to somewhere else another day. And, although it was only a few days, it gave me

time to catch my breath. My husband to this day hasn't talked to me about it because I think that's his way of coping with it. So I'd nobody showing me sympathy. You can be strong if somebody's nasty to you, but if somebody's kind to you, you fold, you know.

INT: YES, PEOPLE DO.

Patient: So it did me good. I did the right thing. I got away, I came back, I kept myself busy. I was putting things away, I was washing and ironing and goodness knows what, and then I went back in to see him to find out what the next stage was gonna be. But I needed that break, just to be sure it was right: I have heard this, I haven't dreamt it after all, you know, and ... then you sort of progress from there.

INT: RIGHT, YEAH.

Patient: Erm, but the following week, when I went back to see Mr Chadwick, yes, Mary was sort of in the background again and she then comes forward and says, 'If you need me I'm here,' and you know, 'If you've any ...' yes, she was there but she's a very quiet, caring lady, and just, it didn't have to be anything spoken about, but just her being there was comforting and supportive.

INT: YEAH.

Patient: I think the longest talk that I probably had with her was after surgery and she came round the ward and spoke to different people. I mean some of them it was with their prosthesis before then went home, and things like that. And of course to me it was, it was different because I'd still got my breast. Erm, but she doesn't force herself upon you, but she's there and what she does say helps, erm, and of course I said to her, 'I'm very, very angry about the tears,' I says, 'I just, you're trying to be so strong all the time, and then the tears will come,' and she'll say, 'Well, why did God give you tears, if he didn't give you them to shed?' She says, 'I cry. Why do you feel guilty? It's part of the healing process.' Which helps.

INT: YEAH, OF COURSE.

Patient: But, as I say, up to now I haven't felt that I've had to ring her because I've been supported by family, friends, the Church, everybody's praying, I've prayed, and I know they've been answered, I've never been so strong in my life. So I know that it works. But then ... the bubble gets pricked and froze [?] me.

INT: YEAH. SO AFTER THAT INITIAL CONSULTATION, WHEN YOU HAD YOUR BIOPSIES AND THINGS, DID YOU SPEAK TO ANYONE ABOUT WHAT HAD GONE ON THAT DAY, ERM, THAT YOU'D, YOU KNOW, YOU'D BEEN, SORT OF MENTIONED THAT YOU'D HAD CANCER AND STUFF, DID YOU SPEAK TO ANYBODY ABOUT IT?

Patient: No.

INT: JUST YOUR FRIEND, THE NURSE?

Patient: Just, yeah, yeah.

INT: AND AT THAT POINT, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF SURGERY, ANYTHING LIKE THAT? DID THAT GO THROUGH YOUR MIND AT ALL?

Patient: No, erm, as I say, erm, it was that, that first consultation with Mr Chadwick, although he'd said the results of the biopsies would be through the

following week when I had another appointment, he already knew because he'd said, 'Yes ... erm, abnormalities ... are you prepared to have the treatment?' and he did actually tell me what the treatments were going to be. So I knew that he wouldn't have said any of that if he wasn't already sure without seeing the results of the biopsies, he already knew it was cancer because he wouldn't have told me otherwise.

INT: AND WHEN YOU WENT BACK FOR THE SECOND CONSULTATION, YOU WENT ALONG WITH YOUR FRIEND, THE NURSE, IS THAT RIGHT?

Patient: Yes. My husband went as well but I knew that he wouldn't, like me, wouldn't grasp everything ...

INT: RIGHT, OK.

Patient: ... because emotionally, er, attached as well, things sort of become too much so your mind just blots them out. But with this retired nurse having nursed cancer patients before ...

INT: RIGHT, OK.

Patient: ... and also just being a nurse, I knew that she would grasp and understand and retain, and then be able to explain to me anything that I hadn't picked up.

INT: RIGHT, YEAH. AND WHEN YOU WENT IN THE ACTUAL CONSULTATION ROOM, THERE WAS YOURSELF, YOUR FRIEND THE NURSE, AND MR CHADWICK AND MARY ...

Patient: And my husband.

INT: ... AND YOUR HUSBAND WENT IN AS WELL? SO THAT WAS IT.

Patient: Yes, yes.

INT: WAS ANYBODY ELSE THERE, CAN YOU REMEMBER?

Patient: No, no. No ... oh, the nurses that are sort of on duty in the clinic, er, yes, there's usually a nurse, erm, because when you have to go behind the curtain to be examined, there's always a nurse there, so she must be sort of hovering around as well.

INT: AND SO HOW DID THAT CONSULTATION START WITH MR CHADWICK? CAN YOU REMEMBER WHAT HE SAID?

Patient: How did it start?

INT: YEAH, SORT OF ... WHAT WAS THE FIRST THING HE SAID, DO YOU REMEMBER?

Patient: Erm ... I can't actually remember because he'd already, as I say, that week was a long, long while because he'd already indicated that, yes, it was. I couldn't remember everything that he'd said because my mind had just blotted it out with this wall ...

INT: RIGHT, YEAH.

Patient: ... erm, so I wanted to know more to put my mind at rest. I can't remember how it began, I can only assume that it was, yes, he'd received the results and that, erm, it definitely was cancer and that I would be going into hospital for surgery and which ward it was, etc, etc. But, no, it ... you cannot

sort of put things, looking back it now seems a long, long time ago, although everything ...

INT: IT'S BLURRY, ISN'T IT? YEAH.

Patient: Yes. It's such a lot happening all ... it's a lot to take on board and retain. Er, because you're also fighting your emotions, your fears. I mean the fear of that one, that week, er, is unbelievable. I'd heard enough to frighten me but not enough to comfort me.

INT: YEAH, [CHUCKLES] RIGHT, [???

Patient: But then they can't, I'm not blaming anybody, because they cannot suddenly say, 'Oh yes, you've got a lump and, yes, it is cancer, and we're gonna do this and we're gonna do this and then ...' it would be too much. So how much is enough and how much is too much?

INT: YEAH, [???

Patient: Every patient is different, so I'm, no, I'm not blaming anybody.

INT: NO, OF COURSE.

Patient: If I, if you were to say, 'If you could would you change anything?' the answer would be no, because there's no other way they could do it. Every individual is different and they don't know what your make-up is before - you don't know yourself.

INT: YEAH, OF COURSE, YEAH.

Patient: You don't know yourself until it happens. You don't know how you're gonna react or how much you can take. Some people can laugh it off, other people can dissolve in tears, other people will probably get angry and refuse to have it and ... I don't know, everybody is different ...

INT: YEAH, THAT'S TRUE.

Patient: ... so I don't think they could have done anything any different, but it was, although it was only a week, it was a long week because it was ... come to terms with it, yes, you did hear it, you did live through it, it's not a dream, and then ... I'm scared, I am so scared. Not of the surgery, but of what's gonna happen after. This treatment, am I gonna come through it? You know and ...

INT: BIT SORT OF UNKNOWN REALLY.

Patient: So then you try to blot it all out, this is where you take it a day at a time 'cos you think, 'Don't think about, think about today.' So you've got your own protective mechanism in there somewhere that then takes over, and it says, 'Just live for today,' but anybody that doesn't believe in God doesn't know what they're missing, because the prayers, the comfort ...

INT: YEAH, YOU'VE MENTIONED A FEW TIMES THAT YOUR SPIRITUALITY'S KIND OF BEEN A VERY IMPORTANT FACTOR.

Patient: That gets you through. Oh, very much so, very much so, mm.

INT: ERM, AND WHEN YOU WERE TALKING TO YOU ABOUT TREATMENT OPTIONS, YOU SAID THAT HE DREW A DIAGRAM FOR YOU ...

Patient: Yes.

INT: ... DID HE USE ANY OTHER KIND OF VISUAL AIDS LIKE MAMMOGRAMS OR PICTURES OR ANYTHING LIKE THAT?

Patient: Erm ... not that I can remember. I mean at this point I'm sort of, also I've pushed out, 'Forget your Mum, that's so long ago, they don't do that, barbaric things like that any more. Forget that because you know yourself when you have the lumps removed from your right breast it doesn't look anything like that.' I've even got topless sunbathing since, so it's not an issue. Erm, no I can't remember him showing me any pictures of any ... erm, no, I'm sure, I'm sure he didn't. But he did draw sort of what I looked like, where the lump was, what he was going to do, how much ... but he said, 'What the naked eye sees as being healthy tissue, when you have actually had the lumpectomy ...', which we'd both agreed upon, that was what I always wanted but that was what he thought was enough in his experience, and I trust him implicitly. We seemed to have that rapport. IF he'd said, 'You've got to have your head taken off, I trusted him enough, I would have said go ahead.' You know, that's how comfortable I felt with him.

INT: MM, I WAS GOING TO ASK YOU HOW YOU GOT ON WITH HIM?

Patient: Very, very, very well. Although he is a surgeon and I'm only an ordinary housewife, I suppose because of my job I was taught that no matter ... I used to speak to solicitors, doctors, the lowest of the low unemployed, because I worked as a civil servant in the Employment Department, part of my training was everybody's just a person, a man or a woman, they're no different to you. Don't let, er, different titles get in the way, they're still only people. And I used to have to ring these people up on a regular basis asking for information about a certain patient before I could sort of consider putting them into certain types of jobs. And I did it, and I did it well. I really enjoyed my job, and I got past this grade thing: they were just people, and it's, it brought me out of my shell from being a quiet little background I'm-a-nobody housewife, to I am somebody that's helping people to get jobs and I can ring an employer and say, 'Look, you need this person because you need to do this, this, this and this,' and I could get them to create a job for somebody that I'd got that had had either an illness or an operation or something, and my confidence in 24 years grew enormously, and I could talk to these people. So when I saw Mr Chadwick he wasn't a consultant, I'm a great know-all, I can do this, that and the other, he was a man with a beautiful smile and we got on like a house on fire. So I could say to him the things like, since the operation, in graphic detail, 'Well the worst part is trying to get to sleep because I sleep on my left side, the surgery's been on the left side, and of course with the lymph nodes it's all your nerve endings are raw, etc' I said, 'I lower myself very, very gently, try and put my feet into bed, but then I need a hoist to sort of lift my trunk into bed,' and he's there and he's laughing his head off, he is, he's normal, he's a person. He doesn't put himself on a pedestal, 'I am better than you,' we're equals. And, yeah, I feel that I could talk to him about anything.

INT: SO DO YOU FEEL THAT HE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes. Yes, there was no hurry. I didn't feel, I was told I could take in whoever I wanted, or however many I wanted, which was only, only two. The, he didn't look at his watch, it wasn't hurried. I had chance to have my say and he answered anything that I asked, so he was there for me. He wasn't, 'I have got a clinic full of people and you've got to hurry up and go.' It was excellent, really excellent.

INT: AND HOW DO YOU FEEL YOU GOT ON WITH MARY?

Patient: Very well. But, as I say, through no fault of her own, I haven't felt the need to get in touch, but I now have the need and I know that she can help me just by listening if nothing else. She's got a very, very calming effect: she's a very, very quiet lady, a very caring lady, and I know that when I turn to her, she's going to see what she can do to help. No, I like her, I like her a lot.

INT: AND YOU FELT THAT SHE UNDERSTOOD YOUR NEEDS AND CONCERNS, THAT SHE WAS LISTENING TO YOU?

Patient: Very much, very much so, yes.

INT: WHEN YOU WERE SPEAKING, WHEN YOU WERE CONSULTING WITH MR CHADWICK AND, OR SPEAKING TO MARY, DID YOU EVER GET THE IMPRESSION THAT EITHER ONE OF THEM HAD A PARTICULAR PREFERENCE FOR THE TYPE OF SURGERY?

Patient: With Mary, no. Erm, we didn't sort of discuss the options of to which one because it had already been agreed upon with Mr Chadwick anyway. And, erm, he explained the two options, either lumpectomy or mastectomy, and then what would come afterwards. Erm, and, as I say, I'd got my own preferences because of my Mum mainly, and also my own vanity if you like. I'd try to hide the breast to see how I could react, and I just ended up in tears in front of the mirror ...

INT: YOU DIDN'T LIKE IT ALL, DID YOU?

Patient: ... and thought, 'No, no, no. That's not me.' Not anybody else, 'I am a freak, without that I am a freak.' Now I know, I've got friends that have had mastectomy and I don't think they're freaks, but for me I would be a freak. I could not live with my ...

INT: IT'S YOUR SELF-IMAGE ISN'T IT?

Patient: Yeah, I could not ...

INT: YOU SEE YOURSELF IN [???] YEAH. [???]

Patient: I could not live with myself with only one breast. And, as I say, it comes from here. I don't think it comes from the heart, it was, I'd got this feeling in my head, 'No, no, no. I can't lose it. I cannot lose it. I've got to keep it, unless I've no option. Then I will go with it. But if I have a choice, I'll go for the lumpectomy. I know there are no, no guarantees, I may at a later date, if they find in the biopsy when they've actually got the lump out, if when they slice it up under the microscope, yes, it proved that what appeared to be healthy tissue isn't after all, I am then prepared to have the mastectomy, but whilst I have a choice I want the lumpectomy.' But Mr Chadwick was 100 per cent sure that that was all that was needed at that point in time, and that was fine by me.

INT: RIGHT, YEAH.

Patient: So it was both of us. He didn't try to say, 'But, I know this is ...' he didn't, 'I know this is what you want and, yeah, well I will try that, but I think possibly ...'

INT: YEAH.

Patient: If he'd said that, then I would have gone into it deeper, and said, 'Well, why do you think I ought to have the mastectomy?'

INT: RIGHT, YEAH.

Patient: And if he said, 'Well, there's a 60 per cent chance that it has travelled further and it may have gone to the lymph nodes or it may [???] further in the breast,' I would have said then, I'm sure I would, 'Right, go for it. Do the lot, and mentally I will come to terms with what it's done to my body,' but it wasn't, it wasn't an issue.

INT: LET ME SEE, WHERE ARE WE? ER, HOW MUCH DID YOU UNDERSTAND ABOUT YOU WERE BEING TOLD ABOUT THE CANCER AND ITS TREATMENT?

Patient: Not a lot.

INT: NOT A LOT, NO.

Patient: Initially, no, no, it's too much to take on board.

INT: RIGHT, OK. ERM, AND DID THE DOCTORS AND NURSES PICK UP ON THAT AT ALL, DO YOU THINK?

Patient: No I don't think so because I don't think I gave any inclination, this was why I'd got my retired nurse there with me ...

INT: OH RIGHT, YEAH.

Patient: ... so I could then toss it about with her afterwards if I needed to. But I'm a very trusting person: if I've got trust in somebody then it's 100 percent trust; if I doubt them, then it's almost a 100 percent ... and I'd got utter, utter faith in Mr Chadwick. WE gelled immediately and, as I say, if he'd said, [chuckles] 'We've to remove your head,' I should have thought, 'Well how'm I gonna chatter like I usually ... but, yeah, go ahead,' you know. Whatever he said I would have gone along with it because I walked into the room and before he even spoke he'd got this beautiful smile and this aura of ... of calm. There was no hurry. I didn't feel that he was saying, 'I'm a consultant, I'm very, very busy, come on, number two, number three, four, five, six and seven are all waiting out on the corridor,' there was never any of that. He was there purely for me, and I felt very, very comfortable with him. It was a pleasure to meet him, and each time I went I still felt the same. I'd got utter faith in him.

INT: HE DID THE OPERATION AS WELL, DID HE?

Patient: Yes.

INT: YES, ALL RIGHT.

Patient: Which I didn't know for some time afterwards because I had this side effect from the morphine, and it was Mr Holt that came to see me the following morning, and all we discussed was, because I was still feeling ill at this point because this was two hours before I actually had the morphine taken out of my hand, and all that was being discussed really was how ill I was and how ill I'd been all night, and as he was leaving the bottom of the bed he said, 'Oh by the way, the operation went well.' The operation had never come into my head at all because I was just too busy retching away on an empty stomach. [chuckles] So the operation sort of just got, that was a by the way, it's just that, er-er-er, you know.

INT: AND WHEN YOU, DID THE BREAST TEAM GIVE ANY CANCER OR TREATMENT SUPPORT INFORMATION, SUCH AS LEAFLETS OR BOOKLETS OR ANYTHING?

Patient: Yes, yes. Right at the beginning, the very first time. Then, when, after surgery, once I'd gone into hospital, when my husband and friend came to see me, they left the bedside, erm, ... I don't know if it was when they ... I think it was when the consultant was doing his rounds, and they picked up two more leaflets that I hadn't had from a stand at the entrance to bay 1, which is where I was, and they brought two more in ... erm, which covered sort of breast cancer and whether or not it's genetic, etc, etc ...

INT: RIGHT, OK, YEAH.

Patient: ... which was also useful for me to read regarding Mum, Dad, etc, and my offspring, because I've two daughters, you see, and a son - and men of course can get breast cancer as well but not as often as ...

INT: COMMON, YEAH.

Patient: ... yes, it's not as common as it is in women. So, yes, I've got lots of literature on it, and yes I have read it all, and I've read it twice. So, yes, it is very helpful.

INT: WHAT ABOUT THAT INFORMATION WAS HELPFUL, DO YOU KNOW?

Patient: The most helpful?

INT: YEAH.

Patient: Erm ... as I say, it seems so long ago now. There's ... it's been a fast succession of moving forward - all to the good - erm, and because I've not, I mean it's almost three weeks now since surgery, I can't remember which was the most useful, but at the time, yes, it's enough information to ... keep you happy, if that's the right word for it, erm, to put your mind at rest, I suppose, without instilling any more fear than you've already got. Because right at the beginning, once you get the realisation that, yes, it is true, then fear takes over. Or in my case it did, everybody obviously isn't the same, but in my case, yes, I was very, very afraid of the unknown. Erm, not the surgery. I'd never, for some reason ... the nurse up at our surgery was going into hospital just prior to me, about a week before, and she was petrified, absolutely, and I said, 'Oh, but you're a nurse, what are you afraid of?' She said, 'The anaesthetic.' I says ...

INT: IT'S VERY COMMON THAT.

Patient: ... I'd not given that a thought ...

INT: MM, IT'S VERY COMMON.

Patient: ... all that I was worried about was after surgery and the treatment and what is that going to do to me? The operation and the anaesthetic, I didn't realise there was anything to fear in the anaesthetic, and the surgery, you're out of it anyway.

INT: YEAH.

Patient: So, I suppose in a way she could have instilled but she didn't because of her own fears, and she was genuinely very, very, very afraid of the anaesthetic, but then being a nurse she knows more than I do. So probably hers was justified. Nor morphine is just something that I've heard about, and heard a lot about through watching all the hospital programmes, but I always thought morphine is good.

INT: YEAH.

Patient: Morphine to me is bad, it's a no-no.

INT: YEAH, YOU DIDN'T HAVE A VERY GOOD EXPERIENCE AT ALL, DID YOU?

Patient: No, no, erm, which is why before I seeing Mr Chadwick I will say, if ever I have to have surgery again for whatever reason, do I tell them that, yes I had a bad experience with the anaesthetic or was it really the morphine that I think it was, because it started to get better after they removed it from my hand? But they did give me an injection to help relieve the nausea. But I need to hear it from his mouth that it was the morphine and not the anaesthetic so that, should I ever have to go into hospital again I can tell them.

INT: YEAH, IN ADVANCE, TO PREVENT THAT SORT OF ...

Patient: Yeah, that's all ...

INT: ... HAPPENING AGAIN, RIGHT.

Patient: ... not for, not for sort of me getting over this or anything, 'cos I'm over it now, it's sort of, yeah I was ill but now I can laugh about it 'cos it's over and done with, but at the time it was anything but funny. But I need to know, am I right in thinking it was the morphine ...?

INT: ABSOLUTELY.

Patient ... or could it possibly have been the anaesthetic? Just to hear it from his mouth, so I can if necessary pass it on, because you never, ever know if and when you're going to have to go in hospital, and because they asked you, erm, 'Are you, did you have a bad reaction ever to anaesthetic?' they didn't ask me about morphine, but then I've never had it anyway, and I did say to the Sister, 'Why am I the only one that's ill?' out of the six of us that were in that bay, 'Why I am the only one who's ill?' because I am normally, for my age, I think very fit, 'cos I've always been active. I eat well, I eat healthily ... well you can see my fruit, I mean fruit and vegetables and salads are the way I love to eat, wholemeal bread ... I seem to do all the right things, I've never smoked, I hardly ever have a drink, erm, 'Why am I ill and even the 80-odd-year-olds are all sat up and ...?' She says, 'Because you're the only the one that had morphine,' and I said, 'Why?' It depends on who the anaesthetist is.

INT: OH RIGHT.

Patient: But he must have thought it was the right thing. I mean I'm not blaming anybody, it was all done for my good, it just turned out that my body didn't like it and it really [chuckles] didn't like it. But I can laugh about it now, it's gone.

INT: WHEN YOU, ONCE YOU'D HAD THAT UNDERSTANDING YOU HAD CANCER, ONCE YOU'D BEEN TOLD, HOW LONG DID IT TAKE YOU TO MAKE YOUR MIND UP ABOUT WHAT SURGERY YOU MIGHT HAVE?

Patient: Immediately.

INT: IMMEDIATELY, MM.

Patient: Well, it's all right for me to say that now, but I'd got to take on board, 'Have I really heard this?' 'cos, as I say, I can't remember him saying cancer, but he must have done. All I can remember him is saying, 'Yes ...' now he wouldn't say yes by itself, but that's all my mind is prepared to accept.

'Yes ... abnormalities ... are you prepared to have treatment,' and honestly they're the only things I can remember from that consultation, or that part of the consultation, because it was right at the beginning, before he'd got the results of the biopsies through, that was a week later. But he knew from the ultrasound. And I think that the doctor that, although she said, 'Close your eyes, the machine isn't working,' I think on my files somewhere it must have said, 'This patient's frightened of needles,' I've just got this thing about needles and injections. Yes, I have them, never, ever refuse them, but I don't like them.

INT: I'M EXACTLY THE SAME.

Patient: So I have to turn away. I don't look because if I see a needle coming for me, my ...

INT: [CHUCKLES] I'M EXACTLY ...

Patient: ... my body will just move. And I think that is why, because apparently this other friend of mine I keep going back to, that had the mastectomy, she said the needle's like this ... and because it's your breast it's on your eyeline so you can see it. So, on reflection, she must have said, 'Close your eyes. No, don't look, close your eyes, the machine isn't working,' because she must have seen on my notes that I was afraid of needles.

INT: MM. SEE, I'M THE SAME. I DON'T, I DON'T FIND, THERE'S NO PAIN INVOLVED, IT'S, FOR ME ...

Patient: Well it's just a prick, but it's, it's a second, isn't it?

INT: YEAH, EXACTLY, AND FOR ME IT'S FOR THE, IT'S THE THOUGHT OF SOMETHING INSIDE, METAL INSIDE MY BODY IN THAT WAY. DO YOU KNOW WHAT I MEAN? IT'S A SORT OF, IT'S THE SORT OF, THE WAY IT SLIDES IN AND STUFF AND IT'S JUST, OH, IT'S WEIRD FOR ME. I MEAN I LOVE HORROR MOVIES AND SCIENCE FICTIONS MOVIES ...

Patient: Oh, I don't.

INT: I WATCH THEM ALL THE TIME.

Patient: Oh, I don't.

INT: AND I'VE SEEN SOME GROSS THINGS ON MOVIES, REALLY GROSS THINGS LIKE THAT, BUT WHEN IT COMES TO ANYBODY, THE MAD SCIENTIST GIVING ME INJECTION, I HAVE TO TURN AWAY. [laughs]

Patient: Well, I tell you I watch 'Holby City', 'Casualty', but I like the real-life ones, you know how sometimes they'll put an actual operation on ...

INT: OH YEAH.

Patient: ... on screen, I can sit there glued to it. Now I am not morbid, never have been - I've got a sister that was all blood and guts stories, you know, when we used to be kids and she'd tell stories when we went to bed - I'm not like that, mine is a sincere interest, but if they come to give a patient, and it's not real, an injection, I have to turn away just for that, but I can watch them make the incision with the scalpel and do the operation, it's only the needle that I have to look away from.

INT: IT'S [???] ISN'T IT, REALLY?

Patient: Yeah.

INT: YEAH.

Patient: But I don't think metal, I suppose I think pain, although it's only sort of split-second.

INT: OH RIGHT.

Patient: I think it's the pain. I've never ever thought, 'Oh I'm being invaded by a piece of metal,' no, it's not that, to me it's just, it's just pain and I think I'm mardy. [chuckles]

INT: ERM, IN BETWEEN SORT OF YOUR, WHEN YOU DECIDED, WHEN YOU HEARD ABOUT THE CHOICES, IF YOU LIKE, OF WHAT SURGERY TO HAVE, AND AFTER YOU HAVING THE OPERATION, DID YOU LOOK FOR ANY OTHER INFORMATION ABOUT BREAST CANCER AND ITS TREATMENT FROM YOUR GP, DID RELATIVES AND FRIENDS, NEIGHBOURS, SEND YOU ANYTHING? SUPPORT GROUPS, BOOKS, MAGAZINES ... DID YOU LOOK ON THE INTERNET? ANYTHING?

Patient: No, well we've not got internet anyway, but no, I didn't feel the need.

INT: RIGHT, MM.

Patient: I felt that the information that I'd been given or that I'd asked about was sufficient in my case. I didn't want to know, erm, more or going into the treatment. I didn't want to know, I felt that I'd got enough information. If I need this, get on with it, don't explain it to me, because then you're instilling fear. I am a very trusting person and if I'm told I need this, get on with it, don't show me, don't tell me, just do it.

INT: RIGHT, YEAH.

Patient: The only thing that I think that, er, as far as the side effects are concerned, yes the most important one is do be sure that your patient understands they're going to lose their hair, because that's a major thing and it takes a long while to grow back. But insofar as the things that might cause pain, might cause a rash, might cause bleeding, might cause this, that and the other - skim through them right at the very end, when they're about to have it so that they don't dwell on it.

INT: YEAH, MM.

Patient: It's the dwelling on things in my case that can cause more fear. So for me I always say, 'Just do it, don't tell me,' because that way I can accept it without being afraid of it. If anything happens afterwards, so bit it. Like if they'd said, erm, 'We may have to give you morphine and you're going to be really, really, really ill and it's gonna go on for 16 hours, and you're gonna just not know what's happening because you're going to be sitting up and doing ...' I can now do sit-ups for the first time in my life without having somebody sitting on my feet. [chuckles] Now if they'd told me beforehand I would have been petrified. I've come through it. It was nasty at the time, but I've come through it. So no, don't tell me, just do it.

INT: ERM, THINKING ABOUT THE CHOICES THAT WERE DESCRIBED TO YOU IN TERMS OF SURGERY, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED IN TERMS OF SURGERY?

Patient: Yeah, because I don't think there were any other choices: it was either go for the lump and hope that everything was as the consultant thought it was, who's a very experienced person, he ... to me a lump is just a lump, it's not

what's going out from it, where it is or anything, but to the consultant he's been doing it for a long, long time, he can make his own experienced judgement, which isn't gonna be far out, but at the end of the day he's a man not a god, so if he's wrong I won't blame him ... or be sure you get the whole lot and go for the mastectomy. I don't think there is any other choice in this case. It's either just the lump plus the surrounding area, or the whole lot and be sure. I can't see that there could be another choice. The only other choice is don't do anything and hope you're not gonna die. Well, no, that would be stupid.

INT: WHAT DO YOU THINK WAS THE MOST IMPORTANT THAT YOU WERE TOLD, THAT YOU HEARD, OR ANYTHING, THAT HELPED YOU TO MAKE YOUR DECISION WHAT SURGERY TO HAVE?

Patient: I was just so convinced he knew what he was talking about when he said in his opinion the lumpectomy would be sufficient.

INT: RIGHT, OK.

Patient: And that was playing straight into my hands because that's what I wanted to hear, and I did hear it, and so there was no question, yeah, good, great, you know, that's it.

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

Patient: Excellent.

INT: YEAH, OK.

Patient: Excellent.

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

Patient: Well, I didn't have ...

INT: DID YOU HAVE ANY EXPECTATIONS?

Patient: I didn't have any expectations. Erm, Like the petty things, erm, when two days later I was allowed to get up and go into the dining room for a meal, whereas the other patients had all been going off and of course I hadn't been having anything because I was ...

INT: YEAH, BEING SICK AND EVERYTHING.

Patient: ... so busy retching and even after that the nausea still continued, and I couldn't even face water, when they came with the little lollipop stick to moisten my mouth, because through the night I was saying, erm, 'Can I have a drink?' my tongue felt that it was like a shrivelled up, dry prune, and my lips actually were stuck together, I had to sort of prize my lips apart, which would be the morphine, and I could scrape residue from the corners of my mouth, which again must have been, 'cos there was nothing coming up, not even any liquid, there was absolutely nothing, just noise, just wind and gurgles and goodness knows what, horrific. Erm, and they came with just this wet stick and touched my lips just to moisten them, but it made me retch even more so I had to push it away. So of course, erm, the operation was on the Monday tea-time; Tuesday morning the Sister came, the Day Sister then was on duty and she came and she said, 'Are you going to try and have a little bit of breakfast?' Well I wasn't hungry, I didn't want to eat, but commonsense said to me, 'You need something on the lining of your stomach now.' I said, 'Yes, I've ordered half a slice of dry toast, half a cup of tea with no milk in it, just tea,' because I couldn't milk or butter or anything. Now the nurse came with it and she brought me half a

slice of toast with butter on it and the knife was still there, and where I was reclining it was at eye level and I could see the butter on the this knife, and the tea with the milk in it, ... I pushed it to one side and I shouted, 'Nurse, please can you just come and move this tray?' I couldn't stand the sight of it. Now if they'd brought it dry I was going to try and nibble it, but she'd put butter on it, and my stomach just said 'No way,' so I didn't have anything. It was, erm, I can't remember whether I had anything to eat later, but I do know I tried again later on, but it was the following day before I actually went through into the dining room and I had a cup of tea, which was absolutely wonderful, with milk in it, and I thought, 'Yes,' you know, 'It's now ready to accept something,' and my eyes when they lit on this cup of tea, I thought, 'Great, that looks good,' whereas before, as I say, ooh, no, my stomach, straight over, so your stomach tells you when it's ready to accept anything, and if it can't accept water on the end of a lollipop sponge ...

INT: YEAH, OF COURSE.

Patient: ... you know, it's not going to accept anything.

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

Patient: To know about the diagnosis?

INT: MM. WHAT DO YOU THINK THE MOST IMPORTANT THINGS ARE THEY NEED TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: ... Well I think the most important thing is that you trust the person that you're speaking to. If I'd had the person that I've seen since in another clinic, I think I would have had doubts. But because I had utter faith in the consultant that I had, I just trusted everything he said. My own wishes seemed to be right: I didn't have to argue a point and said, 'Well you think this and I think this, can we sort of compromise?' There was no compromise, we were on the same, on the same wavelength all the while with what he was saying was his diagnosis and follow-on, this was what I was looking towards as well, so we were always working together for my benefit. I didn't have to think, 'Well he knows better than I do so I'll go with what he says,' and he wasn't thinking, 'Well I know she wants this but I think this.' Erm, there was never any confrontation, never any 'Well I'm not quite sure, but he must know best,' it was always, 'Great, this is what I want, and he is saying that that is what he's suggesting,' so we were always parallel.

INT: RIGHT. AND NOW YOU YOU'VE BEEN THROUGH THE EXPERIENCE, WHAT DO YOU THINK ARE THE MOT IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: ... Keep it brief ... offer it to them in terms that they can understand: in other words, I suppose, some people could get a little bit technical, make it more clinical rather than personal.

INT: RIGHT.

Patient: You've got to, as a consultant, I suppose you've got to quickly assess the person in front of you as to what they can accept and what they're wanting to know, and bring yourself to their level and explain it to them at the level they're asking, so that they can totally grasp what is on offer, that they have a choice ... but also be prepared that the consultant might say, 'Well, in your case this might be better,' but it's the feeling of knowing that you're included, you're not being told 'You are going to have this, you have got to

have this, and this is what we're going to do to you.' That never happened to me: I was a person, my feelings were taken into account, and I was lucky that what was being suggested to me was what I really wanted to hear and what I wanted anyway. In every case that possibly isn't going to be the case ...

INT: YEAH, OF COURSE.

Patient: ... because every case is so different. Everybody is an individual and it's the consultant's job to assess where on the ladder is that patient and what can they accept and explain it to them in a way that they can accept it. But as I know through my job, it's very, with years of interviewing, you can very, very quickly assess where that person is coming from and how they're going to accept what you are giving to them, in this case an operation and also what's going to come after or what can happen afterwards. But somebody with experience can assess that, and can be most of the time accurate.

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

Patient: ... No. My own worst experience has been the fact that I can no longer go to my local hospital for the follow-on treatment, which I knew about from the word go, everybody's heard of Weston Park and they know it's the cancer hospital, so you do not talk about it. But then when it happens to you and, yes, you've got to talk about it, you're not the person you are normally, you are a vulnerable person, a person that from the word cancer was mentioned, you are getting support right, left and centre - if you're lucky, and I have been lucky - you're getting considerable support, and then all of a sudden you've got to get to this place miles away, you haven't a clue where it is but you know it's a city, and you've assumed that you're going to be able to have transport there because it will be arranged later when you've asked about it. And then all of a sudden you are told, erm, you will more than likely be turned down because you haven't got a disability that's going to mean you can't drive. So all of a sudden, all this support and everything that you've had is taken away, and you just feel totally alone for the first time, and unable to cope. But through the surgery and talking about the treatment and everything, everything has been brilliant, everything, you've been so cosseted and cared for, er, it's been unbelievable, and then all of a sudden, in one fell swoop, you feel totally, totally alone and fear just takes over. I cannot do this; I cannot do it for myself. If I was fit and healthy and somebody else needed it, I would probably, once I'd been told where it is, be able to do it, but because I'm probably going to be sore, light-headed, tired, unsure, I cannot with a new car that I am not aware of or familiar with, I cannot suddenly do this very long journey into a very busy place, possibly through rush-hour traffic as well - I can't do it, I just cannot do it. So I feel now thoroughly vulnerable.

INT: MM, RIGHT.

Patient: And I need help.

INT: YEAH. I THINK, YEAH, I THINK THEY NEED TO GET YOU THAT HELP, TO BE HONEST, [???

Patient: Yeah. I mean this fear might not be warranted, but there's nothing like ...

INT: BUT IT'S REAL ...

Patient: ... fear of the unknown ...

INT: IT'S REAL AT THE MOMENT.

Patient: ... and it's something I would not do under normal circumstances, I wouldn't do it for pleasure, I would go, if I wanted to go to a show in Sheffield I would go on an organised coach trip.

INT: YEAH.

Patient: If I was going shopping I would do like I did in the past when I used to use Sheffield regularly, park way, way, way on the outskirts and walk in. Now I can't do that, I have got to be there but I can't do it myself. Or I won't do it myself. It's just beyond me, because I've still got the unknown: I know there are side effects, I know I may not have any of them, but on the other hand I could ...

INT: YOU COULD DO, YEAH.

Patient: ... but I know I am going to feel tired and it's not the same sort of tiredness that we're used to apparently, I've been told, plus I'm going to feel sore. I'm still having difficulty on full movement from surgery. I'm not ready for this.

INT: MM, NO.

Patient: I just can't do it.

INT: YEAH, I THINK YOU NEED TO SPEAK TO THE BREAST CARE NURSE.

Patient: And the person that told me wasn't somebody that I'd got a lot of faith in. I felt that I was being talked down to. For the first time I was being talked down to: I was a number on a sheet ... and that's wrong.

INT: MM. I THINK YOU NEED TO MENTION THAT TO THE BREAST CARE NURSES AS WELL BECAUSE I THINK THAT INFORMATION NEEDS FEEDING BACK ... DEFINITELY./

Patient: Yeah, and also, when he pressed on my arm on the bed, he didn't warn me he was going to do it, and he didn't do it gently. He did it in one quick blow ... 'You are not doing your exercises.' How does he know? I am doing my exercises more than the stipulated number of times they said, twice a day. I do it continually throughout the day. I have tried to bring my life back to normal by doing as many of my normal household duties as I can, to incorporate the stretching and everything that I need to do, because I'm adamant I'm going to get back to normal as soon as I possibly can, because I'm a fighter. And he's taken all that away. 'You are not doing your exercise,' or 'You need to do your exercises,' I can't remember which it was, but he insinuated I don't do exercises at all. He's never met me before, he doesn't know. And I felt like saying, but I didn't say anything, erm, it hit me sort of after I got home.

INT: YEAH.

Patient: He'd no right to treat me that way.

INT: YES, QUITE RIGHT.

Patient: Yeah. No right at all. Getting back to right at the beginning, I've just remembered, I knew there was something I'd missed. When I found this lump and then I'd seen my GP and then I'd been referred to the hospital, you tend to do a lot of, that week when I'd been told about the, yes, the abnormalities, etc, you do a lot of thinking, and I'm thinking back and I thought, 'Ah, at the beginning of the year ...' I don't sleep well at the best of times, I don't know

why but I just don't any more, and you toss and you turn and you roll over and you get up and you heat up some milk ,and if that doesn't work you know you're going to be awake for the rest of the night because if hot milk doesn't work, nothing does. And I tend to roll onto my stomach and put my arms under the pillows, and on occasions I'd get discomfort in this left breast, high up, but all you think, because you're trying to go sleep, is, 'Just move ...' you know, it's like, you trap a fold of skin or whatever and you think, 'Ooh,' you know, your body just moves. So thinking back during this week of waiting from the first consultation to the second one, 'Aah, do you remember when you couldn't sleep and you felt that discomfort? It was there.' So where I'd said it's two or three weeks since I found the lump, but before that I used to get this discomfort and I just used to move. Because if you're sort of half asleep but you can't go off, you don't think, 'Oh dear, that hurt,' or 'Oh dear, that was a bit uncomf-ort-' you just move, and then it's gone, you don't think any more of it. But that discomfort that I felt on several occasions was there. So that means the lump was already growing at that time.

INT: RIGHT.

Patient: So, if I hadn't actually decided, get rid of this, erm, feeling that, this paranoia about the lumps and my Mum and everything that I'd had, I'd gone through that, I then thought, 'Come on, it's time you started feeling again,' and I found the lump. This triggered back to this, so it was meant to be. I found it early; I got early appointments; everything just suddenly started to fall into place. But it was there much earlier than I'd originally thought, otherwise why was there discomfort in the same place?

INT: YEAH.

Patient: I can incidentally now, I can lay on my tummy, the worst part is trying to lay on this shoulder, [chuckles] it's not the breast that causes, it's not the surgery to your breast that causes the problem, it's the removal of the lymph nodes, and it hurts right down to there, and in a morning when you first ... you see because I've not done it for an hour or so, it's ...

INT: MM, YEAH, IT SLOWS YOU DOWN.

Patient: ... you have to warm up. You have to build up to the biggest stretch. You start off, you do your warm up, which is sort of your shoulders backwards and forwards for ten; then you do the lifting and it says to there but ... but I do it to there, and I can get them higher than that, but you need to do, you need to go through your warm-up exercises ...

INT: YEAH, PROGRESS TO IT, YEAH.

Patient: ... you don't go straight for the straight up one. 'Cos you see, that now isn't as high as I showed you before.

INT: NO, OF COURSE.

Patient: So this is why you need to keep doing them throughout the day.

INT: YEAH, MY MAM BROKE HER ARM A FEW YEAR, WELL TEN YEARS AGO, AND SHE HAD TO GO THROUGH VERY SIMILAR [???] AND I REMEMBER THE FIRST TIME SHE USED TO GET IT LIKE THAT ...

Patient: That's it.

INT: AND SHE WAS DOING THIS ...

Patient: You're forcing, you are, and it feels as if something's going to go 'ping', you feel as if it's going to snap, so for, I'd got my arm like that and he just ... that is cruel, that is cruel, and that's what he did to me. And when I winced, no apology, 'Oh you need to do your exercises.'

INT: YEAH. I THINK THAT INFORMATION NEEDS FEEDING BACK TO BE HONEST.

Patient: Well, I mean, I couldn't name names because I don't know his name.

INT: NO, BUT ...

Patient: But it shouldn't happen.

INT: YEAH, OF COURSE. ERM, I'LL SWITCH OFF NOW AND ...

[End of interview]