

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE:

*ID: Patient11

INTERVIEWER: DJW

INT: THANK YOU VERY MUCH FOR AGREEING TO BE INTERVIEWED. I'LL START WITH QUESTION ONE IS CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Well my sister had breast cancer 17 years ago so obviously I knew a little bit about and obviously I'd read quite a lot in the media, erm, but [???] at all.

INT: MM, AND YOUR SISTER HAD WHAT, DID SHE HAVE SURGERY FOR IT?

Patient: She had surgery, yes, she did.

INT: WHAT DID SHE HAVE.

Patient: She had, erm, she had just a lumpectomy same as me, didn't she, yes, yes. And then she didn't have the chemo but I think she had, erm, the radio treatment, yes.

INT: OK. AND YOUR OWN SORT OF MEDICAL BACKGROUND, ARE YOU GENERALLY A WELL PERSON OR ARE YOU ...?

Patient: Yes, well, both fit, had five healthy children [chuckles] no problem with breast feeding them at all, and really was totally surprised anything was wrong.

INT: RIGHT, OK. AND CAN YOU JUST TELL ME BRIEFLY HOW YOU ACTUALLY GOT TO FIND THERE WAS A LUMP THERE OR ...?

Patient: Erm, I found the lump about, [???]

Husband[?]: about six weeks.

Patient: About six weeks ago and, might be eight weeks, actually eight weeks ago, sat on it for two weeks, my daughter and my husband kept nagging me to go, and go to the doctors. 'Yes, yes, I'll go, there's nothing wrong, nothing wrong.' And, erm, and the doctor actually said she thought it was a cyst but she referred me to the hospital, who said that he actually thought it was a cyst but he said, 'Whatever it is has got to come out.' And then, erm, and then I actually, erm, ...

Husband: A biopsy.

Patient: A biopsy, that's right. I had a biopsy which was very, very painful, erm, and we went back the week after for a result and were told that it was actually breast cancer.

INT: OK. SO, ERM, YOU WENT TO YOUR GP AND HE REFERRED YOU. CAN YOU TELL ME IN A BIT MORE DETAIL ABOUT THE FIRST VISIT TO THE ACTUAL CLINIC AT CHESTERFIELD, WHEN YOU WENT FOR YOUR TESTS, IS THAT RIGHT?

Patient: [???]

Husband: Sorry, I didn't hear, I was listening to what [???

[General laughter]

Patient: First visit to the hospital, that was, [???

Husband: Well, no, the first visit was after the, erm, when you were referred to Chadwick,, wasn't it? For the biopsy. That was your first visit, wasn't it?

Patient: Second, because I saw him before.

Husband: No, the first visit was after the doctor referred you.

Patient: Right.

Husband: And that's when you went for the [???, when you had the biopsy [???

Patient: Oh that's right, that's right, yes. Sorry, I'm getting lost.

INT: IF YOU CAN JUST TELL ME AS MUCH AS YOU REMEMBER ABOUT THAT FIRST VISIT.

Husband: It was long, wasn't it?

Patient: Yes, it was very long actually, yes.

INT: WAS IT LIKE A ONE-STOP CLINIC, WAS IT? DID THEY DO ALL THE TESTS AT ONE ...?

Husband; Yeah, they did yeah.

Patient: They do, they actually left me in a cubicle for about three-quarters of hour and I honestly thought they'd forgotten about me. [chuckles]. Erm, but, erm ...

Husband: You didn't get any warning about the biopsy or anything, did you?

Patient; No, no, there was no warning about that. And that was extremely, extremely painful but, erm, the nurse actually said, 'Oh, I'm sorry, but I'll have to do it again,' so I actually had it done twice, and it was very excruciating, painful.

Husband; But no-one gave you any information, did you, there. It was just sort of go in, it's got to come out, biopsy, goodbye, you know, that was ...

INT: WAS IT MR CHADWICK YOU SAW?

Patient: It was Mr Chadwick, yes.

Husband: It was, yeah, he was OK.

Patient: Yeah, he was very good actually.

INT: SO AFTER YOU HAD YOUR BIOPSIES AND THINGS, DID YOU SEE MR CHADWICK AGAIN?

Patient: I did, yes.

INT: AND WHAT DID HE SAY THEN, DO YOU REMEMBER?

Patient: Erm, I didn't see directly, though, did I? I had to wait for the result?

Husband: Yeah, it was the week after [???

Patient: It was the week after, yes.

INT: AFTER YOUR TESTS YOU KIND OF WENT HOME, IS THAT RIGHT?

Patient; Went home, exactly, yes, went home quite saddle sore, kind of thing, but no, no, no, he's ...

Husband: But we went home believing it was still a cyst, didn't we?

Patient: Yeah, we did. And they obviously take, erm, some tissue away for, to analyse it. Went back a week after and then Mr Chadwick, well, sat us down and just told us, told us the news, and, erm, I think we were shocked.

Husband: I don't know whose jaw hit the ground first really.

Patient: Yeah, [???

INT: YEAH, RIGHT, I CAN IMAGINE.

Husband: We were shocked.

INT: WHO ELSE WAS IN THE ROOM AT THE TIME, DO YOU KNOW?

Patient: The breast nurse. Actually there were two, I think there were two nurses.

Husband: There was a nurse and a breast, breast care nurse. [???

Patient: Yeah, there was, there were two, there were two nurses, that's right, yeah. Erm, and then obviously, we, we had a cry, didn't we, with the shock. And, erm ...

Husband: And then they took us into a sort of room beside there and sort of just, sort of held your hand for a bit, I think, that's more or less it, wasn't it?

INT: RIGHT, OK.

Husband: And gave us the telephone numbers and said, 'If you feel you need to talk, any help or anything, they are you,' but I think the problem is, is that they hit you with a lot and I mean, it was different for me because obviously it's not happening to me but I can take some of it in, but it's very difficult to take in what they're actually telling you, you know.

Patient: You really do need to have someone with you because what with sort of being bombarded, I just couldn't take any of it in, and I think having your partner or friend or someone, or mother, or whatever, is very, very important. You know, you don't, something like this, you don't need to be on your own, you do need support. So ...

INT: YEAH, A LOT OF CANCER PATIENTS TEND TO SAY THAT WHEN THEY'VE HEARD THAT WORD, THAT DIAGNOSIS ...

Patient: Yes ...

INT: IT'S LIKE DROPPING A ROCK INTO A STREAM,

Patient: It's disbelief ...

INT: EVERYTHING JUST GOES ROUND YOU AND IT'S LIKE ...

Patient: ... it's disbelief.

Husband: Exactly, I mean, it's like everything around you's silent, you can see it moving but you can't hear it, you know. It's very much like that, yeah.

Patient: It is, I suppose.

INT: SO WHEN HE TOLD YOU YOUR DIAGNOSIS DID HE DESCRIBE ANY TREATMENT OPTIONS AT THE TIME? DID HE TELL YOU WHAT ...?

Patient: The surgery ...

Husband: What he actually did, he actually draw some diagrams ...

Patient: He did.

Husband: .. but I mean you were crying and sort of, and it was to me, and it wasn't to the patient, you know, and I mean in fairness to him I think it was his only way of trying to communicate at that time, you know.

INT: RIGHT, YEAH.

Husband: He actually did some drawing and explained what he was going to do and said there's two options: more or less that one is to remove the breast and one is to remove to the lump, and in his opinion removing the lump would have been the better of the two options.

INT: RIGHT, OK, YEAH.

Husband: So he did actually offer some advice, but really I mean we went away and it, it sort of, you start to think about it when you get away, but at the time you're just in, or you appear to be in shock.

Patient: Yeah, you are.

INT: YEAH, OF COURSE, I CAN IMAGINE.

Husband: But he did actually make an effort to explain, so ...

INT: OK. AND THEN YOU WENT AND SAW THE BREAST CARE NURSE, AND HOW WAS THAT? CAN YOU DESCRIBE THAT? WHAT HAPPENED IN THERE WHEN YOU SAW HER? WHO WAS IT? WAS IT DONNA OR CLARE?

Patient: It was Donna, yes.

Husband: It was Donna, yes.

Patient: Yes, she was very supportive, wasn't she?

Husband: Yes, she was OK. I mean ...

Patient: She gave us some [???

Husband: It was difficult to know what to do in those situations I would imagine, you know, when two people are sort of devastated I mean, what can you

say, you know? But I mean she was there and she offered all the phone numbers and everything.

Patient: And she'd got some information off the internet for us for the children because, you know, having to tell the children's quite difficult, erm, to explain to them, because I've got a 13-year-old and a six-year-old, and obviously older children, but I mean they're [???], they're able to cope with it, but I think the children it is quite hard. It's confusing enough for adults let alone children.

Husband: And it seemed to us a little strange because the way we saw it is that it's not always older people that have breast cancer, there's obviously quite a lot of young women, and there was no, there appeared to be no gearing, no obvious way to sort of advise parents on how to break it to their kids, because as we said to them, you know, we could go home and explain to the kids, 'Yeah, Mum's got breast cancer but everything's gonna be all right,' they'd go to school and then someone'll know their granddad who died or something like this of cancer, and I mean all of a sudden it takes on a different meaning. So it's really sort of advice on how you break it to kids, you know ...

Patient: Well we just said to them ...

Husband: It's really difficult.

Patient: 'Mummy's got to have a bad cell taken out,' and left it at that, but I think it was quite horrifying for the children, you know, but, erm ...

INT: THAT'S THE THING WITH BREAST CANCER IS THAT IT'S KIND OF REALLY IN YOUR FACE AT TIMES, I MEAN THERE'S A LOT OF IT IN THE NEWS, ON THE TV, ADVERTS ...

Patient: It is, especially the [???]hospitals, an awful lot in the media at that time, that's right. It's all doom and gloom, you don't hear the good stories, you always hear the bad stories, you know. But, erm ...

INT: SO THINKING ABOUT THAT WEEK IN BETWEEN YOUR FIRST VISIT WHEN YOU HAD THE BIOPSIES AND UP TO WHEN YOU HEAR YOUR DIAGNOSIS, THINKING ABOUT THAT WEEK, HOW WAS THAT WEEK FOR YOU AND YOUR FAMILY?

Patient: Very, very anxious. [???] knew something was wrong. But it was just, I just wanted to get it over and done with, didn't I?

Husband: I think we were confident that there was nothing wrong because no-one had sort of intimated anything that, you know, it was, as far as they were all concerned it was a cyst and we thought, 'Oh well, it's just a cyst, it's just a matter of going in and having an operation,' you know, and that was it.

Patient: Mm.

Husband: In fact I don't think that week was a particular, we were worried, ...

Patient: No, we were anxious, no, we were anxious.

INT: SO YOU SAW MR CHADWICK AND YOU HAD YOUR DIAGNOSIS AND YOU WENT TO SEE THE BREAST CANCER NURSE, HOW DID YOU FEEL YOU GOT ON WITH MR CHADWICK?

Patient: Very well actually, he's very, very nice guy, very approachable.

INT: DID HE DO YOUR OPERATION AS WELL?

Patient: Yes, he did, yes, yes, he's very ...

INT: AND THE BREAST CARE NURSE? HOW DO YOU FEEL YOU GOT ON WITH HER?

Patient: Fine, yes, fine, no problems at all.

INT: OK, RIGHT. ERM, [???] AND WHILE YOU WERE TALKING ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, HOW MUCH DO YOU FEEL THAT BOTH OF YOU UNDERSTOOD ABOUT WHAT YOU WERE BEING TOLD?

Patient: I think you understood it more than I did.

Husband: Yeah ...

Patient: Because I mean Trevor read up on the ... I didn't want ... all I was ... I didn't want to know about the operation, I wanted to know about after care. Trevor would, he read up on the internet [???] information. I said, 'I don't want to know what they're going to do, I just don't want to know. But aftercare I want to know, obviously.' And that's what we did, we got a lot of information off the internet and wherever and ...

Husband: The problem was that they didn't identify there was two types of cancer, one that one was obviously a little bit more invasive than the other: there's the hormonal based and the other cancer. And I mean they didn't sort of say, you know, that, you know, 'If you've got this one then these are the options, if you've got this one then ...' you know ...

INT: IS THAT SOMETHING YOU FOUND OUT YOURSELF?

Husband: Yeah, it was, yeah. I sort of found on the internet and I mean, you know, my first impression, if you've got the oestrogen based one then you're doing not so bad, I mean, you've got cancer but you're perhaps in a better position than the other because it's not quite as invasive I don't think as the other one. So, I mean, it was all what we found out ourselves, and I mean I found it out and it worried me more than, because obviously I kept it to myself [chuckles] you know.

Patient: I didn't want to know. Ignorance was bliss as far as I was concerned. [chuckles]

Husband: But I'm not sure whether, I mean, I would assume that most people are reasonably intelligent and could understand, you know, these types and whether they do it not to worry you or not, or, I don't know, but it would be nice to know, you know, what's going on really.

INT: YEAH, OF COURSE.

Patient: [???]

INT: DID THE BREAST CARE NURSES OR THE BREAST TEAM THERE GIVE YOU ANY INFORMATION ON THAT SECOND VISIT?

Patient: Yes, they did. Yes, I've got a mass of information here, they gave me lots.

INT: AND DID YOU, DID YOU READ THAT INFORMATION?

Patient: I did read, yes.

INT: AND DID YOU FIND IT USEFUL?

Patient: Yes, I did, yes, yes.

INT: SO WHEN YOU CAME HOME FROM THAT, FROM YOU'D RECEIVED YOUR DIAGNOSIS AND WHAT-HAVE-YOU, AND YOU'D BEEN TOLD THERE WAS TWO TREATMENT OPTIONS, IS THAT RIGHT?

Husband: Yes.

Patient: Three .. oh ...

Husband: No, from the diagnosis, yeah.

Patient: Yeah, from diagnosis, yes.

INT: [???]THE LUMPECTOMY OR THE MASTECTOMY, IS THAT RIGHT?

patient: Yes, that's right.

INT: AND HOW SOON AFTER THAT DID YOU GO BACK?

Patient: It was two weeks: I had my pre-med the week after seeing Mr Chadwick ... [???]

Husband: [???]

Patient: Yes.

INT: PRE-ASSESSMENT?

Patient: Yes.

INT: PRE-CLERKING.

Patient: And then, and then I was actually in two weeks after being told.

Husband: Yeah, it was, it was exactly two weeks.

Patient: Two weeks, exactly two weeks.

INT: YOU WENT FOR THE OPERATION?

Patient: Yes.

INT: OK. WHEN YOU WENT BACK FOR YOUR PRE-ASSESSMENT, CAN YOU TELL ME A LITTLE BIT ABOUT THAT, PLEASE?

Patient: Erm ...

Husband: Shifting around from room to room, [???]

Patient: Yes, I had to be weighed and my height taken and all sort of things. And was I allergic to avocados and ...

Husband: Oh yeah, that's right, wasn't it? I mean, that, the [???] , all the obvious things were done, I mean you're moved around here, there and everywhere to do it, but what happens at the end, you're put back into the waiting room and then the nurse comes along and says, 'Well, we're very sorry ...

Patient: Oh, yes.

Husband: ... 'You can't see Mr Chadwick because he's gone on holiday.'
[chuckles] That was a cracker.

Patient: 'Nobody knew, and nobody's told me,' she said. [chuckles]

INT: OH RIGHT.

Husband: So that was, that was handy. But, you know ...

INT: DID YOU SEE ANYBODY THAT DAY? DID YOU SEE ...

Patient: No doctors, no, just the junior, junior doctor, obviously took my details, what drug I was going to have. Erm, so, erm, and they were very good.

Husband: No, they were OK, it was no problem. I mean that was the real thing about the days that obviously you're supposed to go and see the consultant and the consultant's on holiday ...

Patient: He does need a holiday.

Husband: It's not his fault, I mean everyone has holidays but you think they'd ...

Patient: He needs a holiday.

Husband: ... try and co-ordinate things, but there you go.

INT: AND SO, ERM, WHEN DID YOU SIGN THE CONSENT FORM FOR YOUR OPERATION?

Patient: Just before the operation.

INT: OH RIGHT, SO YOU WENT IN THE DAY OF THE OPERATION?

Patient: Yes, yes, yes, before my pre-, sort of pre-med, [???

Husband: [???

Patient: They gave me something, I was taking some pills [???

Husband: It was when the anaesthetic came up [???

INT: OH YEAH, IN CASE YOU'RE SICK WHEN YOU WAKE UP.

Patient: Yeah, which I was anyway, so.

INT: OH RIGHT, YEAH.

Patient: That wasn't very good.

INT: NO. AND THOSE TWO WEEKS WHILE YOU WERE WAITING FOR YOU OPERATION, I MEAN, CAN YOU, HOW WERE YOU THEN?

Patient: We were in limbo a bit, weren't we?

Husband: Mm.

Patient: Mm, and shock, disbelief.

Husband: It is, yeah, shock.

Patient: And I just, I just went into a frenzy, just cleaning everything. The kitchen was, everything was taken out of the cupboards and shelves were ... and he said, 'Well, you are coming back,' and I said, 'Well I know, but I just want ... want it tidy when I come back because I know I'm not going to have the energy to do any of these things.' But, erm, yeah, because I do feel quite, quite tired.

Husband: But, I mean, just, well you're lost really, I mean, don't know, it's a bit like waiting for a holiday, you know, I mean you're waiting and you're waiting and anticipating all sorts of things, you know, and you're running all sorts of scenarios through your mind, you know, the good ones, the bad ones, and everything. And I think personally that a follow-up from the breast nurse might have perhaps, halfway through the period, have sort of helped a bit, mightn't it?

Patient: Yeah.

Husband: Just to say, 'How're you doing?' you know, 'There's no need to worry ...' or anything, just a sort of, like ...

Patient: I don't think we had any phone calls from the breast nurse.

Husband: No, there was nothing, no.

Patient: You phoned a couple of times, there was a couple of things ...

Husband: yeah.

Patient: Queries you wanted to ask them [???

Husband: Yeah, I mean, obviously, with what I found out on the internet, you know, I just wanted to be clear on what I'd found out and I asked a few questions.

Patient: WE did have trouble actually locating, we left a message, didn't we and we couldn't really get hold of her [???

Husband: Yeah, 'Phone us any time' and then you can't get them any time. [chuckles] You know.

INT: WELL I CAN'T, EITHER.

Husband: No, that's right. [chuckles] But, er, you know, I mean ...

Patient: Probably her day off.

Husband: I would much prefer someone to say, 'Phone between here and here because that's when you'll get us' rather than 'Phone any time, we're always there,' you know.

INT: BECAUSE WE ALWAYS RING TO DISCUSS, THEY FAX US THROUGH INFORMATION OF ALL THE PATIENTS THEY'VE [???] SO WE KNOW WHO TO EXPECT, IF THEY DO COME, ERM, AND A COUPLE OF TIMES OBVIOUSLY THEY'VE BEEN A BIT LATE - THEY'RE BUSY [???] WITHOUT DOING OUR PROJECT, WE HAVE ACTUALLY RANG AND JUST HAD TO LEAVE A MESSAGE.

Husband: Yeah.

INT: 'WE ALWAYS GET BACK' [???

Husband: Oh no, they do return the calls, yeah.

Patient: They are very, very busy ladies, aren't they? Important job.

Husband: The problem is when, when you're in this situation it's an immediate thing you need, you don't need any more anxiety over waiting for an answer to something, you know, and I mean it's, but, I mean, you know, they do return the calls so there's no problem in that respect, but

INT: SO DID YOU CALL IN BETWEEN THOSE TWO WEEKS FROM THE DIAGNOSIS ...

Husband: I called a couple of times.

Patient: Oh you called, yes.

Husband: Yeah, I did, you know, I called a couple of times.

INT: AND DO YOU FEEL YOU GOT SATISFACTORY TO YOUR QUESTIONS?

Husband: Yeah, definitely. No, I mean, they were very knowledgeable, they were very understanding and, I mean, I'm sure they've heard the questions a thousand times but they didn't give me the impression, 'Oh, God, another one,' you know.

INT: RIGHT.

Husband: They were very, very good, you know. So, I mean, you know, and they, they sort of elaborated on some of the things as well, so I was a bit clearer, so that's good.

INT: SO CAN YOU TELL ME A LITTLE BIT ABOUT THE DAY YOU WENT IN FOR YOUR OPERATION?

Patient: Ooh, I was absolutely terrified because I was really, really frightened of the general anaesthetic, not actually waking up from that. And I was just so, so worried. [???] sweating buckets. [chuckles] It was a really hot day and it was just, quite frightening actually, but I got told off for drinking too much water. [chuckles] But, no, but, it was very, very frightening, yes.

INT: SO WHAT HAPPENED ON THE MORNING? DID THEY, THEY CAME AND DID THE CONSENT FORM, IS THAT RIGHT?

Patient: Yes, yes. I had to be in for, erm, think it was ...

Husband: Eleven o'clock.

Patient: ... eleven o'clock, that's right, eleven o'clock, and I actually had my operation at three ...?

Husband: You went down at three, yeah.

Patient: ... yes, down at three o'clock. So, erm, you know, which was quite frightening. But, erm ...

INT: AND WHEN YOU WOKE, WHEN YOU WOKE UP YOU SAID YOU WEREN'T VERY WELL, IS THAT RIGHT?

Patient: No I was quite ... no actually I was really starving hungry because I hadn't eaten for like 25 hours or something because you're not allowed to eat ...

INT: YEAH, OF COURSE.

Patient: ... was it 25 hours? It wasn't ...

Husband: I don't know, I can't remember.

Patient: ... 25 hours, well, no, it wasn't 25 it was ... oh I don't know.

Husband: We hadn't eaten for a long time.

Patient: No, since the morning, exaggerating that. And, erm, really, really hungry, so I badgered the nurse for me to have some tea and toast. Of course I had that and couldn't keep it down. [chuckles] It was really, really, felt very, very sick. But I did expect that because I'm not very good with [???] and sea-sickness and things like that.

INT: OK. AND SO HOW LONG WERE YOU IN HOSPITAL?

Patient: I went in on the Thursday, out on the Saturday morning ... lunchtime?

Husband: No it was afternoon ...

Patient: Lunchtime/afternoon.

Husband: No it was afternoon, yeah, Saturday afternoon

Patient: Which, erm, my Saturday thought it was a little bit too soon, erm, because ...

Husband: Well it was too soon because we had to go back on the Sunday to have some drain, more fluid drained off.

Patient: Drained off.

INT: OH RIGHT, OK.

Husband: [???

Patient: I think it was taken out too

INT: DID YOU BRING THE DRAINS HOME WITH YOU?

Husband: No.

Patient: No, we didn't, it was taken out because that, the Saturday, the Friday night, a very, very small amount of liquid came out so, I think it was Mr Holt, wasn't it?, said, 'OK, I think you're fine, you can go home,' which we do actually think it was too soon because I did have to go back on the Sunday to have it drained off because it was like a hamster, wasn't it?

Husband: It was.

Patient: It was just disgusting, it was awful, and that was quite worrying, so, and that was quite painful. And, erm, but obviously when they released it it was, that was good, but ... but, and then I had, erm, and I had a blood clot, didn't it?

Husband: What did they call it?

Patient: Same, was it the same ... no, the Tuesday ...

Husband: Yeah, it was the Tuesday, this haematoma, wasn't it?

Patient: Haematoma, yes, on the Tuesday I had to go, go up and have that, erm, well released, [???] gas and air.

Husband: It was like an [???] wasn't it?

Patient: Yes, it was awful. So, erm, yeah, so that was quite frightening. And I was in there, ooh, half a day.

Husband: Mm, easily.

Patient: Yes, that's right. So, so we have actually done a lot of to-ing and fro-ing one way or another, haven't we?

Husband: The problem is that I think she came out too early and this haematoma, what they ended up doing was actually opening up the wound and a month later she's still got an open wound, you know, I mean it's ...

Patient: It is healing.

Husband: Well I mean I hadn't seen it because between the midwife and yourself they'd been dressing it and when I saw it it was just unbelievable. And I mean, you know, it's, well ...

Patient: It was quite frightening.

Husband: ... there was no warning, no sort of explanation as to why this was like this, and I mean you had a wound like that ... and [chuckles] ... you know ...

Patient: And you also had a clot

Husband: ... the way I saw it you shouldn't be able to look inside someone's body from the outside. Yeah, and that's what it was like, you know. And it was terrible and, you know, I sort of, I really got upset and got onto them and we saw Mr Chadwick that day, who actually had a look and said, 'Really there's nothing to worry about,' and you're thinking, 'Well, it's not your body,' [chuckles] you know, ...

INT: HE PROBABLY SEES THEM QUITE OFTEN ...

Husband: Yeah, exactly, yes.

Patient: Well actually he did say to me, 'I've seen better but I've also seen worse,' so I'm thinking, 'Hang on here ...' [chuckles]

Husband: But it went from what was after the operation a very neat scar ...

Patient: Oh, a fine line, very fine line.

Husband: ... to like something that appeared to need a manhole cover to cover it, you know, and I mean that's ... and there was no warning, no explanation, no nothing, you know.

INT: IT'S QUITE DRAMATIC I THINK.

Husband: Oh definitely.

Patient: Yes.

INT: I MEAN NOT JUST FOR YOURSELVES ...

Patient: There was a lot of bruising.

Husband: Yeah, exactly. Well it scared the life out of me.

Patient: Well the children were horrified because I mean they come in the bathroom and they were very, very upset by it. So ...

Husband: Well I'm always a believer that what's inside should stay on the inside. [chuckles] But, anyway ... but, no, I mean, in fairness to Mr Chadwick, I mean, after we'd been there, we had another appointment after that, didn't we? About a week afterwards ...

Patient: We did, yes.

Husband: We got one the same day and then we had another one the week afterwards.

Patient: That's right.

Husband: And he left it that, you know, 'If you've got a problem just phone me and I'll fit you in.'

Patient: He did say, he did say that, yes.

Husband: And, I mean, there was no problem with that. But the way it was, it was a problem because it shouldn't have been a problem in the first place, if you understand.

INT: YEAH. SO WHEN DID YOU GO BACK AND HEAR ABOUT THE RESULTS OF THE OPERATION?
[???

Husband: [???

Patient: Er

Husband: It was the 9th July, wasn't it? Because that's the day ...

Patient: Yeah, it was the week, it was 1st July I had the op, yes, a week after, it was a week after, wasn't it? Yes.

Husband: Yes.

Patient: Yes.

Husband: But that wasn't the actual, what, that wasn't the actual results of what the tumour was, that was just to tell you that he removed it successfully.

Patient: And the lymph nodes were fine.

Husband: And the lymph nodes were clear, that's when we got to know, but we didn't know what the tumour was or what type of cancer it was that day.

Patient: And we've since been told it was type 3, which is a fast-growing cancer, because it was 1 cm when it was actually diagnosed and then when Mr Chadwick removed it was 1¾ cm so it had grown ...

Husband: [???

INT: [???

Patient: ... it had grown in two weeks nearly another centimetre, so that was quite scary. You know, if I hadn't have gone to the doctors ...

Husband: We were expecting it to have arms and legs, weren't we? [chuckles]

Patient: You thought [???] but you didn't have it [???] Oh dear.

INT: RIGHT, SO WHEN DID YOU HEAR ABOUT THE ACTUAL RESULTS OF THE TUMOUR? WAS THAT ...?

Patient: That ...

Husband: That was two weeks after that visit, wasn't it? Yeah, so that was like towards the end of July.

Patient: Yeah. [???

Husband: Well it was the 1st July you went in ...

Patient: Yes, it was.

Husband: ... the 9th he told and it was two weeks after that ...

Patient: It was, yes.

Husband: ... that you found out, and that's when he told you it was a grade 3 and it was hormonal, because I think there was a score of 211 out of a possible 300 or something, so it was a positive hormonal not a borderline.

Patient: But the crazy thing was, back in January I actually had a mammogram because I was going to go on HRT last year because I thought I was pre-, pre-menopausal, but before they put you on HRT they always check to make sure your breasts are clear anyway, and in January clear, nothing at all. But there again, having said that, Trevor's sister is a nurse and she said sometimes they can't detect if there is something wrong, not always, but, erm, because she's a cancer nurse [???

Husband: That's another problem is that, is this business with like the different hospitals, different opinions. She's a cancer nurse and she deal, she actually deals with terminally ill patients but obviously she experiences a lot of what cancer is and how it affects people, and she was appalled with some of the treatment that we got, you know, she said, 'Well this just shouldn't be happening this way,' you know, 'You should do this and you should do that,' and, you know, I'm certainly of the opinion that, fine, we had to do this and had to do that, but really, she was right, it shouldn't be that way, you shouldn't have to demand thing and sort of shout about things and ...

Patient: When I explained to her what was happening, she said, 'You get yourself to the doctors,' she said, you know, 'It's a haematoma,' didn't she? She knows, she was diagnosing it over the phone because she was like 200 miles away so she couldn't really ...

INT: OH, RIGHT.

Husband: But with the haematoma, that was another nonsense that seems a ridiculous sort of paperwork exercise, is that you were told to go to the doctors, weren't you? You went to the doctors ...

Patient: Oh ... yes.

Husband: ... then the doctor said, 'Well you need to go to the hospital,' so we phoned the hospital, 'No, you can't come to the hospital until you're referred to the doc-, by the doctor,' so we had to go back to the doctor to get a referral. And you just think, 'Well, what's going on?' you know ...

Patient: It was [???] so you had to get onto the blower to actually say, 'Look, can we please have that letter to be referred back to the hospital?'

Husband: I basically phoned up and said, 'Look just pull your finger out, we're coming,' you know, and that was it. So, I mean, but you shouldn't, you know, it just seemed a ridiculous exercise that. Sort of knowing the history, knowing what had just happened and the recency of everything, you know, it just seemed ridiculous that you were having to do that, you know.

Patient: Well I don't know who was to blame at that, I don't know, you can't blame anybody, it's just ...

Husband: But this is what makes you think it's a systemic problem.

INT: [???] YEAH, IT SEEMS ALMOST, LIKE, WHERE DO YOU DIRECT YOUR SORT OF ...

Husband: Exactly, yeah.

Patient; That's right, yes.

INT: ... ATTENTION TO REALLY?

Husband: And, I mean, I'd have to say that I was appalled by the care of these, what do you call them, district nurses, some of the things they said to you, you know, and er ...

Patient: Yes.

Husband: I mean ... I was in a psychological state after the operation and it didn't happen to me, but that was going to the district nurse and she was saying, 'He's made a real mess of you,' you know, and all this, and I mean it's really what you want you want to hear, you know.

INT: WELL THAT'S A BIT OUT OF ORDER REALLY [???]

Husband: Exactly and I mean, there were stupid, throw-away comments like this that, you know, you'd expect someone in that position to be a little bit more thoughtful about what they were saying ...

INT: A BIT MORE, NOT JUST THOUGHTFUL BUT EMPATHIC, YOU KNOW, [???]

Husband: Well, exactly, a little bit more professional perhaps, you know. And, but, you know, it happened, we experienced it, and it's, you know, that, to me, was totally wrong because at the end of it all I was the one who had to pick the pieces up afterwards ...

INT: EXACTLY, MM.

Husband: ... say, 'Well, what do you think? Do you think it's as bad as she says?' you know, and it shouldn't be that way.

INT: NO, NO, THAT'S, YOU'RE QUITE RIGHT THERE, THAT SHOULD NEVER HAVE BEEN SAID.

Patient: Yes, that's was quite hard.

Husband: It was.

Patient: Because I was on my own, I went on my own, I wasn't, you weren't there at the time were you? So ...

Husband: And it seems to be that, our experience is that, if you're the patient, you constantly need an escort for someone to support you everywhere ...

Patient: Yeah, [???

Husband: ... because some of the people just don't seem, as you said, to empathise with the situation, you know.

INT: YEAH, AHA. AND I THINK ALSO WITH CARERS, I MEAN, QUITE OFTEN IT SEEMS THAT THERE'S NOTHING THERE FOR THEM ANYWAY.

Patient: Well, that's right.

INT: [???] THERE FOR THEM.

Patient: [???] I mean you had your sister, and my sister has been very, very supportive, erm, ...

Husband: Well, we've been lucky, we've had a lot of family support, but ...

Patient: We've had a very traumatic [???

Husband: ... having said that, our family is 250 miles away.

INT: YEAH, OF COURSE.

Husband: ... so, you know, they're not a local family, so it's all telephone support. And you just feel that people who haven't got any support at all it must be an absolute nightmare for them, you know, they must feel so down and disgusted about the whole things.

Patient: Especially the elderly, it's the old folk I felt very, very sorry for. Erm, you know, it's, because people, old folk won't ask for help, you know, you know it's, which is very sad.

Husband: And they've got no-one to sort of act on their behalf a lot of time either, you know.

INT: YEAH, OF COURSE. ERM, I THINK WE'VE MOVED ON QUITE A BIT. THINKING ABOUT THE TIMES YOU WERE TALKING TO MR CHADWICK, DO YOU FEEL THAT HE WAS LISTENING TO YOU, THAT HE UNDERSTOOD YOUR NEEDS YOUR CONCERNS?

Patient: Yes, yes, I did. Yes, I did, he's a very caring, understanding man. I mean he's obviously very good at his job, yes.

INT: AND THE BREAST CARE NURSES, DO YOU FEEL THE SAME WITH THEM, DID THEY LISTEN TO YOU?

Patient: Yes, I did. I only met Donna, I didn't meet the other, [???], I think you spoke to Mary.

Husband: I spoke to Mary, no, she was fine ...

Patient: She sounded very, very nice, very sympathetic,

Husband: I mean she was actually, she was the actually the one who organised the sort of emergency appointment with Mr Chadwick, so. And I mean she was very empathetic as well, you know, and I mean there was, nothing seemed too much trouble for her. She listened, she acted and she did what she said she was going to do.

Patient: You know, we've no problems with the team at all. It's just rally the after-care that, you know, we've, erm, had problems with.

INT: THINKING ABOUT THE OPERATION THAT YOU HAD, FROM WHEN YOU HEARD ABOUT YOUR DIAGNOSIS, HOW LONG DO YOU THINK IT TOOK YOU TO MAKE UP WHAT, YOUR MIND UP, WHAT SURGERY YOU WERE GOING TO HAVE?

Patient: I'd made up my mind, erm ...

Husband: About the actual, the removal of the lump?

INT: YEAH.

Husband: Yeah.

INT: BECAUSE YOU SAID THERE WAS, I THINK HE OFFERED YOU TWO THINGS ...

Patient: He did, yes. He did, yes.

INT: HE OFFERED YOU A MASTECTOMY AND A WIDE LOCAL EXCISION, LUMPECTOMY.

Husband: Well, to be honest ...

Patient: I didn't want ...

Husband: ... you made your mind up on the day, didn't you?

Patient: ... a mastectomy, [???] I'm quite a young woman so there was no way ...

Husband: Because he actually, he was of the opinion that, you know, it wasn't necessary to carry out a mastectomy, he made it clear that he felt that, and I think really that helped the decision really.

INT: SO HOW SOON DO YOU THINK YOU ACTUALLY MADE THAT UP, WHEN YOU ACTUALLY SAID, 'YES, I'M GONNA HAVE THIS,' WHEN WAS THAT DO YOU THINK?

Husband: I think as soon as he mentioned mastectomy ...

Patient: I didn't want ...

Husband: ... you went for the other one. So it was like an immediate [chuckles] you know.

Patient: Yeah, exactly.

INT: OK. AT ANY POINT BETWEEN THAT POINT THERE AND THE OPERATION DID YOU CHANGE YOUR MIND, DID YOU HAVE ANY SECOND THOUGHTS ABOUT WHAT YOU WERE GOING TO HAVE

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

Husband: I think he appeared very confident ...

Patient: He was confident.

Husband: ... no, which if you like made you think that, you know, that's the right choice as well. So ...

INT: AND, ERM, WHAT, THINKING AGAIN ABOUT THAT CHOICE, THAT OPERATION YOU HAD, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU HEARD, THAT YOU READ, THAT HELPED YOU COME TO THE DECISION TO HAVE THE LUMPECTOMY?

Patient: I don't know. [???

Husband: From an outsider's point of view I think it was the fear of having her breast removed that made the decision, wasn't it?

Patient: Oh yeah.

Husband: Because there was no real information, I mean he explained what both operations entailed, but that was it, you know, and, I mean, obviously, you know that taking a breast off is a fairly serious business.

Patient: It's quite [???

INT: YEAH, OF COURSE. AND NOW, YOU'RE, CAN YOU TELL ME WHAT LIES AHEAD FOR YOU NOW IN TERMS OF YOUR TREATMENT?

Patient: I've actually got to go and have another operation, erm, have my ovaries removed by keyhole surgery and we haven't got the appointment for that but I think it's imminent in the next few weeks, and not looking forward to it, but it's got to be done.

INT: RIGHT, OK. AND DID YOU SAY YOU'RE HAVING RADIOTHERAPY AS WELL, IS THAT RIGHT?

Patient: I'm having radiotherapy, yes ...

INT: AND WHEN DOES THAT START?

Patient: ... starting in October.

Husband: The problem is again we don't really know what's happening because we don't know when the operation is and I think, we get the impression from speaking to the radiotherapy people that it's a tentative date depending on the operation because obviously they've got to wait until - well I assume they have to wait until the operation's healed or whatever, so I don't know.

Patient: I don't know.

INT: RIGHT, OK. SO IT'S ONE STAGE AT A TIME SORT OF THING?

Patient: It is, it is, yes.

INT: LOOKING BACK FROM WHEN YOU WERE FIRST SORT OF DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED? IF YOU CAN PUT THAT INTO WORDS FOR ME.

Patient: Well the care, the operation, the hospital, [???, were fine, it just really was the after-care. We had to really seek advice, attention and, you know, all those things, and that's really, [???

Husband: Yeah, we're certainly both of us of the opinion that the hospital stay was too short and that perhaps a lot of the after-care wouldn't have been necessary if there was sort of, like, as an inpatient the care had been ... just, personally I think another 24 hours would have probably done it, but they obviously chose to, not to do that and we were back within 24 hours, and I think a lot of the after-care may have been avoided if perhaps someone had made a different decision at that time, but ... we're not experts so ... you rely on the people who are.

INT: RIGHT, OF COURSE, YEAH. AND NOT JUST THE AFTER-CARE, I MEAN, THE ANXIETY I THINK AS WELL ...

Patient: Yeah, that's right.

INT: DISTRESS OF IT ALL.

[Interruption ???]

INT: YEAH, SO AFTER-CARE, NOT VERY GOOD; COULD HAVE BEEN IN HOSPITAL A BIT LONGER ...

Patient: Yeah, could have been better.

INT: IF YOU WERE TOLD YOU COULD CHANGE ONE THING ABOUT THE SERVICE THAT YOU WENT THROUGH, THE BREAST CARE SERVICE, WOULD DO YOU THINK IT WOULD BE?

Patient: Maybe the after-care.

INT: HOW DO YOU THINK THAT COULD BE IMPROVED? IS THERE ANY WAY YOU THINK IT COULD BE MADE BETTER?

Patient: Well I think by the district nurse coming more regularly because she only came to visit twice and then she said, 'Well come to the surgery,' erm, you know, so I was sort of pushed into that. Erm ... so [???] anything else.

Husband: Yeah, I think that's ... yeah, I think that's it.

Patient: [???]

Husband: Because it just seems that you got too many people involved in the loop.

[Interruption ???]

Husband: It just seemed that there was too many people in the loop, you know. It just seemed that perhaps because of this communication wasn't as good as it could have been I think. And personally I think some of the professionalism of some of the people in the after-care wasn't as good as it ought to have been.

INT: YOU MEAN THE DISTRICT NURSE AND THAT?

Husband: Yeah, particularly the district nurse. I mean however busy you are, you know, your patient are still individuals, you know ...

INT: OF COURSE, ABSOLUTELY, YES. ERM. LAST COUPLE OF QUESTIONS, NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: Erm ... [???]

Husband: I think, to be honest, it's to give some preparation for the big drop, if you like, just in case it's there, because I mean basically we went in believing it was a cyst. You have a bit of anxiety because, 'Oh well, it might not be,' but they're very confident it's a cyst, and then all of a sudden the hammer comes down, and I think, you know, it would be nice if there was perhaps just a little bit of preparation to explain what's going on, what the potential outcomes are. I mean obviously you've got to be careful not to scare people too much but I think if you had a little bit of information it may perhaps not be quite such a shock, you know. Or even perhaps to make the biopsy, erm, results available more quickly, because I mean you're waiting a week and, I mean, if you've gone and within a couple of days you go back perhaps the shock isn't so great, but after a week you've convinced yourself there's nothing wrong. [chuckles] And I think ...

INT: WHEN YOU ACTUALLY HAD THE BIOPSY, DID ANYBODY AT ALL GIVE YOU AN INDICATION THAT IT MIGHT BE CANCER?

Patient: I think the nurse who did the biopsy was sure because she said, 'Look, I'm gonna have to do it again,' and she said, 'I'm sorry about this,' because it really did hurt, it really, because I didn't see the gun but I knew it was just like a staple gun. She just, she turned her back to me, she said, 'It's just gonna ping like a little elastic band,' and I knew, I knew it was gonna be like a gun, and I didn't get the sight of it because she didn't let me see, she said, 'Close your eyes.' Did it once, so she said, 'Sorry, got to do it again,' I said ... she said, 'I'm gonna have to do it again,' and I said, 'I'm sorry, if you do it again I'm out that door.' [chuckles] She said, 'Well you don't really want to come back and have it done another time,' which was right, because you, you know, having had it done once you won't want to come back in another week and have it done again, so she said, 'I've got to get enough ...' which is fair enough, you know,. But, erm, it was ...

Husband: Did she actually say, you know why she needed to do it twice?

Patient: No, but I knew, just knew by her reaction that she said, 'Sorry, got to do it again,' I just knew, mm. Just [???

INT: AND A SIMILAR SORT OF QUESTION, WHAT DO YOU THINK ARE THE MOST IMPORTANT THING SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATION THEY CAN HAVE?

Patient: What actually could happen after, you know, because really I didn't know about the drain.

INT: OH RIGHT.

Patient: It wasn't ... they did tell, actually they did tell me, didn't they?

Husband: They did mention it.

Patient: You know, I couldn't visualise a bottle or whatever, but that was just me. But, no, [???

Husband: I think it's difficult for them to know how much information to give you, you know, because I think in that situation it's very easy to become very scared, because I mean you were incredibly frightened anyway, weren't you? But, erm, I think it's the timescale of things that perhaps the most, certainly was for me, is that you have the operation, that's the first hurdle, and then you've got to go back to the consultant to find out what it was, but then you have to go to another consultant to find out some more information which extended the time from the operation to almost three weeks, erm, before you actually find out

what type of cancer it was, because, for me certainly, having looked at the internet and knowing a bit more, I was really worried about what was going on. And, you know, I think that's one of the worries is the timescale: if they could make it quicker I think it would perhaps be less traumatic. But, erm ... because I mean you were incredibly scared, weren't you?

Patient: Mm.

Husband: And, I mean, at the time there was no lead-in to the results either, erm, it was basically, 'Bang ... this is what you've got. Bang ... this is it.' and then 'Bang ... that's the, this is the treatment.' And there was no ... you know, like a sort of introduction, if you like, into what's going on because basically you've got a grade 3 tumour, it's hormonal base, these are what you can have and these are the options, and ... I don't know if that's the best way or not but it just seemed a bit of a, one punch after another, if you like. Because I mean you ...

Patient: Well I was totally confused, I really was so confused with it all.

Husband: But there was no pressure with the guy, erm, [???] who's the guy who decides on treatment and stuff, there was no pressure to make a decision on the day, but there was a sort of inclination towards chemo ...

INT: RIGHT.

Husband: .. he gave you three options. I asked the question, you know, 'Well, is there a good or a bad one of these three options? Is there a more effective than the others?' and the answer was basically, 'I wouldn't offer you any if there wasn't,' you know, and I mean that was sort of [???]

Patient: But I found that very difficult. I had to make a decision, you know, of the three choices, and I found it very, very confusing. I was just totally confused, and I'm just so glad you were there to take it on board for me as well. Having said I'd have the chemo and then when I got home I suddenly thought, 'No I can't have the chemo because I'm gonna be so ill,' er, but I didn't want the ovaries removed because of another operation, another general anaesthetic, and that even, it's even worse the thought of having the needle, [???] needles, [???]

Husband: And I think, although they did explain briefly what it was, there was no, I mean I actually had to phone up for Donna again and ask for the sort of consequences of each type of treatment and, you know, it wasn't made clear at the time what they were.

Patient: But they all bring on the menopause.

Husband: Well they said, basically that's something we weren't [?] told, I mean, whatever treatment you have brings on the menopause. You remove the ovaries and, bank, the menopause starts the next day, erm, but this is what we found out after the consultation and not during, you know.

INT: RIGHT, OK.

Husband: And we had to ask again, you know, so, and I think when someone's messing with your body it's nice to know what the outcome are gonna be, isn't it?

INT: [???] THE LONG-TERM OUTCOMES.

Patient: That's right.

Husband: Exactly, well we still don't know what the long-term outcomes are.

INT: IT'S NOT JUST SOMETHING THAT'S GONNA POP AND GO AWAY FOR A COUPLE OF DAYS.

Husband: Exactly, yeah.

Patient: Exactly, yeah.

Husband. Well that's right, there was no sort of implication of what the chemo was over, was it 12 weeks, I think, wasn't it? he suggested.

Patient: Twelve weeks, 12 weeks, yeah.

Husband: But there was no sort of idea of how long it took you to recover after the 12 weeks because your body's been well and truly knocked around for three months and then obviously it's not going to be the following day that you're, you know, 'Right, I'm fine, I'm getting up today and I'm running round the block,' you know.

Patient: Well it not only kills the bad cells but it also kills the good cells.

INT: THAT'S RIGHT, YEAH.

Patient: And that's why you're so poorly.

Husband: And there was very little made of how it knocks your immune system around either, and, you know, you've got to be very careful about those things. And that really came from my sister who said, you know, 'Well, if you have chemo,' you know, 'basically all your blood cell count and whatever goes haywire and you are open to all sorts of infections.'

Patient; Well she did say, actually say to me, 'Have everything you can have,' but if I can have the ovaries removed without having chemo I will try [???] because I think chemo's got bad press obviously but it's quite frightening.

Husband: Well I think some people tolerate it better than others, because we're all different [???]

INT: AND THERE'S DIFFERENT TYPES OF CHEMO.

Husband: Yes.

INT: THERE'S SOME MILD ONES ...

Patient: [???]

INT: I MEAN I KNOW IF I'VE GOT A FLU OR SOMETHING OR A COUGH OR A, EVEN IF IT'S A SNIFFLE, I REALLY CAN'T GO AND INTERVIEW PATIENTS AFTER CHEMO BECAUSE IT COULD GIVE THEM AN INFECTION THAT THEY DON'T REALLY NEED.

Patient: Exactly, yeah.

Husband: And I mean this is the problem with young kids around as well, you're open to all sorts because you can't keep them off school. [chuckles] That's the problem.

Patient: And they bring bugs home, [???]

Husband: But, you know, we're still, we're still really not aware of what the long-term, you know, how long ...

Patient: Well my sister was diagnosed 17 years ago and she's been fine. She obviously has check-ups but, no, she's been fine. So it must be hereditary, I mean, I don't know, who knows, you know.

INT: SO HAVE YOU ANY IDEA WHEN YOU'LL GET A FOLLOW-UP WITH MR CHADWICK?

Patient: No, I haven't, haven't heard anything.

Husband: Well I think we believe the next stage is a follow up with Mr [???], whatever because he's the one who apparently will organise the operation for the ovaries now, see ...

Patient: [???]

Husband: But that's, and apparently he's on holiday at the moment so, I mean, that's probably gonna be 3 weeks to a month before we hear that. I mean, that's one of those thing that can't be helped because he was, seemed to be of the opinion that you'd go on Tamoxafen straight away just to sort of keep things ...

Patient: Which I have.

Husband: ... ticking over, if you like, I would assume, and then we'll work the rest out when the holidays have finished and things, so ...

INT: THE LAST QUESTION I'VE GOT TO ASK YOU, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT? ANYTHING IMPORTANT THAT WE'VE MISSED? ANYTHING THAT WE HAVEN'T COVERED?

Husband: I think something you mentioned earlier on is basically the carer's role, because I mean ...

Patient: [???]

Husband: ... we've both had good and had days, you know, because I mean it hit both of you. I mean obviously I'm not the one with the illness but you're taking on ...

Patient: Somebody else's problems.

Husband: Well, I mean, you have some good days, don't you, very tearful and basically it means that everything that normally happens in the house isn't shared any more, and one person gets it as well as the worry. And things like that. And I mean you get on with it but it take its toll after a while.

INT: YEAH, OF COURSE.

Husband: You know, I think both of us now feel that sort of a month down the line you're mentally and physically exhausted.

Patient: Drained [???]

Husband: You really are totally drained. And you find you shout, yourself becoming short with the kids and things like this, you haven't got the same level of patience maybe you would normally have. And ... how you resolve that I don't know, but it just seems that ...

Patient: [???]

Husband ... you need someone around who's got the ability to sort of take on some of the worry, you know, and you know you feel for people who don't have that, you really do. And I think that is a very important part of it. And knowledge is a very important part ...

Patient: It is, it is.

Husband: ... as well, you know, most of what we know we have found out ourselves. Erm, some of it is quite technical and you don't really understand what it is, and, but I mean some of it you can pick up on and you get an idea and the problem that I have with that is that you perhaps are getting some of the wrong information, erm, you know, and maybe you're getting yourself more worried than you need to be and ...

INT: CERTAINLY WITH THE INFORMATION ON THE INTERNET I THINK, I WAS TALKING TO A CONSULTANT NOT SO LONG BACK AND SHE SAID, PUT IT A REALLY NICE WAY, SHE SAID, 'THE INFORMATION ON THE INTERNET, IT'S NOT KITE-MARKED IN ANY WAY.'

Husband: Yeah.

Patient: Mm, that's right.

INT: SO YOU REALLY DON'T KNOW.

Patient: You don't know what you're getting.

INT: I MEAN, YEAH, IF YOU CAN, STICK TO THE BRITISH WEBSITES, DEPARTMENT OF HEATH, BACKUP, THAT KIND OF STUFF.

Patient: That's right.

Husband: Well some of the cancer websites were very good, but then obviously you get links and you start clicking around and ...

INT: EXACTLY.

Husband: ... and you find some others and you're not sure where you are any more. But, but I think generally, having spoken to the breast nurses, is that the information we found was sound but maybe we found too much and, you know, that's the worry I think.

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

Husband: Yeah.

Patient: Yes, that's fine.

[End of interview]