Fear of Cancer Recurrence (FCR)
Qualitative Review of Patient’s Experiences
Excerpts categorized according to the Emotional Scheme

**Emotional scheme** (Elliott et al, 2004)

- **Perceptual-Situational** elements represent the person’s past or current environments and include immediate awareness of the current situation and episodic memories.

- **Symbolic-conceptual** elements are verbal or visual representations of the emotion scheme processes produced through reflective self-awareness of perceptual-situational and bodily-expressive schematic elements. Symbolic representations often take the form of verbal statements (e.g., "I could be attacked at any moment"), but they also include metaphorical qualities (e.g., the color black) associated with the emotion scheme.

- **Bodily-expressive** elements represent the emotion scheme processes through the body, including both immediate sensations within the body (e.g., a round, knotted feeling in the gut accompanied by feelings like electrical impulses in the arms and legs) and expression of the emotion (e.g., a fearful facial expression and nervous laughter).

- **Motivational-behavioral** elements are activated by the emotion scheme processes and represent it in the form of associated desires, needs, wishes, intentions (e.g., to be safe from attack), or action tendencies (possible actions; e.g., get rid of the fear by trying to ignore it).

- The emotion **scheme nuclear process** organizes all of the different components around a particular emotion (in this example, intense, trauma-related fear), and is often only recognized after self-reflection on the other four elements.

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“Every time that I get a new sharp pain somewhere I think: ‘Oh, my Goodness.’ So fear, it repeats, for me.”

“Every time I had a headache or a stomachache, I thought it was the cancer.”

“But that also gets back to the question of: Is it just age or being out of shape? Or is it... Was there something there that I was missing?”

“Sometimes that ache might be something more.”

“It’s just a trigger. It’s not an all day thing, but, in the morning when you wake up, your breasts just don’t feel the same because the way they construct it with the muscle or insert, you can feel all that. They just don’t feel like natural breasts. It’s just another trigger.”

“I don’t think that I worry about recurrence maybe more than once a week or something like that, if that. It’s not like everyday I try to talk myself out of it. It’s more of an occasional thing. Somebody really dying of cancer on TV or something, then...I think about it.”

“Other times, it can be reading an article or hearing a news story, because cancer is everywhere now.”

“I do try to avoid the cancer subject, but it’s hard. It is on TV; it is on commercials... and before I had breast cancer, I didn’t even notice it. It just hit me in the face, right here.”

“Now that I’ve had breast cancer, I’m so sensitive to other people that have been diagnosed or have had people in their family that have passed away recently,” “I feel like I’m more tuned into that because I have more triggers around it, but that could be me.”
“You know, I don’t love talking about this stuff, because it brings the fear running in my head (talking about cancer) and I prefer these fears not to be running.”

“You always have to keep your thoughts and perspective because if you share your story, which I don’t do often—not that I don’t like to hear other people’s experiences, but it makes my mind go off in an area that it doesn’t need to be in. I’ll be thinking that it could happen to me when listening to people for whom it has come back. So you kind of have to keep yourself in check, especially in those chemo rooms. You’re there for such an amount of time.”

“If they had bad stories, I really didn’t want to hear it, but even good stories I really didn’t want to hear because I felt like none of them had anything to do with me. You know, if their best friend had cancer and lived for 30 years: It was completely irrelevant for me, and I was not interested—I just find it to be really irritating when people would say: “Don’t worry, I know that people live for years.” I was like, “Shut up, you barely know me.” And they had opinions about what I should be doing.”

“Like today I was looking at my upcoming appointments and I saw that I have one... It just reminded me that I had cancer and that it’s going to come back.”

“When I go in to get a mammogram, I’m nervous because that is a possibility.”

“big dread” (of recurrence)

“I’ll just give you a concrete example because I just had a follow-up appointment recently, and the nurse practitioner that I saw at that appointment felt something under my arm, and she said that I had to get an ultrasound and mammogram and all of that stuff. And obviously I was afraid that all of that meant that it had already happened and that I had gone through recurrence.”
“Until the surgery was finished and the pathology report came in, where you have more definitive answers to these questions, your mind goes everywhere.”

“After the receptionist said: “Oh, the doctor has your report, I’ll put you through to him,” so I knew he had it in front of him and I thought: “Oh, [expletive], he is not in a good mood because I got cancer”...You know, for 10 seconds there, there is an actual fear that just crippled me. I thought: “Oh, he is in a bad mood because he doesn’t want to give me the bad news.”

“During those times, it was very emotional and felt like being back to square one, but a very scarier square one...Because for the most part it was an abstract thought, but it was just that under layer.”

“under layer” (of FCR)

“I’m trying to think: I’m taking it, so I won’t get sick again, but you are still thinking about getting sick again.”

“I don’t really have feelings against it. It’s just kind of a trigger that I had cancer. That’s all.”

“My hair reminds me of cancer, and every day I comb my hair and I think about cancer, when I see hair that falls out in the sink...it gives me a sick feeling [crying]. It reminds me of how I am....I’m thinking: “Because of a stupid pill, I’m going to go bald again or in patches.”

“The reality is always present and that I have to do this, you know, I have to take that pill everyday that’s making me feel so bad. This white pill, I have to swallow that pill every day....And this is toxin, I’m swallowing toxin. That’s pretty strong fear that you would take that kind of pill. So yeah, it’s present. It is very present.”

“When you are alone at night and starting to think these negative thoughts, you don’t have a connection to other minds.”
“when I’m in my apartment by myself, and then I started thinking about maybe something is wrong.”

“The questions that you get on a standardized form, they are often subject to various interpretations or they don’t fit quite right. I understand that you have to do that to get your data to do the statistics on. Sometimes it is a little frustrating.”

“walking the plank...and maybe I’ll be fine, but maybe I’ll just jump into the ocean. That is how I felt.”

“always walking with uncertainty that nobody really knows how long they are going to live.” “It’s just like when some of your loved ones go on a plane trip. You don’t really expect them to die on the plane, but you are aware that that could happen.”

“rolling the dice” or “waiting for the other shoe to drop.” “It basically means just a deep-seated kind of boogie monster that could resurface again.”

“It’s not a slam dunk cure kind of thing, which is kind of the impression I had gotten for a lot of the stuff that I read about.”

“It’s like a record skipping over and over and over and over and over. That feels to me like hurt. That feels to me like pain.” (also emotional experience)

“The worry part of it is not over so I wish that I just broke a bone and it’s reset and I’m all healed now and I can close the door, like desperately I want to close the door, but I feel like I can’t because it is not over.”

“It’s like anything else that it is part of your life, like if you had a broken leg that didn’t heal well and that is part of your life.”

“It is very real and it is definitely a nightmare. It’s not a pleasant way to live; it’s not a pleasant way to die.”

“like a sword”; “you could be falling off of this cliff right now.”
“like a little ghost that hunts you.”

“It’s like if you study tarantulas and then you were shut in a room with one, it would be kind of a shock, you know. It was just kind of weird.”

“It’s like a petri dish….I’m creating an environment that cancer will grow or I’m creating an environment that cancer will have a hard time growing, even if it tries, because evidently we have cancer cells in our body, anyway. So, for me, those cancer cells are like lice, you know, they are all walking around and you don’t know where it is going to show up. So, you have to take care.”

“I’m a visual person, so when I’m thinking I usually feel it in my brain. I guess I would describe the one dimensionality of the worry, as it feels that there is not a lot of choice in how you approach it. I’m not sure if choice is the best word, but it seems very linear. It starts from something and it goes in one direction. Whereas, generally looking at something from a lot of different angles I would describe as three-dimensional. There are possibilities there. And with the worry, I feel like it starts and only goes from point A to point B, and that’s that. There’s no possibility in my worry, which is another reason why I don’t like it.”

“a realization of my mortality, like with cleaning the drawers. Once you’re gone, you’re gone. There is no second chance to go back and clean the drawers, or other stuff, you know, that is just an example. How do I want to leave things? How do I want my family to perceive me?”

“I do think of it in terms as a river with rapids in it and a current that is too strong for you to control. You might be able to swing a little bit to this side or that side, but really, those are comparatively minor adjustments and life is much more about you adapting and riding that wave. Life happens and a lot of what you do is reacting to it and if you are absolutely rigid, you are more likely to get damaged than if you can bend and adapt.”

“Sometimes I worry that the worry is going to grow. As it’s developed over the past two years, is it going to be linear or does it get bigger as I get
further away from the experience? Or will it be more like a bell curve where I hit a peak and then get past it? The 7 years past treatment or 10 years past treatment, when I'm at a lower risk of recurrence—will that somehow let the worry subside? So yeah, when thinking about the future, I worry that the worry will continue to grow when I really just want it to be there and then fade. Maybe it’s a little like the beginning: the climb. It feels like I’m at the beginning of the section of time because I’ve been told that the highest risk of recurrence is within this window, so that’s in the back of my mind that I’m still in this high risk zone. So, yeah, will the worry continue and will it start to interrupt my daily life? Maybe I’m worried about the worry [laughs].”

(FCR as) “morose”

(FCR is like a) “pang of sadness when you realize that you have lost something, you know, kind of like a sharp regret… Regret to me means the loss of something that you really wanted, hoped for, or something that you have done wrong and you wish that you could make amends; that’s what I mean by regret. In this case I think that it would be something more like a loss, not something that you did wrong.”

(FCR is) ”extremely stressful.”; “scary.”

“‘dread’ or ‘anxiety.’ There is no question that it can become almost crippling if you let it.”

“‘fearful state because it limits what you can do to fight it.”

“If…there were words there, I would be crying, it’s not like I do that. Not anger, because I don’t like to be angry. It’s just more [that I am] scared.”

“Sometimes crying, sadness, real conscious sadness, but also stuff that is more like depression, where you are not that conscious that you are sad or grieving or something like that, you are just more…everything just seems bland and unrewarding. And then things like, I’m having a lot of
Perceptual-situational      Symbolic-conceptual      Bodily-expressive      Motivational-behavioral      Emotional experience

difficulty sleeping, and I’m a little shaky.”

“I live with a lot of fear that I’ll have cancer and that it’ll come back now that I have had it. It is very real. It’s no longer abstract: Will I get cancer? Yes, I will get cancer.*

“[FCR] was there from the beginning of the diagnosis because people know that, you know, how many times the doctor thinks OK, it’s gone, and then it comes back, so as soon as you get the diagnosis, that is the fear: that if it hasn’t already spread, it is going to. It isn’t after treatment that you worry; you worry from the beginning. Of course, in the beginning you don’t know the situation and you don’t know if it has already spread, but that’s the basis of the fear.”

“I mean it was fear. I was also confident that it was going to happen, but I was afraid of it. The fear of... what I considered this inevitable recurrence. I call it fear because it was paralyzing. There was something that was paralyzing to me, and I can only think of it as fear because it was this. And I don’t know what I was afraid of. Was I afraid of being sick again? I don’t know what I was afraid of. ...maybe it wasn’t fear of recurrence. Maybe I was confident that the cancer would come back, but not being at peace with it? Or not being accepting of it? But I called it fear and it felt fearful. It took a lot of energy and caused a lot of sleepless nights. And every time I had a headache or a stomachache, I thought it was the cancer.”

“It’s kind of an undifferentiated fear, not solely a fear of dying, but just fear of having a serious disease and having heard so many awful things about what the treatment of the disease would have been like.”

“When you think of recurrence, you think of what would the treatments be. Will it mean another surgery? Will it mean the possibility of chemotherapy? What does that mean to your life?”
“It worries me that if it comes back, it’s going to be stronger.”

“Well, what’s going to happen to me? What’s going to happen to my dog? What’s going to happen to my parents? Am I going to have to move away from [the Bay Area]? And if I do, and I have to move back to XXX, will I have to move to XXX because there’s not good care there for cancer patients? You know, sort of playing out the whole situation as though it had already happened. So then I would have myself having cancer, and what do I do? Do I stay in [the Bay Area] or move back to XXX? Okay, so I stay in [the Bay Area], but then I don’t have the supports here in [the Bay Area], so I have to move back there. But then my family is going to have to drive me back and forth to XXX clinic all the time. And that’s going to be so horrible on them. It’s not just that. It would be me imagining myself bald and being driven back and forth to the XXX clinic and feeling sick, and my poor family, and my mom and dad being worried. You know, I’d be taking it so far, to the point where I’d physically feel sick about the whole thing. And the next day, because this would always be at night when your mind starts going, I wouldn’t even be able to go to work the next day because I would just be drained and depressed. And, you know, it just sucked me dry. But I wouldn’t be able to stop once those thoughts started—they would always spiral out of control. They would go down the most extreme path they could go. You know, the cancer starts in my liver, and then it ends up in my bones, and that’s the worst place—it’s so painful. And then I’d think, “Oh my God, Vicky, why are you doing this to yourself?” and then boom, right back into it.”

“You are afraid of your cancer recurring; I can’t think of any more complex or deep way to say it. It is obviously something you have if you have a fear, you have an emotional reaction as well as an intellectual awareness but...just that phrase doesn’t really say whether it’s an unreasonable fear or problem or not.”

“The fear of cancer recurrence means... it is totally a fear that I have and it manifests in terms of... I’m worried about the breast cancer coming back.”
“I feel like cancer is not over for me, because I’m worried about recurrences and other cancers.”

“You know that getting endometrial cancer while on Tamoxifen is very rare, but there is a link there. Like I worry: ‘Oh, [expletive], now I have endometrial cancer, because of the medications that I’m taking for the primary cancer. This is just so messed up.’ So I have to get tests done for that and I find it ironic and horrifying.”

“It’s not just limited to one cancer.” “It’s like everything that happens could be cancer, rather than what it was before...oh, it’s muscle, or it’s this or that. Now it’s always: well, it could be cancer.”

FCR an undercurrent” that could be “spiked” at any time; “It’s sort of like rippling under there and then every once in awhile a wave comes up, but it never socks me in the gut with it. The way I think about it is that it’s always there, and every once in a while I think about it. Sometimes I’ll think more about that, but sometimes it’s just “that.”

“I mean the fear...just happens out of the blue....It’s just: Here you are again. Or when there is something that you really love and you get the jolt: What if I lose this? But that doesn’t change; that is a constant. It’s not all that frequent, but it always sits there.”

“There would be period of times where I’m thinking about it more and maybe there will be six months where I’m not really thinking about it very much, but it’s always there.”

“So I’d say that everyday, something triggers the thought—maybe three times a day—maybe for five seconds or five minutes, and then I’ve moved onto something else.”

“It’s there all day.”

“I’m always aware—the back of my mind is always aware—that there might be the possibility of a recurrence.”
it “never ends;” it “consumes me.”; “This is life.”

“it’s not like an irrational thing or something that I should get rid of; it’s like anything else that is part of your life, like if you a broke leg that didn’t heal well and that is part of your life.” 200

“I won’t call it a feeling because calling it a feeling makes it seem less—it’s in my bones (also bodily-expressive), you know? It’s part of me. It’s one of the strongest held beliefs that I have....So it’s almost like I’m again saying that I have cancer. It’s like a part of me again.”

“I don’t remember a specific moment.”

“I haven’t absorbed it into the deepest part of my being that yes, I’m going to die, and it could happen now. So it’s a big shock and there maybe be other things going on there that I don’t recognize, that I can’t articulate too much to myself and that they only come out in things like the shaking or not being able to sleep and stuff like that. But as far as consciously, that is all I can say is on an unconscious level.”

“People don’t really get it.”

“I expected it to be this kind of joyful period. You know because you think of everyone finishing their cancer treatment and it’s like ‘Yay, I’m done!’ And it was almost the exact opposite of that.”

(she did not talk about it) “because for almost everyone else, I think that the door is over and closed.”

“It was like “What? But don’t you need to see me back in three weeks? Who is going to make sure that I’m okay?” And even when they wanted to see me in six months, I asked to continue to be seen every’ three months, I think for a year because I was just not ready to have those strings cut. So that was just a very fearful time.”
"I think that a lot of doctors don’t want to talk about this. I mean it is a 15-minute appointment! There is not enough time to share what is really happening inside, and plus I think that they are pretty scientific. They don’t really care about the subject very much."

“She said: ‘You are OK, aren’t you? Everything is going OK?’ And I said yes. She wanted to hear that.”

“Oh, God no. No, no, no. I wouldn’t talk to anyone in my family about [FCR]... If I told my parents...they would flip out and be out here and would be sure that there is something horrible going on in my life and that this wasn’t just it...In terms of the cancer, I don’t talk to them about it. Because they need for it to be in the past, so no, we don’t talk about it. I don’t really talk to anyone about it because I don’t think people understand it.”

“I didn’t tell anybody about it, because I didn’t feel it was right to worry them when I didn’t know what... you know, why to make someone else worried when it might be nothing?"

“If you have a spouse, you don’t really have to worry about that, because your spouse is going to help you, but when you live alone, you have to figure this out. I don’t want to have to go to live with my daughter if I get sick. She’s got three little children to worry about, so you kind of have to think about how you are going to plan this. So your mind goes to all these places, which probably doesn’t need to go there yet, but it happens.”

“I have noticed that the people that I’m closest to don’t like talking about breast cancer; don’t like talking about healing; don’t want me talking about worrying.... If you are going out to dinner, then everything is fine. And now I understand a little more about the process of healing, just in general. It’s not a topic that we normally share that much in friendship, because we want each other to be healthy.... We want it to be lighter, the relationship and the topics of conversation to be lighter.”

“I feel that I just need to get [FCR] out, because I feel very worried and I feel that is being redirected in many ways.”
“There is a whole bunch of new people that have been hired since that time who don’t know and I don’t want them to know [I had cancer] because I sometimes feel like... well, “What if she gets sick again?” and... “Maybe she is not dependable.” I don’t want people to feel sorry for me.”

“This is totally irrational, but I worry a little bit like getting into a relationship with someone and then this recurrence happens and then they have to take care of me and is that fair? And I know that that is like projecting and is not even... is not going to happen... But that’s the thought process in my mind.”

“It might be very different from what you are feeling and thinking, but it is just reassuring to hear everybody’s experience.”

“Just talking about it is a comforting thing and a sharing thing. Maybe for me the worst part of it was feeling like I was going to be all alone dying.”

“It’s such a humbling experience to go through because you meet so many people that care about you and don’t even know you.”

“I try just not to go there.”

“I’m dealing with trying to manage the negative places where the mind tends to go. Negative thinking is a disease of its own.”

“There is obviously no guarantee, but that helped me a lot to make me feel that maybe I had some control over a possible outcome, that I could change my diet and my living habits in a way that would help me, and my body, and perhaps could prevent recurrence... You know, to kind of help in an active way, instead of just sitting and wondering: "Is this going to come back?" and being helpless. I think that that really helped me to kind of turn the corner away from feeling kind of like the victim.”

“Well, part of me wants to say that this is over and done with. Like, I put my head in the sand and I read one more article about cancer or cancer...
Almost every day I think, I’m losing my muscle tone because I can’t exercise because I’m so fatigued, and it’s because I’m taking this pill that I take every day. Why am I taking this pill? I’m taking this pill to reduce my chance of a recurrence, so it’s almost something that is in my mind all the time. The only reason I put myself through this physical misery and not being able to lead a normal life, is because my cancer might recur and it’s reducing the risks of my cancer recurring.”

“For me, a lot [of FCR] stems from having no control of outcome... With any serious diagnosis I think that you feel like there is no way to have control over this. So there is always the: “What’s going to happen next?” type of feeling and uncertainty and helplessness.”

“There are a lot of feelings of powerlessness and I just felt like: ‘OK, I’m back in this [expletive] cycle again.”

“Illness in general—not just cancer—illness in general, you don’t get to choose; it happens to you, and there is a lot of luck and whether you catch it in time, you treat it, how your spirit hold up and keeps you going. You can’t choose not to have it...There is no reasoning in how you...live your life...There are small things that you can do, like diet and exercise and stuff like that will keep you healthier, but that they won’t prevent it, if it’s coming... That is not something that you can talk away from occurring, you can only reason with how mentally you deal with it, but not with the disease itself.”

“It feels very coincidental. So I think there’s that element of ‘When’s the next coincidence?’”

“I mean, when I think about what the process caused, I look at how I run my life, and I think that probably I have had instances where I would worry about something, but take action because, you know, I could foresee what could be a consequence. In this case, I can’t foresee. It is
impossible to foresee. If they came up with a way to foresee when cancer is growing in your body, great, I would be the first person to sign up for that, but that’s not a realistic hope.”

“You have this sense of helplessness of how can I prevent this. I don’t know. Could I have prevented the cancer to begin with or was it an environmental or genetic thing that just happened?”

(she felt a lack of) “a sense of security, stability. Because it seems like things are not in my control. I hold whatever I can in control, but I really have to let go. I miss feeling in control.”

“When it starts to feel out of my control, that is the big thing: That I can’t control it, that there is nothing I can do... I can almost start crying, that there is nothing I can do.”

“I don’t have control over it, which I think is a big part of our culture, a lot of stuff about control and autonomy and sort of making the world doing what you want. I’m not going to be able to do that and in some ways life is turning me around. I can have some control, but I don’t have control over the big stuff and it’s a lot more about sort of learning to float with whatever happens.”

"Definitely. Especially in the beginning, when I was eating the food, it’s like I was taking medicines."

“I’m doing all of this so I will not have a recurrence, so I’ll die when I’m 75 instead of dying when I’m 58.”

"Who knows, it could be all superstition, but I’m doing it, because it makes me feel like I have some control and that wards off the worry. I guess my whole strategy is that in order not to worry, I do something."

“It is on the news all the time... maybe if we don’t use certain shampoos we will not get breast cancer. And I think: “Oh, my God, I used those shampoos and that’s what caused it. No, I don’t think that that’s really what caused it.” It’s almost like voodoo; it’s almost like superstition. Sure,
I know that there is environmental stuff that we have all adjusted to, which probably makes the pathways of the proteins more vulnerable to cancer growing. I understand that realistically, but in my mind, it is so mysterious, that is almost like voodoo. If I only did that twice, maybe it wouldn’t have happened, but I did it three times, so that’s why it happened.”

“But it’s now an aspect of life for me, that if I don’t do what I need to do, I will get cancer.”

“I feel it is a bad breast and I want it out, and I’m glad I did because I don’t want to go through these surgeries again. Let’s just do it and get over with and say goodbye to cancer because I don’t want it to come back.”

(Shesaid about her hats 😊 “I don’t like them. I didn’t like wearing them... I hate them, but having them there. ...maybe I won’t get [cancer] back. Because if I put it away, maybe I’ll have to take them out again.”

“Whenever I sit down to it... and I am debating fried chicken over salad, it’s like I’m thinking about recurrence and minimizing that.”

“Maybe I shouldn’t say this, maybe I’ll cause it to happen, but I have the feeling that I’m not going to live a lot more than 10 more years [crying].”

“They say that stress is a trigger for getting cancer. So, it’s like every stress has extra stress with it. It’s not only the issue that you’re dealing with, but it is also: ”I hope that this doesn't make me get cancer?”

“I’m afraid of the connection between stress and cancer.... is that going to cause a recurrence?”

“I try to talk myself off of ledges all of the time.”

“It’s not the best death in the world.”; “This is not how I want to die.”
“...it is really horrendous. I don’t know if there is pain involved. I don’t want to be in pain.”

“...would have spread already since the last check up and... that’s scares me, because I don’t feel the pain. I don’t feel anything like that, so I would not even recognize it being there, and it would just shoot through my body quickly. That’s my fear.”

“This is how people go down to the road of suicide because they feel like there is no hope; they are not going to get any better.”

“The sadness of thinking that I might not be there is horrifying; it really is.”

“I just don’t want to die soon. I don’t care if I live to the old days; I don’t care. I just want to have these next 20 years.”

“Once in a while I think: How many years do I have? Everybody has got to die.... So I got it in the back of my head that I got 10 more years.”

“And it’s not that I thought that I was going to die of breast cancer, because I actually don’t think I will because there is pretty good treatment.”

“I would say that that is the biggest change is the need to accept the fact that you are mortal.... You could think it in general terms: ‘OK, my life is winding down.’ But then a recurrence brings it much closer.”

“(through FCR, to gain) ‘recognition of mortality. It’s sort of like, I don’t like getting old; I don’t want to die, but I don’t have any power about it and it’s going to happen whether I like it or not and I will have to find a way to deal with it. I sort of psychologically attuned myself to this reality. That is [long pause], that’s a big deal for me. I don’t know that that is necessarily a big deal for everyone but that’s where I was. That was kind of a big deal.’

(she had to) “just find peace with it. Peace and acceptance that we’re all going to die] Yeah, I had never thought about that before. You don’t think about that when you’re young either.”
"When I think of recurrence, I really think of dying."

"Well, this is how I’m going to die."

"I’m pretty certain that when I get to that point where it would be the end of my life, it would be cancer. That’s how I see it. I got it on my skin; I got it on my breasts; there was more than one tumor. Who knows, it could be anywhere."

"The scariest part of the whole thing was my kids. I think that if I didn’t have kids, I don’t think that it would have been that scary, and even now if I think about getting sick again, I worry about my kids [crying]."

"Just kind of imagining your children in the world without you...."

"I know that data show differently, statistics, scientific studies...but this belief I have is not just in my head, but it’s in my body. I feel it. I’m going to have a recurrence."

"I feel my breast and I don’t really think cancer because this breast where it started is safe, I think [laughing]. Unless it went to the wall, because they didn’t take the chest wall muscle, so it can happen. I don’t know."

(feel something in the breast) "What is this? How come I can feel something like that?"

(when she was hiking and does not feel in shape) "It was a struggling in a way that didn’t feel normal, so was there something there that I was missing?"

"Well, the test showed nothing. There was nothing there, which was very comforting....But then I was like: 'Yeah, but what was it that you felt there?' And so there was still this uncertainty."
“But part of me is saying, uh, why didn’t it show on a mammogram? So the part of me that is anxious about anything started to pick up.”

“I may have a seven percent chance of a recurrence, and even if I know that that’s not a huge risk, I have already learned that even things that are really low risk happen to you. So I cannot be totally comforted by the idea that it is low risk.”

“But I’m thinking, if this breast was so diseased. What’s going on with the other breast? You know, maybe there is a lot of abnormal cells there too, and I don’t know.”

“The Tamoxifen is meant to try to prevent a recurrence. I’m at this stage in my life where I believe a recurrence is inevitable. I feel that there isn’t anything that I or anyone else can do to prevent it. I already take a laundry load of medication for pain and I was going through my pills one day, and thought, why am I taking this? To what end? Stop taking it. Just stop.”

“It’s not irrational to acknowledge… That’s why I don’t think that you should be afraid of it, because it is just the reality.”

“If I was not aware that there was a chance that my cancer may recur, I had to be crazy. And if I was not aware that there were some chances that it could kill me, well, at the very least I would be coping with it by denial.”

“I didn’t want to dwell on having cancer; I wanted to get beyond that, because there was no reason to think that I still had it. Obviously nobody knows, and it could come back at any time, but there was no evidence that I still had it.”

“I am working way too much and what if I had a recurrence? I should be spending this weekend with [my children]. And then that just kind of unfolds because you feel guilty and you start thinking about death, and I need to ask myself, “Where am I going with this? I’m cured.”

“It wasn’t like I could say: There is nothing there.”; “You don’t know, and lately I have been losing weight and I’m thinking: ‘That’s a sign of some people having cancer.’”
“It is not an irrational fear; it is true that it might come back, because it does and it does for a lot of people and there is only so much that you can control….I feel like it could just happen.”

“It’s not going to go away, so you have to live it. I guess you are going through the five stages of grief, because you are angry, you don’t want to know, I didn’t do anything to deserve this! And then you have to accept it, and then you are treated and then, you know, you go on. You go on, not expecting it to recur, but you know that it could. So I don’t know how…when you can see the statistics, and the people that you have known, and that it has come back. I don’t know how…when you can see the statistics, and the people that you have known, and that it has come back. I don’t know how you erase it from your mind.”

“What causes anxiety for me when I read this stuff is anything that could indicate that I made a bad decision, either what I chose or I didn’t choose…. I want to keep everything as normal as possible, and reading that [recent research] made me really anxious and made me feel like: “Oh, [expletive], did I make a bad decision in not doing that?”

“The thought of recurrence kind of snuck up on me and I didn’t expect it. I had felt like the treatment was good and enough. And so, in some ways, this kind of makes me question whether enough was done and whether I can trust it.”

“My treatment—all what I had—was to have a lumpectomy. I didn’t do radiation; I didn’t take Tamoxifen, so even that scares me because I realize that it could come back more. There is more of a chance that it will come back…even though I’m not sorry about what I did.”

“I want to learn how to deal better and not inflict upon myself extra hurt and energy that is negative. And it actually made me think about the whole topic of forgiveness, because there is a part of it, where I think the worry is connected somehow with forgiving ourselves; worrying is partially revisiting that pain. I must have done something wrong. I must have really screwed up.”

“I felt like I was very diligent, however if I got a recurrence, that would just be evidence that I made a wrong decision, and to make a wrong
decision, in this case where your life is at stake, is little devastating. So, I would be devastated, and I would never forgive myself actually.

“It’s like, nothing is safe.”

“The worry undermines that things will always work out.”

“now I know that my body would do that.”

“I’ve gotten more insight into what life is like and that I can get sick, that these things happen. It’s part of life.”

“I have a much more sense of a future that is not guaranteed. Yeah, that has totally changed and that’s because my cancer might recur....While I’m doing my best to make sure that it doesn’t recur, I don’t control that. Who knows what is going to happen! Yeah, that is a big change.”

“see myself as being more vulnerable than I realized. I never felt vulnerable. My husband and I do a lot of crazy, risky stuff: mountain climbing, scuba diving, and going to the strangest countries in the world. I never felt vulnerable. This made me realize that I will die—not maybe—but I will die!”

(FCR) “makes you feel a little more mortal....Reason doesn’t apply with cancer.”

“The FCR makes me feel a little weaker, a little less strong willed and so forth than I usually feel, and [it’s] an embarrassment and disappointment to me. because I like to stay on top of things and I like to stay positive, but you can’t do that all the time.”

“I would say that that is the biggest change is the need to accept the fact that you are mortal. And I’m sure that until you are not really close to death, you are not going to believe it.’

(noticing a new) “dullness of my thinking, not that I was a great thinker, but there was a spontaneity and a liveliness to my thoughts, and I’d say I
was very easily inspired. Now it’s so rare to get that.”

“I see myself differently now in this worry and anxiety, and lack of patience, and all of that.”

“I’m much more aware now when I’m feeling anxiety because of these experiences I had where I might not have noticed so much before, so nothing has stayed the same. The truth is that everything is different.”

“There must be something really bad with my body.”

“I’ve lost how I access the world or what I really felt was integral to myself, and so that’s hard.”

“You just feel set apart and you can’t free yourself up from this issue [FCR], to really enjoy yourself.”

“Are you ever really done?”

“I lost exploring new things, getting new ideas, adventures. Just new exciting things that are stimulating.”

“I used to have such larger reserves of patience and kindness and...I don’t feel like I have that anymore. I don’t.”

“Maybe part of the reason why people say that I’m more serious...is actually that I do take people more seriously. I just didn’t know that people could feel such pain before...I’ll always wonder when it will come back.”

“Before, I thought it was really positive to send out that message that cancer doesn’t really need to change you; that it can be just something that you get through and you can put behind you. But...when I finished my cancer treatment, that’s not what I experienced, and I felt like an ugly duckling because of it.”
(FCR made her feel like she was an) “ugly duckling.”

“I feel like I had been “false-advertised” [chuckles], you know? “Just wait until you’re done with treatment, it’ll be great!” “You’ll put this behind you and you’re going to move forward.” “You’re going to have come through this stronger, and learned something, and have a positive attitude, and come through this as a better person.” And I don’t know if I really came through this as a better person. You know? I just feel like someone should stand up and say, “You know, I went through it and it pretty much sucked, and I got done, and I was still the same person, except I didn’t have any boobs, and didn’t have any hair, and I was scared to death.” I want that person to be on TV [chuckles]. But that’s not the shining star they want to put out there, so I get annoyed.”

“I think that I made self-changes, so it’s kind of like I eat healthier; I exercise more; I think that I spent more money, I think I used to be a little more frugal and now I’m, “Hey, you know, I could die.” So I think that it has changed me enormously, and so I see myself more like just kind of “What do you want to do? Just do it.” Not like: “We’ll do these things in the next 3 years.”

“First thing you have to deal with is the issue of mortality: You have to recognize that it is there, so this kind of starts you on that journey, at least, and maybe I’ll live long enough so that I have fear and I will come to terms with that, and that is a big deal, I think, emotionally and psychologically and that is part of a development of a person. I think that there is something there that has made me a kind of different person. I don’t know that it is a better person, but it is certainly not a worse person.”

(She said that she gained) “empathy too, for people who go through other life-changing situations, of whatever sort. I have a little bit of empathy for them. And then also perspective on what is really worth fearing. For me, if it’s inevitable, there’s no reason to fear it and no reason to rail against it, and I take that in all parts of my life. If there’s something you can do, then you should do it. But if you can’t, why waste your energies? So I guess I’ve gotten that perspective on things. I’ve gotten some peace of mind, too, from the acceptance. I don’t have the same level of
Before I had cancer, I was so worked up and worried that I was going to get cancer. And then I finally got cancer; it was sort of a relief. “Oh, I’ve got it, now I can get it over and done with.” But then once I was done, I was worried about when it would come back, so I had a grace period of about six months when I wasn’t worrying about anything during the treatment because it was “Okay, finally it’s here, let’s get rid of these things, do the treatment, and then I’m done.” But that’s not how it worked, so I was then worried about when it was coming back.”

“I don’t think I have stayed the same. Maybe somebody else who knows me well would think differently, but I think that I have changed. For the better, mostly, in learning to cope with that and learning to appreciate life.”

“What I have learned is how to be more compassionate for people that do have worry and do have concerns. It’s different being inside these experiences; I just know now what I’m talking about.”

(Shesaid FCR provided) “perspective into what is right in my life and what is wrong.”

(N. said FCR made her) “more proactive in savoring everyday things.”

“I think it shifts just a little bit more of putting priorities, like “I love what I do; I love my work,” but finding that work-life balance a little more and prioritizing life experiences, and being with people, and being present. That has definitely been pulled into focus much more for me.”

“Now, when I’m with friends or with my dog, I’m more with them. I used to always be thinking about the next thing, you know? I was really a bad listener....I do that better now.”

“Fear of recurrence made me unable to think about the future. It made me unable to think about goals...Where I’m at today, I don’t know when cancer will come back, and so I think I now am calmer than I was. I think I live in the moment better than I did before, but I am thinking better about future plans now than when I had the fear. I’m thinking about things I want in my life better than when I was just so paralyzed by fear.”
“It is the overall shift, definitely. Yeah, it is no longer the feeling: ‘Oh, I have millions of days. I don’t have to put any effort into making this day special.’”

“I also don’t keep putting things off like I used to. I used to even put small things off, like if a friend asks, “Do you want to go to the movies?” and I’d say, “No, let’s do it another time.” Now it’s more like “Yeah, let’s go see the movie.”

(Through FCR, D. began to make each day special and learn) “how to live in the moment so that it is a gift.”

“Enjoy what you’re doing right now, even if it’s taking a shower.”

“If you are going to have that fear, try to turn it into something active and you better be moving otherwise you need to guarantee that it is not coming back.”

“Maybe just a little bit more perspective on doing what I need to do for myself, taking care of myself. That really I need to take care of myself, so in some ways that is probably something that it’s good beyond the cancer anyway.”


“Sometimes I can become terribly angry, which I express in sport. In sports, I can release my aggression. I am just angry at my body, it let me down.”

One woman felt that she was responsible for her own chances of survival. She felt that by taking her medication, she could directly influence her
The majority of these women thought that being positive, thinking positive, and changing negative views into positive thoughts help against FOR.

One woman noted that when she has an appointment with her doctor, she always writes down all her questions, so she never forgets something because of her nervousness. Two women told that they do extra self-monitoring at nodules. If the cancer would return in the breast, then five women already know in advance that they will opt for a mastectomy. These women explained that they see breast cancer as a cancer that is not inside their body, and when you take the breast away, they think the risk of metastasis is minimal.

“Last year when I went for my check up. They initially only did a mammography. I said that I wanted an echography because my breast cancer could not be seen on a mammography. I immediately got an echography.”

“I enjoy life much more now, I have a different view on life.”

Moreover, two women said that by expressing their opinion earlier, their family relations had become closer. In addition, the women said that they had learned to “listen to their body”.

“Sure, it could happen again, but I could also speed with my car, and accidentally drive of a cliff.”

The majority of the women had regained an interest in moving forward with their lives. One noticed that when time passes, you get more confident. Four women debated about side-effects of treatment. They concluded that every surgery inherently changes something and that you should disregard that.

A couple of women confirmed that the fear resided in themselves. When the women had a fearful moment, they nearly all tried to keep this to
themselves while thinking about their fear, consider telling about it, and/or reflect on their fear before they might tell their loved ones. There were also women who do not share their feelings and solved it on their own. The reason for some women was that they did not want the persons around them, who have done so much for them in the past, to suffer from the fact that the women every now and then felt anxious.

Different women even isolated themselves, so they could handle a fearful situation. Someone told she often has a conversation with herself: one voice who tells her that everything is alright, and another voice who tells her that she felt something wrong.

A lot of women tried not to be anxious for the checkups, but never succeeded. When they were told that everything was good, they felt relieved. A woman reported that she was emotionally inaccessible weeks before the scheduled controls. One other woman expects bad news when she gets an X-ray and is very relieved when the news is good.

Four women reported that they did not try to think about their FOR.

“Being busy with walking or being physically active outdoors, works for me, just get away from it.”

One woman said that it is not good to laugh everything away, but she called it her protecting shield. Two women described the situation in which they, after the controls and/or doctor’s appointment, escape the hospital as quickly as they can. Afterwards, they have questions they did not (dare) asking.

Another woman avoided going to the movies or reading books that may remind her of breast cancer. One woman shared that she avoids a thorough examination, i.e., she refused an echography because she is afraid of what they may find.

“When I have a fearful moment I tell my brothers, sisters and partner that I am worried.”

These people give comfort and help the women through their fearful moments. Besides family and friends, health professionals are also assisting.
“I was getting a lot of get-well cards and phone calls.”

“It is nice to have someone with whom you can share the same experiences and feelings together.”


“A situation in which I had noticed a cancer tumour in my chest, that had been painless, which, on excision proved to be the size of a golf ball. Did this failure, on my part – to not notice the tumour – not demonstrate my incompetence to retain a responsible degree of self-monitoring? Shouldn’t I have been more alert?”

“Functioning on a day-to-day basis necessitates suspending awareness of impending death, in order to find meaning in doing things, planning etc. After cancer, this proves difficult. Does one just stagger on, or do something one really wants to do, with one’s ‘last few days’? A Sartrean ‘vertigo of possibility’; spoiled for choice decision-making under radical uncertainty. How to commit time, resources when one doesn’t know how long one has to live?”

“This morning I have a shooting pain in my right shoulder-blade if I blow my nose. Perhaps I lay awkwardly in bed, but I feel under attack again.”

“…I’m trying to be level-headed about this discomfort in my chest etc.”
“Unsurprisingly, this aspect of treatment further complicated my difficulty in making sense of the bodily sensations I was experiencing, and in trying to decide what was now ‘normal’, and what might conceivably be indicative of serious pathology. My anxiety about the threat of recurrence seems to have reached a peak some six months later.”

“…my concern at that time was that the cancer had spread to my bones. This unspoken concern seems to have been understood by SBCN4, who mentions the option of a bone scan.”

“I’ve been looking at the various side-effects of the treatments and trying to understand why my chest feels tight throughout the day... I don’t feel breathless, just tight. I’m trying to be more precise, but it’s complicated by the loud clicking on my left side, front and back, if I flex muscles, move shoulders etc. I note that the drugs can create joint and muscle pains. Indeed, I feel thoroughly arthritic, ankles and knees ache, back aches (shoulder-blades and sciatica-like low back). I haven’t got any persistent pains, they come and go. My right (surgery) side has also been aching, so I guess the left may be because of some kind of compensation posture….

1. I had not noticed the growth of a tumour, allowing it to develop and spread in a life-threatening manner. It had been painless, and I had found it purely by chance. Rather than losing trust in the healthcare system, it might be argued that this experience led me to lose trust in myself, or more specifically, in my capacity to monitor my own body effectively.

2. It seems not unreasonable to argue that, had I failed to obtain an urgent referral from Dr A, then the resulting delay might have resulted in a further spread of my cancer, with possibly grave results. Arguably, this factor served to reinforce the sense of personal responsibility I felt for monitoring my bodily sensations.

3. There was (and is) a not insignificant probability of the cancer recurring and developing secondary growths.
4. Should the cancer metastasise, then there are multiple forms, and locations, of possible expression. Would I recognise new sensations as cancer, if it did indeed recur?

5. My sense of confusion about what my normal, healthy body felt like, post-cancer, was further confused by new sensations which probably resulted from the side-effects of various treatments.

6. Noticing the signs of possible recurrence at a range of possible locations, at some possible time in the future, was a time-urgent matter.”

“Seen in this light, my development of the fear of recurrence syndrome was a completely rational response to the peculiar circumstances in which I found myself. Urging me to ‘keep a sense of proportion’ or providing me with statistical information about recurrence rates was hardly likely to assuage my anxiety, or temper my obsession with bodily sensations.”


“Like the anxiety was it sometimes it’s just almost crippling and you feel and sadness too like thinking God you know you’re starting to make your funeral arrangements. You don’t know if you’re gonna live through it or not. You start to be faced with your own mortality.”

“I: So when you do have those thoughts, when you kind of do slip down, how do you feel when you’re experiencing those thoughts.

P: Alone.
I: Alone. Alright, so even though you’ve got this support system around you, you’re the only one that experiences these?

P: Mhmm. Because they can’t really feel what you’re feeling, and they can’t let it out 100% right.”

“I see it as invading me and this time spreading and I won’t have any control over it no matter what they try to help me [...] it’s kind of like this big monster that would be out of control this time.”

“I: And how long does the thought or image last?

P: Oh, it can go a good part of the day. Or it can just be an hour.

I: So when it’s a good part of the day, how long would that be like?

P: Six hours maybe.”

“One minute you could think of it and the next minute it’s gone, and then it’s back again, so you’re bouncing back and forth [...] I don’t dwell on it, but I mean it’s there. It’s – you know, it’s there.”

“I: So could you tell me how long you believe you’ve been having these types of thoughts about recurrence? When did they start to sort of pop into your mind?

P: Closer I think to the four-year mark.

I: Okay, so before that you weren’t worrying much about recurrence?

P: Well, I worried a little bit, but then it’s like you know when you do the self-exam, it’s like you can’t tell anymore if you’ve got a lump because
of the scar tissue and the clumpiness, and if you go to the doctor it’s like well do I get her – like how does she tell? You know and yeah, it’s because – it’s altogether different.”

“I: To what extent do you think the thought or image could actually occur or be true?

P: [...] quite a bit actually. To what extent? I almost feel as if it’s inevitable.”

“I’ve got to say though, all along, that every time I get an ache or a pain your thoughts go back and you start to worry and I do find I worry more now.”

It’s very tiring. [...] I think it changes, it changes your personality in some ways too. You know just the negativity that you pick up on once in a while. Not all the time but it’s there, it’s always there.”

“I guess the not knowing. Again, you know, like I questioned one of the doctors “Is it recurring –am I in remission? Do you call it remission? How do you know it’s remission?” and she said, “Well you’re free of cancer right now, you know, like what are you worrying?” and I thought, “My God lady, you don’t have it!”


“What I imagine, that maybe ... it may be the end ... May be the end and ... That this would take you ... I think that is really, maybe why I don't want to, I can't picture it [recurrence], I can't see, ah, how I would handle it because of that.”

“You know it is not only the anxiety ... well, the anxiety of recurrence, not only in terms of what happens if I get it again. I mean, I have gone to hell and back again. And you know, I managed, but then the same question again, you know, if there is a recurrence, what are your chances of
survival at that point in time and if it is a recurrence, you know, has it metas ... has it spread? Will I get through that, you know. Will I get through it the second time around? So then it is a whole... then it becomes a whole other issue. Then you have to learn to ... I guess deal with the question... How can I put it? Of then really learning to accept the fact that, you know, to accept death.”

“I was scared. I said to myself — what would I do if it ever came back? Will it be as bad as before? Will there still be a chance for it to be cured just like the first time?”

“I was scared because I didn't think that I would make it... I saw death in many ways ... I saw death in front of me ... I would have dreams about my family, like say in "John take care of the kids."

“Well, I worried that I was going to die, I suppose. That is what came to my mind... The thing that scares me the most is time. I just worry about how much time I have to get things done that I really wanted to have done... And I just wondered how I would accept it, you know, how do I do it, whether I was going to go out with a blaze of glory, ha ha ... or be a raving maniac or what... I think I feel cheated of time.”

“[There were] two halves ... on the one side of the balance there was the fear of enjoying life because of the other side of the balance which was the possibility of recurrence... This is like a step along the way: that I might be able to actively enjoy life on that side of the balance. On the other side of the balance is the fear of recurrence, and after that — death.”

“Ah, I didn't like it [the thought of death]. I really like living. I don't want to leave...

“I used to think about dying and I used to get this terrible shiver when I really realized what it was, because I felt I am so happy ... Basically, I loved just living, being here ... [the thought of] not being here, not enjoying everything I had, you know. That is what I found very difficult.”

“The chemo just destroyed me, destroyed me ... it just completely depleted my system ... It is usually not the bloody cancer that gets you, it is the damn cure or result of it. Basically it is a Catch-22 situation. I mean, if you don't have the treatment, yes you are going to ... and then if you go through the treatment, chances are you might, you know, go into remission. But as a result of the treatment, you know, you may catch the common cold, develop pneumonia and, you know, croak, or you know, whatever. Your immune ... because it is ... it totally depletes your
immune system. The slightest thing could trigger... so it is a Catch-22 situation. I am a gambler, but I take calculated risks. If I don't have the treatment, yes I am going to die, so I know that death is at the end of the road. If I do have the treatment, I could possibly die but it won't usually be because of the cancer, it will be because of some complication ... Quite frankly, I don't know what I would do. I haven't been confronted with that situation yet.

"I am not really scared of getting cancer again... It is the treatments that scare the hell out of me ... It is the process of getting cured that is a killer. ha ha. I always tell my friends I don't want to wish this on my worst enemy ... because it is terrible ... There is no way I want to live through that whole hell again ... I always say now there is no way I am doing the treatment [again]... I will just live my life out the way it goes, and sometimes I say don't be so stupid ... go and get cured and live through it, stick it out... You know, mixed all of the time... I am always struggling with it."

"[I dread] the pain of going through it again: the side effects of treatment... First I had to lose my hair... then nausea and vomiting ... diarrhea and loss of appetite... for two years. It depends on the medication I'm gonna get whether it's really worth it [to take treatment again in the event of recurrence]. If taking it would guarantee I would survive another 10 years, I would take it. If only 1-2 years, I may not consider going through the chemotherapy again."

"At this point I don't want to go back on chemotherapy so ah ... you know, I suppose if it had to be done I wouldn't refuse it. I would probably accept it but... it would be with a lot of dread. Because I really dreaded going."

"I was apprehensive for the first while [about check-up results]. I think basically to me, it is not because I was afraid of the cancer even. I think even to this day, that is not the fact. I have seen worse ways of dying, to me ... than dying of cancer... I think the worst for me was if they find the cancer again, would I have to go through the chemotherapy treatments again? That is my biggest fear. To the point where I feel... I wouldn't go through it. I would just say I am going to take my chances if it ever occurs again you know... To me it was awful. It was just a real nightmare. I think being sick all the time, being weak ... It was very depressing to me to the point where ... I felt... if I die I couldn't care less ... You know,
every time I have a little you know ... I have a pain somewhere or if I have something unusual, right away at home [I think] my God what if it is cancer. I will have to go through this again. I think it is just as strong as it was five years ago. Yeah. It is a real... it is a real fright to me.”

“Frankly, I don't know if I would go through [treatment] again because of my vein situation. I don't think I could go through it... The fear that I know I couldn't do it ... The driving and all that... I couldn't do that because I know I would have to be lying here and they would probably have to do it in my legs you know ah... I think it is an awful thing to say maybe but I don't think I would bother. Just let nature take its course ... Oh no; I say that now, but who knows.”

“The hardest part was going up there [for treatment] when you are so sick. You still have to go and that is the hardest thing I ever had to go through. In life that is the hardest. Nothing has hurt me as much as this chemotherapy ... And I wouldn't go back on chemotherapy again. No...

Because it is so devastating. The treatment is so bad ... I have never felt anything like that in my life ... I can't explain it... It is bad ... [It] scares me. The thought of it ... [if] something else comes back again, then you have to go over the treatment again ... Now I am saying I wouldn't, but who knows, maybe I will when the time comes...

“The treatment was hard on me because it is very ... I had ah, not right away, but it slowly broke me down and blew me away ... like I was down, you know ... Not down for the count, but I was down to my knees ... It would take me five years to overcome all of the effects it had on me ... I could not have gone any more ... I could not have forced ... My mind could not have forced my body to walk in there ... I would greatly fear all that would be associated with being treated again.

“I wouldn't want the people who are around me ... who are close to me ... I wouldn't want them — I mean, they would see me like that... And I wouldn't want them to have to ... like, it was very hard on my father ... it would be that much harder again, and I wouldn't want that.”

“Oh the most dreadful aspect of it [the possibility of recurrence] to me has nothing to do with the cancer but... has to do with my children ...

Because ah... I found my family fell apart, and still is, like, it is ... it has had drastic effects on my family and so I always worry you know,
because I have a young child and she worry about what is going to happen to them if... something should happen to me. And I find that is what I sort of concentrate on ... all the time.”

“I dread ... my kids, you know, they are going to see it all over again and I don't think that they could really face that. I don't think they could handle it. My husband — I don't think he would be able to handle it. That is what I dread ... putting them all through it.”

“One of the things that bothered me most... was the effect it [the initial occurrence] was having. The guilt that I felt, that is silly ... I couldn't help being sick ... It sort of threw them both [husband and daughter]... Oh they never let it show and ... they were chronic worriers, too. We all are. And I felt that I probably dampened her years that should have been good by having to worry about me and ah, my husband developed angina which I also ... blamed on it... And that [the effect on family] is what would worry me the most, if it happened again.

“Probably, it probably would bother me less, I think, if I was alone. I wouldn't be potting anybody in misery.”

“I really don't warn to... um, my children to be ... I don't want to be a burden to them. I don't want them to think of me as a burden. I don't want them to wish me dead. That is what it is. I don't want them to wish me gone before my time.”

“... I wouldn't want to put them in that type of position.

“I know it [cancer] could happen again and that I will still have the same feeling of not being able to do anything for myself, you know ... I like to be able to help myself... You become very dependent on people, whether you like it or not, because they are the ones who can do something for you. I guess you are born with that feeling... the feeling of liking to be independent... to take care of problems yourself. You lose that completely... the whole way through.”

“What I dread [about recurrence] is the dependence ... In relation to my ex-husband ... there was a great deal of anger and resentment and a need to be independent — and ah, I didn't want to include him at all in my care or my diagnosis ... I don't NEED you, it is okay ... I had a fear of
becoming, of losing my independence, and becoming more dependent on him ... I think that would probably be the worst part, and then again, the dependence on my children ... uh, maybe one of them will have to drive me or pick me up or take me home or look after me.

"I just wouldn't want to be an invalid again ... I was like that, (invalid) I wouldn't want to be like that again."

“Well, if I can't look after myself... somebody else has to look after me ... I wouldn't want that... If I get it [again] and I die right away, or you know... This would be my biggest worry — something that is prolonged over months and months. If I had it again and I knew that within a very short time I would go, I wouldn't mind having it. Not something prolonged so that I would be dependent. It is probably because I am so independent, you know."

“...There is always something behind me, always the fear that it will come back. I try to put it behind me.”

“...it is always ... I think it is always there ... it is constantly playing. I think it is constantly playing on your mind ... Automatic instantaneous panic [when the phone rings at the time check-up results are expected]. I guess the panic, I relate it to ... if there is a recurrence... what is the next step, you know, undergo chemo again... It just plays on your mind. When that starts playing on my mind ... then I do something ... I try to yeah ... you know, try to keep my mind active ... in other contexts.”

“At first I was coming in for the checkups and waiting to hear the confidence from the doctors ... but there was always a shadow saying ah, we found something ..."

“I have my blood done and I always, there is always that little nigging thing in the back of my mind that something is going to show up there [in the testing for recurrence]. There is always that, but it is not a major, I mean I don’t, you know go in there sweating ... but ah... yeah, there is that ..."

“I am always struggling with it (the fear)... I just broke down... it just hit me all of a sudden ... Yeah, suddenly it hit me... Even when I break down like that, I kick myself... I was kicking myself [for] getting down like that... As fast as I snapped into it, I snapped out of it... If I fall into that situation, eventually I will say what are you doing? ... Because I don't like to be like that. I like to always be cheery and have a smile on my
face all of the time. I always make sure people I am around do that too, or else I get mad at them. So whenever I feel myself getting like that, I get... yeah, really mad... As time goes on it sort of... I will sit, and it starts to bug me until I snap out of it.”

“I have thought of it, You know, it comes to you all of a sudden sometimes... then I put it out of my mind again... Oh well maybe... I am all right now so that is the main thing... I put it aside and ah... forget about it. I can’t say that I forget about it because it is something... but it is not a nagging thing with me. It is something that pops into my mind once in a while. But it doesn't... but I don't let it stay there and bother me, you know.”

“The thing that... was always on your mind... It was always on your mind... Are they going to find anything? Is it this time? Will it be this time? That more or less does stay in your mind and you don’t... you can’t forget it... Once in a while if I sit down or anything... it does come to your mind, but then you try to put it out... I will think of it even more so when I get close to that [the five year mark since treatment]... It will constantly be on my mind... Right now I do think about it, but I have other things to distract me...”

“I am afraid it is still there. I think it is just as strong as it was five years ago... I think about it less and less... It is completely gone... out of my mind. I have put it out of my mind... I don’t bring it back again... I started to get these awful cramps and I was really frightened again because I really thought that this time... it was cancer and... then it stopped again and I put it out of my mind again... You know, not keep living with it... You seem to keep living with it all the time.”

“Sometimes it pops into my head gee... I hope [the doctor] doesn’t find nothing... (These things come, all different ideas come in your head... you know, and lots of ideas come in my head and I am really scared sometimes... I do anything just to get the fear out... anything to get it away. And it goes. It goes because it is something, that as long as you have got fear and you sit down and you feed it, it is going to get you. You can’t feed it. If I am scared I am going to die, I will sit here long enough and believe it. I have got to get up and say Annie listen, forget about that. You have come a long ways, why do you want to give up now?... It is hard not to give up. When you give up, it is easy.”
“I tried to shake it out of my mind... It is easy to think negative... That was a bad thought, a negative thought, and it just had to disappear... It is a lot of playing with your head you know, and... I just try to get those thoughts out of my head basically...”

“I think it is there all of the time, and I can't say in what way it is there except that it is always there... Sometimes you walk around with it and it is very comfortable over your head. Sometimes it is pressing down... It was some time in October and I had been going along with my chemotherapy, and now I have to go and have the check-up to see where the cancer has spread to and wow, maybe they are going to find something somewhere in spite of the chemotherapy and I would wake up in the morning and it was like I was at the bottom of a black hole...

There are times still when I wake up and it is like climbing out of a deep hole. Maybe it is sort of a... before I am completely wide awake and I don't want to get up. I think that is what it is... I don't want to get up, and then... feeling I have to get up because this thing is so oppressive... and I have to get up, because it just becomes too... too oppressive... the feeling that if I don't get up, I may not be able to get up... It is an emptiness really, an emptiness that I have got to get up and fill, and do something to fill it... and the emptiness is inside me... I am way down there, and then the emptiness comes inside and I have to get out... and fill it with something pleasant, read a book or clean the kitchen or anything that is life... When the time comes to go and have the testing done... there is more of an unconscious... but I will work harder to fill it because I know what it is. It doesn't sort of sneak up on me as much... Sometimes these things, the emptiness as a whole will sneak up on you but when you know that they are coming and that they are there, then I can work harder to fill them up... to keep the days filled one way or another so that the fears are not as noticeable.”

“It is this word cancer... that is touchy. I think it has such a reputation of a terrible disease, that almost like it's... not a curse, but it is something that was sent to punish you... Cancer. And everybody is so afraid to get it that it is not mentioned. The same thing with AIDS now, you know. I think it [cancer] was looked upon way back when as... as an ugly disease, as a punishment for something you know, rather than just something that occurs. I think most people still again haven't gotten over the idea that you don't get cancer by touching somebody else. You know, you don't
“Go into hospital and it jumps on you ... Certainly fatal every time. And it can be caught. You can catch it, yeah. I probably had the same ideas when I ... when I was very young.”

“I know I was a lot more worried about cancer before I had it... It was terrible ... I think everybody has a fear of it. It is no more or no less but I did have a fear of it and ah, I had two aunts die of it... I thought you died automatically when you got it... Everybody treated it as a dirty word you know... I had somebody come in to visit me, and refused to shake hands with me, you know? I used to get a peck on the cheek — not that day. My father was in hospital last year and in the same room with a man dying of cancer and ah ... the man... went home for the weekend. While he was gone they washed the walls. My father said you know, they are not telling us everything. This thing is contagious, you know? ... [And] preparing food for people that know you have had cancer — they will die of indigestion when they know that they are eating food you have prepared you know ... What is in it? Any germs, you know?... Don't cough on my baby ...”

“I think I knew before I even had the results [of the biopsy], I knew that it was that [cancer]... It was like a subconscious feeling... Yeah, I knew myself... My doctor was going on holidays and he ... waited before going, to wake me up and tell me what he did [whether he had removed breast] and I just said I know. I already knew ... It [cancer] has always been my nightmare. It is the one thing I have always prayed I would never get. My aunt and cousins had cancer on my grandfather's side ... [They] had lung cancer... I guess hearing about them, and they were nurses, and I kind of wondered how nurses get cancer, I guess. They are usually more careful than other people... They were two sisters and the mother... but they weren't blood relatives to me so I didn't worry as much, and then my mother passed away, not with cancer but with other illnesses and so I guess ... My mother is almost... I think sickness has been on my mind perhaps ... I have always ... I guess the one thing you ... that people worry about... You just hope it is one thing that you never get ... And here, I mean... it is like living a nightmare over. I have always worried about it and I... as far back as I can remember, at least ten years ... I sometimes think I should have had a mammogram earlier in life, and I never did ... If I had had [a mammogram] a couple of years ago, maybe I would have caught it, they would have caught it at an earlier stage ... And any time my children have something, I was terrified to take them to the doctor these days because I figured well, what if they find something with them? ...
Like my son has a lump on the side of his neck, and it took me five months to take him to a doctor to see about that... He has always been the one that I thought if anything was going to happen to any of my children it was going to be him. I am more nervous with the children [since having cancer]. Before, if they sneezed, I would take them to the doctor. Now, when they sneeze, I say don't go and sneeze so much... I worry about it more... But I am scared to do something about it more.”

“I was diagnosed for cancer and it came on very fast. I thought... either it was an infection or either (it was you know the big C)... After the surgery, it was clean ... [Then] there is that overkill in treatment [chemotherapy]. Since then, knock on wood, I mean, everything is still a clean bill of health ... Now mind you I have had a clean bill of health on record ... He [friend with cancer] had the same thing [cancer of the testicle] and then it was clean, given a clean bill of health... I guess that through clean living and proper food and ... I think half the battle is your mental outlook.”

“He [the doctor] took every thine out — he took the bad cells. I asked if it was likely to come back because it's cancer and I knew that it will always have the possibility of coming back... He says there is a possibility ... I said I'll give it [chemotherapy] a try and see if it really helps the bad cells not to recur.”

“He [the doctor] was explaining how cancer is and how it spreads to the lymph, and he said he got... he cleaned up everything that was there, but it did spread to the lymph... Later on I found out it was still in my body...”

“I had a couple of attacks in my stomach... I had a recurrence of that again... a very bad one ... [the doctor] said I had a small tumour and it was a bad one.-it was a very bad thing... But... I did have this mentality about this illness of mine that (I am not going to let it beat me)... That [my stomach] is where it hit me. It was a very very small tumour... so apparently they killed it... It is gone ... I am very grateful to everybody for ah... curing me, or killing this thing... I know that cancer is not curable] but don't give up. I would say that if you have the disposition that this is going to be cured or stopped ... I figured I have- to fight this thing all the way.”
“You have got to fight against the sickness. You can't give in to it. If you give in to it then you might as well say forget it. From the time that you say I am fed up... You can say you are fed up, but inside if you are fed up you are done.”

“[cancer] affected the whole course of my life... a personal holocaust.”

“They came to me and told me that I have the cancer. With the invasion of the uterus, I was going to have to have you know chemotherapy, radiotherapy, and all of that.”

“When I saw it [cancer] on TV and I saw it always being... people dying, they got six months to live. That was always in my mind when I got told... how long do I have to live? And ah, I kept saying I wish I would never get that. And it happened... That was the first thing that entered my mind. I was diagnosed as having it... and it hit me hard. The first assumption with cancer... I am going to die. [But I was] tackling this thing head on... I am heading onto this thing... I was attacking this thing right on... After five years, if it doesn't come back, you are cured... My father's parents were dead before... My father's father... um, died when my father was ten years old. Back then, everything was tuberculosis but they say now that he had what I have [cancer of the testicle]. Cancer really wasn't really coming up then. So they are saying now I got mine through heredity. They are saying that is probably what he died of... Everyone assumed it was tuberculosis until they told us, when I went through it, that that was probably what... my father's father died of... Well, see my father told me that his father died when he was ten years old... and ah... so when I went through it, I said geez I guess I would only live another ten years maybe.”

“Well, they say you never forget the day you find your lump and it is true. It was last year... and it was Mother's Day and I had just come back from my mother's... and I scratched and I felt a lump... and he [my boyfriend] said it is probably just nothing you know. But now, you know', now that I look back I think I knew it was what it was. I just had that, that feeling... Yeah, I don't know why. I just, I said I bet it is malignant... And he [the doctor] did the biopsy and everything and told me it was malignant. Malignant, yeah... I thought it was all a bad dream and for a long time I thought it was a bad dream... It took months to get over... I would wake up in the middle of the night and I would think cancer. I mean I would think cancer 90% of the time during the day. Even at night I would wake up. I have cancer. I can't believe it. I would wake up in the
morning and that is the first thing you think of. That went on for a few months. Completely obsessed by it... I just didn't think of anything else. I thought of cancer and I thought of dying ... I had thought about dying ... when my girlfriend died, yeah. I guess, you see my girlfriend died of cancer a few years ago and that also... and I had an aunt that died, a cousin actually, who died at 35 of breast cancer... I knew her very well... she was my godmother and I knew her... and she died twenty years ago actually at 35, of breast cancer and I was 33, so all this put together made me feel... and I am a fatalist you see. And I also felt that this is the way... maybe I am meant to die young... I thought maybe this was all the plan, the story of my life and that was it you know, I am going to die in a couple of years... My mother had told me, yeah. Yeah, she told me about it and I knew a lot about it. She [aunt] probably had had it for a long time ... She probably felt that ah, she was dying. I have that feeling. It was too late to do anything ... And like I was 33 when I had this and I thought oh God. I was very close to her. She was my godmother and I thought oh, there you go, I am going to die like her too ... I felt that... I am a fatalist and I felt that well, this is the way it is going to be. I am, I have got this thing and I am going to die. I always ... and that is funny, because I always used to say ah, long before this I would say I don't want to be old, to be wrinkly. And believe me, I have changed my story since getting breast cancer... I want to live ... [They say] you develop it [cancer] because your immune system at that time is low. It takes advantage of that — the cancer, the bad cells... I really believe that stress didn't help and ... if you have positive vibes you will help your body on its own, will get rid of those bad cells ... I think the less you talk about cancer, I think it, just saving it, I could feel it go through me. You know, I can feel what it does to me, just the sound of that word ... It's a constant battle. You do dread it [cancer] but you shouldn't think about it. It probably does do weird things to your body... I felt that I wasn't going to stay at home. I ah, I felt that if I stayed home I would let myself die, I guess... There is a point where... you either say you are going to lie there and wait for it to come and get you, or you are going to fight it.”

“Well, from the... let's say [age of] 18 or 20 years old, I started you know thinking about it [cancer] really... and getting to know more about it and 60 that was always behind ... in my mind that there is a possibility that it could happen because she [my mother] had it... In my late 30s... I started really reading more and more about it, but... from the age of 20 ... I learned ... I knew what it represented but I ... it could mean death ...
And I knew I could get it because... of my mother, but never until I was in the late 30's, when I started reading more about it... Before, you always had it in the back of your mind that you could... Maybe it is possible... Right now with my sister... she is OK so far... but now she, too, thinks of it more than ever before because she found out that I have it so there is a possibility that she might so... I did start thinking more and more about it since then... It was my mother who died earlier [than father, who also died of cancer] and was always on my mind... I never associated cancer to him... as I did with my mother... I kept insisting on a biopsy [of lump], because my mother had died of breast cancer... It was in the back of my mind as I grew up and I kept insisting, I want to have a biopsy... And when I did have the biopsy... they asked if anybody is going to come and pick me up and I said yes, my husband. Well you should call home and say you are staying in, you are not going home, and I knew right away that there was something... I didn't need the doctor to come tell me... And finally... when my husband came in I told him what I felt... what I think it is, and he said well just wait until the doctor comes, don't make up your mind before he... and I told him no, that I know... “I think she [her daughter] is very frightened, although she doesn't talk about it, about cancer... She had cysts in her breasts... She will phone me up... did you ever have that? I know she thinks a lot about it but she doesn't talk about it you know.”

“By this time [biopsy] I was probably pretty sure that there was a malignancy in my left breast... I told my daughters, and they in turn told the family that I had had surgery for cancer, and that had the kind of devastating effect that the word cancer has on most people. I was very calm [when told it was malignant]. I think I kind of expected the result to be what it was and I felt very calm at that point... I tried to downplay it [the seriousness of diagnosis of cancer]... but we had a very strong history of family cancer so... and of terminal cancer, too. You know, people in the family who had cancer. So I guess maybe it was a little bit false reassuring when I told them [family] that it really wasn't going to be that bad...

My own mother had been side and died of cancer... it was a brain tumour... I had a favourite aunt, my mother's sister who had died of cancer, but I was only about 18 at the time... but again it was again it's this thing cancer. My grandmother died of breast cancer as well. A couple of uncles had had cancer, so it seemed... I think I always sort of knew that someday I was going to have breast cancer... It seems weird maybe but there is a family tendency — the possibility seemed quite real... Maybe it was something that was always in my mind for all of the years and I was always...
saying well, if I ever get cancer, I am not going to get treatment that is for sure. There is no way I would go and do anything about it... based on the idea that I can't do anything about it anyway, except prolong the agony... why do that, and prolong a terminal state or something... I assumed that someday I would... I wouldn't have heart disease, I probably wouldn't have arthritis, but I probably would have cancer...)

“I was scared about it — if it would come back... I think about it, I thought about it — I asked if it will go back to the same place or if it will spread to all other places... I always feel that it will come back... Maybe not in 5 years, maybe in 10 years... I still feel the same way... I have accepted it to myself more freely than before... I have accepted that I am in great risk now compared to anybody who hasn't had cancer. It's already there and there's no way of escaping it now... Sometimes I just try to ignore it. Sometimes I tell myself it's already there and there's not much I can do but just to face it... It could be in the colon, or in the liver. Possibly in the breast... I have been reading a lot of medical books. I have frequent constipation and frequent diarrhea. I think it could be a growth... I check my abdomen for possible lumps.”

“Basically, I have come to well, if they find it, it is there, it is there, there is nothing I can do about it... They sort of reassured me but every time [this pain] recurred, I kept thinking in my mind: Is there really something there, and they are not finding it?”

“ ‘I wonder if it is working there slowly... and ah...’

“ ‘It [recurrence] is at the back of your mind... They tell you that there is a possibility. I would say probability but they say possibility...’

“ ‘Well, obviously they didn't get everything or... it is coming back or something and... um, here I go again. Basically I think that is what I had in mind... I always think about it, every... Like I have a problem with my periods... and I worry about that being related, and then I found that I had a cyst on my ovaries... and so then I worried that there was something wrong there, that they weren't telling me and...’

“ ‘Whenever I did [think of recurrence] I would start crying... because I thought oh my God, you know... You know, you get worried, you know, you get a pain in your stomach... you say that is a recurrence thing. You do. I did... I don’t know from now on how it is going to be... but up till now every time I get a pain or something I would think oh my God, maybe this is it, because I know that breast cancer if it is to spread it goes like to the...’
And she [her aunt/godmother] died when she was 35. And like I was 33 when I had this [breast cancer] and I THOUGHT OH GOD. I was very close to her. She was my godmother and I THOUGHT OH, THERE YOU GO, I AM GOING TO DIE LIKE HER, TOO. And my girlfriend like I said was 44. She didn't have breast cancer, she had all kinds of other things but, urn, she died like three years ago and I thought I would be exempt of it because I felt that I had gone... I had been very supportive of her... Not because it was owed to me ... I just felt that you know, it just won't happen to me. I guess everybody does, but because you have gone through it with someone, you figure maybe well, it might not happen to me, and it did. That was terrible because I SAW HER DIE. LIKE I REMEMBER WHAT SHE LOOKED LIKE, those last few weeks. And I would lie in my bed and I WOULD SEE MYSELF LIKE THAT...
AFTER I HAD SEEN HER, JUST SHRIVEL TO NOTHING. You know, she had lost so much weight. She had morphine. She couldn't... HER EYES WERE LIKE THIS ... SHE WAS A SKELETON. SHE WAS JUST LYING THERE. You talk to her and she SEEMED to understand that she couldn't talk anymore. So I HAD GONE THROUGH ALL THAT...

You had been there with her all...

YOU KNOW, I KNEW WHAT IT WAS LIKE TO DIE OF CANCER. I HAD SEEN IT AND THAT IS WHAT SCARED ME, YOU KNOW, TO DIE LIKE THAT AND NOT TO BE HERE.

I think during the whole time I was in treatment, I ... for a long time up until October I guess, in the hospital, I guess I FELT THAT, well mainly the summer I think, during the chemo, you get so down, so weak and ah, I REMEMBER LYING IN BED AND THINKING OH MY GOD, THIS COULD BE LIKE THIS YOU KNOW, I AM DYING. You know, I DID GET THOUGHTS LIKE THAT ...

YOU EITHER SAY YOU ARE GOING TO LIE THERE AND WAIT FOR IT [cancer] TO COME AND GET YOU, OR YOU ARE GOING TO FIGHT IT...

What was that image of it coming to get you? Did you ever have a picture in your mind of what it is? JUST GETTING WEAK, BEING LIKE I WAS — LET'S SAY AT THAT PARTICULAR TIME — AND JUST GETTING WEAKER, AND ALSO I SAW MY GIRLFRIEND DIE. SO I SAW ... I MEAN I HAD GREAT IMAGES... VERY VIVID.

Of her?

Well, that is exactly how I would ... that is exactly it. I REMEMBER, like I remember I said it while we were taping. That you know, I would be in bed and tired and you know after our session of chemo I AM THINKING IF I LET MYSELF GO I WILL LOOK LIKE JUDY LOOKED, DYING THERE. I just... which I tried to shake out of my head.

You mentioned that when you first found the lump, that you sort of had a sense
Yeah, I don't know why. I just, I said I BET IT IS MALIGNANT. He [her boyfriend] said, oh don't be silly. Obviously, he is going to say that but, I don't know, I just, I can't explain, IT JUST FELT... BECAUSE IT HAD SOMETHING TO DO WITH WHAT WAS GOING ON WITH US... He was working very hard to pay off some debts so that we could eventually have a family and, ah, what happened is that he was spending absolutely no ... the last year he was spending absolutely no time with me at all because he was working all of the time and I couldn't take it and I tried to make him understand, you can't build a relationship when two people don't see each other. I was having a very rough time dealing with that because I didn't feel... I felt that we were getting further and further apart... and I tried to make him understand ... He just felt that he could put everything on hold, and I didn't... AND I ALWAYS THOUGHT SOMETHING IS GOING TO... HE IS GOING TO HAVE A HEART ATTACK. HE IS GOING TO GET HIMSELF SICK. HE IS WORKING TERRIBLY HARD. I WAS AFRAID FOR HIM, AND THEN THIS ALL HAPPENED ... IT IS ALMOST LIKE I SENSED SOMETHING WOULD HAPPEN, WAS GOING TO HAPPEN. EXCEPT I THOUGHT IT WAS GOING TO HAPPEN TO HIM, AND WHAT HAPPENED WAS IT HAPPENED TO ME.

And I have a friend of mine whose father died from cancer two weeks before his retirement. And HIS DEATH REALLY AFFECTED ME, and that was almost four years ago, three years. What had happened was that he had planned all his life to buy a place in Florida to retire, and two weeks before his retirement, he found out he had lung cancer and died. I mean HE DIED LIKE BANG ... It was very fast... I didn't know this man but just the whole thing about waiting and waiting for later... just totally ... And him and his wife were very close still, and they held hands together when they went shopping and they were really really, you know, really close to each other and then they'd worked their whole lives to ... for tills retreat in you know, in Florida and then bang, and I tried to make my boyfriend understand, you know, for a long time, maybe I just can't always ... wait til tomorrow ...

He tried ... basically he tried ... basically he wanted to put our whole life on hold for two years while he paid off the debts and I thought in the beginning of the relationship that it would, that that would be part of it, but I thought I would be able to handle it, but obviously I don't think I was able to handle it very well. THINK I GOT MYSELF SICK OVER IT BASICALLY. AND AH, SO THAT WAS, AND THAT IS WHY
WHEN I FELT THAT LUMP, MAYBE I THOUGHT IT REALLY WAS IT. I DON'T KNOW, I JUST ... I DON'T KNOW, I JUST HAD THAT FEELING. I can't explain it better than that, you know.

... Just sitting in that room [waiting for her check-up] with all those ... you know everybody there has cancer, and you have got people laying down that they have brought from rooms on stretchers. I mean ah, people that LOOKED terrible — no hair, skinny, white. That is hard. I found that very difficult... You just get so scared you know. And I DID THINK, I THOUGHT I WAS DYING ... Well, in the beginning it was that I WAS GOING TO DIE, basically. Ah I FELT THAT I WAS AH, THAT THIS WAS IT ... I guess ... this First reaction you know, you find out you have cancer. The doctor tells you you have 40 to 50 per cent chance of living or dying. I guess it depends which way you LOOK at it. And ah, so YOU DON'T, YOU DIDN'T, I don't know. IN MY CASE I DIDN'T THINK OF ANYTHING ELSE. I THOUGHT OF CANCER AND I THOUGHT OF DYING ... You are constantly in that environment [i.e., the Clinic]... And you are SEEING people around you who are, that you feel... I felt just terrible you know, just terrible.

... And sitting there, you only get yourself... You SEE people around you that LOOK worse, a hell of a lot worse off than you, and you SEE how many people have cancer. It is devastating to SEE the quantity. The [other hospital], the couple of times I had to wait in that terrible Oncology Department, it was just so terrible that I had to walk out I mean I just got so upset. And I SAW a poor kid who came in with is mother and aunt... He was in a wheelchair and he was green. Obviously he had been on chemo, he had been throwing up because he LOOKED it, and he was just like, he had no strength, he was sitting there LIKE THIS ... I couldn't take it. I couldn't take WATCHING that. And I think that is disgusting that they make people wait like that. It is really disgusting and um what happened last week... they put me for the examination in the room where everybody gets their chemo, where I got mine, and I thought really ... I was so surprised at that. And they put me you know, in one of those little cubicles where they shut the curtains and I could hear the nurses talking with the patients, and there was some guy moaning next to me. Like
YOU JUST GO BACK TO THAT TIME WHEN YOU WERE THERE, AND I HAD A LOT OF FLASHES OF WHEN I WAS THERE, and the nurses that were taking — that was giving me my chemo just died because she had breast cancer [recurrence]. And she [Kathy] was the one who came to me when I was in the hospital and told me, you know, about the treatment and the chemo and what would happen and about the department and she, she gave me my first two chemos and we sort of got to be, not friends but SHE SORT OF REMINDED ME OF MY GIRLFRIEND WHO HAD DIED ALSO and then I found out she had a recurrence... And one day I had to call the hospital and I JUST HAD THAT FEELING THAT SOMETHING HAD HAPPENED ... and they said to me well, tomorrow when you come for your routine examination it may be a little longer because we are all going to a funeral. So I THOUGHT, AND I HAD THAT FEELING AND I LOOKED in the [paper] and sure enough, she had, she had died, and that really, that was hard for me to take because I had known her, SHE REMINDED ME OF MY GIRLFRIEND WHO HAD DIED and she had had breast cancer you know, and she was such a lively kind of girl... I WAS JUST DEVASTATED BY HER DEATH, I REALLY WAS. How did I get talking about that? Oh, because of the people, yeah, and I FELT ALL THAT you know. I THOUGHT ABOUT ALL THAT AGAIN.

I am too sensitive a person. I mean, I will cry at anything so I mean... I don't think I could ever work in that [Oncology Clinic]... even before I had cancer and ... then having it and SEEING ... I feel sorry for people there. I have it. I had it... I had it, and I feel bad for the people sitting there waiting. I felt, me it doesn't matter, but this poor old lady who is there or this guy or whoever... I took it too ... I did take it too seriously, and I am very sensitive so it really bothered me.

All that [going through treatment] is like, IT IS LIKE A DREAM. That is exactly what it is. And like I said, I used to wake up, ah, THIS IS JUST A BAD DREAM. It didn't happen to me. I am not going through all of this s ....

What do you imagine it [recurrence/ would be like?
Had you ever thought about cancer before /initial diagnosis/?

Yes, \textit{IT HAS ALWAYS BEEN MY NIGHTMARE} ...

My aunt and cousins had cancer on my grandfather's side... I guess maybe hearing about them ... the two sisters and the mother... Then my mother passed away, not with cancer but with other illnesses and so I guess ... Ah, my mother is almost 20 years ago now... \textit{I THINK SICKNESS HAS BEEN ON MY MIND PERHAPS} ... I HAVE ALWAYS ... I guess that is one thing you ... that people worry about, you just hope it is one thing that you never get... And here I mean ... \textit{IT IS LIKE LIVING A NIGHTMARE OVER}.

... Did you ever actually dream about it, in terms of...

I probably did ... It wasn't a big \textit{IMPRESSION} at that time... But... You know, \textit{like I have always worried} about it and I ... as far back as I can \textit{REMEMBER}, at least 10 years.

Did you read about it ...?

No, no. I didn't then. My doctor advised me not to ... \textit{If you read}, you get... \textit{you IMAGINE that you have got everything}, ha ha ... And I am that type of person ... \textit{I am a worrier}, so ... Friends ... A lady that used to look after me when I was younger, she passed away recently. \textit{One of the nurses [Kathy] that gave me treatments passed away and} ... \textit{and THAT KIND OF HIT ME HARD}.

How did you feel? How did that...
Very scared. Because she was the one who ... after my operation, came up and said hey, look, at me, I am still here. I have had breast cancer and I have had the surgery, I have had treatment and I am still around. And then after she had treated me for about a year she has a recurrence and in less than a year she is dead so ... You know, \textbf{I JUST FIGURED IF IT CAN HAPPEN TO HER IT CAN HAPPEN TO ME AND SO IT PLAYS ON YOUR MIND A BIT MORE ...} 

Are there any other fears that are more now than they used to be?

No, not... I am... Not any stronger than they were ... \textbf{Since I have had cancer \textbf{I HAVE WORRIED ABOUT IT COMING BACK. I STILL WORRY ABOUT IT COMING BACK} and ah, I guess \textbf{SOMETIMES I VISUALIZE MYSELF DYING} you know ... And then... I try and talk myself out of that one because that is too morbid ... And \textbf{IT HAS BEEN MORE ON MY MIND} since the thing happened with the nurse [Kathy, in the Oncology Department, who had recently died of cancer recurrence.] \textbf{It HAS BEEN MORE OFTEN. AND THAT REALLY HIT ME HARD} ... 

As the months go by, every time you find a lump some place, \textbf{you start worrying ... Because I remember when I was going to the hospital for my first time ... and I just went like this, and I found a lump and \textbf{THE FIRST THING I THOUGHT OF WAS OH GOD DON'T LET IT BE ANOTHER LUMP...} I remember because \textbf{I was in a sweat by the time I got to the hospital, because \textbf{WAS SO WORRIED ABOUT IT ... MY NERVES WERE SHOT ... I felt that THE PIT OF MY STOMACH HAD FALLEN OUT, I WAS JUST ... ALL NERVES, AND JUST WAITING FOR SOMEBODY TO TELL ME SOMETHING.} 

What did you imagine ... \textbf{WELL I JUST WORRIED THAT THEY WERE GOING TO TELL ME THAT I HAD TO HAVE ANOTHER OPERATION OR THAT THE MEDICINE THAT I WAS HAVING WASN'T GOING TO DO THE TRICK OR SOMETHING TO THAT EFFECT.} 

So when you have to go for a checkup, can you tell me some of the feelings you go through...
Basically I ... I START TO WORRY as soon as I have the tests done and ah, I SORT OF IMAGINE ... WHAT I WOULD FEEL LIKE IF ... SOMETHING DID SHOW AND ... I AM JUST A BUNCH OF NERVES until they [test results] come back in. And ah, I get pains in other places in my body, I know they are probably just pains because MY NERVES ARE SHOT ... Until I hear something, my stomach is usually upset. I get constant heartburn ... I will probably call a thousand times and ask them [about results]. I bug them a lot ... I would sooner have me phone them because I figure if they are phoning me, I would start to worry why are they phoning me ha ha ha ... MAYBE IT IS SOMETHING THAT I DON'T WANT TO KNOW ... THE ONE THING THAT WORRIED ME MOST when I went in there [to the Clinic] was ... Dr. Hanley ... He is so gentle, he is always patting you and telling you good luck, and HE USED TO WORRY ME ... I THOUGHT THERE WAS SOMETHING WRONG WITH ME ... I ALWAYS KEPT THINKING THERE WAS SOMETHING THAT THEY ARE NOT TELLING ME PERHAPS OR MAYBE I AM MORE ADVANCED THAN THEY SAY I AM AND MAYBE THEY JUST DON'T WANT TO TELL ME ... (this is also a memory)

How has this ... being ill... changed your outlook on life in any way?

I don't plan things too far in advance any more ... I find I am not as interested in things as I used to be ... I wanted to buy furniture for the house, and then I FIGURED WHY BOTHER. MAYBE I WON'T BE AROUND in a couple of years to enjoy it so why put the money out ... I don't go and buy myself a lot of clothes like I used to ... I GUESS I FIGURE ... SOMEHOW THINKING THAT, MAYBE DOWN THE ROAD I WONT NEED IT, ha ha ...

And I have SEEN lots of my friends ... I haven't SEEN them die but I have heard that they died, you know ... Do you know about Kathy [the nurse in Oncology]?

Yes, I do.

She died at [this hospital]. Well, she was giving me treatment.
Was she?

And when my marriage was falling apart, she was telling me to hold on when I was crying and had to take treatments. She told me not to give up, and when I heard that she died IT DEVASTATED ME. I said why? Why did she have to go. It is not fair. And I cried because I couldn't understand it. Why? You know, there are so many miserable people, nasty people, but she went. And I said you know, THERE IS PROBABLY A GOOD REASON, THERE IS A GOOD REASON WHY THAT SHE IS GONE. And even when I go up for my treatment, there are good people that hold on my arm [and say] guess what, Kathy died. I say sure she died, but you can't bring her back. Forget about it. Nothing you do or nothing you say is going to bring her back. I said but I don't want to talk about her anymore because she is gone and you cannot bring the death ... the dead, you cannot bring them alive. Only God can do that. ... In the beginning I was scared because I DIDN'T THINK THAT I WOULD MAKE IT. THE FIRST THING I THOUGHT ABOUT WAS DEATH ... When I started taking treatment I said well I DON'T THINK I AM GOING TO MAKE IT ALL THE WAY BECAUSE I THINK I AM GOING TO DIE, you know? ...

... But ah, Dr. Lane, I don't know. He is a very nice doctor... but WHEN I LOOK AT HIM, I SEE DISCOURAGEMENT. Because one week I was supposed to go there. It was a holiday and he was there and I said I am not taking my treatment today. And the nurse says why and I said because Dr. Lane is there and WHEN I SEE HIM, I DON'T THINK I AM GOING TO MAKE IT ... I can't take that man ... Even when we were in the meeting I couldn't stand him. I just barely swish beside him, swish. HE GIVES ME THE CHILLS. But I am ... I mean, that is just the way he is... I could never be comfortable around him. I don't dislike the guy, he is doing us a favour. He is a lovely man. But I ... for some reason HE REMINDS ME OF MY MOTHER ... Because he said ... he said when he had the conference with us, me and my husband, he said: "Your mother was a very sick woman." She had cancer too [and died of it], and EVERY TIME I LOOK AT HIM, I SEE MY MOTHER, I CAN'T STAND TO LOOK AT HIM.

What about him ... What about your mother do you see in him? What way ...
IT IS HIS EYES. IT IS HIS EYES THAT FRIGHTEN ME. YOU KNOW LIKE...

Like the eyes of what?

THE EYES LOOK LIKE DEATH TO ME. THAT IS WHAT I SEE IN HIS EYES. Now I am not mad at him. I don't hate him. I just don't like him ha ha ... He hasn't done anything to me. But HIS EYES SCARE ME AND I CAN'T LOOK AT HIM FOR VERY LONG.

No ... Was it the same with your mother? Her eyes?

MY MOTHER HAD NOT DEATH EYES, SHE HAD A SAD LOOK ... SHE HAD A SAD LOOK IN HER EYES, LIKE ... YOU KNOW, THIS IS THE END AND ... YOU KNOW, THAT IS THE LOOK THAT I FELT. I DON'T KNOW IF THAT IS WHAT I SAW BUT ....

WHEN I LOOK AT HIM, I FEEL THAT I AM NOT GOING TO MAKE IT BECAUSE I SEE THE EYES ARE SOMETHING. They are not big, they are small eyes but THEY ARE LIKE SEARCHING EYES and I can't stand those eyes.

Okay, because they are looking ... almost... they are looking into you, do you feel that?

WELL I FEEL LIKE HE IS LOOKING INSIDE ME. AND BECAUSE I HAVE GOT THE SICKNESS AND MY MOTHER HAD IT, AND HE WAS LOOKING AFTER MY MOTHER, WHICH SORT OF LIKE GETS ME.

That is about it, because I could never take my treatment when he was there. I mean, if he is in the room and he doesn't have to EXAMINE me, fine. But if he has to EXAMINE me, I am not going for my treatment. Forget it. I told the nurse I will come back next week so the next week I went in he wasn't there. I was okay.

It was okay, yeah.

But if he walks in while I am taking it, it is nothing. I just don't want him to EXAMINE me ...

Can you imagine different things happening or... Do you sort of picture how things might go?

I can IMAGINE my husband taking me all over the world and making me happy and KNOWING THAT ONE DAY ... Or I CAN IMAGINE MYSELF DYING AT THAT MINUTE. MY HUSBAND WILL SAY LOOK
... NO, I CAN IMAGINE MYSELF ... THE DOCTOR TELLING US LOOK, YOU HAVE ONLY GOT A CERTAIN TIME TO LIVE, I CAN SEE MY HUSBAND SAYING LOOK, LET'S GO AND HAVE FUN. LET'S SPEND AS MUCH TIME AS WE CAN TOGETHER BEFORE YOU DEPART FROM US. I IMAGINE THAT. I IMAGINE LOTS OF THINGS BUT THAT I IMAGINE THE MOST ... MAKING UP FOR THE TIME WE LOST TOGETHER. I SEE THAT. ...

So when you think [now] of recurrence, of treatment...

... I am not ready for the doctor to tell me if anything is wrong with me. I am not ready TO FACE that. I mean, I am talking about it now, but I CAN'T SEE MYSELF SAYING SURE I WILL TAKE IT [treatment]... I CAN'T SEE THAT. I CAN SEE MYSELF RUNNING AWAY FROM IT because it is so... it is so dramatic and so painful and so ah, you get so many feelings. And you are mad. You get mad. You get mad.

My own mother had been sick and died of cancer... it was a brain tumour... I had a favourite aunt, my mother's sister, who had died of cancer, but I was only about 18 at the time... but again it was again it's this thing cancer. My grandmother died of breast cancer as well. A couple of uncles had had cancer, so IT SEEMED ... I THINK I ALWAYS SORT OF KNEW THAT I WOULD HAVE BREAST CANCER. IT SEEMS WEIRD MAYBE but there is a family tendency — THE POSSIBILITY SEEMED QUITE REAL... MAYBE IT WAS SOMETHING THAT WAS ON MY MIND FOR ALL THE YEARS ... I ASSUMED THAT SOMEDAY I WOULD ... I WOULDN'T HAVE HEART DISEASE, I PROBABLY WOULDN'T HAVE ARTHRITIS, BUT I PROBABLY WOULD HAVE CANCER...

From my point of VIEW ... It was in 1967, so my children were young. I was about 33 I guess and IT WAS PRETTY HORRENDOUS. IT WAS JUST A HORRENDOUS THING TO HAPPEN TO ME AT THAT AGE. She was 59 and she just seemed too young to go. [N.B. This woman is now 52.] It was a brain tumour that she had, and she was a very brilliant woman and also a very independent person, and IT WAS VERY DESTRUCTIVE I THINK FOR ME TO SEE HER become dependent on us and everybody and ah, I didn't deal with her death very well because I didn't cry for about two years I guess. I was just, just a terrible anger and ah, it was something that I tried not to deal with at all, and just...
shut it away. So in the last few years I have been able to deal with it better and, as a matter of fact, ah, my father died [of cancer] just a month ago and I was able to deal with that an awful lot better...

Well, I was angry that she should die. I was angry at God because I guess that is where I drew my faith from, and where I drew my security from, so naturally that is where I would throw it back when I was angry. It just seemed like — I don't know the word to use but IT WAS VERY DESTRUCTIVE. There was no need for her to die. There were so many other people around that were so much, so much less useful ha ha ... and attractive and good and kind you know, and every time I would SEE someone on the street, a little old lady who was 15-20 years older than her...

Why are you here and she's not?

So that took some time for you to begin to deal with that...

Yeah, a whole lot of years, yeah. It was three, four, five years really before I could really put it into a PERSPECTIVE, into the right PERSPECTIVE and NOT LET IT BE WEARING ON ME......

I think IT [fear of recurrence] IS THERE ALL THE TIME ... I would wake up in the morning and IT WAS LIKE I WAS AT THE BOTTOM OF A BLACK HOLE ... There are times still when I wake up and IT IS LIKE CLIMBING OUT OF A DEEP HOLE ... MAYBE IT IS SORT OF A ... before I am completely wide awake and I don't want to get up. I think that is what it is ... I don't want to get up, and then ... feeling that I have to get up, because IT JUST BECOMES TOO ... TOO OPPRESSIVE ... THE FEELING THAT IF I DON'T GET UP I MAY NOT BE ABLE TO GET UP. IT IS AN EMPTINESS REALLY. AN EMPTINESS THAT I HAVE TO GET UP AND FILL, AND DO SOMETHING TO FILL IT ... AND THE EMPTINESS IS INSIDE ME ... I AM WAY DOWN THERE, AND THEN THE EMPTINESS COMES INSIDE AND I HAVE TO GET OUT ... AND FILL IT WITH SOMETHING ... ANYTHING THAT IS LIFE ...

I think there is also the thing of sitting in the waiting room [of the Oncology Clinic] and LOOKING around at other people ...
I have been going through a period of crisis over the past 3 months. My divorce had to go to court... my father was ill, my daughter was in the hospital... my little grandson was sick. So there was, you know, this was just in the last 3 months. St) now ... I haven't been eating properly, and I have been smoking and shouldn't be smoking at all...

Can you tell me what you would imagine feeling and going through, if it [recurrence! were to happen?

Yeah, oh ... I AM JUST GOING TO HAVE TO REVISE MY WORK SCHEDULE ... if there is a recurrence, and I have to go for chemotherapy ... I AM GOING TO LOOK TERRIBLE ... I WON'T EVEN BE ABLE TO GO OUT ANYWHERE BECAUSE I WILL LOOK SO AWFUL. I AM NOT EVEN GOING TO BE ABLE TO GO TO WORK ... I CERTAINLY EXPECT TO FEEL WELL FOR ANOTHER YEAR OR TWO OR WHATEVER... BUT I FEEL I NEED TO UH ... TIDY UP, LITTLE THINGS ... ANYTHING WORTH DOING HAS GOT TO BE DONE TODAY, TOMORROW ... OR SOON BECAUSE, AH .......

So you weren’t really looking down the road several years at that point [after diagnosis! —

No, no. Not really. AT THE TIME OF DIAGNOSIS THERE WAS ONLY THIS IDEA THAT MY TIME MAY BE LIMITED AND DIFFERENT THINGS GO THROUGH MY MIND ... CRAZY THINGS, LIKE WHAT WILL I DO WITH MY GRANDMOTHER'S BOWLS NOW ... Yes, I REMEMBER one of my daughters asked for those ... AND YOU DO THINK IN TERMS OF YOUR TERMINALITY ... THERE WAS ALWAYS: BUT I FEEL WELL NOW, SO I MUST HAVE AT LEAST 3 MONTHS, OR SOMETHING LIKE THAT ... I KNOW AT THIS POINT THAT IN FIVE YEARS' TIME I MIGHT NOT BE HERE and ah, that is okay. SUPPOSING MAYBE IN TWO YEARS' TIME I MIGHT NOT BE HERE. WELL, MAYBE I HAVE SIX MORE MONTHS TO CLEAN UP MY HOUSE AND GET MY PAPERS IN ORDER ha ha. But I really don't want to spend all my time doing that because like I said, time is precious ...

Did you imagine it [cancer! coming back?
I did, I think about it, I thought about it — I asked if it will go back to the same place or if it will spread to all other places. ...

Do you have any pictures in your mind of this?

It's the recurrence. It would not only affect the original place, it would go to the adjoining cavity and get bad beyond help. ...

What is the worst thing about this, to you?

Death. The next thing after that is death. ...

Where do you imagine it is [i.e., the recurrence]?

It could be in the colon, or in the liver, possibly in the breast.

Do you ever check?

Yeah.

If you have a pain?

Yes, ha ha. I have been reading a lot of medical books. I have frequent constipation and frequent diarrhea. I think it could be a growth. I check my abdomen for possible lumps...

When I see other people being treated, you know, I am really glad that it isn't me. But I am really sad that it is them you know ... ... And I like to talk to the people that are more ... I would like to talk with them more it I .. I do feel that I might be able to ease their mind somewhat... I had ... my experience was such that I could feel it better than maybe some other people that... But like, when I am sitting there, I can almost think, you know, seeing people, be hearing what they are talking and trying to wonder what they were thinking.....
But I mean I SEE A LOT OF SUFFERING, like books I read, and stuff about the ancient civilizations ...

... I was distressed to feel that I WAS LIVING IN A COMPLETELY GODLESS WORLD AND ALL THOSE NASTY HORRIBLE AWFUL THINGS WERE you know, I was reading about all of the time I THINK ABOUT THESE THINGS ALL THE TIME ...

Each drug ... prednisone had its own wild effects ... It has A STRANGE EFFECT ON BODY IMAGE ... Anyways, having thought about it, after a couple of years after, was when I re-read The Catcher in the Rye, and at the end ... Have you ever read it?

Yes, I have, many times.

Yeah. At the end when Holden Caulfield STARTED TO A LITTLE BREAK DOWN, and he is starting to lose control a bit... He described this thing where he was walking and when he got to the end ... walking so that he would cross the street and he would um, feel that he would be walking his ... and he would go ... HE FELT LIKE HE WAS SORT OF DOWN INTO THE MATTER OF THE PAVEMENT ... That is the only way I can describe it. It was similar to that I felt that was very similar... I remember I used to drive my girlfriend home, thinking now maybe I shouldn't have but... At any rate, I used ... We lived in the basement of a high rise and I used to get out of the car to open the garage door, and when I would be coming back into the car like this, I FELT LIKE I WOULD JUST KEEP GOING you know ...

I am quite sure that if there were a recurrence, then I would notice it BY WHAT MY MIND WOULD BE DOING. But I have felt that a lot and ah I was scared to PROJECT AHEAD and nervous about it and ... maybe don't want to because it would of course make me think of why was I not PROJECTING AHEAD and so forth. ...

WHEN I WAS IN THIS EMOTIONAL STATE CONCERNING NOT LIVING ANY MORE... THE IMAGES THAT WERE ON MY MIND ... IMAGES OF, OR FEELINGS OF, THAT I WANTED TO AH ... DO MANY THINGS AND ... LIVE A LIFE AND HAVE A FAMILY AND GROW OLD I GUESS. AND TASTE FOOD ... THE FEELING WAS IN ME THAT, YOU KNOW, I COULDN'T ... THAT IT MIGHT COME TO PASS THAT I WOULD PERISH FROM THE EARTH. I WOULD PERISH FROM EXISTENCE. AH, WHAT I ... WHAT I CAME... I NEVER ACTUALLY REALLY THOUGHT THAT I WAS GOING TO DIE ...
What are your sources of strength do you think?

Well, I think my own experience. What has taken, what has gone on, WHAT MY MIND HAS SEEN ... WHAT IT HAS THOUGHT OF... WELL I THINK THE THOUGHT THAT I HAD... THAT I... THAT THIS WASN'T SOMEHOW MEANT TO BE, THAT I WASN'T MEANT TO DIE AND...

Yes, I had a fear of cancer of the lungs. Ah ... because I used to cough an awful lot when I smoked ... So I did have a fear of cigarettes ... Of lung cancer... Because [his brother in law] had this, and I have known other people that have had it or I've heard of. So, ah, certainly enough talking about it in the last four or five years. So ah, yeah, I was afraid of lung cancer because I NOTICED that people that got that didn't come back... My hair was falling out like mad. That didn't take too long. So I bought myself some hats and I HAD VISIONS OF MYSELF AFTER CHEMOTHERAPY, after I was going to be declared well, cured or ah, what do they call that... dormant...

Remission.

Remission, yeah. THAT I WOULD LOOK TERRIBLE AND THEREFORE MY CAREER IN SALES WOULD BE GONE. SO I HAD A VISION OF NO ... NO HAIR ANYWHERE. Who in this day is going to let somebody like that... ...

I would just lie on the chesterfield and watch TV ... I would get to the point where I wouldn't see the TV, I wouldn't see anything. I would just be ... staring ... I just subconsciously ... I was afraid. And I would tell my wife, I don't know what is happening but I don't like it.

What kind of... what were you thinking about, really?

Well, I was worried that... It is very hard to explain ... Ah, I had put my faith in the medical profession... I'd thank God, and yet it was still there ... that fear Not that... not that I was afraid to die, [though] I don't like the thought of dying in pain ... like I HEARD A PRIEST UPSTAIRS HERE ... MY GOD ... HE WAS RIGHT IN THE NEXT ROOM THE WHOLE MONTH I WAS IN THE HOSPITAL. AND WHEN THE
DRUG WORE OFF... AAAHHH ... SO YOU KNOW, YOU KNOW THAT HE HAD IT [CANCER]... SO HE PASSED AWAY. SO THAT WAS ON MY MIND.

I think a person can let themselves get into a depression that they will never come out of... I fought the depression: I am going to be all right — the hell with you....... I was depressed [about having been laid off] and worried about the future....... When I had these depressions, I was close to wanting to get the heck out of here [i.e., suicide], because I DIDN'T SEE NOTHING IN THE FUTURE.

WELL, FROM THE ... LET'S SAY [AGE OF] 18 OR 20 YEARS OLD, I STARTED YOU KNOW THINKING ABOUT IT [CANCER] REALLY ... AND GETTING TO KNOW MORE ABOUT IT AND THAT WAS ALWAYS BEHIND ... IN MY MIND THAT THERE IS A POSSIBILITY THAT IT COULD HAPPEN BECAUSE SHE [MY MOTHER] HAD IT ... IN MY LATE 30'S ... I STARTED REALLY READING MORE AND MORE ABOUT IT, BUT ... FROM THE AGE OF 20 ... I LEARNED ... I KNEW WHAT IT REPRESENTED BUT I ... IT COULD MEAN DEATH ... AND I KNEW I COULD GET IT BECAUSE ... OF MY MOTHER, BUT NEVER UNTIL I WAS IN MY LATE 30'S, WHEN I STARTED READING MORE ABOUT IT ... BEFORE, YOU ALWAYS HAD IT IN THE BACK OF YOUR MIND THAT YOU COULD....... You mentioned that there was a lump found in your other breast, before the cancer... Can you tell me a little bit more about that, or how you felt about that?

Um, I don't know ... I know I was nervous about it. I remember. I was very nervous, it being the first time and ... again, as I said, IN MY MIND ... WAS ABOUT MY MOTHER.......
So you found out that it was just a cyst and that was all there was.

That was it and I... IT DIDN'T BOTHER... OCCUR TO THINK ABOUT IT... I THOUGHT ABOUT IT, like I said, IN BETWEEN...

EVERY ONCE IN A WHILE BECAUSE THERE WAS ALWAYS, AT THE BACK OF MY MIND, MY MOTHER HAD DIED OF IT BUT...

it never got to the point where I worked myself into a nervous state......

You talk, and I know... I met many people who were saying that they were in remission and they were talking about how [when they get] close to the 5 year period [since treatment — i.e., the criterion of cure]... it is the worst... And I know two of them out of the three... are already back on the treatment...

And this, I think, is what makes you more nervous because I am close to that period......

I have met other people who got through it [chemotherapy] — not in one year, it is true... They finished their treatment, but I knew they got through and they were in remission and I just took it for granted that I would be the same, and I DIDN'T WANT TO SEE... MAYBE I DIDN'T WANT TO SEE IT ANY OTHER WAY... But I THOUGHT MAYBE IT [THE CANCER] WAS WORSE THAN WAS REALLY...

REALLY IN MY MIND, THAN I PUT IN MY MIND......

There is one man that I meet quite often over there [i.e., at the hospital] and he has been going now for 7 years on treatment... When I think of him and I think of myself, I haven't... I am glad... I mean, I am not glad for him in that sense, but I know I have a chance maybe... And when I SEE him going, he is still alive... That is wonderful but... I don't know how, I don't think I would be able to cope with it the way he is...

The way he is...

Doing it... I often wonder what would I do, if that was the case with me. How would I accept it. How would I... because I CAN'T SEE IT. I CAN'T... IT [recurrence] COULD HAPPEN MAYBE SOME OTHER WAY [i.e., other than lung cancer, from her smoking]. It is possible that ah, but, mainly because of the cigarettes... I THINK OF THAT MOSTLY. BUT IT COULD HAPPEN ANY OTHER WAY, TOO. When I go for these... in November, all of the X rays, everything bothers me at that time.
Yes, like what are you thinking?

Oh, well, WILL THEY FIND IT SOMEWHERE, THAT IT REOCCURRED ... WHAT, I WOULDN'T KNOW. I really don't know THIS TIME: how I would accept it or how I would handle it... I really don't know. AND THAT IS ON MY MIND QUITE OFTEN. WHAT WOULD I DO ... WILL I ... WILL IT BE WORSE THAT THE FIRST TIME? OR ... WILL I ACCEPT IT JUST AS WELL... I JUST CAN'T ... I CAN'T PICTURE IT. I CAN'T. You can't picture it ...

I CAN'T SEE IT AT THE MOMENT. ...

When you imagine it happening, what is the worst part of it to imagine?

WHAT I IMAGINE ... THAT MAYBE IT ... IT MAY BE THE END ... MAY BE THE END AND ... THAT THIS WOULD TAKE YOU ... I think that is really, maybe that is why I don't want to ... I CAN'T PICTURE IT, I CAN'T SEE AH ... how I would handle it maybe because of that ...

My father's father... um, died when my father was ten years old. Back then everything was tuberculosis but they say now that he had what I have [cancer of the testicle]. Cancer wasn't really coming up then. So now they are saying that is probably what he died of... Everyone assumed it was tuberculosis until they told us, when I went through it, that that was probably what... my father's father died of... Well, see my father told me that his father died when he was ten years old ... and ah, SO WHEN I WENT THROUGH IT, I SAID GEEZI GUESS I WOULD ONLY LIVE ANOTHER TEN YEARS MAYBE. ...

I was aware of the girl that had the cancer. She was working down there. But I CAN IMAGINE THIS WAS VERY TRAUMATIC TO THE PEOPLE WHO KNEW HER, BOTH THE STAFF AND THE PATIENTS THEMSELVES. The parents probably need a lot of encouragement,
to the point where... YOU KNOW, BECAUSE THE FEARS OF THE PATIENT WOULD BE BROUGHT UP BY SAYING OH LOOK, SHE HAS HAD CANCER AND SHE HAS BEEN TREATED AND SHE IS DYING. SHE IS DYING. The staff can get over it because I think they are very used to it...

Everybody and everything else and they have SEEN it happen. I mean they have SEEN numerous patients die from cancer. BUT I CAN IMAGINE IT MUST HAVE BEEN DIFFICULT ... ON ANYBODY, ON THE PATIENTS.

I had two aunts die of it [cancer]... I THOUGHT YOU DIED AUTOMATICALLY WHEN YOU GOT IT ...

I THINK IF I DO HAVE TO GO BACK [for treatment of recurrence], I WILL BE very supported ... And as I mentioned to you about Kathy [nurse in Oncology who died of recurrence], IT BRINGS IT BACK PROBABLY MORE VIVIDLY.

(You mentioned! you talked with her the day that she heard the news of her illness (i.e., recurrence?) It was the week before ... She had been worrying about this cancer that she had had ... She had pains or something, and she found out that she had [a recurrence]... IT WORRIED ME ... IT REALLY DID AFFECT ME WHEN SHE DIED. SHE WAS 40 YEARS OLD. THAT BOthered ME A LOT. AS I SAID, MY AUNTS HAVE HAD IT ... I WAS BOTHERED.


‘To be honest *I do feel sort of depressed* at times when I think about it.’

‘It seems its 10 years before you’re deemed to be on a level playing field from the cancer.’

‘Even if that risk of it coming back is only 1% – that still could be you.’

‘Having lived with the knowledge that someday I will die. I am now facing the reality of how I might actually die, which I find most *distressing*.’

‘At the end of the day, there is this huge fear element it still has. opens that huge fear element all the time.’

‘I’m just frightened to say 100% really. I suppose but from the operation I’ve had now but I still have not got over the feeling that the cancer might come back anytime.’

“But let’s face it; it can happen again at anytime... you could go back for a check up feeling well and yet be told the cancer was back’ Oh yes! I would have to ask, “Why tell me now when I have just been through all this.”

“Every day is a bonus if my health is there. I am looking to the bigger picture.”

“I was grateful that I came through, you know, I’m 80 and I’m still alive.”

“I mean psychologically it’s all a matter of get on with it, don’t obviously ignore important aspects, if you’ve got pains say something, get something, but don’t obsess yourself with it, don’t get obsessed.”
“Just checking myself over to make sure there is nothing new,”

“I am much more aware now of how I am feeling, like the other day when I had a headache, it is never just a headache anymore. I start thinking, is this the cancer back?”

“You notice the normal minor aches and pains in your body that never bothered you before cancer.”

“Yes, you think, well if they made a mistake then, then they could again. You just don’t know whether that is how it should be or not…”

“I realized that as long as you did as you were told then all would go well…and it has!”

“My son heard it on the radio: “Aluminium causes cancer and you have the cancer from that’ So out my saucepans go.”

“I am going to try to eat more fruit and veg once I have got my bowels under better control.”

“Well my diet is faultless so I just need to keep on top of things a bit more.”

“I am careful in some of the things I eat. I have found it helps to cut out the sugary stuff.”

“He was marvelous that man (the surgeon)...I knew that he was there for me.”

“That’s why it’s hard to sleep because you’re just lying there. I try and tell myself to think about something else, even if it’s just a song or something, if it just keeps wandering back, it’s like you can’t get rid of it. During the day you can think ‘oh can’t think about that now, I’ve got to go to the shops’ or ‘I’ve got to do this’, ‘I’ve got to pick up someone’.

“I never get the doctors [GP] to check I just go straight to the specialist because that avoids a lot of anxiety for me because the doctors don’t really know, and usually if I can get an appointment then I will see the specialist and then my fears have been allayed.”

“Pt: With Google everything is tangential, you read something then it goes on to something else and then you are constantly clicking to the next thing and you can work yourself up a lather about it...... I guess it’s meant to lessen my anxiety so that I can sleep and not worry so much.

Interviewer: How does it affect you?

Pt: Well it takes time I guess, it takes time out of my day to obsess about it.”

“i mean you could worry and make yourself sick about something that is never going to happen.... I think I naturally by instinct challenge negative thoughts. I reckon it is just part of the way I’m made.”

“I came home with a list, that if I do this the cancer won’t come back. And so my whole mission then became you know organic food, to be juicing, to be exercising, to do this, to do that which, you know, ... I had to do too many things all at once otherwise the cancer was going to come back. And it all, you know, it seems very illogical now but back then it was just, you know, put me a tailspin that I just couldn’t get out of.”

“Chemotherapy was worse than cancer itself, I remember thinking at the end of the treatment if it ever came back I’d just take a tablet and go to heaven. I wouldn’t do the chemo again, I wouldn’t do it again.”
“It is not that I’m going to have to go through that experience again, oh my God, I’ve got secondary cancer, I’m going to die, it’s not that I’m going to die, it’s that I’m going to have a really horrible life. I’ve seen people die of cancer, it’s them dying bits, it’s not the end of my life bit that’s the fear, it’s .... having no quality of life, I think that’s really scary.”

“You tend to think of whether it might lead to a long unpleasant illness that my whole family would have to view and I would have to manage, and leading on to death which is not the sort of ideal way anyone chooses to go, those thoughts go through my mind.”

“I really don’t want to be dependent on anyone and I don’t want to linger on and on and on and become more and more incapacitated, that’s what I worry about and also I always want to have enough money, like I know I’ve got a husband …but I also want to have enough money on my own to support myself while I’m sick.”

“I think of death, suffering and think of not being there for my kids, not seeing them get married and all of these milestones, and I think about my husband having another wife after… I think about not being able to enjoy my retirement if I go to soon.”

“You don’t want to wreck the lives of those around you... you wouldn’t be able to do your job you’d be letting other people down”


“sometime I wonder if it is all out of my body ... I figure if you get one spot, who knows, maybe it comes some place else, you know. I figure once you’re diagnosed with it, it’s there.

“Well I have to hope it’s not gonna be soon... but one day I think it’s gonna come back. Cause most of the people, once you have, you know cancer, so then later you die from cancer.
“I do not worry about it every day. I mean I worry because two of my, two of them [tumors] were aggressive . . .

“Maybe in some recess in my mind . . . I’m trying to live more for the moment and there are these thoughts lurking that, um, I’m doing these things but am I going to be around to need that, or enjoy them or whatever.

“Try not to think too much about it [recurrence] . . . like I said my husband’s not well. He went through a big surgery in ‘94, and he still . . . he just didn’t come out of it.”

“Yeah, these other things (job, ending relationship, . . .) have distracted me probably because they’re really in your face. Yeah, I don’t know if that is a good thing or . . . the boy-friend thing is very upsetting and it, it hits to the core.”

“I just consider myself blessed because I feel confident that it’s not going to come back . . .

“I tend to be a worrier in general, but I must say I don’t worry about a recurrence, and I think that’s only because my prognosis is good . . .”

“. . . the other thing [severe intestinal problems], as I said, is still going on and it distracts me from my bosom.”

“Maybe because I didn’t have chemotherapy . . . maybe because I didn’t suffer, I wasn’t in pain . . .”

“It might mean I’d die. That’s what it might mean. I’m not ready to go yet.”

“I’m not afraid of the death itself. I’m not. I’m afraid how I would leave people behind.”

“When you have children, you know, that’s what you want . . . you want to be around for your children.”

“That’s what I’m afraid. I’ll be older, more weak, and I don’t want to take the chemo. Oh my god . . . No . . . No . . . They have to find something
“Chemo. I don’t know if I could handle chemo again.”

“I’m only afraid of the pain. If I got some medication for the pain, I don’t care.”

“I know that . . . if it comes back it usually is not treatable, successfully.”

“I hope I don’t have to lose my breast because I was lucky this time . . . I kept the breast.”

“So this is the things that upset me, when I hear from someone else what happened to them, I always think it could happen to me.”

“. . . whenever I went back to the check-ups and that kind of thing, or treatment, it seemed like everyone had their breast removed . . . I begin to get concerned that maybe I didn’t do the right thing.”

“They left me waiting in the room . . . for like half an hour and I was starting to really freak out. I was like, can you please get this over with because I’m about to go crazy here.”

“One day I touch here, something very hard, and right away I sit down, I say ‘Oh my god I have another tumor here’ . . .”

“. . . it [her breast] always hurts and . . . I think it’s always going to be swollen and it’s a little different color so it’s always, what does that song say? It’s always there to remind me.”

“. . . why did I buy this, why did I buy that? I won’t be wearing this . . . I won’t be wearing that . . . I might be ill before I wear it or whatever.”

“I am trying to just not worry too much,” telling themselves that treatments would improve or believing that their doctors could prevent a
recurrence. Others used the strategy of hoping their cancer would not recur or telling themselves that it would not recur.

“You know like it’s not going to happen to me, it’s not coming back, the only way to come back is if I worry it back. I’m not worrying it back...”

“. . . as long as I’m occupied and have something to do that I like, I really don’t think about it that much.”

“Pray . . . Pray or cry... and I go in the bathroom, I turn on the water, and I sit in there and I pray.”


“I’m not afraid of dying...I’m afraid of being bedridden because I have been an independent person all my life.”

“Well, you know, just lying there, being ill for a long time. You’re not dead, but you’re suffering. Then, it’s better to die quickly.”

“As a cancer survivor, one of my biggest fear is the 5 year waiting period, to find out if we are going to survive or not. That creates suspense, fear, and negative emotions. Five years is a lot and I never know if I’ll be the one winning the battle. I feel like I’m standing on a balance just waiting to see which way it is going to go.”

“It is not the pain, but it is the anxiety, the fear of it becoming positive. The anxiety is worse than the pain. Pain, I can deal with it. When you’re given pain medication, it’s relieved. But anxiety, it sticks in your mind.”
“They give surgery, they give you treatments, they say, ‘we got it all’. But you feel a pain, you wonder what is going on, or you feel dizzy. I try not to obsess about it. But I feel it’s a legitimate fear. The fact that it might come back and I might have to physically suffer.”

“As caregivers, we worry about those who depend on us because if something happens to us, who would care and provide for our family, children, parents, etc. who totally depend on us?”

“All I want to do is to make sure my child grows up and that I’m there for her. She is six years old. I want to be here until she’s 18. After that, you can take me.”

“I feared the most the pains that I have seen others suffering. I wasn’t afraid of death, but the pain… I didn’t want to show myself screaming from pain to my family.”

“They tell the women, go get the mammogram. But when you find out that the mammogram didn’t pick it up, and I found the lump myself, why is that?”


“You walk under a heavy load thinking if and when it’s going to come back’.

“I feel like if I am caught off guard it will sneak round the edges … I’m always waiting for it to come back, always. Whenever I say something now which is a plan for the future, I always feel it’s like touching wood.”
“I still think in ten years’ time I will always panic and I think you will always have that, I don’t think you’ll ever never have that, not have that fear because it’s always there in the back of your mind, always.”


“I mean the first few visits are quite anxious because you don’t know if anything else is going to be found or transpire in the course of the visit…”

(_constant anxiety) “There’s always that, that thought there that it, it could come back again.”

“Absolutely [she agrees she gains reassurance from follow-up] yes, which is what it’s all about from 6 months to 6 months, you know.”

“It’s inconvenient and uncomfortable more than anything to worry about and once it was explained that it was, um, nerve damage you know, because of the actual surgery and that it was nothing sinister, nothing to worry about, that was, that was fine.”

(“When would you start to feel uneasy about it [the follow-up appointment]?”) “Oh, the day before, the day before. And then I keep thinking should I telephone up and cancel…”

“about a week before you go, or I used to go for the check-ups you’d start feeling a bit nervous about going in case, you know, anything else was found. So it was nice when you went in and they sort of said everything’s okay, see you again in 6 months…”
“it’s nice to know that there’s nothing else wrong with you for a start you know, I mean I rely on them telling me that there’s nothing else wrong. I don’t need any other treatment. So that’s a relief.”

“I was very, um, insecure. I mean that was understandable but, er, no I don’t think, um, that they can tell you all the things they can.”

“I was reassured by [the consultant] that the chances are [pause] minimal, comparatively, you might as soon get run over…”

“I’m reasonably aware and I [laughs] wanted to know exactly what was going on and why, it’s very nice to know why, um, certain procedures are, are being gone through because if you don’t know that’s when you start to worry…”

“I’ve only got to see like in a magazine or anything, see the word cancer and I’m there, I’ve got to pick it up, I’ve got to read it no matter what… and it’s silly really cause I think I’ve got those symptoms, and you know very well you haven’t.”


“I want the reassurance of knowing that it hasn’t reared its ugly head. There’s always that, that thought that it, it could, um, come back again.”

“If you’ve got a stomach bug or something untoward happens the questions always there are, you know, is it, is it the cancer coming back or is there a problem here so, er, you know there’s always that uncertainty I think once you’ve had cancer.”

“But the anxiety part is thinking, it’s something else that will come back to me.”
“...so that sort of follow-up is much more worth while, er, a check everywhere because it’s not going to get cervical cancer again cause I’ve, because it’s gone, but it might come back lung cancer or skin cancer, you know so I think what, I would find most beneficial would be an all-over check.”

“You hear of people where it’s gone and all of a sudden it’s reoccurred. I think that’s always at the back of your mind, to a degree.”

“Every now and again if I hear of anything else or read in the papers, I mean [her husband] threatened to bin all those newspapers when, you know, Linda McCartney, all that was in there.”

“Just be about a week before you go, or I used to go for the check ups you’d start feeling a bit nervous about going in case, you know, anything else was found.”


“Like I count my freckles and my spots and I feel them....whenever something happens.... the first thing that comes to my mind is cancer.”

“It’s like, winter, everything’s sleeping...that’s how I feel about the cancer inside of me too... That it’s still sleeping And I feel very exposed, all the time.”

Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast cancer survivors: information and support after treatment. Clinical nursing research, 16(4), 278-301
“What happens is at night, when things are quiet and the kids are asleep...I try to relax . . . but I begin to think about things . . . That’s the time I begin to think about things . . . like recurrence...Thoughts about having the disease back run through my head and I start to worry.”

“Thoughts and fears about recurrence were common and these things create a great deal of anxiety . . . They are hard to experience. I have young children, and I was worried about the future . . . What if I get this again, will I have the strength to do more? . . . What if it is somewhere else?”


“Everything . . . If the cancer will come back. How do I live without thinking about my cancer? Why hasn’t my hair grown back? How do I resume normal life or feel normal again? What happens financially to me if the cancer comes back again? How do people view me now? How do I regain confidence?”

“That the cancer will come back. That I cannot have children now, and I know this disappoints my husband, even if he won’t admit it. That even though I’m cancer-free and, according to my gynecologic oncologist, “as close to cured as I’m going to get,” I still have complications to deal with, even over a year out from my debulking surgery and almost a year since the end of my treatment. When is it ever going to end and when is life going to get back to normal—if it ever gets back to normal? It’s a combination of all these things . . . and menopause.”

“Dying before I’ve been able to help my daughters (who have many medical issues) be independent. Dying before my husband and I can have some free time together. I’ve been in remission for three years and feel great but am not so naive as to think it couldn’t recur.”
“Will the next test bring me to more treatment? The length of time I have left to live, will treatment keep me from working? How will I have health insurance if I don’t work? Will my illness leave my husband in debt? What will dying be like? Will we have to move from our remote mountain town home? Will I be able to leave my husband with enough money to survive?”

“The cancer returning and I will no longer be able to support the people who depend on me financially.”

“REOCCURRENCE!!!!!!!!!! How close I came to dying.”

“The uncertainty of the disease—could this twinge, could this ache, could this pain, could this feeling be signs of a recurrence?”

“I thought I was the only one who had this issue. After all these years, I still lay awake not knowing what the next day will bring. I am thankful that I have a next day, but cancer never leaves my mind.”

“That the cancer will, at some point, come back and not be treatable. My oncologist told me that I probably have seven years to live, according to the latest research. I’m trying to remain hopeful that something new will come along before I get to that point, but it’s not easy.”

“Waiting for the other shoe to fall and how it will fall. All of the info on my OvCA sites scares the daylights out of me, but I feel I have to keep reading so that I will know when the shoe does start to fall.”

“I worry that I won’t survive at least five years. I want to live 10 years more for sure. Since I only had a three-month remission after the first line of chemo[therapy], the doctors sounded like that was not a good thing. ... I try not to think of the poor stats regarding ovarian cancer and know that I can be a survivor of 10 years too. I try to focus on knowing that I may not have a remission but can still maintain a good life with chemo[therapy]. I try to focus on today, and I am doing a lot of fishing.”

“I am scared most of recurrence. Once cancer recurs, I would lose all hope. I cannot imagine going through it again. If it does happen, would I really want to keep on living?"

“I developed heat rash this summer. The rashes were large and red and were all over my body. I felt so scared and went to see an oncologist. I asked, ‘Is it skin cancer?’ He replied, ‘No! It’s not’...I suffered from a fungal infection rather than cancer recurrence. Consequently, I was psychologically relieved.”


“After the bone marrow transplant and the radiation, it’s like, for a while you feel like Dr. Jekyll and Mr. Hyde because a part of you says I’m so glad to be finished with it, and if I never see that place again it will be too soon’ type of thing. So part of you feels that way. And then another part of you feels that you have an umbilical cord to this place and you’re terrified not to be here, because as long as you’re here, somebody constantly is looking at you to make sure that the cancer isn’t back. And so you’re terrified. I suppose, like a kid whose parents tell him he has to move out of the house. You’re terrified that ‘how do I know it isn’t growing back right this very second.’ Nobody is looking at it.”
“Going home was traumatic. It was traumatic. It was wonderful to be home, but (I) feel very frail and fragile. I think you have a lot of time to think of all the terrible things that could be going on inside your body as you lay there at home. All of a sudden you go from people checking on you every half hour to going through a 24-hour day with a lot of time on your hands.”

“It was very strange because I had never had trouble with appetite. In fact, I was always the opposite, you know. How could I not eat? And so that kind of alarmed me because, being that I always wanted to eat more than I should, you know, suddenly not wanting food was worrisome to me.”

“It's like a loss because there's always like an emptiness because something has been lost. Whether it's just time, a breast, or whatever, there's always that element of a little bit of fear . . . which, really, any of us should have. You know it's like . . . just take a room full of people, and no one should have a feeling that everything's going to be fine tomorrow. And yet, we all, until something's happened, we all operate under this false sense of security. But once something has happened, like this, it's kind of like, the bubble's been burst. We realize that something could happen because it has. So we always have that element of fear, where (others) don't have that. Not because they shouldn't have it, but because they've never had to deal with it.”

“I don’t trust my body, no. I am really a positive person, but it's failed me once, you know. It's like I don’t have control. I always felt like I had my control and I think that control, once you face this, you've lost control. I mean, it's taken away from you. And so, I don’t think I'll ever really trust (my body) again. I trust in my mind that I can kind of, you know, calm myself down, this kind of thing. But as far as the body, I've kind of lost that confidence.”

“... you don’t know how long you’re going to be here anymore. You haven’t got that luxury of knowing that you’re going to be here for the next 60 years. The future isn’t quite as clear as what it used to be. You talk about your kids getting married and grandchildren and you think, ‘I don’t even know whether I’ll still be here then’ That’s really, really scary and nothing can ever change that, that is what breast cancer does to you.”


“Not being alive in five year’s time, having a child ... are you being selfish bringing a child into the world when you have got this cloud?”

“I don’t think I’d want to risk it again [pregnancy] even though I felt that I would take that risk to have a second child, I don’t think I would again. I mean, two is lucky.”

“Checks don’t really help. As your breast gets bigger and fuller and everything, it’s harder to find stuff... When I found this lump [original diagnosis] I went off and had a mammogram and that didn’t see anything and then I had an ultrasound, and that didn’t see it. I could feel it. It was like a bloody olive in my breast but they couldn’t see it on the ultrasound because I was breastfeeding. So, I mean, that’s a bit of a worry, so if they’re trying to find something little, the chances are they’re not going to find it.”

“If I breastfeed for another 6 months, that’s going to be a period of time that I won’t be able to [have regular breast checks], I mean you can have mammograms but they don’t show anything!”
“I’ll probably be a one-sided feeder.... I’m not sure whether I want to take that risk since I developed breast cancer feeding last time,... but I haven’t quite decided on that because I’m a staunch follower of nursing mothers.... I mean I was one of the real converts, so it’s going to be difficult.”


“I don’t feel . . . that that’s the end of it, that I have fought cancer and won, because . . . I certainly have felt, from the moment I was told I had cancer in my body, that would be something I thought I had to live with for the rest of my life . . . here could be a cell somewhere dormant that one day might . . . some way I act or react or something might set it off again.”

“Now I have to do the most I can to not let that prey on my mind because I feel that is the most dangerous, dangerous thing you can do . . . I’m sure the most damaging thing you can do is to let it eat away in your mind . . . That’s what I felt was the most likely way it could return.”

“Once you’ve had an invasive cell in your body you must feel always under . . . threat . . . You can take the bit out you’ve found, but you still feel that you’ve got more chance . . . The fact is that an oncologist still thinks that I need to go every three months to see him.”

“I think sometimes it bugs him because I’m always thinking or worried that it’s going to come back. Like I had my five year last year, and his comment was, “Now you can think of it less.” But for me, I don’t think I’m ever going to stop thinking about it, I just try to not talk about it a lot because it really bugs him, so that’s a little bit of our challenge together.”

“Probably . . . how long, maybe the 1st year or 2nd, I couldn’t have a cold, because if I had a cold I was just convinced that the cancer came back and it was everywhere. And you know, you can’t have a pain. It’s the process of oh my god because I have to say that just hearing that word the first time was difficult to go through . . . that thought that it would recur. It’s just, you tell yourself, I could never go through that again, but I guess you do what you have to do. Every time I’m going to any of these [doctor appointments] I get upset; it depends on where I am that day, but especially if it’s a test. I’m crazy . . . I don’t even know my name, and they make you fill out all these things and they ask you. One time, I couldn’t remember my name. I was so nervous . . . you don’t get the results right away, so you’re waiting to get those results. So those are kind of, like, the side affects for me, but I don’t dwell on it.”


“My life is a project of uncertainty. One never knows what one will experience the next day.”

“I wonder daily, has the cancer spread?”

“The furthest I can think is the coming weeks and months. I don’t make long-term plans.”
“I think a lot about the future, especially when I have to go to check-ups once a year. I experienced this when I was here for a mammogram of the other breast and they found something. I have this constant fear: have they succeeded in removing my cancer?”

“Recurrence is my concern. I’m unsure whether I want breast reconstruction.”

“If I have nothing to do, I think about it more. If I listen to the radio or music, I’ll sing and manage to push away thoughts about the cancer. When I sit in silence, thoughts arise.”

“I feel sick just being in the hospital corridors. It evokes lots of emotions.”

“People talk about cancer. One becomes reminded. I’m scared of hearing about other cases.”


“Yes, I have felt somewhat frightened since I have been off treatment. I felt that while I was on treatment and continuous doctor and medical care that if my cancer was else where in my body that it would be found sooner; I sometimes feel that if I could be on a treatment of some kind and could be on it forever maybe my cancer would not come back. I am always wondering if and when and where it may show up and if I will be here this time next year. I guess having medical people taking charge of your life and body makes me feel more secure and being on treatment made me feel that at least I had something in my body fighting to kill the cancer. Now there is nothing fighting to kill the cancer (except prayer and positive thinking). To be honest, it scares the hell out of me sometimes not having that “safety net” of treatment. The treatment may have made me sick but at least I knew there was a fighting chance of it killing the cells. Now if there are any cells (cancer) in my system, there is nothing fighting them. This makes me frightened sometimes.”
“There didn’t seem to be anything or way left for me to do that would lessen my chances of having the cancer return.”

“Things that you may not have paid much attention to before—lumps, bumps, small pains—you are now aware of. You don’t want to be a hypochondriac, but you fear if you ignore them. If you were still in treatment, a simple question might be all that is needed.”

“I have definitely felt terrified when my chemo was finished. I felt alone and abandoned and started having anxiety attacks (also bodily-expressive) two months after my last treatment.”

“Any fear that I had was overshadowed by the Christmas holidays. The fear came later when I had my checkup in June. I had a very hard time with that, but fortunately the tests were all negative and I relaxed again—to the extent that I can ever relax about this.”

“Before my last chemo, I loved being alone in the house when my husband and daughter were out of town, but now I hate being alone and fear choking to death while eating alone, or getting very ill in the middle of the night when I’m alone.”


“Every year when I take… the examination that is arranged for me, I cannot help but indulge in a wild fantasy, which is essentially the fear of the disease recurrence. Therefore, I have been visiting the psychiatric outpatient service since then. That’s it; maybe there is a little depression.”

“I would just be nervous because I never know when my life is going to end [my brain would go through so many things that I could only fall asleep by taking some pills] just like that.”
“Sometimes, my thoughts just ran wild [which basically are] how long can I survive? When will the relapse occur?... What should I do [to alleviate this excruciating pain?] If there was some illness in one place of my body... I would just say... “Ohl Has the cancer migrated to that place?”

“I was very scared and had no sense of security... I asked the doctor, “Can I get pills at the next visit? Am I going to die?”

“I was also concerned that not taking the drugs I might cause a recurrence! I do feel reassured by the pills.”

“I might go online to take a look... and there, many things would appear, some of which were quite similar to what the doctors said. But some... I am not so sure! But I have to try and see whether I can adapt.”

“If there were some new target drugs, I would create a newspaper clipping and show it to the doctor. However, I don’t read them because... in fact... oftentimes, I don’t understand them.”

“It appears that there are very few of those (seminars) I sometimes really wanted to go, but could not find it I after hearing about it [a seminar], I feel like I absorbed the information faster!”

“I have not been eating items like chicken. As for shrimp and such, it appears that they are toxic, and I have not been eating [them] I given my physical condition... Although the doctors said that it’s fine if I eat anything, I still prefer to stop eating certain items once a while.”

“Now, I want to change and think of [eating] all kinds of food. We therefore bought some items such as red barley flour and made a soup or got some pearl barley, which is a healthy food! Ah, we are scared of relapse, so we try to eat some alkaline items.”

“I don’t eat mutton, goose meat, or salted egg these [foods] are not very good [for you].”
“There was a time when someone told me that if I only ate sweet potato leaves without any meat, I might develop anemia. When [the doctor] examined my heme level, he found that it was indeed low. Because I had been informed that sweet potato leaves were good, I just ate a lot every day and at each meal, and I thought it would fight the cancer or something like that.”

“Because of [breast cancer], we must exercise; otherwise, you just lay there or sit there, which cannot be good. I have to get out and exercise or occasionally clean the house, just like that.”

“Sunbathing can boost your calcium level. With this in mind, I often take a walk for almost an hour every day.”


“Probably one of the things being cancer free for almost 2 years now, one of the things for me, (is) the fear of recurrence; it was real strong in the beginning and then it went away. But, it seems recently the longer I am cancer free, the more people I hear about are having recurrences, like one of the women who went through the BMO unit just found out last week she had a recurrence. I guess it just never goes away. You think it’s going away and you don’t think about it until you come around the time of your check ups. I had a little spider bite and I thought it was a brain tumor. Brain cancer. My skin itches, I have a rash, no matter what it is, it’s cancer. But, it’s pretty scary.”

“I think at the beginning it just haunted me, and I wasn’t able to sleep at all. I was very worried and up all night.”

“I would say that maybe once a week I’d wake up at 1:00 [a.m.] or 3:00 [a.m.], thinking, ‘I have cancer.’”

“I think it was more psychological, ‘cause I haven’t had to take any chemo or radiation so I don’t know what the effects of that would be. This psychological thing, once they tell you you’ve got cancer, it is like a death sentence. Your mind goes to playing tricks on you and it is devastating, and it is hard to overcome.”

“But on the nights that I wake up, or I can’t get back to sleep, my mind just—it starts rolling. And the more it rolls, the more I’m convinced that the reason I can’t sleep is because cancer is coming back and so I have to just—I have to find some way to shut off my mind, because the more I think about it, the more I’m convinced that, you know, it’s coming back.”


“Hi! I found a small lump in my lower lip. In the beginning I thought it was a mouth sore, but in fact it is a little hard lump that moves back and forth. It doesn’t hurt. I don’t think it is of importance, but do you have any comments? I’m afraid of every little change in my body”

“I walk around with my nerves on edge, terrified of the slightest sign of pain, no matter where it might arise.”
“I can also feel that there is some pain/discomfort in my hip on my right hand side. Of course I am a little bit worried whether the cancer has already developed and spread to the skeleton.”

“I just called the hospital to find out what the PSA test result was that was taken before the last day [of treatment]. I started in December and the hormone treatment had a good effect. In March it [the PSA result] was already 0.57. Midway through the treatment it dropped to 0.3 for the last test and went up to 4 for the last test. Is this usual? I had expected it to decrease further, and became worried.”

“I am so afraid of every little change in my body.’

“Can I be sure that the treatment I receive is the best?”


“I’ve had a cough I can’t get rid of. I just told my doctor, “Well, it’s worrying me. You know, if these sinus pills hadn’t stopped this postnasal drip that I thought was causing the cough, I was gonna get real worried that maybe I had lung cancer or something.” So it sits in the back of my head all the time, “Did I really beat this thing the whole way?” But I’m not feeling tired or anything...”

Perceptual-situational  Symbolic-conceptual  Bodily-expressive  Motivational-behavioral  Emotional experience

(if she) ‘worried about everything every day she would not be able to live her life’. Nevertheless, she did worry ‘if it’s coming back’. She said, ‘the hardest part is… not knowing if it’s there, I remember sort of thinking, how can you have cancer and not know it’s there’.

‘I’d like to say that 1 day I didn’t wake up and think of cancer but it hasn’t happened yet’.

‘And I do worry, I still very much worry about a recurrence, about it coming back’.


‘… through all of this…is the fear of waiting for the other shoe to drop’.

‘My question is not if it’s coming back. It’s when’.

‘I can say that I probably think of it coming back every day’.

‘…I started having pains and the first thing I thought was ’Oh my gosh, the cancer is back’’.

‘I have this weird rash skin thingy I’m wondering if is it some other type of cancer because one of the side effects of the treatment is that you can get secondary cancer’.

"I would feel a lot better if I had some sort of treatment... I'm not looking forward to it but I think I feel better getting it done."

"Now every sore throat I get is going to be: is this a lump? You do [worry] a little bit. One part of your brain says don't be like that and the other part says, 'Well?'"

"It's important to me. I mean I want to know... The truth of the fact is that I felt perfectly all right and yet I was walking around with breast cancer. God forbid I should be walking around with something else. So I want to know."

"My life is a question mark".

"I still have my breast. And so I'm still the same person I was before and yet I'm walking around with a time bomb. It's not a time bomb, it's too strong a word, but let's say it's a lingering type of thing. It's still there and you know, we don't know, it's still a question mark what's going to happen. So there are times when I just don't think about it and there are times when it hits me. That's the only way I can describe it."

"I think that I decided from the very beginning after the surgery. I would feel a lot better if I had some sort of treatment. There's that fear that will never go away that one tiny little cell got in there somewhere. I know the chances of zapping it while it's still small instead of waiting until it grows into something else and maybe going somewhere else. That's a lot easier to cure and take care of. I mean I'm not looking forward to especially during the summer, 6 months of who knows what? I'm not looking forward to it but I think I feel better getting it done. When I got it in my brain that I'm going to do something, I've got to do it now. I don't want to wait. I want to do it now."
“If you worry it's not going to help you any. It makes it actually worse. You wake up so tired and miserable. You might as well just sleep and then worry the next day.

“I just say to myself [when I'm worried], "Now cut that out. There was nothing found, everything was clean so the radiation is just precautionary."

“You really have to not worry about it.

"I face the specter of death everyday."


“It can come back anytime. And it was scary for a little while. Scary enough that I called my doctor and said I know my appointment is not for 3 months but I want to come in now. ... It just kicked me so good ... physically and mentally that I’m just really afraid of getting it again. I really am.”

“Now I’m just so paranoid for everything. ... And it’s like every single thing that happens now is so scary for me. ... How can you not worry about it, you know? So I think I stress myself out a lot more now. .... It’s always there. You always think about it. It is in the back of your mind constantly."

“This last PET scan I think I got nervous because I started having ghost gut pains pretty much right where it was before ... I was so nervous.”
I have anxiety every time I get blood work done or a bone marrow biopsy no matter what ... So, you know, you don’t lose that fear.

I woke up at about 5:30 just covered in sweat. ... I was like, oh shoot. Actually the first little fear is oh s***, night sweat, and then it’s like you are just overreacting ... you just broke your fever. This is good. This is good ...” For a little while there I was sweating a little bit at night but apparently not...I talked to a doctor and he’s like no. So he’s like you’ll know if you have night sweats.”

I do worry about it coming back. Every little pain or lump on your body, you know, it scares me ... that’s the main thing. I sometimes worry about it coming back...It is uncertain whether or not I’ll get my cancer back or not and that scares me.


(same subjects of Jones 2015; we used the additional quotes)

“...it’s always there. And so I think that’s how it has affected me emotionally and psychologically.”

“The psychological part, that is chronic...it’s always on my mind, there isn’t a day I have not thought about cancer since I was diagnosed.”

“The first couple times I went back for my check up...I would be like okay, I go back and I have to prepare myself in case I hear that it’s back...I asked him [oncologist] the time before last, you know I do get a little bit of anxiety before I come here and that’s not like me to do that. I don’t usually worry about anything but I notice it a little bit before a check up. He says well, that’s normal.”
“But then there are things like thinking about you know, am I going to be here when I’m 65? Am I going to see my kids go from elementary school?”

“It’s scary to think that I would have to do that again…at the back of your mind it’s like what if I’m part of that 1% that does relapse. That’s scary…especially now cause I don’t want to leave my kids.”

“I hope that my cancer doesn’t come back so I can retire and so my wife and I can travel and see the world.”

“I think about each decision I make in terms of cancer. Like, should we have two kids because then if something happens to me, they’ll have each other, but would he [husband] be able to handle two kids alone?”

“So going in, every time I go in, it does bother me. Oh what if she finds it, it’s just going to change everything…I’d have to stop work again. I’d have to rearrange finances.”

“Here I am a month until I start working and I’m like kind of freaked out that something is going to happen between now and then…that is going to ruin my plan to buy a house and I’m going to be trapped in my stupid apartment again and duh, duh, duh, duh. So it’s there.”

“I really fear about finding lumps on my body still…So that’s one thing that affects me - fear of finding another lump anywhere…think about it a lot because it was a major part of like two years I had to go through all of it. But when I really start to think about it is when I have to do scans…it kind of scares me when I have to do scans…Just if I ever have to do it again… it is just a scary thing. Very scary and I don’t want to go through it again. Because I mean I have such a weak immune system. So that’s what I fear - of getting it when I’m older.”

‘That [fear of recurrence] worries me when the time is coming near for going back to the hospital. I would be wondering what the cancer was doing. Was it coming back?’

‘Every morning I think about it all right… will I ever be all right… am I ever going to be okay… you wonder to yourself how long is left.’

‘I don’t think about having myeloma… at all except once a month when I go for blood tests… when that goes well you are relieved… it’s a relief when you don’t hear anything bad…’.

‘I suppose the thing that always sticks in my mind was he [doctor] said it was incurable, but treatable. I suppose it still haunts me’.

‘You can’t lie down and die. You have to live…’.

‘I didn’t feel great, but as time went on like… I live with it… you have to live with it as long as you can… live as long as you can, die when you can’t help it…’

‘… life to me is terrible precious… I love life… I love my home… I love my wife and the lads… life is so precious…’.


“And we all walk around feeling like maybe a bomb is going to go off anytime inside our body and we don’t know when that’s going to be, because that’s what happened the first time. And so, you know, like, you got hit by a truck, you weren’t looking. I would be looking now. What can I do?”
“… So, I knew I was overweight, okay, that's something that I've always struggled with. So, I started on this watching what I eat. Not necessarily a diet, just eating correctly e what I'm supposed to eat, my vegetables, my fruit …”

“But, after I get down to my goal size that I want to be, which is 106 pounds, my next step will be I really don't know! Because, I can, that's one of the things that I can change. If it has anything to do with eating what I'm not supposed to eat, you know, I will do that. Even exercise.”

“You just don't know. With cancer, it just … Jesus, it's a waiting game. But, you know, I don't sit and just wait, you know, like I'm scared to death or anything like that, but …”


“This risk for recurrence is something that I have to face and that I’m going to think about in the future… I know that there's a risk…you have to live with it.”

“...I just felt sick at the prospect of being told something...bad and how that was going to make me feel. I was scared in the first couple of years because I didn’t know if it was going to come back and I wasn’t really sure of what the success rates were. Just the thought of it coming back and it being a death sentence was a worry for the first couple of years.”


“Quando vou ao médico, fico preocupada com o resultado dos meus exames”.

“Não deixo de fazer meus exames nunca mais, mas tenho medo de fazer e dá de novo a doença”.

“Tenho medo de acontecer tudo novamente, não quero aquilo de novo pra mim não”.

“O câncer pode voltar a qualquer hora, às vezes penso que estou curada, mas não estou”.

“Deus me livre tudo novamente, mas pode acontecer com qualquer uma de nós”.

“Vejo muitos casos de recorrência do câncer, mesmo a pessoa fazendo o tratamento correto, canso de ver mulheres nas consultas, a gente fala muito sobre isso aqui, aqui mesmo no grupo tem dois casos, a Rosa mesmo estava boazinha, de repente o braço dela começou a inchar e quando foi ver lá estava o câncer”.

“A gente sempre ver casos da doença acontecendo isso aí, por isso não pode confiar na cura total, sempre tem dúvida”.

“A gente nunca pode ter certeza da cura, porque senão deixa de se tratar”.
“Se a gente ficar pensando que pode voltar, se cuida melhor, porque ninguém gosta de ficar doente, ainda mais com câncer”.

“Sei que a minha chance de ter novamente o câncer é muito pouca, antes era enorme agora vejo, mas me cuido bem melhor que antes”

“Não corria atrás dos meus exames, era relaxada, agora faço todos, o câncer pode vir a qualquer momento, mas não vai me pegar de novo”


“I just prayed that I would see my children grow up”

“the only time I’m concerned about stress would be when I start to think about going for my check-ups.”

“I think I am going to have to watch the rest of my life”

“the possibility of my dying of cancer is probably fairly great”

“I have a mental block about it”

(Going for check-ups) “helps us keep things under control”

“It never leaves your mind. If you say you don’t think about it, you are telling a lie because it will come into your mind every now and then, especially when you get a little pain.”

“If I have a headache I always wonder if it is the headache or if there is something wrong? You always think it is the cancer that has returned.”

“Any little thing is extremely upsetting. If we had this conversation in my 6th year [after cancer diagnosis] I may not have the same views as in my 5th year. Until I get to the 6th year I will be upset.”


“When I have a physical problem I do snap to attention - is this cancer again?”

“I, I do worry. I mean, you get aches and pains and say, “Oh, (Sigh), okay, I'll note it on the calendar. You know this ache is here. Is it here a month from now?” you know, and kind of in my mind. But I don't fret or fro.”

“I guess it's always in the back of your mind especially now that I am getting older and a lot of people my age have been dying about cancer of the breast or other things. It's always in the back of my mind. Especially when people—she had this kind of cancer and then it came back. And I thought oh my God if it came back. It can happen. I try to live without fear. I just say that it will never happen and if it happens we will deal with it when it happens.”

“Last year, I had sort of a scare again. I went for my mammogram, and, urn, there was a shadow in place that they couldn't determine. And so, the radiologist said he thought it was okay, but my doctor said, “Well, that's not good enough.” So he did a biopsy. And, urn, he said he could
hardly get the knife through. It was so calcified. But it doesn't hurt, doesn't bother me. But he said it was very calcified on the area where they took it out. That's probably from radiation. I don't, I know I might get it back. But, after all, I'm 82. I can't ask for much better than I have."

“I've had my share of mammograms. And I'm not sure I want many more of them because of the radiation exposure. And, I'm real concerned, if there is any cancer there and they squash your breast on that device that it's going to spread the cells. So, I have been having thermograms lately. I think it's been at least 3 years since I had a mammogram."

“Now tamoxifen is a concern for me from a standpoint of there is a possibility that it might make you more susceptible to cervical cancer or whatever.”

“When I finished my tamoxifen I was happy in one sense because after five years you feel wow I made it to five years. It's great. But all of a sudden you feel so fearful because well my body doesn't take these medications anymore, how is it going to react? So there is a little bit of fear in there. It is the same when the doctor tells you we'll see you every six months and then one day he says well we'll see you once a year. You feel oh my God one year is too long. What if something happens in between?”

(helped them allay their fear of recurrence.) “I have a very wonderful, large supportive, we have 4 children and have a very supportive family and very supportive husband and that has been marvelous. When I went through the cancer, both my daughter and daughter-in-law were nurses and they were wonderful because they, you know, I could talk to them about things and they knew what I was talking about. So, yeah, I just, urn, I'm a very wealthy woman, I mean not in money but in terms of the really important things in life, I think. Lots of love, lots of friends, lots of support. I had a church group that was really supportive and I'm a Hospice volunteer now because I'm out of treatment and that's a wonderful group that I'm a part of and feel very close to and, uh, yeah, I feel like I'm living a wonderful life. I know that when I was diagnosed with breast cancer, I was a member of a women's support group, a very small group, there were just 5 of us. It was just a woman's support group. And they,
when I was diagnosed, they were wonderful in responding, you know. And I believe in support groups. I've been in a number of them in my life and that was very, very helpful to me, just someplace where I could go and talk openly. And I think, being all women was really very helpful.”

“I continue fearing cancer. I continue to be afraid because of the fear. I am barely discovering that I had a horrible panic attack to lose my breast completely. People ask me if my cancer should reoccur will I undergo treatment again? And I say No! I already experimented with it once and I lived it. God gave me a second opportunity. I believe that to put me under the test it is because God wants me to be with him. That is what I think. Many people think that.... [sighs] if I have thought it out clearly, yes, I have thought it out clearly because...because I have already lived it once. No?

“A lot, you suffer a lot.”

It is a permanent injury to your body and soul. No? In the first years, let me tell you that I felt bad, something would hurt and I was afraid that it would be cancer. Whatever it was, the most insignificant, I would say, it [the cancer] already returned. I am telling you that I have passed through difficult periods because two women that were in my support group. They were taking Tamoxifin, older than me and their cancer returned. They were good friends of mine. One died and another is in treatment. [takes a deep breath] The three of us were on tamoxifin. It caused me to have lots of difficulties, and I had a lot of hot flashes. I could not sleep. My eyes were constantly irritated. I fell into depression. I was really irritable and because you don't sleep and you suffer, everything bothers you. I opted to stop taking Tamoxifin.”

"I didn't want to just feel sorry, you know, feel sorry for myself. I wanted to keep busy and so it didn't pull the kids down. I guess I kind of developed an attitude; I have no control over it. I have to make the best of the whole situation. I got a little spaz when it was time for the checkup until they said, "Well, I don't see anything." I was good for another year."
“He [spouse] was extremely support. I was kind of more ashamed uh fearful a little bit. I would say that I have help from him. A point that I would like to bring to your attention is that during this whole process and having my friends, my family, and my husband being very supportive. I still measured how much I let them know about what I was going through because you don’t want to upset them. There is that little thing inside and in talking to other women I feel. One doesn’t want to disclose everything. That is why support groups are good because when you have a body or a person that have gone through you can talk to them on the phone because that allows you to unload. Somebody who gone through that same situation will be there to listen to you. After that you finish that you are back to normal with everybody because what a relief. You see. You are not constantly bothering your kids or your husband and crying about it.”

“I mean, you’re still worried and concerned. I mean, it’s scary. Even when I was going through the [genetic] testing, you know, I would talk a little bit about it and they [her daughters] know that mom went through the test and that, you know, and that it is negative, so they're relieved of that, and I know my older daughter was a little bit concerned. Do I have to go in for testing at all? Should I think about having surgery in the future? And, I mean, 16 year-old thinks of that stuff, so, it's important.”

“If the doctor keeps in mind that patients are scared and have the right to have their questions answered and a right to their body and a right to know what is going on whether they can afford it or not for their treatment. If they can keep empathy I think they can deliver a good service to the patient.”

“You just don't talk to people about it (FCR), they don't want to listen to ya. Because you start talking and they change the subject.”

“I think a big part for a lot of people is that there are support systems that come into play and my mother and I are not close so that didn’t come into play with me. I didn't know who to turn to. I am Roman Catholic and I remember turning to, I remember calling around to see if there is a church base support group and there wasn’t one and I had a visit from the priest. He basically told me uhm "Life's rough get over it." I am quoting
you. He actually used those words I just, I let him talk. You know I am numb from going from the perception of myself as a healthy person to now I am dealing with cancer and there is a stigma to it. There are lots of consequences to having had a diagnosis of cancer. It was really intriguing that the distance that certain people in my family maintained. (...) There is certainly a lack of not knowing what to do uhm but then again my parents have never been supportive of me so you know. After the diagnosis I went through like a post-traumatic stress kind of a thing, I would just have major panic attacks. And I went and saw a therapist also when I was uh going through chemo and just you know and dealt with some things that I haven't dealt with from my past like my folks and my place in the family and my value as a woman, my culture. I think I was very consumed by worry, probably the first four years but once I hit five I became more convince that there was a future that uh there was hope.”

“I said, I don’t want to talk about cancer...I read it about it...I hear it on the air, but I don’t want to go and have lunch and talk about cancer.”

“I think the most important thing is to have a group of empathetic women that you can share with and it is nice, I think it is nice to be in a cancer support group sometimes, because other women have gone through things that they can share with you that are helpful.”

“I think it (pauses) gave me more of a sense that there is something out there that watches over you. Uh, I've always, I'm Catholic, and always, you know, have believed, but, I think that having cancer sort of reinforced it a little bit.”

“There are moments of anxiety, maybe I would feel a little something different in my body. I would feel like, “Oh my God why is that swollen or a little change in some part of me for whatever reason.” It’s that bone cancer, can that be a metastasis? Again because I know how cancer works and I understand how what a treacherous disease it is so I constantly say a prayer in my heart that I will stay well. It is my major defense against any anxiety, I feel I always fall back on my belief in God and it is a very heightened existence.”

“It was like this constant fear of death, and constant fear. Will it come back? Did we get it all? I made the decision for the mastectomy. I felt like they took it. They took the cancer. Like the cancer was out of my body. It's in God and it's in his will for me to live and I don't believe that I am
going to die of cancer I believe that he has a purpose in my life and that I've gone through is uh is something for me to help other people, women you know go through this.”

McLoone, J., Watts, K., Menzies, S., Meiser, B., Butow, P., & Kasparian, N. (2012). When the risks are high: psychological adjustment among melanoma survivors at high risk of developing new primary disease. *Qualitative Health Research, 22*(8), 1102–1113.

“Each time I get another one I have a real sense of “Oh God, here we go again” and I wonder if this is going to be the one that gets me. It's not really a burden but it's kind of like a shadow I guess and progressively it gets a little bit darker each time. . . . It's going to be this constant I guess worry or concern in my life.”

(this fear had) “no sort of peak to it” (but remained) “constantly on my mind”.

(like) “a sword hanging over my head . . . it's scary.”

“Whenever I go back to [Doctor], he says, `Well it is 7 years, but don't forget it could reoccur at any time.' . . . and I suppose all the time I wonder when it's going to happen.”

“I keep my eye on my glands in my legs and under my arms . . . all the time I wonder when it's going to happen.”

“terrified” (of the risk of developing metastatic melanoma and believed that) “if melanoma gets loose in your body, you've had it.”

“I don't want to [get melanoma again], it terrifies me. Because I know that there's a lot of treatment now, but still, bottom-line is if it's already spread and it's not got really soon, really quickly, there's no treatment for it. They can't fix it.”
"When I'm standing at an intersection I sort of find the shadow of a post (believing that even the smallest amount of sun exposure could trigger another melanoma)."

(these fears interfered with daily life) “It changes holidays. That for me was difficult because I loved those holidays where I jumped in the pool. You know, those lovely sort of tropical holidays. That's out of the question for me now.”

“I do it (vigilant self-screening behaviour) every time I think of it. Yeah it could be weekly. It's very scary. By checking I feel much more comfortable after I've done it.”

It terrifies me. . . in the back of my mind there’s still the risk that there could be something there.

I just feel like it’s a sword hanging over my head. I guess because you are always keeping an eye on things, it’s always there – it’s like an undercurrent in your life. If I'm really lucky [melanoma] won't be what kills me, but it might be.


"I didn’t tell them (her family) anything about the cancer probability because I didn’t want them to be worried”.

"It is the most important concerns that what happen about my children's future, if I die".

"I have four young sons that have not married yet, and my only wish is to be alive and see their marriage".

"I hope to be alive to see my daughters growing up. ... All my children are still schooling, they are very young to live without me".
"Now my greatest fear is returning the cancer and progress to the other sites of my body".

"I have not had sexual intercourse with my husband since I got cancer. My treatment finished but I have fear of getting sick if I have sex ".

"Now I consume safe food always. I try to eat fish and vegetables more than before. I rarely eat red meat, fast foods or industrial fruit juices, instead, I drink milk more than before ".

"I did not use to do regular exercises before my cancer diagnosis, but now I participate in yoga classes every day, try to exercise as much as possible. It makes me relaxed and I hope that it helps me to prevent the cancer recurrence”.

"I have planned every six-month routine visits my physician to control and detect probable recurrence ".


“Do you also feel like ...well you have been told that you are cured, but do you believe 100% that you have been cured?

I have a hard time believing it ...In the beginning, I thought that I was coping very well. But after the treatment I think about it every day. It preoccupied me a lot and that surprises me.”

“I go through a lot of fear now. That every single thing, any time I hurt anywhere, it’s cancer related. It’s just instantly, I go there. I keep thinking, I hope this goes away and slowly diminishes.”

Now I feel like the rest of my life is spent fighting and looking over my shoulder. Thinking, “Oh, gosh, what is happening next?” You constantly feel because you were not diligent in catching it before, well, at least that’s how I feel, that I have to be more diligent and watchful so it makes you almost a hypochondriac compared to what I was before.

“Well, it should have been such a relief, but still to this day, you are still scared that it might come back. Still to this day, since 2009, I’m still dealing with it.”

I am going to be dealing with breast cancer for the rest of my life. It will pop back up, and I will get rid of it. It will go away for a while, and then it will come back. I’m young, so that’s just sort of how it’s going to happen.

It makes you crazy and you just have to embrace the fact that you are nuts… I thought for sure I had a new tumor pressing on my e-spine… one doctor actually broke out the anatomy books. And he said, “Okay, this is why I’m telling you this isn’t what it is and then it made perfect sense to me and I’m good with it…and, you know, they’ve said to me, “If it’s going to make you feel better, we’ll order a CAT scan, but we don’t think there is a need to.”

Yeah, I’m healthy. Yeah, my cancer so far is still gone. But I still want that peace of mind of seeing my doctor. Just to touch base. Getting a mammogram done and it being okay, it gives me peace. Okay, I’ve done everything I can do, so whatever happens after this is okay.

I refer to it as post-traumatic cancer syndrome. That’s my new thing. It’s weird. At one point you sort of feel like there’s always this little ticking clock off to the side where you’re like, “If I could go in for a mammogram on a weekly basis, I probably would.”

“I am always looking over my shoulder, just thinking, “I hope it doesn’t come back.”

“[The anxiety] comes and goes. I can go for weeks and then months and think, “A piece of cake. There is nothing to this.” Then all of a sudden something will happen. Race for the Cure is coming up. I always participate. I don’t do that without thinking about it and bringing it all back. Coming tonight is certainly a step of—“Am I OK with this?” It is always there. It is right below the surface.”


“Because it [tamoxifen] doesn’t say it mops up any stray cells there may be. It says it stops your oestrogen, connecting with them. Oh yeah, alright, so what happens that day you take the last one. Oh my God. ...Thinking do I have 20 years, do I have 10 years, how long do I have? . . . emotionally dealing with that has been tough. In your mind, whenever you’re having your treatment, you’re thinking, the treatment’s keeping the cancer away. When the treatment stops, you’re thinking, well what’s keeping it away, now. You had so many doctors watching you, making sure you’re safe, and with all these tests and everything, and then all of a sudden there’s no testing. You think is it coming back? . . . Is that sore back a sign that it’s coming back? You know, you can get a little paranoid.”
Perceptual-situational  Symbolic-conceptual  Bodily-expressive  Motivational-behavioral  Emotional experience


“Every ache or pain is ‘oh my god what’s this?’ You tend to be building yourself and freaking yourself out and it’s nothing. After the first year I found that that has eased off a bit.”

“Every now and then I might be lying in bed and if I am not feeling too good I’ll wonder if there is something happening to me. It mightn’t necessarily be the prostate it might be something else. I sort of wonder if it’s going to rear up in some other form?”

“I would have a mammogram every month if I could”

“When I went for my three monthly checkups and my monthly check up and I would get a bit, not short, but I worry a bit. I get a bit irritable”

“It’s another scan that can go either way”.

“There will come a time when I will just say to the doctor’s, ‘look I don’t want to have these scans any more because they are actually less beneficial; they are actually causing me a bit of grief’.

"It’s with you constantly. You know, first thing on a morning when I wake up, I can feel great. I stretch in bed and the sun can be shining, and for a moment I almost forget that I still might die. Then it’s like a cloud comes over . . . I remember that I’ve had cancer and chemotherapy. Life is suddenly not so rosy, and it’s like a fear grips your heart. You know, I think . . . I still might die”.


living with that “bit of fear” that it could come back but not “letting that run my life.”

“It is very hard… I mean, it’s crazy, you know, I will be in the shower and I will think, ‘when she gets married, what if I am not here, you know, or when she graduates from college, what if I’m not here, or when she has kids, what if my cancer has come back and I am really sick and I can’t see my grandchildren”— yeah, I think about that stuff all of the time… I have never said that to anybody. I mean, I just try to live every day and watch her grow every day. I want her to remember who her mommy was.”

the thought of finding a second primary cancer “scares me to death” and her risks should be lessened by the surgery.

“My biggest fear was that I would die and I wouldn’t be able to take care of my children… you know what? I wasn’t as prepared as I thought.”

“waiting for the next shoe to drop,” as though her fears were still strong.

I was probably about 12—and I was lying in bed, and you know how you start thinking about something that is just really hard to grasp…I remember the first time I thought “someday I am going to die” and it scared me and I sat up in bed and I remember just yelling for my mom. Then when you are in your teens and 20’s you have that whole immortal thing going…I remember when I had my children my biggest fear was
that I would die and I wouldn’t be able to take care of them… I had to face that, you know, smack—face to face—when I had the cancer diagnosis. That was a very scary thing for me… here I was, and I have been a Christian for a long time, and I know it is a better place, but that is still hard… you know what? I wasn’t as prepared as I thought.


[...] um frio na barriga, por mais fé que você tenha, dá um medo, medo mesmo.

Meu coração acelera quando sei que tem que fazer exames de novo, sei que o médico vai pedir os exames, você fica com medo do resultado. Tenho muita fé que os exames não vão dar nada.

[...] estou traumatizada, sinto caroços no meu peito, nas costas. Toda hora tenho vontade de estar dentro do consultório do médico. Enquanto eu não chegar no médico e ele falar que não tenho nada, que estou curada... Eu sei que tenho fé, que tenho Deus, mas preciso me livrar disso. É um sentimento que só quem passa mesmo por uma quimioterapia para saber [...].

No primeiro momento que fiquei sabendo do câncer o medo era morrer, hoje, o medo é o tratamento. A gente já tem a noção do que é uma quimioterapia, do que é uma radioterapia, então já fico pensando no tratamento [...]. É sofrido demais.

[...] você vai fazer os exames, mas você vai com aquele aperto no coração, deprimida!

Eu sentava lá [no consultório médico] e ficava igual uma corda de violão, bem esticada. Principalmente quando o doutor, falava: “olha, agora a gente tem que fazer um exame, tem que apalpar... relaxa”.


É uma sensação estranha, nem sei como explicar, mas eu me preocupava sim. Toda vez que ia fazer o preventivo era rezando, pedindo a Deus que o resultado viesse normal, era angustiante, até que não pegava o resultado na mão [...]. Depois que vi que toda vez de fazer os exames, dava sempre a mesma coisa e o médico falava que era normal, aí fui me tranquilizando. Mas só com o passar do tempo mesmo.

No começo tudo assustou, até uma dor de cabeça: “ah, o que é isso!”?, mas com o tempo você já não associa mais. É claro, a gente sabe que se tiver uma dor constante, ela precisa ser investigada, [...] só que se a gente for pensar assim, você vai esquecer até de viver, então você vai ficar pensando no amanhã?

[...] hoje eu fico ansiosa só quando eu tenho que fazer uma biópsia mesmo, daí eu fico, mas os outros exames não.

Ah... é uma coisa assim, parece um “fantasma”, que nunca vai sair de dentro de você, acho que nunca sai, acho que você pode estar lá no finalzinho da vida, vai ser sempre assim. Quando você tem uma dor e tem que fazer uma biópsia, você sempre fica com medo, então não adianta, porque isso eu acho que acontece com qualquer um que já teve a doença, é esse “fantasma” não sai não [...]

[...] é assim, você acorda lembrando que tem isso, é o dia todo pensando [...] a família inteira é assim, meus irmãos que moram lá em Porto Velho, falam: depois que deu isso em você eu não esqueço isso um minuto.

[...] e quando você sente uma dor, você fica com a cabeça “perturbadinha”. Fica! Se eu sentir uma dor aqui na ponta do dedo, já corro no médico. Até ontem fui no doutor, estava com dor nas costas, mas ele não pode me atender...

O meu câncer foi na mesma época que o da Maria Rita do Roberto Carlos, ela foi [...], mesmo com tanto dinheiro que tinha para fazer de tudo pela vida dela [...]. Meu tio também teve um câncer no intestino na mesma época e faleceu. Ah, não sabia nem o que pensar, na hora fiquei arrasada.
Perceptual-situational  Symbolic-conceptual  Bodily-expressive  Motivational-behavioral  Emotional experience

Vem na minha cabeça lembranças e eu mudo de pensamento, falo: “não quero lembrar isso”. Tem que evitar pensar! Não gosto de passar em frente da clínica, quando tenho que levar os exames, conversar com a médica, dá arrepió só de ir lá, sinto cheiro dos medicamentos, eles têm um cheiro forte. As pessoas que não passaram por isso não sentem...

Passado é passado, não quero lembrar e não vou lembrar, passou! Vida nova [...] Quando lembro me dá uma coisa ruim, às vezes lembro de momentos que passei, quero esquecer aquilo.

Não me importo de falar [do câncer], mas parece que te dá uma agonia ficar falando muito. Lógico, quando vejo alguém procuro sempre animar, mas procuro não ficar lembrando disso. Procuro esquecer.

Se falar assim: “Camila você está com câncer de novo”, lógico que vou lutar, vou fazer todos os tratamentos, mas lá no fundo você sempre tem aquele fantasma, você nunca vai falar: “ah, eu não tenho medo disso”, você vai falar: “tem cura”, mas lá no fundo sempre o associa com a morte.


“[...] I say this, that I am well, but all of a sudden the others begin talking, someone has died from this or that, and I begin to feel lower. A friend of my daughter died recently, my colleague, her mother wants to say, she died… She had cancer too, five years ago, and she despaired, I started crying. And recently, many memories have come back and I say ‘I don’t want to think about this’, but soon afterwards, the news comes that someone died of this, and we get all of that in our head again. I do anything I can to get it out, but it’s hard, for example, in June I have to do the
tests again, every time I go I start praying, I pray that nothing will come up in those tests. When the time of the tests comes close, I become distressed, that distress with fear”

“The first few times, I got into such a state, any little thing that was different, I would straightaway think, is this something to do with it? Could it be something? Once I had rectal bleeding, sweat was worried, could it be…? I looked up a GI specialist, and I went to do tests”.


“The only fear is who will look after my children on being parted from them, of not being there for them, which was my fear, my drastic fear.”

“Then I started worrying about my daughter, she is not even married, what if I die?”

“I still get scared that what if it comes back. So I did not think about it much. Even now as people talk about it, I do get tense. Like people say, whatever you think will happen. So I try to prevent negative thinking because it makes me uncomfortable.”

“Once you become ill you are dependent on others. One thing I never want is to be dependent on my family for anything. I want to die healthy, not being a burden to anyone.”

“My heart sinks, and I feel worried when I see people in my village dying because of these diseases even years after treatment. I also start fearing that I will die.”

...now it’s not a big issue for me really. Most of the time. You know, you obviously get the odd moment when you think, or if you have a particular ache or pain, you think, “ooh what’s this all about?”

She gets a ‘nagging feeling’ that certain pains could be a sign of recurrence.

‘God, it makes me scared just thinking about it now.’

‘I couldn’t even bear to talk about it (follow-up appointments) or admit that it was happening or say the word “cancer”. I literally couldn’t bear it.’ Follow-up appointments were ‘really horrifying’ and ‘absolutely terrifying’ as she felt she was being given her life in ‘3-month segments... so most people you’ve got this horizon, you’re whole life it’s a limitless horizon, and mine was just fed to me in measly little chunks.’

(now attending an one-yearly appointments) ‘obviously the fear recedes to an extent the further you go in’ but she still feels nervous.

‘I do, I do, I do (worry about recurrence).’

as the fear had ‘worn off’, she began smoking again, which results in ‘enormous amounts of fear’. ‘it’s mad and that terrifies me.’

...if I’m smoking, I’m freaked out that God is going to punish me because I’m spoiling my gift of life that he’s given me, by not making me die of cancer. I mean, I have this awful, biblical sense of doom and wrongdoing... It’s totally overshadowing me and filling me with doom:

fear has receded over time, as ‘time does its usual healing thing’  However, ongoing issues, such as occasional blood in her urine, continue to cause spikes of fear, which result in cancer having a constant, yet oscillating, place of in her life. (finds blood in her urine) it ‘always fills [her] with horror and fear and brings back the horrible fear.’
(To what extent do you worry it might come back?) Oh, all the time. I mean it’s a constant thought in the back of your mind. What happens is, you get a, say for instance I had a really bad back pain recently, which is very near to where all the radiotherapy was and all the damage was and my first thought was, not that I’ve sprained my back, but that the cancer has got into my spine, which is rubbish, it hadn’t, you know it was a back pain and it went away but that’s the kind of thinking, perverse thinking that you get when you’re constantly worried that it’s going to pop up somewhere else.

Well, I think you just try to put them (anxieties) to one side as much as you possibly can. I don’t let it destroy my day, constantly thinking “oh my God, it’s going to come back tomorrow”. I don’t think like that, I try to put it out of my mind, keep busy, do interesting things, whatever. But it’s lurking, it’s like anything really that’s troubled you for a long time, hidden away in the back there, somewhere, it’ll pop up every now and again.

She only worries ‘when you feel a pain and you think “oh shoot, is it my bra’s too tight or is it something else?”’ One reminder, however, is that her breasts ‘are all odd, now odd, yes, that’s just a little sad but there you are.’

She also said bone-thinning makes her ‘a little bit nervous’ because it serves as a reminder that she had cancer.

‘The cancer could come back, or a different cancer could come back.’

But if you don’t know what’s caused something, it’s very difficult to do positive steps and feel that you’ve done something to actually prevent it coming back. So, that’s why I just have this niggle, yeah it’s been here once, what’s to stop it coming back? (...)I think it does make you look at your overall lifestyle, and think “what should I be doing, is there anything I’m not quite good enough at?”
she has a ‘niggling fear’ it might come back, and is frustrated she cannot do anything to prevent it.

‘That’s what worries me more than anything. The fact that I might not be around to see those things.’

It’s at the back of your mind the whole time. It sounds, you’ll excuse me if this sounds crude, whenever I go to the toilet, I have to check. I always look. I have to make sure... and so that’s a daily habit... It could come back. And I think that’s just a niggling little fear that, unless you’re the sort of person who can overcome that, it’s always going to be there.

But I do think it will rear its head eventually. One day I’ll wake up and that will be, you know, I reckon it will come back. Well you either die of a heart attack or cancer don’t you? So, I reckon it will come back.

...a little pin head floating around in your body all the time and then it just stops somewhere and it might sit there for a little while and the, that’s how it gets you I reckon.’

‘Even now, if I think, if there’s something wrong with me, I think “I’ve got it.” Even now.’

recently had an ear infection and one of his glands was swollen: “and I thought “oh that’s one of them things in your neck.” What is it? Lymph nodes. Cos they used to check all round there and that, and if I find a lump, that’s it.”

I do, I do. I do worry about that (recurrence) and I worry about the fact that the treatment, you know, the chemo radiation... oh sorry, going back to your last question and how I feel today, of course, chemo radiation has, carries a risk of bowel cancer later on, recurring cancers in the pelvic region, caused by the chemo radiation, so that’s another reason, you know. I’m pretty upset I had chemo radiation rather than surgery... I became, there was one thing in favour of having the chemo radiation, in that someone said it sterilises the whole area, that was doctor speak again, so I sort of felt, in some ways, it felt like there had been a nuclear war in my pants... I suppose it’s more safe from recurrence from that
But in the early years I was obsessed with recurrence, I was terrified. Every time I had a pain I was, you know. I mean if I have a pain now, you know, it always flashes through my mind, is it a recurrence, and they say if it’s still there in 2 weeks, you know and it never is, touch wood.

I don’t sort of think “oh gosh, it’s going to come back”. If it does, I got through it once and there’s no reason why I wouldn’t get through it again. But I think if it was going to come back it would have come back between the two and five years, although I have heard people, there was somebody who it’s recurred five times. But I don’t sort of worry about it now.

you have to ‘learn to deal’ with the fear, and that can only be achieved by giving it time.

he feels cancer is potentially ‘brewing’ within him.

I don’t dwell on it, most of the time, just occasionally, there is always that little nag that you get an ache or a pain. That will never go away because you always know that there is a slight risk of... but it certainly doesn’t pray on my mind.

Apart from the bladder legacy, which terrifies me and makes me think about cancer, about blood, I would say I do think about it every day because I’m constantly looking at my urine and thinking “is it pink?”

‘that’s when, all of a sudden, you remember “God yeah I had cancer”’. She went on to say: ‘Just probably leading up to an appointment, you get a little bit “oh God here we go again”, back to there...’

(Going for a mammogram)’I suppose there’s a bit of anxiety... there was always that bit at the back of your mind...

...if I hear on the television or read in a magazine or anything, or the newspaper, of somebody who’s died of the cancer that I’ve had... I do find that it hits me and I feel low when I see that somebody has actually died.
...apart from this terrible feeling of tiredness I had, I can’t say that I felt anything at all that was any different. And that’s a slightly frightening thought, really to think that you can, and people do, develop cancer without really knowing that it’s there.

‘as time goes on, you feel much more relaxed knowing it’s all passed...’

Up until probably five years, I absolutely controlled my life. Totally. Totally overshadowed it and totally controlled my life.’


“I kind of think that now I have lived this long after the operation… So I wonder when will something new turn up again, right?”

“When I hear of people I know, it comes very close (…) I have some really restless days.”

“Liver cancer! It wasn’t realistic at all… (…) I have to sort it out…(…)…yes, it’s just like balloons I have to poke holes in… when I’ve done that, it’s okay!’

‘It has something to do with the graveness of it all…and it’s clear that cancer affects your whole life situation and future, and you wonder what’s going to happen…You kind of never get over it!’

(about struggling with FCR) ‘My mental state may have been different if I’d had someone to talk things over with afterwards! …You have many thoughts in your head, right…and you can’t air them and relieve yourself of your burdens… so I think that talking with health personnel would have been of considerable help!’
Shachar Siman-Tov, E. (2008). The experience and the role of spirituality among women who have had breast cancer and who have completed their medical treatments (doctoral dissertation). University of Hartford, USA.

(\textit{the threat of cancer reoccurrence lingers in the back of her mind}) but she \textit{does not "dwell on those thoughts."}

She \textit{never knows if "it's going to happen again."}

She stated she \textit{tries not to think about cancer}, but that the \textit{fear comes through her dreams}.

\textit{everything I had I thought it might be cancer. Once you have it you think; pain here pain there, you think, "Oh dear is it cancer?"}

\textit{And I know it could happen, but I have a feeling that I am not alone and that I can do what I have to do if something happened.}

But then, \textit{the checkups are a reminder}, and then my \textit{anxiety rises up}. I had an \textit{anxiety attack}. (…) So I am lying on the floor, everybody is around me, my friend gave me the phone and E said, "everything is ok!...I said "Hooray! Hooray!" (Laugh). That was very funny. But my friend came and stayed with me. So it is definitely there in the back of your mind! Fine! You don't have lung cancer!

\ldots \textit{emotionally as well as cognitively, because it is always something that I am aware of} and I still have \textit{fears}. Like I said, every time I have to go and have a mammogram; about what the result's going to be, and I don't think about that. It \textit{does not make me stagnant} and \textit{it does not cause a huge amount of anxiety} but there is \textit{some anxiety} about it. \textit{It just changed how I am in the world, and one more thing that I have to pay attention to.}
I get all anxious sometimes. Whatever thing they gave me kept me in bed. Two years out, less affect. Three years out, less affected; four years out! You know. I was in a good place after the treatment because I had the treatment. And nothing came back. They could not find anything. But it wears off, you know; that's what I thought it was (sic). I am hoping, I am hoping. But they do say it comes back. It's a risk getting it. So I guess there is a risk it (breast cancer) comes back.

"But uncertainty, fear of recurrence is there in a very small way. But I just pass to the next thought because it is ridiculous, if it is it is. I don't know. I just adjusted to it. And for the worrying thought; it does not last, it is just a fleeting thought because I know if I have a mammogram and if something is there, I have it taking care. If it comes, it comes; if it does not, it's great...[a]nd about the fear that everything. It is cancer and the fear of recurrence? I think that there is a little bit of that remains straight through. I really do. I suppose it is because my mother died of breast cancer. My sister had has two done; mastectomy on both sides, and there is a lot of cancer in my family. So, it is pretty hard to put the whole thing to rest, but I am not dwelling on it. But it is there.

Well, the only time that I notice that fear, is when I go to a mammogram, or I go for my checks up with my oncologist and my surgeon; during those days, yeah. And I also have concern of possibly getting other cancers. I had a scare not too long ago; after April, I started coughing all the time. They did an x ray and nothing was wrong; but they did find something and I had to go for CAT scan; and while I was waiting for the CAT scan being read, I had an anxiety attack and I did not pass out but I was lying on the floor of a restaurant, because I was so convinced that I had lung cancer, which I don't. It just was scar tissue. But I tend to be more easily frightened. And when I go yearly to the dermatologist to check my skin. It is all because I feel pretty susceptible, and I think that I have changed my susceptibility by my increased calmness and awareness and slowing down and doing the art.

Yes. Absolutely. I was diagnosed with cancer; like I said, I had a recent mammogram when I had to wait after the biopsy to make sure that my cancer did not reappear. That is the reality. The statistics of breast cancer is that often it often reappears; you know in other part of your body.
and I had lumpectomy and not mastectomy because that what has been recommended to me; and especially because of my mother's history, my maternal aunt and my first cousin had it. So yeah, there is uncertainty; and always will be and as the years increased, please God, my spiritual self, that there is no cancer, I will feel little less anxious worried about it. But it still... I just finished radiation last March, so it is a year ago. So it's still very present in my life. Very present in my life.

So it is not in my mind. (...) So, there is always something. I mean we would go. Something would get us! I don't know what it will be. It might be a truck, which hits you. Who knows! I honestly do not concern myself with that anymore. That is not my fear at all.

Yes. I think so. I live with the fear of one day waking up and feeling another lump. It is always in my mind. It's uppermost. It's here. I think it subsides through time. Through time, you feel more confident that you're going to live. (Laughs). And you kind of put it up here. And that's why I think I lost the thing that I said I did not want to lose. When I was feeling so wonderful just about living; be able to live another day, another year, whatever. It's waning a bit now. Because you getting into the routine and it's not eminent; it is not right now. You are not going to treatment. I am into my fourth year so, you don't have guaranteed. And when this thing came with my arm flared up, it all came back. I was flooding with fear. Yes. And it is more eminent. It's there. Everyday I feel the pain. The cause of the pain is something else.

I try not to think about it all the time in between, but when I go to my tests, it is impossible for me to avoid it. Just impossible. You know. I still have nightmares and I get scared; and I hate going; and instead of getting easier to go, it is getting harder. Yes. Because I never know if it's going to happen again. Yeah. Yeah. And I never know when I am going to have the test they going to tell me that the cancer came back. So I can say that it is a disruption in my life now too.

I think about it more when I have to go for the test. I go to see my breast oncologist twice a year now and that's ok. I like her and she is very supportive. You know I can deal with that. Mammogram I go once a year. I don't like going, but I go and the sarcoma thing; that have been the
toughest because it is CAT scan and two years ago, I had a CAT scan and they told me everything is ok, and then they called me two weeks later. The doctor had gone back, and he told me they found spots on my lungs, and they thought it traveled to my lungs, which it is a death sentence. But it was early, and they could not tell. So, I needed to see a pulmonary specialist. They wanted to repeat the scan. I did not want to wait. It was horrible! Because they much more cautious with everything they see. It was horrible. You know, until they did not see any change; but I still worry. I mean I thought that's it! And then I had gone for an ultra sound, and they also found something unusual and they wanted to watch it; and I freaked out when they told me that. For a normal person, it might be ok, but with my history I cannot wait and be relaxed with those kinds of things. I cannot say, "Oh yeah, I will wait six months and see and find it!! You know, I can't! So, for me it's traumatic! Those things, while for somebody else they might not get crazy about it. I had to call my oncologist to deal with that. It's a lot! It a lot! Because anything abnormal I had to pay attention to it. May be most people do, but I am probably more sensitive to it because of my history. So, you know this was upsetting to, and this happened two summers ago. And since than (knock on wood) things have been ok.

Occasionally, I do because I am fearful that it might come back in a different form. That it may not come back as breast cancer, but it may come back in a different form. That worries me! Only because if it was in my system in one time....I think about it specially when you know, I hear about people that have been diagnosed recently.

Oh, yeah, completely. I get scared and I feel very vulnerable. And I think the other thing that happens, you know, is losing both my parents over it too. And feeling my own vulnerability is very scary. But, I don't have to worry about having the cancer anymore. I don't have to worry about that because I'm already there. I had the cancer first before I found about the genetics. Every time need a decision to make (sic), I knew I had to have mastectomies because I would have been crazy to have ninety percent risk and live with that, because that's what the genetic risk was. It was 85 percent that I would get cancer. So, it was an easy decision. There is nothing else I could do I could not take tamaxophen. Probably three to four times a year I was asking my doctor, "should I take tamaxophen?" No! it would not help you!! I had another surgery one time because I
decided that it was too much breast tissue under my arm that they did not take in my mastectomy, so I went back to my surgeon and I said "I don't like this." And she said, "What do you want to do?" And I said, "I want you to take it all away." So I went back and had another surgery. She said, "You know, there was some breast tissue there, that's good, you had a good idea." I had seven surgeries. I think I'm mostly tired. Sometimes, when I see my friends or people who did not had all of this, they go on with their lives, but they don't have this burden on their backs. And I do all the things I always did with this. It makes me tired.

Oh Gosh, Yes. I don't feel it is over. Treatments are over long ago. But I don't feel my experience of breast cancer is over now. Because one of the things the way my life has changed, is that everything has to be checked out. It used to be that if something had happened; it used to be that if I had some kind of physical symptom, it wouldn't be necessity to make sure it is not cancer right away; where it's now, when tests results come back and the numbers are funny, we have to find what it means. For example, I broke a bone. I needed to make sure that it is not bone mass and that it just regular fracture. Those kind of things. So, I am going to doctors a lot more often. I am getting checked a lot more often. So, yes I feel uncertainty, because with breast cancer, at least the one I had, I am so glad I don't have recurrence; but at the same time I don't feel I overcome that because it can come back; and I know other people that it came back after a long time. But, on the other hand, I also know that you could live with it for a long time, and so it could be seen as treatable disease rather than a death sentence. So, it is not that I am expecting it to come back. I really hope it won't, but I haven't got to a point that I think I am done. No. I am not done. I would like to able to think that, but I am not. I can't. Especially, since you know, I go and I see my oncologist doctor and she says, "Hmm when did you do your last chest x ray? It's time for that." (Laughs). There is always something! She asked me to do the genetics test. I did not do it yet. I was thinking to do it. I talked with my sister about it. Yes, it would mean a change of treatment for me if it would come out that I do have this gene. It might be that I would have to think to have a mastectomy on the other side, and hysterectomy. I delayed, I guess, because I don't want to think about it. But, also for my sisters, they need to know and her daughters. So, I should do it. I haven't done it. But I should do it. But, I have done everything else. I have done the MRI's
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and I have done the chest x rays. But the genetic test I have not done. It is the one thing that I did not have the courage to do. So, I do feel uncertainty.

It's there. I am aware that I have had breast cancer; but I am not thinking about that, except on those lunatics times. And then I can go immediately into hysterical mode.

Once you... my experience, because I have had cancer, the concern is that it may return. So it is part of my reality. I talk with my friends about it and I call my therapist friends. Like, for example, the anxiety I had... recently having to go to the mammogram, and having to have another biopsy and having to wait for five days to hear what the in pathology report was. I promised my family and friends that I would not keep secrets from them; so I called them; and once again, I got flowers and cards; and people calling me; telling me how much they love me, and wanting to hear what the news was. And there was a lot of noise and celebration that the results were benign. So acknowledging the anxiety, dealing with it, and talking with other people about it, calmed me and soothed me.

I think the way I cope with it is to realize it can come back and prepare myself for that (laughs). I just make sure I have insurance! Go to the doctors and make all the check ups. And then if I will get it I make sure the insurance will cover it; and also I thought if I would retire... because it is so expensive; and whether I would be able to be as strong as I was the last time. If it will come and I need financial... I will sell my house very quickly and go on.

Yes. I have to have a plan. It gives me the next step. I know what's coming. I like to know where I am going. If I drive a car to somewhere and I never have been there, I like to know how to get there (laughs). If I am driving, I want you to tell me three blocks before I turn right! Don't tell me when I got to the right! I need to know.. That just in case and hopefully it is not (Knocking wood). Just in case, I know what to do.. It
Perceptual-situational  Symbolic-conceptual  Bodily-expressive  Motivational-behavioral  Emotional experience

lowers my anxiety. It gives me sense of control. I know my next step is. I am not sort of floundering. I don't give myself time to panic. Because if I don't know what to do I would panic.

So it is not, I never forget about it, because it's something I face everyday. But, you know, I don't dwell about it. I think I am ok with the breast cancer experience. Well, you know. I don't know. I mean. Just by trying to live my life. Not to think about it everyday. Not to think about it obsessively.

Occasionally, I do because I am fearful that it might come back in a different form. That it may not come back as a breast cancer, but it may come back in a different form. That's worries me! Only because if it was in my system in one time. I am pretty sure it was because of stress...but if it was not. Then I don't know what is my case. But, I think it was stress. I really believe it was stress. So it comes one and then...I think about it especially when, you know, people that diagnosed recently... I think about how I really do not have the reason to think this way. As far as I am concerned, it is a conversation with myself, you know. I just escape; I read, or listen to music. I get my mind off of it. I am very good in turning things off. Or I do something else. Or I would draw from my spirituality. I would go outside and just enjoy where I am, the trees. I am a big trees person. I love trees. Big trees. That's my favorite, trees and now flowers.

Sometimes, I feel like I am afraid to go too far away from it because if it gets to distance, I won't remember how to deal with it, if I had to go through it again. It's like being afraid to believe it is over. You know, because it's still the unknown. I don't know. I hate the word survivor of breast cancer. I hate that word. Like I tell somebody I had breast cancer, and they would say, "Oh you are a survivor." And I would say, "No, I am somebody who had breast cancer." That's all I had. You know. I don't know what "survivor" means! You know, if you die? Is that means that you are not a survivor? And what if you fought as hard as you could? It's not fair, you know: is not being a survivor means that you failed? And that's not fair, because it's not in your control.
I have been experiencing anxiety a lot. My hardest time is at night. If I start to fall asleep, and something wakes me, then I am in a big trouble, because that when I get scared and I think about all this things that I'm scared about. And you feel all the things that you don't think during the day. "What is that pain? What is happening there?"

I need to always to be talking. Some of it got too big to talk at home. It was too much of a burden on everybody. So, I needed to find somebody outside to help give me perspective. I feel that the treatment has never been over for me, because even the hysterectomy still was part of the cancer. I feel like seven years of getting various treatments. But it is very funny, because at my last appointment with my oncologist doctor, she said to me, Do you think we can do it once a year now?" Laughs at me. She said I can't break away.

I mean there are times... there is still those times (sic) when I wake up in the middle of the night, with just... scared that still happens. It doesn't happen very often anymore.

And, living with the uncertainty every day.

Just by having this kind of attitude, confronting breast cancer and the fear it's evokes, and at the same time letting go, and surrendering kind of approach.

Yeah, it helps (spirituality). I am trying not to think about it in between times. More comes in my dreams than my daily life. The fear. You cannot control your dreams. But otherwise, it's getting better. As time goes on, it gets better. Because there are different markers. After a certain time, the chances are lower. It gets better. So now I am sort in between time. The breast cancer is over five years. Knock on wood. And so far so good.
It (spirituality) helped me to come out. And about the worries about cancer. Spirituality gives me confidence. That everything will be OK for me.

Absolutely. Yes, because even though I think about it occasionally not very much. It really takes something unusual for me to even think about it. For me it is in the past. It’s gone. But of-curse it is in the top of your head. And, like I said, I would go and do the things I love to do. Or helping at work and sharing. This is very spiritual for me.

Yes I think when I do; I mean the uncertainty never goes away, but I take such a great comfort from the response I have from people, in the bonds that I have with people, the connectedness; it helps. It's helps so much, and then for the day to day coping, I found that one of the things is that when I am stressed out about things; if I am next appointment coming up in the calendar or something like that, is that one of the things that I do to cope with that is to bake cookies with my daughter; things like that, bonding things, which is something so much more than baking. It's being in the moment with her, and doing something together.

I have a therapist that I can talk about my fears, and my training helped a lot. So it helps me be balanced about that.

And the worry was, that might mean that I have cancer in other parts of my body. So the biggest fear that I would die earlier than I wanted to. That I would die relatively young woman. But it made me take stock. It made me take stock. It made me stop and choose to take care of myself. It made me even more reflective about my life and the challenges; and just to realize that it is all what life is all about.

I was frightened. I was uncertain. I did not know what to expect. I was very pleased with how I have been treated by my team at [confidential] in that I am less afraid of the diagnosis of cancer; meaning for me that I am going to die in couple of years. I have educated myself. I have gone through it. I have met the challenge. Like I said before, I was always afraid because of my family's history; because it is on both sides of my family, of having the diagnosis of cancer. Been there. Done that. And it has given me a different meaning to life. It made life even more precious than it was before. It has been growth producing. It was hard. It was scary. I still have some moments of anxiety, but in the big picture, it just
helped me I think, be a more present, and be a person who understands that connections heal; and that there are people out there who will help me in that, and diagnosis of cancer does not mean necessarily a death sentence. So, that's very calming and reassuring for me. It's giving me some wisdom.

I don't want to get it again. And I don't want to because I don't want to experience this kind of fear again, that sort of disruption. And I just want to live my life. I want to live it as fully as I can.


“I’ve heard of cancer . . . being kind of jump-started by pregnancy because of hormonal changes. And sometimes you think breast cancer, ovarian cancer, you know, whatever is hormonally related . . . That’s really it. And you think to yourself, "Am I really clean? Because if I get pregnant, and if I’m not {clean}, stuff happens."

“Where’s the sense in having a child you won’t be here to care for.”

“I’ve been mostly reassured that pregnancy couldn’t initiate a recurrence. But then I feel like, well no one knows for sure . . . I guess the main risk I think about is recurrence and . . . I don’t survive it and die, and then my kids are left without a mother.”

“I knew from my mother that I was left alone . . . Emotionally she didn’t want to leave me alone, but I was [left alone] physically. . . . My sister was in school and my mother was at the doctor’s. I had to go with her. And even as a small child, I felt I was taking care of her. I think that’s the worst thing in the world for a child.”
“I worry about . . . [my child and my husband] seeing me suffer. . . . I’ll suffer quietly, but still, I don’t want someone else to suffer because of my suffering.”

“It is devastating to a child to lose a mother. So . . . I think that when it came down to . . . [becoming pregnant], no matter what my spiritual attitude is toward it, I guess I would probably feel pretty guilty if I had a child, and the child was young and I died from cancer knowing when I conceived the child that there was that possibility.”

“Just the thought, because it’s not known and the possibility exists that it can shorten my life for this to recur. It’s not fair to my children . . . or to me. Being their mother, that’s more important than anything. . . . If the situation were to exist that I didn’t have children. . . . the answers would be different.”

“The idea of having and abandoning the child . . . would just be unthinkable to me. . . . I certainly didn’t want to bring into the world a child without a parent. . . . That to me is just too difficult for the child. Even if my need was so great to have the child.”


“I always worry about mets going to other parts of the body. I do worry, especially when I hear people dying from breast cancer. That hits me; I get really sad.”

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dissertation). The University of New Brunswick, Canada.

“I mean I didn’t mind losing the breast. That wasn’t the thing. I think the thing was, um (pauses), the worry. Knowing that I had had cancer and then I like, it’s always on your mind, the back of your mind, any little thing that goes wrong. And um, now this is my, I had a biopsy yesterday and that’s my third biopsy. Luckily, two of them were fine. This one is 99 per cent okay. And, uh, so I won’t know until next week... I am thinking more about it today and this last couple of weeks because of this biopsy I just had. You know I think this has worried me a bit because I got so I could relax and not think about it and all of a sudden this came up. I thought I could go the whole summer without having to have an appointment for a change with a doctor and this came up. So, you know, I’m sure I will be all right... we’ll hope it’s just the inflammation.”

“Um, it bothers me at times, but if I’m busy, I don’t think about it. It’s when it’s fairly quiet and there’s nothing for me to do. Sometimes I will think about it, but it doesn’t stay with me very long because I just tell myself I’m not going to worry about it. If it happens, it happens. Deal with it then.”

“I chose the mastectomy because I was afraid to leave it. Anything there that could bring back the cancer.”

“It was a hard go at first. The morning I went into the hospital, my husband was there and my daughter and I can remember going into the operating room and when I came out, they were there. And it was almost like this peace came over me. It was like, “Gee I made it. I’m not dead.” And that’s your first thought, is you’re gonna die... I find that I don’t dwell on it, but if I have an appointment with the doctor or something, that’s when I think about it. I don’t dwell on it. I live every day to the fullest, or I try to. And I found I learned to live one day at a time and try to enjoy it, because you just never know.”

“I do take tamoxifen and I’m on that until December. It will be five years in December since I’ve been taking that and they suggested I take it just for five years. I’ve been doing a lot of thinking about that actually because it seems when you’re on... when you’re taking something like that,
the only reason that I’m taking it, is that I feel inside like that’s helping me and when December comes and I’m not on it, it’s going to be like, gee, I’m on my own now completely. And I found that too with the chemo. When I was on the chemo, like I was very, very fortunate with my chemo. I did not lose my hair. I wasn’t sick. I didn’t always feel exactly like myself. I was tired and stuff like that, but I wasn’t throw up sick at all and I was very fortunate. And the very last treatment on my chemo was scary for me because I thought, "I’m on my own.” And it’s the same way with these pills. I have that on my mind now and it’s not even December. It’s like I’m gonna be on my own. And the prescription — I just got the prescription refilled and that is probably going to do me right up until December and then that’s it. So you know, I think that you still always live with that fear.”

“One of the biggest fears I always had of course was that it would recur. When I would go for the yearly mammograms, I would be so fearful, I would have to have my husband come with me to receive any negative reports or whatever. After five years, I felt confident enough to go and listen to the reports the doctor had to give. It’s sixteen years now and you feel if you do have a recurrence, it’s obviously not from the initial one.”

All the time (think about the possibility of a recurrence). And I think if any cancer patient told you they didn’t, they’d be lying.

“I do like keep a closer watch on the other breast now and I’m very, you know I can get very paranoid. If there’s a tiny lump, I’m right there to the doctor.”

“I guess that I would say that before I had breast cancer I never really thought about my body that much uhm. now I guess I know it’s something that can betray you without you even knowing what’s going on. Because there were no symptoms, there was no feeling ill or pain or any problem then all of a sudden there’s something just there. I think it makes you a little more stressful. What’s it going to do next? Not only what’s it going to do next but there’s probably nothing I can do to stop it if it decides it’s going to spread. I think it makes you a little more, are you going to get something else? It also makes you, before if I had an ache or a pain somewhere I’d say, “Oh I just pulled something.” Now when you have it, you
think all sorts of other thoughts so if there’s pain somewhere you think, “What’s happening here?” or “Why is this doing that?” It’s sort of like when I was on a business trip, when my hand swelled, if I’d never had breast cancer, I’d just think, “It’s hot” or “I pulled something,” and it’s fine. But you start to think other things so I think, probably I’d say that I don’t trust my body as much as I used to.

“It’s always there in the back of your mind, like I have to go twice a year, once in Saint John and once to the surgeon and the night before I go to Saint John, I’m always nerved up, that whole week before. I’m always nerved up because you always think, “Okay, are they going to find something?” They never do. I guess you just have to have faith. But it does get hard because it’s always there in the back of your mind, always. You might not even realize it’s there but find a lump and it’s right there, you think, “Oh no, not this again.” But you live with it.”

(fear of recurrence is) “with you 24 hours a day. It never leaves.”

don’t know maybe I’m a lot more inquisitive now trying to see what the future holds for me, I don’t worry about it, but I am very aware, let’s say, that it has happened and can happen. So therefore enjoy every day that you have that you feel well. And basically I do feel well. But like you’d go to the oncologist and he’s sitting there, that’s something I’d never experienced. To go visit the oncologist, you have to go to the oncology clinic. While you’re sitting there waiting for your appointment there’s people there with no hair and there’s people there very frail and it’s, you know, you’re aware that could happen. That could happen to anybody but I’d never considered it could happen to me before so that’s a little different.”

“think about it... think about it coming back, whether I’ll have breast cancer, bone cancer or what. Not necessarily that I’ll get it again, but you never know.”

“I’m prepared to make some accommodation and I do...I try to eat healthier...I did lose the weight that I gained and I do try to eat healthier and make sure I don’t get overtired which is always easy to say, but not easy to do. I changed my work habits a little. What I won’t change is certain
other lifestyle issues people talk about. We like to entertain so we do that fairly frequently and entertaining doesn’t have to involve alcohol, but I like to have a drink...Some of the research says probably you shouldn’t be consuming alcohol. So far I haven’t made that choice... I guess you are responsible for your own body to some extent, but I guess when I said I’m not prepared to make those lifestyle changes, I work hard, if that’s what I like for enjoyment, that’s what I’ll do.”


The scans “don’t phase me.”

One patient referred to the experience as “scan-itis.”

One participant stated that they are “terrorizing”: most felt that the scans are “a big thing.” The time between having the scan and receiving results is particularly difficult and was described as “whole other kind of fear.”

“I have a lease on life for one year and I can start all over again.” Therefore, scans are a double-edged sword. “They are fine ’cause they tell the doctor if there’s anything wrong with me, but as far as the experience I really hate it.”

“Even if you know that the statistics are in your favor, and you know that you’re feeling all right, you still have a huge amount of anxiety that goes away, oddly enough, it goes away immediately when you hear that it’s fine. It’s a complete relief.”
The scans can be a reminder of the cancer. "The week leading up to it is very nerve-racking, and it’s a lot of the thoughts that I had when I was first diagnosed start to come back. Once it’s over, a sense of relief."


“I’m concerned that the breast cancer might come back. But that will make me go more to get the care. But at the same time, you know, I try to be mindful that it’s not a journey that I would want to go on again because the second time around is definitely going to be worse than the first time. So, you know, I do try to do what's necessary, in order to avoid that experience again.”

“And sometimes some of them are scared to talk about their breast and some of them are fearful to go [for followup care] because they don’t, like, if they had it [breast cancer] before they don’t want to think they might have it again so they don’t go, and things like that.”

“I think also some people do want it to be over and you can bring some sort of finality to it if you are not seeing the same people as you did before.”


“It never goes away. You get on with your life and you have to deal with it but there’s no guarantee; there can’t be.”
"I always think about it coming back, I think about that all the time. I had backache about 6 months ago. The doctor gave me an x-ray just in case it spread. But it hadn’t. But that’s the first thing you think. I suppose that’s what it’s gonna be like for the rest of your life."

"If I get like a pain somewhere else I’m like ‘oh my god has it shifted?’"

"I do worry a little bit about August because I thought ‘oh God, it’ll be my luck you know. I thought I might change it to September because we’d like to do something for Ben’s birthday but I thought ‘ooh you might regret it if you postpone it’"

"At one time I couldn’t book a holiday or book something months in advance, cus that frightened me. I couldn’t look forward to something I might not be able to enjoy. That’s gone now. I just think ‘oh sod it! If I can’t go, I can’t go? I [laughs]

"It’s in the papers all the time, somebody that’s got it or recovering from it and I find that quite difficult to cope with. And it’s good, because it makes people aware of it, but it isn’t always good for everybody. It’s just reading about things ‘thought she’d got over it’ you know ‘its 5 years then a month later she drops dead’. Those sort of things really bug me. They really sort of eat into you somehow.”


"When I have a little ache and pain I want something done about it but I think sometimes yeah it’s kind of like it’s ok—don’t worry about it too. But then I do anyways."

"I call it waiting for the other shoe to drop."
“The ache and pain that I have—like my thumb getting locked—I think, ‘Oh my God—cancer of the bone’. You think that every single day.”

“You never stop worrying about it ... if you’ve got it—it is a living nightmare.”

“You just have that uncertainty. Ok my treatment is over with, now what? What’s going to prevent the breast cancer from coming back?”


“We are so wary of abnormal symptoms even [if we only have] a little uncomfortable feeling or a little pain, we will go and get it checked immediately out of fear of the cancer returning.”

“People are strange, aren’t they? [I have a] hospital checkup once a year. If I am going to get my blood tests tomorrow, today I am panicking and nervous for no reason. Actually, there is no need to be nervous, is there? I have lasted nine years since diagnosis. I am not sad if I die now. But I still get very nervous. When I eventually see the blood test report, I think] oh, thank god, it’s ok.”

“As soon as I feel pain somewhere, I think it’s the cancer coming back and I’m scared. When this happens, another cancer survivor telling me ‘it’s okay, don’t worry’, would be such a great comfort and I wouldn’t feel scared any more. If not [if there’s no other cancer survivor to reassure me], I just can’t stop thinking about it [the pain] and the pain just gets worse and [I worry even more that] the cancer has come back.”