



### **Interview Transcript: Sandra**

Sandra works for the federal government as a Research Assistant in Strategic Planning. She is married and is a mother and grandmother.

Type of Cancer: Breast Cancer

Age at Diagnosis: 34

Year of Diagnosis: 1991

Treatment: Bilateral Mastectomy, Total Hysterectomy, Chemotherapy, Radiation Therapy and Breast Reconstruction

Date of Interview: March 2010

My name is Sandra Henikew and I was diagnosed with breast cancer when I was 34 years old. I had bilateral mastectomy and I've also had an oophorectomy and a hysterectomy. I was also tested and found to have a genetic mutation, the BRCA1 gene. My mother died of cancer when she was 30, her sister died of breast cancer in 2003. Her other sister is currently dying of cancer right now. My two sisters, myself, there's just so many that my brain is ticking and going through my family tree because there isn't a generation of our family where cancer hasn't touched it. So it's like my cousin Cancer, that family member that you don't want to invite to family functions but they come anyway. And they stay late. That's what it's like in my family.

We've just... there's just so many of us that I feel almost numb to it. When I hear now that somebody else has been diagnosed with it, I feel—at first I feel that the shock of it—and I cry like everybody does. I think with all of us that have been diagnosed it's become such a common thing that it's almost not as devastating when you hear now that somebody has cancer. Because we're seeing more of us living longer with it, so more of us are living than those of us that are dying, so it's... yeah. It's crap, but that's life in our lane.

#### **Waiting**

Out of the whole... everything that I've been through, the waiting was the hardest thing, that I had to wait and wait, because I felt every second of the day. The day didn't fly by and there was never a moment where it wasn't on my mind or on my heart. I carried in my heart the knowledge that my mother had died of cancer and left four children behind. I had four children. I was young, she was young. The whole time I just thought I was going to die and the longer that they waited to take it out, it just was driving me insane. I would just burst into tears for what seemed like no reason.

My head wouldn't shut up. My brain just kept going and I thought I'd get relief at sleep time. And it was so hard to sleep, and then I'd dream about it and it's been 10 years of waking up every day and thinking about cancer, because I do. When I get dressed I'm reminded and...

but I have a really great love of life. If cancer's done anything, I'd thank it for making me appreciate my life and what's important. My children, my family and making good memories. And it took a knock on my head like cancer for me to feel this great joy of my life.

### **Let people in**

I withdrew from my children completely because I believed that I was going to die. So I prepared, I thought I was preparing them for a life without me. So I didn't include them in any part of my healing journey. I thought I was protecting them. That was the biggest mistake that I made by not allowing them to be a part of it, to help me through it. For them too, because the disease doesn't just hit the patient, it's your family and your friends, and they feel it. I know now. I hope I never have to do that again, but I know now that to let other people know, share it with your family. It's a horrible thing to go through and if you have support then you should lean on them to help you.

### **The surgery**

Once I absorbed the information, I told him that I wanted to have both breasts removed. Although the cancer was only in my left breast I wanted to have them both taken. So, we decided that that's what we would do and from that I chose to have implants, and then it was the final surgery, which was reconstruction of nipples. Because they had to remove all of the tissue, as much as they could, they couldn't save my natural nipples and reattach them. So we made manmade nipples from skin on the side, right under my arms. And that was very difficult, very difficult thing. I would say to any woman that's going to consider that surgery to make sure that you and your surgeon are on the same page, that you understand exactly what's going to be done before he puts you to sleep. Because my definition of a nipple and the surgeon's definition of a nipple, they were different. So, I had to accept some really, what I thought was really... I could say like Frankenstein porno movie or something; they sewed on this great big piece that I wasn't expecting.

### **Looking for normal**

Yeah, it's like looking for normal again. Will my life ever be normal again? I'd never had that opportunity, there wasn't a point where I could just pause and allow this to happen, to just sit back and relax, because at the time I was a single mom. I had the four girls. I was the only person at that time bringing food on the table, paying the rent, so although I was sick, I still needed to work. I was... I had to drop out of university. A good thing was that I was just doing some freelance writing at the time so I was able to maintain that. I don't think I've ever really come back to normal but now I'm at the point where I'm looking back and seeing... "Man, that was a big bump in the road but I'm OK. I'm here and we're looking forward and if cancer comes back, I'll deal with it then." But I'm not afraid of it. I'm not afraid of it. Everybody will die at some point in time. But it's not about how I die, it's about how I live my life. And that's what I'm doing. I'm living my life. I give no more power to cancer. It took enough from me.

### **Advocate**

I've sacrificed my right breast and my ovaries and my uterus but that's OK... but that's OK, I'm still a woman, I'm still here. I get to be a Coco, a grandmother. I've been gifted with five grandchildren since my diagnosis so I'm very, very thankful that I had the surgery, that I knew enough to go see my doctor, to ask questions and not just accept the things that they say. When you know that something is wrong with your body and you've brought it up with your physician, if you're not happy with what he said to you, or she said to you, go see another

doctor until you feel comfortable. And that's easy for us to say when we stay in the city. So, always trying to keep in mind that the aboriginal people that live in isolated communities, that they're not participating because they can't. Not because they don't want to but because they can't.

### **The power of many voices**

I'm an aboriginal woman and trying to deal with the social disparities that a lot of aboriginal people face. The geographic isolation. Why is it that they're not participating in screening? They're not so willing to talk about cancer, particularly when it becomes cancers in the breast or your ovaries, your uterus. There is a lot of misinformation and a belief that cancer is a death sentence. So it's not talked about and those people that have been diagnosed, a lot of them have kept it to themselves so they've suffered alone.

We're at the point right now where we just need to talk about it, to be able to sit down with each other and talk about it. I just feel like the more people that can stand up and say, "Yeah," that's when things get heard. One little voice doesn't get heard often but thousands of voices, they get heard. So—and my hope is that I can get thousands of aboriginal people to bring the power of their voice, the power in numbers and strength in numbers, and let's do something. Let's do something about the cancer in our communities. Let's help those people, because we can.

### **Warrior**

I don't call myself a survivor. I call myself a breast cancer warrior because I'm still fighting, knowing that you have a genetic mutant. Even finding out that it was a mutant was funny, but, you know, it's a gene mutation that I have no control over. But just knowing that I have that—it weighs on you. I have four daughters so I feel the weight of that and now I have a beautiful granddaughter. So I know that this journey is still going to happen. Cancer, it will come back. But that's all right, we'll fight. We'll fight it. And when we're done here on this earth, there'll be something left for aboriginal people and I hope that the people listening, the aboriginal people listening and those nonaboriginals too, will be supportive of this initiative trying to engage the aboriginal communities and survivors too to bring some hope and joy to those people that are listening and watching.