



Interview Transcript: Janet

At the time of the interview Janet was an artist and a mother of two young boys. Janet passed away in November 2011.

Type of Cancer: Metastatic Breast Cancer

Age at Diagnosis: 40

Year of Diagnosis: 2001

Treatment: Mastectomy, Chemotherapy and Radiation

Therapy Date of Interview: June 2009

My name is Janet Belray. I'm 44 years old. I was first diagnosed with breast cancer—I had just turned 40 and had just given birth to my second child. I was diagnosed with Stage 3A invasive ductal carcinoma. I had six positive lymph nodes, and I started my journey.

Talking about your illness

I think that a lot of people must have the experience of—you know, it's so crushing, especially at the beginning, or having a setback, that having to re-tell your story many times can be difficult. I had a great sort of relay system going with family, with friends. For me it was OK to let a family member or a friend inform other family or friends. That worked for me because there are times which are really private and just wanting to just sit there and hug your kids. So I think that's a good strategy sometimes. Letting people help you disseminate information about yourself is totally acceptable and I think people really do understand.

I feel so lucky I have so much love and support in my life; I'm just so grateful. Sometimes I want to talk to everyone individually, but the whole process of going through treatment is time consuming so it leaves less time for family and friends. I do have to resort sometimes to sending out mass emails but I've heard from people that they really do understand and that they're happy to hear from me.

Honesty is the best policy

As a parent our instinct tends to be, "OK, let's protect our children. This is too heavy for them; let's pretend that this isn't happening." In fact, studies have shown it's the complete opposite. The more information that you can give to your children, the more real you can be with them, the less fear and anxiety that they have because they know you—they're going to understand hushed tones on the phone, even perhaps jump to a worse conclusion and perhaps even blame themselves for something that's going on. We've sought out counselling for our kids in combination with that so that we can really help them through their grieving. Things have changed, definitely, knowing that now my breast cancer is considered terminal. That's something that moved us into a new stage of being honest with the kids.

But kids are really good at balancing opposite ideas. They can understand the reality of the situation: OK, they know that Mommy has cancer they know that the doctors say that Mommy's going to die. But they can understand that—but they can actually hope for something different and they can balance those ideas at the same time even better than an adult can. So I've actually learned a lot from my kids in that regard. They can process something quite seriously and then when it becomes too much for them, they go off and play, and that's a good thing kids are able to do that. So I would definitely advise to be open and honest with your kids.

Be involved

I ended up doing a lot of research myself; that's kind of one of my coping mechanisms. I like to understand my options, my treatments. I do a lot of research, I use the Internet a lot and it worked for me. I think having just a sense of involvement in my own care was—it has and continues to be hugely important to me. As I say, some people want to just put all their faith in their doctor, and that's good too for some people. I just haven't ever been like that. But I do have great doctors and I'm very grateful for their advice. I would say that if you're the type of person that likes to be involved, I would say absolutely do all the research you can, understand all your options, really trust your instincts.

If I had to do it all over again

I think, looking back, I would have even been a stronger advocate for myself and I would have let my voice be heard even more. There were certain times where I went back and forth a little bit with my doctors on research I had found... They give their opinion. At the beginning there were a few issues that I sort of dropped. I thought, "I've got to trust these guys. I want to develop a good relationship with them." In hindsight I wish I hadn't dropped a couple of those issues. But because you don't want to be labelled like a difficult patient... There is this huge expectation to do what you're told, in a sense. But you know what, if my only risk is pissing off my doctor, that's kind of small in comparison to just being here for my kids. Now I really, really make sure that I've got a second, third opinion, that I've done my own research, that I feel comfortable with what I'm going to do. I mean, there's still a certain amount of not knowing and you have to accept that, for sure, but I would definitely be an even stronger advocate myself.

Something else that I would change if I had to do it all over again: I would say on an emotional level I would just take a little bit more time for myself. I think as a mom, I sometimes have a hard time just really carving out time for myself. But I think in the end, kids benefit from a mom taking care of herself and that was a good lesson for me to learn throughout this. I think in the long run that you can give more if you take care of yourself as well on an emotional, spiritual, physical, whatever level, all the levels.

Finding hope

Sometimes I don't know where the strength comes from. For sure you find, tap into, places in your own self—there's resources there you never even knew you had. Certainly in the world of metastatic breast cancer there have been a lot of disappointments and I'm sure there will be more. I have and continue to live with an amazing amount of hope that in huge part comes from my amazing family and friends. And I think as a mother there's also an incredible personal drive to just be here for as long as I can for my kids. It is not always easy. It is OK to be upset about what's going on. It really does just plain suck sometimes to be going through this. But to still—to

live with as much hope as possible and... that has really helped me.

Studies have shown that having a positive attitude doesn't actually give you a survival benefit for cancer but it's not something that you still wouldn't want to strive for. I had a beautiful home filled with love before my diagnosis. I just want that to continue and have as much love and happiness in my life now for my whole family. So definitely just wanting to maintain a certain amount of normalcy in my life, I think somehow that's where the strength to get through each treatment comes from.