

## **My story, embarrassed to death**

This year, it is estimated approximately 25,000 women will be newly diagnosed with breast cancer. Of that number, approximately 10% will, having just received their initial diagnosis of breast cancer, also receive the news that their cancer is incurable. Their cancer will have already spread from their breast to distant organs, and hence they will be diagnosed with metastatic, or stage IV, breast cancer.

So, 2,500. That's not too many, right?

Who are these 2,500 women? How did they get to be metastatic before they even knew they had cancer?

Some are women who had regularly scheduled mammograms, and the cancer was there but unfortunately could not be detected. Sadly, that happens. Some are very young women who have no reason to ever suspect they would have cancer at their age, and with no family history, they do not fit the risk criteria for screening. They don't have access to mammograms. Sadly, this also happens. Then we have women from different socio-economic backgrounds who may not even have a place to live, never mind a health care card. They don't have the resources to get annual mammograms. Sadly too, that happens. Then there are women from ethnic and cultural backgrounds where there can be trust issues with the medical system, and they either don't know this screening tool is available, or they feel they cannot access it. Very sadly this also happens.

Then there are women who are well educated, articulate, intelligent, have a good support system and lots of resources, but they choose not to have a mammogram. Yes, they choose not to, even though they are in a high-risk group and are entitled to access screening programs. They choose not to go.

I know, because I am one of those women.

When this happened to me, at first there was shock, and then deep shame. I felt so stupid, because at 61, here I was having my first mammogram, and already I was metastatic. If only I had gone regularly, from age 50, I could have found this cancer early. I could have. I could have been cured, and moving towards a happy retirement with my family around me. But that would not be in the cards for me, and it was down to my own decision.

I would have taken my secret, and my shame, to my grave but I started to wonder if I was the only one. I started talking to other women and found out, I really am not the only one who actually makes this decision to not have a mammogram. And that is truly perhaps the very saddest happening of all.

I cannot tell my story without talking about why I made the decision to not go for a mammogram. For a long time, I would not talk about why I didn't do it, other than to say I just thought it would never happen to me. I felt I looked after my health (though I

didn't really), there was no family history of breast cancer, AND I did regular breast self exams. I was SAFE.

When I ask other women why they also make this decision, the answer is similar to mine. They either don't want to know, or they think they are safe. The only thing I question, and it's just really my intuition, is that what they say is not really the reason they won't do it. For some of us, the decision to have a mammogram is a complex, very personal and extremely emotional decision. And although I would not say everyone has the same reasons as I do, I think some might.

Because there are others like me, I knew I could not keep my secret to myself. I have to speak out. Although I have an incurable cancer, I am still quite lucky because I have access to some very good drugs that are giving me a good quality of life right now, and perhaps also some longevity. I have the gift of days. Every day I get is a day I did not know I would have four years ago. And for that, I am grateful. But the gift of days comes at a great cost, and so, I must give back.

So, why would I not go for a mammogram? Why would I ignore a simple procedure that could save my life? I said I felt safe, but that was really just me convincing myself I was safe.

The real reason was that I was embarrassed. I had hated my large breasts all my life. I was ashamed of them. There was no way I was going to drop these lumps of fat onto a hard surface and have someone squeeze them flat. It just would never happen and in fact, I convinced myself, it did not have to happen because I was safe. Yes, I knew I would probably have a heart attack or a stroke, but I would not have cancer.

My hate affair with my breasts had started when I was very young. Developing much faster than my friends, I remember the giggles from the other girls in the change room, and my friends parents commenting to my mother on my "progress" (why they felt they had to, I don't know). Then in senior high school, already very large breasted, I found a love of running. It was one of the few physical activities I was good at. I had long legs and strong lungs and was one of the best distance runners in my class. I could even out run a lot of the boys. But one day, my last day of running actually, a group of boys ran past me and called back, "Watch you don't hit yourself with those", and "Yeah, more than a handful is too much". Overwhelmed with shame, it was the last day I ever ran.

Years later, as a young women in my mid 20s, I found what I thought was a lump in my breast. We were all doing breast self exam then, as mammograms were not yet used for screening tools. If you found something, you went immediately to your doctor, which I would do. But I remember this one time, having to see a new doctor whom I was sure was even younger than me. I was mortified, but then to add to my shame, after the exam he announced that my breasts had a lot of fat and I would have to learn to distinguish fat from a lump. (do you think?). I felt so stupid, and so ashamed of my fat breasts. That was the last time I ever would talk to a doctor about a lump in my breast. If I found

them, and I did, I would just live with them. Sometimes they would go away, and sometimes not, but they never were cancer.

Years later still, when I was in my early 30's, I had older friends who were going for mammograms. I remember one friend, who was also large breasted, telling her humiliating story of having gone for the exam and the technician, a man, (yes! this was many years ago) had laughed at her. Well probably not laughing at her, but laughing nervously as she had tried to manoeuvre her large breast into position. As she told us her story, once again the shame came over me and even though that did not even happen to me, I knew then that I would NEVER EVER do that to myself. And I didn't. Not for years.

I eventually hated my breasts so much I would cry when I did my self exam. I used to wonder why God would hate me so much to put these large lumps of fat on my chest. I could do nothing to get rid of them, it seemed. I even bolstered my courage (it took years) and went to see a surgeon about breast reduction. He took one look and advised me that my breasts were not large enough to warrant the surgery. I cried, and it was the last time I would even talk to a doctor about my breasts. In fact, shortly after that I think I just stopped going to see a doctor for regular checkups altogether.

So, as I moved into my fifties, and into the breast cancer high-risk category, no amount of "targeting" or advertising by cancer care groups could reach me and change my decision. Friends might from time to time ask me about mammograms, or they would talk of how cancer had touched their family, but somehow, I was able to remove myself from this and keep my illusion that I was safe. I never again would think of how much my hate affair with my breasts had influenced my decision. I would never speak of this to anyone. I would just say I knew I was safe.

And truly, I would have gone to my grave with this, but now I know there are other women like me who make this decision about not going for a mammogram. They usually practice self exam, as I did, so I have to tell them that self exam is ok, if it's all you have. But often, by the time you find a lump, or realize it's a lump, it's too late.

That was the case for me. In all my years of finding strange lumps, which came and went, THE LUMP OF ALL LUMPS, did not even feel like a lump at first. In fact, it wasn't even in my breast, but under the arm. It was just a very strange and painful swelling, with no lump that I could feel. No lump, no fat, just strange sore swelling, and nothing in my breast. It really is that difficult to find, and diagnose a lump as cancer. Even specialists cannot always diagnose cancer from the feel of a lump, so why would we even begin to think we could.

No matter what our reasons are for thinking we could be safe by choosing self exam, we aren't. It's just that hard to find a lump. Even if you actually found a lump, and knew it was a lump, or you noticed a change in the way your breasts feel, at that point you would still have to have the mammogram, or another diagnostic procedure, to find out if its cancer. Yes, you will still have to take out that breast and squeeze it flat anyway.

Thus, whatever your real reason is for not having that mammogram, its quite likely that you will not get through this life without having to do it at some point in time. I know your reasons may not be the same as mine, and I know they are still deeply charged with emotion and no less complex or personal than mine, but regardless, at some point you really may have to do it anyway.

And I want women to know, that when the day finally came that I went to my first mammogram, it really was not at all like I thought it would be. I sat in the change area, crying, scared, embarrassed, and angry at myself for crying. I sat there inside that curtained change area until they called for me, so I could hide and no one would know I had been crying. The young technician who took me in to the exam room knew immediately how scared I was, and with wisdom well beyond her young years, treated me with such respect, kindness and compassion, that she calmed my fears and I stopped shaking. She spoke to me of her mother's difficulty coming for her mammogram screening. What a gifted and insightful young woman she is. No words or actions of frustration as she tried to manoeuvre my breasts and underarm into position for the scan, but only patience, compassion and gentleness. For the first time in years I had shown my breasts to a stranger and did not feel ashamed.

But, the reality is, if I were to have read this article 7 years ago, about the time my cancer had started to grow, **it would not have changed my mind** and made me go for screening. I would not have listened to 'me' 7 years ago, as I was so entrenched in my belief that I was safe. I wonder if any woman who reads this, having already made the decision to not have a mammogram, would change her mind as a result.

And yet still I choose to speak out about myself, because I do hope that someone would rethink her decision to not have a mammogram, even just one woman. If you have made a decision to never have a mammogram, and you are reading this and maybe rethinking your decision, if would like to reach out to me, you can contact me through Dense Breasts Canada.

And I promise you this, **I will not judge you**. I will listen to you. I will not try to make you change your mind, though I hope you will. I will not trivialize your reasons. I know, and respect, how difficult the decision is for you. But if you do change your mind, and you want help, I will help.

If you are reading this article, and you are "ME", and you will not change your mind to have that mammogram, I ask you one thing. Reach deep inside yourself and find the real reason you won't go. Ask yourself why don't you want to know if you have cancer. If you believe you are safe and will never get cancer, then ask yourself why you won't face a mammogram to hear your foregone conclusion that in fact you don't. What is the real reason you will not access screening? When you are certain you know the answer, then ask one more question. Ask yourself, "Is my life worth more than the cost of facing my own fears?"

For me, I think if I had realized that my real reason for not accessing screening was the embarrassment I felt at the size of my breasts, instead of just stating that I knew I was safe, I may have seen my own denial. Perhaps I would have realized that my life was worth more than the embarrassment I feared. I know its sounds trivial, but I assure it was not. Again, I say that a woman who makes the decision to not have a mammogram does not do so lightly and it is often an extremely complex and emotionally charged decision.

Finally, I also wonder if the women I want to speak to will probably not even read this article. Hence in closing, I leave you all with these thoughts.

Of all the regrets I have, the only one that haunts me still is that when I made that decision so many years ago, **THAT I WOULD NEVER HAVE A MAMMOGRAM**, it was at that moment that I stole hope from my children and my husband.

I could not even have imagined at that moment so long ago, my decision would hurt a man I now love deeply, yet had not even met then; it would steal hope from children that had not even been conceived; and it would come back to haunt me at a time when I had everything to lose. I am fortunate that my children and my husband have never asked me why I did not get a mammogram because I don't think I could bear it if my family said, "Why did not care enough about us to do this?"

A few years ago, I was asked by someone from the Canadian Cancer Society, "How could we have gotten this message of the importance of mammogram screening to you? What could we have said that would change your mind?"

I don't think it was the "message". It's not **WHAT** they could have said, that I would have listened to and changed my mind. Maybe for me, and others like me, it is **WHO** delivers the message. For surely if one of my sons had asked me 7 years ago, "Mom, why won't you go?" Or my husband had said, "Please go for me." I don't think I could have said no.

So, to all the daughters, sons, husbands, daughter in laws, sisters, brothers, all of you who know and love a woman who falls into the breast cancer high risk group (over 50 years of age), **IF YOU DON'T KNOW FOR A FACT** that the person you love has a regular mammogram screening, you need to ask them. You need to ask, "Do you go?"

And if the answer is no, accept that you might not be able to change their mind, but you need to remind them over and over again that you love them. Ask them, if they won't do it for themselves, will they do it for you.

You don't want to lose them.

You don't want them to become me.