# Loneliness in CancerLand

What I wish you knew about being a survivor, part 1

September 10, 2018 By Lisa Vento Nielsen

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Part 1 is what I wish you knew about how I experience the disease; part 2 is about what I wish I could teach you — the “good” that I learned… watch this space for more.

I have lots of friends…

I have lots of acquaintances…

I have folks I love fiercely…

I have folks I fight with fiercely…

I’m a mom balancing 2 kids one husband a puppy 3 businesses and a house and all that entails — I guess I can stop at “wife and mom” because we ALL know that means

- Laundry
- Cleaning
- Cooking
- Lunch bags
- Homework duty
- Studying duty

Wellll, you get the idea.

Sometimes I get lonely. I have survivor friends from literalllly all over the world — someone from Guatemala (hi, Misch), someone in Ireland (love my Ro), someone in Florida (Amberrrrr) and even Queens (Vicky and Irene)… and the list goes on like Ohio Kelsey and if I forgot you know I love you xoxo

Local I have some amazing people too (Deb and Deb, Colleen, Gerri) …

And then I have the mom club — the folks I love so much who I trust with my kids to do anything go anyplace but who sometimes I can get paranoid and think omg they don't get me…

Or why did I joke like that about having one boob and that's why I didn't help my son with his homework more…

Or they don't "like me…" And honestly, I am used to people not liking me. I spent a decade and change just being super focused on my home life only and not interested in being a good friend or being a well-rounded person…and even now, I am ok with it BUT I know I need these folks and I like to think that maybe, they need me, too.

I am still the girl I used to be awkward and unsure of myself in social situations and unclear how to make and keep friends lol. Sad but true.

Now more than ever I need friends -and I do think I add value and can help others, even those who have never been told, "you have cancer."

And I'm so lucky for the ones that I know put up with me and my idiosyncrasies and the fact that sometimes I feel there are two camps of people who make up my social circle.

Those who think I should be over it and maybe think I use it as an excuse for everything I do wrong or that I should stop talking about it because obviously I'm "fine…" I know the gossip train always goes around the station and I'm guilty of jumping on it too at times — though less now — I just don't have the time. But I think there is not enough education about what cancer and it's continued treatments entail for anyone who is unlucky enough to get this disease so consider this my crash course for those of you in this camp… (The other camp is below…)

I never complain.

That is one thing I will boast about — I just have never been a complainer. It doesn't help me it doesn't make anyone get it and to me it's wasted energy but if I were to complain this is what I would tell you, my friends, who God willing will never "get it."

1. I often have pain in my right side it comes and goes it is from the tightness of the mastectomy operation they took all of my skin and cut it out then pulled it super tight and thankfully left me flat, as per my request (some women are left with "dog ears" or extra skin despite asking to be left flat — this is horrendous and I will write more about it at a future time). My right shoulder hurts on and off from the weight distribution being off between left and right side.

2. I am in menopause which means my whole body is off. I should have continued my periods until about 56 (going by my mom) — instead mine stopped at 40 via medical acts to turn it off — so nothing natural here. My cancer was hormone positive which means the cancer was fed by my hormones of progesterone and estrogen. I am now stripped of these hormones which actually do many things for our bodies that most of us take for granted despite hating the monthly "curse." First and foremost is sleep. Sleep is a thing of the past for me — in order for me to fall asleep I

have to run 5 miles, unwind for 3 hours, take a sleeping pill or an Ativan and lay down and keep my fingers crossed it works. With 2 kids who come in and out the slightest upset from them and I'm up and can't sleep. Period.

Then there's the whole my body no longer has moisture and I get a lot of issues around skin that rubs together and enough said on that but you will often find me with a hot pack on my crotch…

Also, weight is a big issue — hormones are stored in fat so I MUST keep my weight and belly fat as low as possible, which for a carb-loving, junk food junkie, has been a hard thing for me as I now am a "skinny bitch" at 128-132 pounds to best help my ability to NOT have the cancer come back (which, ultimately, no one knows if it will help anyway but it is considered a good thing to do, so I do it, I would do anything to be "healthy" and die of something other than cancer).

3. fear of recurrence or spread — this is a big one but I'm not letting it be number 1. No matter how much I smile and joke and be nuts (and maybe make you consider taking 3 steps away from me) there is no guarantee that I'm ok — let's face it there's no guarantee that any of us are ok but I see the dichotomy a lot clearer now — you can worry about anything you can think hard about your problems and then — hopefully — sleep at night — I literally cannot. My problem is that cancer might spread or come back (God forbid).

No one who has had cancer is ever cured.

The word "cured" is a lie. Once cancer is in your body despite surgeries and chemo and radiation and all that if it can find a place if it can hide out enough it can get strong and come back.

Recurrence means it is back in the same location. Despite cutting off my breast and removing allllll of it and the skin and the tissue there could God forbid still be a piece of cancer there somewhere that wants to grow and since it was there before it knows how to do it.

Spreading of cancer though is worse — it would mean it floated elsewhere as it did get into my lymph nodes (5 out of 25) and therefore could have spread throughout the lymphatic system (hence the 8 round of chemo I did to hopefully kill it) — so if it were to spread again God forbid to any other organ it would be a death sentence for me. It would be metastatic and the stats on that are 3-5 years … let's see, my daughter would be 16 and son would be 13 — at the high end … see why I say God forbid a lot.

4. I chose to be on a clinical trial, which lowers my immune system and makes me susceptible to illnesses that would need to be checked in hospital. So I literally cannot get run down. If I run a fever I have to pack a bag and go to the hospital and be checked out and if I'm not cleared to be released I would have to stay for IV antibiotics.

5. The whole chemo brain is real and I really often cringe at what comes out of my mouth and how it might be perceived and how there are things now that go over my head in a whole new way — I always had no common sense but now it's so much worse. I try not to get too wrapped up in it because I often assume my real friends will get it and those who aren't real friends will just

consider it another weird thing about me — and that's ok — but I do occasionally worry about my real friends getting fed up with it.

6. I am consumed by my work — I am proud of it and want to share but don't know how and it causes me to be confused about how to act in some situations — what I do is to me meaningful work it makes my soul happy and yet it also means I live amongst cancer and disease and you know what, it's not easy but it's a big part of my life now to help others who are still fighting (though we are all fighting in our lives, even you my friends who never had cancer — may it always be so — we are all fighting battles we each know nothing about)…

And in conclusion, cancer is a world of crap and it puts pressure on everyone in your life — including you all my sweet lovely friends and I hope this post isn't going to alienate you or make you into the other camp of friends the ones who look at me constantly with pity and say "are you ok" multiple times per hour.

You're probably thinking, "Well, what does she expect after this post I just want to ask her if she's ok over and over again…" Or, "OMG get over it, Lee." — wherever you are on the spectrum, I love you. The middle ground, for all of us, is just to be kind — none of us know what battles the other is fighting.

I just happen to have a platform and an immense need to share to get it out so I do not keep it in and have even LESS sleep than normal…

You don't have to like me, you don't have to be my friend but just learn something about what it means to be a cancer "survivor" what it means to be a mom a small business owner a wife a daughter a sister and a friend who also has been faced down by something that if it could would erase my existence from this world.

And that's when I say it again fuck cancer!

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