

Trick or Treat

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October 31, 2018 By [Lisa Vento Nielsen](#)

It is Halloween and also the end of Breast Cancer Awareness Month (AKA Pinktober).

It was an off month for me — after a month or two of being “off,” I am feeling slightly stronger and ready for whatever tomorrow holds again. I have pulled back a bit from being so focused and instead have begun listening to my body and my heart and doing what I want to do to keep me happy instead of what I am expected to do or what I am “making” myself do. I am still focused on my nonprofit and my small business but I am not consumed with it. I am making myself learn the art of balance and also of putting myself first. A big way to do this is to decide to chuck my ovaries. Trick or Treat is definitely a bit of a trick for me!

I have hormone positive breast cancer. As far as I know, I am NED. It will be my second cancer anniversary in November (it feels like 8 or more years ago but it was only almost 2). I asked Sloan during one of my clinical trial appointments if I should consider getting my ovaries out. (Note: Instead of only seeing my medical team once every 6 months, I am here every 3 months with my oncology office and every 6 months with surgeon so I have not yet felt that off-the-cliff feeling of no more medical appointments most survivors go through).

As a hormone-positive breast cancer patient, I get Lupron shots to keep my ovaries off or asleep. These shots are 12 weeks apart (though there is also a monthly option) and the shot is administered at the hospital. Right before my next shot, I find my body going into PMS with cramps, pimples and just the feeling that my period is going to hit again any minute. And let's not talk about the after effects of the shot, always in my right butt cheek to keep the pain on the same side so I can sleep on my left — I laugh and suck it up but damn, that shot packs quite a punch and some weeks of don't touch my butt pain.

When I had first looked into removing my ovaries, my decision was to wait until the clinical trial (of Ibrance or the Pallas trial) was over (I am on cycle 16 of 24 cycles) but then I went to my yearly for my local gynecologist and got an ultrasound.

This was great but also amazingly scary — I stopped to think about how this was a great idea to know what is inside but also then I stopped and asked him, “Are you doing this because you think something is wrong or just as a precaution?” He assured me it was something he does for all of the women in menopause to check their organs. I should have had a monthly cycle until I was about

58 (going by my mom) and instead my cycle was stopped at 40 years old. The body wants to go back to “normal” yet my normal could kill me. (Note: This does not mean that removing my ovaries takes away the cancer recurrence / spread risk that all cancer patients deal with — some folks have one type of cancer, like hormone positive, and then it comes back as a different type of cancer, like maybe Her2 or triple negative, etc.)

I am so blessed that I have my children and that preserving my fertility is not something I need to do. Did I want to someday maybe have a third child? In theory maybe but not in reality. I have my hands full as it stands and when my hormone therapy ends in let’s say 10 years (as recent research shows more time on hormone meds is better than less), I will be (God willing) 49 and my kids will be 16 and 19 (God willing) — would I add to my family at that point? Not unless I lost my mind because come on, I would be a mom of high school- and college-aged kids — am I crazy?

During the ultrasound, 2 sebaceous cysts were found — one on each ovary — and I was assured they are fine, normal and nothing to worry about but my mind remembered my mammogram and ultrasound from April 2016 when slight calcification in my milk duct was found and my 3 specialists I met with all told me it was benign with a 98% chance of remaining benign and I realized that waiting to remove my ovaries might not be what I should do.

So yeah, I decided to chuck more body parts. I did not make the decision lightly but once I decided to move forward, it all fell into place. Today, instead of volunteering at my kids’ school for Halloween, I am at Sloan for my pre-op testing and meeting with the surgeon. Tuesday, November 6, is the day — not just Election Day, also the day I will remove my ovaries.

Sometimes I wonder if I am making the right choice but then I recognize that my ovaries have been rendered obsolete already and keeping them is a risk I do not want to take. For many years, I have had bloating, stomach upset and other common symptoms of ovarian cancer (which is dubbed a silent killer because there is no common test for it or testing regiment and the symptoms can be considered regular PMS-type symptoms) and I recognize I do not want to hazard any controllable risks in my life.

For me, getting the ovaries out is the best choice — but like all choices it has risks and though I am thrilled I made the decision to be as proactive as possible, I still ask for prayers and support as I go forward with this. I will learn more today about the recovery but from my Google search, it seems I will be unable to drive for a few weeks — which means, for a mom of two kids with crazy schedules, a VACATION — no?

Here’s to medical options and decision makings — may your Halloween be sweet & fun! XOXO Li