The Stage Is the Thing

March 13, 2018 By Lisa Vento Nielsen

If you are a breast cancer patient or know one or love one then you might know that there has recently been some new developments around how to stage breast cancer. I had heard of these changes a few months ago but did not have the courage or interest in looking it up—partly out of fear—whenever you google stage 3 cancer (go ahead, I will wait) you see things like "72 percent 5-year survival rate" and you can sit here and worry about which slot you fall into—the 72 or the 28… so I am very leery of googling anything as I think everyone with any kind of symptoms or illness is because you google and Dr. Google tells you, "That's not good."

When I heard about the new staging, I also heard that anyone who was already staged would not be re-staged but I am currently not sure if that is still the case. I was spurred on to look into what my new staging would be after seeing @mycancerchic's Instagram story where she recently presented for an organization (hey, anyone need a speaker in the tri-state area, check me out here) and while there met with a surgeon who had the "cheat sheet," so to speak, of staging. Anna found out she was now a 2A whereas she had been diagnosed at a higher stage. This got my thinking and moving so last night, I spent a few hours tracking down some resources.

Yes, a few hours. You see, the staging change is recent so a lot of information out there is still on the old information. Plus, I did not want to use just any link, I wanted it to be a trustworthy source.

I am sharing here what I found with instructions of how to re-stage yourself but remember, I am not a doctor so you should consider asking if this even makes sense to do for you and your health. I am a nosy wanna know it all so I had to check it.

I had to use my pathology report (readily accessible on my MyMSK app, but for other people might be in a folder you got at your pathology meeting and do not know where it is)… You need that report to figure out the new staging. I found that my "tumor" was a T3, meaning it was larger than 5cm (there is also a T4, I will get into that in a bit). I also had to see what my "N" rating was—this has to do with node involvement and for that I was N2A as I had 5 nodes out of 25 test positive for cancer.

At the time of my surgery, December 2016, this made me stage 3A. I knew, though, even then that if my tumor was 5cm (instead of 5.6cm) and if my node involvement was 4 instead of 5 that I would have been a lower stage. This was disheartening, especially because I was proactive and did yearly mammograms, had no lump, family history, etc and in April 2016 all I had were "microscopic calcifications" that had 98 to 99 percent chance of staying benign and my local

hospital had spoken about me probably being a stage 0 or 1. Then, bam, stage 3A, what's up. It is of course just a number and it is infinitely better than stage 3B, 3C or (God forbid) 4 but it was still shocking to have that out of nowhere happen to me. I got over it quick though and went back to smiling and dealing with it.

Now, though, with the new staging guidelines, my T3N2A GRADE 3 (highest grade, of course, just like in college this 4.0 only knows how to do the "best" but in this case, of course, it is the "WORST" as this means my cells were all kinds of fucked up) and with my ER/PR Positive, HER2 Negative information, I am stage 2B.

Not a big difference you think though as Stage 2 only has A and B but the 5 year survival stats for Stage 2 is 93 percent versus stage 3's 72 percent. That is a big fucking difference. Now, as most of you know, I live my life as though I am cured anyway so I do not get bogged down in the potential for disaster BUT of course I have my moments where it hits me that the clock could run out before I hit my last shots, before I get to see my kids grow up, before I am ready to say "OK, I have done it all and am ready to meet my maker." You know what I mean.

So this is a huge jump and of course, I know that with the re-staging I just did to myself, there is no medicine behind it—as in, I am not sure if I would ever officially be re-staged by my medical team or if this is even valid but in my heart it is something I just know to be true so who cares who confirms it?

So think about it if you re-stage yourself, it might not officially mean anything but it is interesting to see especially for those of us staged within the last few years—I mean, I was staged December 2016 and these new stages came out in December 2017 so it was real recent.

These are the resources I used—you need to go to Cancer.org to figure out what your T and N means given these new classifications and then take that information along with your cancer type (hormone, HER2, etc.) and Grade (1, 2 or 3) and then go to this Komen page and find your "new" stage.

So, what happened? Up or down? Again, please note that I am not a doctor and I do not play one on TV so if you need any help or have questions about what this staging means, ask your doctors and expect them to say it might not apply to you as you were staged before the change.

Thanks!! This is what I do in the time between…

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