N.E.D. versus Cancer-free

January 22, 2018 By Dan Zeller

My current predicament of a post-surgery increasing PSA has me reflecting on terminology that I see used in discussions about prostate cancer, and some of it has been downright annoying to me. (Perhaps it's annoying because I'm now 60 and can claim official curmudgeon status.)

But, if I'm being honest, I'm probably more annoyed with myself than with anyone else.

All of it centers around the use of the phrase *cancer-free*.

I see the "newbies" coming out of their first post-surgery PSA test jubilantly declaring themselves to be cancer-free with their first undetectable reading, as well as with any subsequent readings. Don't get me wrong: It *is* something to celebrate. Hell, ***I* did it.** I declared myself to be cancer-free multiple times, well after my surgery.

But now, facing recurrence, every time I see someone declaring themselves cancer-free, I bite my lip and say to myself, "Just wait five or seven or ten years and see if you can still say that, Buck-o."

"Bitter. Table for one. Bitter."

Fortunately, my surgeon was very clear in telling me before the surgery what the chances of recurrence would be. He was managing my expectations with a dose of reality. However, one thing he didn't introduce me to was the phrase, *no evidence of disease.*

No Evidence of Disease (NED) should be much more widely used to keep us all grounded in the possibility that, no matter how successful our first-line treatment appears to have been, there's always that possibility of recurrence. "Cured" and "cancer-free" both give a false sense of security that none of us can count on.

So to those coming out of your prostatectomies, please declare that there's no evidence of disease on your undetectable PSAs, and hope that you can continue to do that for the rest of your life. In doing so—in managing those expectations—you may be better prepared for that fateful day 54 months after your surgery when there's now, in fact, evidence of disease. You'll still say, "Crap!" (or some other string of colorful expletives that would make a sailor blush), but making the leap from NED to recurrence may be just a tad easier than from cancer-free to recurrence.

You can tell from my last few posts that I'm getting back into my writing for therapy mode (or, as a

friend calls it, “verbal vomiting”). It is therapeutic for me to have an outlet for some of these thoughts; I can spew them and, once they’re out, put them behind me.

Thanks for putting up with them!

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