Day 3,270 — Doctor Visit

It's as though I'm taking another step on a tight rope with each successive PSA test.

October 24, 2019 By Dan Zeller

Tuesday's meeting with the urologist was a bit anticlimactic. In a nutshell, we're returning to the four-month test cycle and we'll see what the next test will bring in late January or early February before we do anything.

The doctor had no explanation for the swings in my PSA level from 0.13 to 0.10 to 0.16 and reminded me that there could be a margin of error on the readings. (But he couldn't quantify what that +/- error might be using the assay that they're using.) He mentioned that riding a bike, other mild "trauma" to the pelvic region, or sexual activity before a PSA test could affect the results. That's something that I already knew, so I make it a point to avoid any of that for at least a week before the blood sample is drawn to avoid introducing that variable to the picture.

He also reminded me that the historical definition of biochemical recurrence has been 0.20 ng/ml and suggested that it was premature to start thinking about salvage radiation therapy. Even so, he acknowledged that my PSA is definitely trending upward and worthy of continued monitoring so that it "doesn't get away from us." He suggested it would be fine to retest in six months; I opted for four.

One of the reasons that he was so comfortable with a longer test cycle and continued monitoring was my lengthy PSA doubling time. He also talked about the possibility that this could be residual benign prostate tissue left behind after the surgery that could be causing the PSA to increase again.

I filled him in on the Ga-68 PSMA PET/CT scan trial going on at UCLA and the option to shell out $2,800 to have the scan done outside of the trial. We talked a little about the successful detection rates at my PSA levels, to which he replied, "You know more about it than I do."

We also spoke briefly about the potential long-term side effects of salvage radiation therapy, as well as the success rates of having no evidence of disease five years later. Nothing new was learned there.

On the whole, I'm generally on board with this approach—for now. But I will say that, mentally, I prepared myself for the meeting to go in a different direction, so I'm still processing that. If I'm perfectly honest, I'm a teeny bit less confident that waiting another four months is appropriate.

It’s as though I’m taking another step on a tight rope with each successive PSA test. The further out I go, the more the rope sways and it’s just a question of how long I can maintain my balance. Can I make it all the way across, or will I lose my balance and tumble into the abyss of metastasis?

Sure, I can opt to use my emergency safety harness—salvage radiation therapy—at any time, but that comes with costs potentially impacting quality of life: increased incontinence, loss of sexual function, scarring from radiation, etc. And—guess what?—at the end of it, I’ll be back on another tightrope taking another step every 3-6 months with new tests to monitor the effectiveness of salvage radiation. (And there’s a 30%-70% chance that I’ll fall off that tight rope into the abyss, too, depending on which study you look at.)

The trick is knowing when to decide whether you should keep walking on the original tight rope or that it’s time to jump into the safety harness. That decision is complicated by your coaches on the ground yelling conflicting things at you. Coach Radiation Oncologist is yelling, “Use the harness!” and Coach Urologist is yelling, “Keep walking!” Your own mind, filled with reliable information you gathered from Dr. Google, is adding to the confusion. It can be maddening to try and sort through it all and make the best decision possible.

That thought led to the last point of discussion with the urologist on Tuesday. He acknowledged that the field of prostate cancer research is a very dynamic one, and that there’s often conflicting guidance as new therapies are being tested and new discoveries are made. He also reinforced that prostate cancer is an insidious disease in how it behaves and how challenging it can be to treat it.

Prostate cancer is not an “easy cancer.” Far from it.

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