Prostate Cancer, Day 4,880 – Full Medical Oncologist Report

At what PSA do you start hormone therapy? What about intermittent ADT? Prostate cancer patient and blogger Daniel Zeller seeks answers.

March 28, 2024 By Dan Zeller

My computer issues have been sorted, so here's the full scoop behind my meeting with the medical oncologist (MO) on Tuesday.

The meeting started with a nurse practitioner (NP) which threw me for a bit of a loop and initial disappointment. Because this was my initial contact with the oncology team, we spent a bit of time reviewing my history and how we got here. She did say that she would bring the MO into the discussion once we went through the preliminaries.

The nurse had actually done a pretty thorough job of reviewing my file prior to the meeting, and was familiar with the recent bone scan and PSMA PET scan results. Her take on my situation was that we were somewhat in limbo with no signs of metastases anywhere, and that the path forward wasn't so clear-cut. (That actually led to a brief discussion on how metastases is defined in the world of prostate cancer. She was of the school that it's not metastatic until it shows up on scans, while I pressed and suggested that, because the prostate is gone and the cancer is somewhere, it must, by traditional definition, be metastatic.)

Once we were through with the initial screening, the nurse brought in the MO and introduced her to me. I did ask if she specialized in prostate cancer and she does not; she's more of a general oncologist. She did say, however, that she reviewed my case with a genitourinary oncologist at the University of California San Diego (UCSD) the day before our meeting. That was a good to know (but not the same as having a seasoned prostate MO in the room).

At that point, the three of us started going down my checklist of questions.

We talked about whether there was value in delaying the start of any treatment until my PSA rose to a level where a scan would detect the location. In the preliminary screening, the NP seemed to be inclined to start the ADT before another PSMA PET scan, and she was a little surprised that the MO said we should do another scan in six months. The MO said that the scan may reveal lesions that could be spot radiated as a treatment option.

That led to me asking about whether there would be value in whole pelvic radiation and, again,

without knowing the cancer's location neither was a fan of pursuing that at this point. Even if we did know the location, they would defer that decision to the radiation oncologist (RO).

Because my PSA is so low (in relative terms), both seemed to be more inclined to start with just ADT and not a combination therapy of ADT plus antiandrogens. The MO acknowledged that the use of combination therapy could be more effective in controlling the cancer, but cautioned about the increased side effects from doing a combination therapy approach. She also mentioned that using combination therapy is generally reserved for when the cancer is more advanced. (I'm not sure that my research agrees with that thought.)

I believe in her discussion with the UCSD GU oncologist that they said they would probably hold off initiating hormone therapy until my PSA reached 2.0 ng/mL. I'm going to have to do a little research to see if that makes sense.

We talked about intermittent therapy and whether that would be appropriate, and the consensus was that, at my low PSA, I would be a good candidate for intermittent ADT. However, that would depend on my PSA doubling time and how my PSA responds to the ADT.

I did ask if cancer in the lymph nodes would be symptomatic and generally speaking, they said, it's not. I asked because I had had a weird pressure sensation in my groin last month that was new. (Yes, I'm at that point where I ask myself if every new ache, pain, or sensation is related to the cancer when it pops up.)

They noted going through my record that there was no baseline testosterone test, so we all agreed that that would be helpful to have. The NP put the order in to have that done when I get my PSA tested on 1 May 2024.

The MO expressed concern about my recent cardiac work-ups after my October emergency room visit (nothing of substance was found). She reminded me that hormone therapy does have a small but real risk of increasing cardiac events.

In the last part of the meeting, I did ask if I'll be seeing the same MO going forward, and the short answer was "indirectly."

You've heard me talk before that one of the drawbacks of getting my care through the VA is that it's a teaching hospital and that I rarely see the same physician/resident twice. It's good that I get so many differing opinions, but it prevents me from building a long-term relationship with the doctor as well. Different residents will filter through the oncology department, but the MO I met with will be overseeing all of their cases behind the scenes, so she would be tangentially involved.

I was asking because I likened myself to being an orchestra conductor, coordinating the efforts between the urologists, radiation oncologist, my primary care physician, and now the medical oncologist. I was inquiring if she or anyone else at VA would take the lead on coordinating all of these discussions and treatment considerations. She did mention that they do have a "tumor board" that reviews much more advanced cases to map out coordinated treatment plans, but

because I don’t have any substantial tumors in the scans, my case wouldn’t come up for review.

Interesting, though, was the fact that the NP and MO both viewed this meeting as me getting a second opinion instead of a hand-off of my case from the urology department to the oncology department. From their perspective, the urology department still has the lead on my case until I decide to move forward with hormone therapy.

One thing the NP brought up early in the conversation was that any treatment plan would have to be aligned with my goals. If my goal was to prevent metastasis (or delay it), then starting hormone therapy sooner would make more sense. But if my goal was to avoid hormone therapy side effects for as long as possible—recognizing the inherent risks—then it may make sense to delay therapy. To be honest, I’m not sure where on that spectrum I want to land.

We wrapped up the meeting, coming to a consensus that:

- We’ll conduct a PSA test and get a testosterone baseline on 1 May 2024.
- Calculate the PSA doubling time including the latest results.
- Evaluate the results and decide whether to schedule another PSMA PET scan.

While I didn’t keep specific track of the meeting, it lasted somewhere between 30 and 45 minutes, which is quite unusual.

I came out of the meeting in good spirits because it was one of the most productive, collaborative meetings I’ve had in a long time. The conversation flowed quite easily, and I attribute that to the fact that women healthcare professionals seem to be much better prepared and much better at listening to a patient’s concerns than some of their male counterparts. This isn’t the first time that I’ve noticed that. (Don’t forget, it was the thoroughness of my female primary care physician that discovered the cancer via a DRE in the first place.)

To be honest, I’m not sure why I felt compelled to mention these observations based on my personal experiences. I just suspect that some prostate cancer patients may be reluctant to discuss problems with their male bits with female healthcare professionals. You might be surprised by the difference in quality of care that you receive, so don’t rule them out.

I have been more than satisfied with my care from the VA so far but, as my cancer advances, I am beginning to wonder if it makes sense to step outside the VA so I can get a team that is dedicated to my case and one that I can build a long-term relationship with.

At the top of my list would be UCSD followed by Scripps/MD Anderson. But the VA already has such

close ties to UCSD, it's almost like I'm getting care from them already. In fact, the MO I saw is a clinical professor of medicine at UCSD, most of the residents I see in urology are from UCSD, and my VA-provided RO is from UCSD but seeing him required "community care" pre-approval. (Community care is generally only approved if the VA doesn't have the capacity or capability, so it could be tricky arguing to obtain it.)

So while I'm on Medicare and it would be relatively easy (but more expensive) for me to step away from the VA, I would explore options for getting approval to move into community care at the USCD GU medical oncologist through the VA first.

I'm not keen on changing horses in mid-stream, but it may make sense in the long run. I'll have to think that through.

And now you know why I didn't want to try and type this out on my phone on Tuesday. Thanks for reading this far!

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