



## Prostate Cancer – a personal experience

Warren D., July 2010

My life changed the minute my urologist indicated a slight asymmetry in my prostate during the annual DRE. Trepidation. Everything had been normal with very low PSA scores (around 0.4-0.7) for ten years. What then was this new finding? My AUA (or Prostate Symptom) score was 3 and Quality of life or 'bother' score 1, but a follow-on PCA3 score of 57 suggested a biopsy would be a smart idea and naturally I agreed. I did not like that procedure at all, even though I'd asked for 'happy juice' and was basically out of it. Or I should say I didn't like the after effects. You know them so I don't need to elaborate.

And then one day came the phone call that really really changed my life. "Warren, sorry to say the biopsy has revealed some cancerous cells and we need to set up an appointment to talk about treatment". Frankly I cried after getting off the call. The Big C. One hears about it all the time, you just hope it won't be something you have to deal with. But here it was – in my face – and I was now forced to deal with it. My wife took over temporarily and arranged a faxed copy of the biopsy report and immediately made an appointment to talk to our GP since I couldn't see my urologist for a few days. Perhaps I was fortunate as only one of 23 biopsy probes had found cancer cells and then in only 20% of that sample. Detected early, seemingly in a small dose and in the 'transition' area, not the 'peripheral' area of the prostate.

Even though it could have been worse, it was Cancer. It wasn't going to go away. I went through the "are they sure?", "why me?", "why now after years of good reports?", "what did I do wrong?", questions and the sinking feelings of despair that accompany them where one anticipates the worst. Coupled with the Big C finding I was unemployed and I lost sleep worrying, I felt sorry for myself, I felt mad at the world. But we (my wife was, and still is, a wonderful supporter) started reading, and set up appointments to talk to several different doctors to get varied input about potential treatments. We were impressed with the empathy we were accorded, and also the optimistic outlook that was uniformly projected. The message we received was that of all the cancers this was probably the third most curable (after basal skin and testicular cancers) – especially with early detection. Gradually my pessimism started to lift although I still felt one of my brothers should have had this, not me. After all I'd had my spate of other medical conditions over the years and they were still both scot free! But no, this was mine to accept and deal with.

By now you too will have found out about the enormous range of treatments and will have done your own reading. Given my Gleason score of 3+3 and T2a designation we identified three alternatives for consideration. One was 'active surveillance' or 'watchful waiting', the other was radical prostatectomy (removal) and the third was radiation – especially the seeding form. The potential beam radiation side effects did not appeal. It's certainly clear that 'active surveillance' has value for someone who has other serious medical issues to deal with but for us we didn't see the value of waiting. First, the cancer was not going to go away. Repeated biopsies would either reveal samples with more cancerous cells – or by fluke nothing at all if the probes missed infected areas, and results in neither case would change the initial information and need for treatment. Plus I intend to live for plenty of years yet so why wait? If I were to wait I'd only worry about not knowing the rate of progression and that definitely would color my emotional state significantly.

So we considered the radical prostatectomy and seeding radiation as our two best options. Our GP was wonderful. He gave us some objective input based on the years he had observed patients in his practice and concluded by saying "Warren, the best thing about your situation is that you can't make a bad decision". We talked to three surgeons and two radiation oncologists and in the end decided to go for seeding.

So why not the prostatectomy? The two things we heard in favor of the radical removal were a) you know the prostate cancer is gone, and b) if cancer recurs elsewhere you still have other options available. Good arguments, and while the prominent process these days is DaVinci robotic surgery our reading and information indicated still a fairly high likelihood of incontinence afterwards and other side effects including the life style change of being impotent. We actually had two younger friends who'd had prostatectomies and attested to this condition.

We know everyone's health status is different and what works for one person may not be as relevant for another. The more we studied radiation seeding (brachytherapy) the more it appealed as the preferable choice. First, the pioneers of the process are all here in the Northwest, so there is lots of experience – and lots of success close by. A very recent 15 year study showed very high rates of non-remission. Plus we also learned that if indeed remission did occur the new cryo treatments are starting to have success (removal is not an option after seeding radiation). And frankly if it turns out my treatment is not successful I may just accept that that is how my life is supposed to be concluded. I am a fighter but at some point if quality of life cannot be guaranteed then I may simply pass on. We'll wait until that point occurs, if it does, to decide.

I studied the Sloan-Kettering Nomogram (Partin table) which suggested a 5 year Progression Free Probability with Brachytherapy of 98% using T1c designation and 99% using T2a designation. This was consistent with verbal inputs from doctors, although probably more optimistic than their more cautious assessments which were closer to 95% probability. That is an acceptable risk level for me personally. One doctor also added a very poignant perspective in that at age 66, with my health, the probability of brachytherapy success 10 years out was the same as the chances of a 'normal' male in the population reaching age 76. I also learned in this whole investigative process that probably over 90% of men have some form of prostate cancer, but that it can be so mild and so slow growing that it often remains undetected. More autopsies are being performed these days to check for its incidence which is where the 90% finding comes from.

No matter. All the data aside it was now time for decision and action. The folks at the Seattle Prostate Institute at Swedish Medical Center were wonderful. Empathic, determined to listen and help answer questions factually, and unrushed. Dr. Stephen Eulau explained options and implications from brachytherapy and Sue, his nurse, even gave us her cell phone number in case we had questions. Incredibly patient oriented. A nice change from the hustle and bustle of our urologist's office. I think we chewed it over for another week and then finally I called Sue and said "Let's do it".

Now, frankly I'm the sort of person who wants lots of detail about what is involved. Many others probably are not so comfortable with intimate details and simply want the doctor to go ahead and get it over and done with. If you are in that category skip the next few paragraphs.

The first step in the seeding process is called a 'volumetric' analysis. That's a benign term that really is a substitute for determining the shape and size of your prostate. This is found by ultrasound using a diagnostic tool inserted in the rectum – just like the biopsy. Frankly it didn't bother me at all. Perhaps it was Dr. Eulau's technique but it was fast and painless, and with zero after-effects. My prostate size at biopsy time had been estimated at 35cc, this study which was a little more specific suggested only 29cc. I got to see the pictures of prostate mass from which a map of the seeding locations would be built.

I was actually most nervous waiting for time to pass until the actual seeding procedure. I'd made the commitment to go ahead, and wished we could now please get on with it! Noon June 17<sup>th</sup> finally turned up. This was to be a joint effort between my urologist Dr. Pelman and Dr. Eulau taking place at the urology clinic. Dr. Eulau to do the actual seeding, Dr. Pelman to assist and do the cystoscopy afterwards to check that the urethra and bladder were clear. There was a new set of operations nurses on duty, and a couple of other folks who asked to watch the procedure. A busy little procedure room. I was Ok so long as no-one was going to take pictures and publish them on the Internet! I had elected general anesthesia rather than a spinal block so once again I was oblivious shortly after placement in the procedure room. Just do your things docs, tell me about it afterwards thank you very much.

I give Anne, the recovery room nurse, a lot of credit as she was outstanding. I don't know how she knew but when I awoke and she asked if I felt like I urgently need to pee and poop and I said yes she hit me with a medicine intravenously that worked almost instantly and let me recover far more peacefully.

The perineum area is pretty small if you think about it. But somehow my doctor found room to thread 22 separate needles through it to the prostate. I elected thin-strand I-125 seeds because I'd heard that the narrow gauge needles were less traumatic. Anne the recovery nurse wondered why I was asking if I had padding down there. I expected 22 little prick-marks or blood scabs. But – there were none! Dr. Eulau's expertise at work. 90 seeds deposited – some needles had 2 seeds, especially around the urethra area, some with 5 responding to the shape of the prostate. Others had numbers in between.

I was surprised that only the first urination showed any blood – unlike the biopsy, and for the next day and a half I drank lots of water and worked hard at icepacks on the perineum area, 30 mins off, 30 mins on. Aleve pills as prescribed to help reduce inflammation and Flomax to aid urination although through it all I just felt 'heaviness' in the general region. Any cough forcefully brought that to the fore – it felt like my prostate was connected to my throat... Things weren't too different in the first two weeks but by week three definite changes occurring.

First I was urinating more often and with different patterns. Sometimes it was difficult to start. Often the stream was very weak. I never suffered from the 'urgency' syndrome that many men face although my wife was prepared to tell me where every restroom in Bellevue was located as she knew them all. Guess the gals sometimes really need to go! What I did suffer from often were feelings that I needed a bowel movement, only to find that wasn't true. Sometimes passing gas or urinating alleviated that feeling. I found it annoying that I couldn't always tell. I also found that hemorrhoids were exposed more often and so I worked hard at increasing my fluid intake, making sure I followed a high fiber diet and added stool softeners every now and then to help out. It all seemed to work for me and by week five I knew I had adapted to a better pattern of managing my body.

I came to a mental and emotional understanding which I'm happy to share. My body had become home to an insidious, powerful disease. To fight it, I'd elected a powerful medical weapon – radiation. This radiation wasn't some trifling little band-aid type approach destined to achieve the right medical response. This was serious war against a formidable opponent. And if the field of war – that is the tissue around the fight area – got a little beaten up, then so be it. What were a few minor discomforts when there was this enormous battle for my life going on? I could stand the small negatives on the sidelines – so long as I knew those things I was experiencing were standard side effects and standard collateral of the war. I re-read my post-procedure documents, I called Sue, and became satisfied that my experiences were 'normal'. Yes, I still got up in the middle of the night, yes I still got irritated at false body signals – but the angst was generally short lived and my wife noticed I was complaining less. There were however still odd days where I just felt 'off'. Firing on only 6 or 7 of the 8 cylinders. More tired than I used to. Again I figured those little radiation seeds were just having a tougher skirmish than usual that day and sometimes I even took a nap to help them out.

And so my 6 week appointment rolled around. My AUA score was now 10 instead of 3 and I am fortunate to not be in the teens where many men are at this stage. Hopefully from this point on my circumstances will slowly improve. I'm mentally reading to find my next 5 PSA readings to be all over the map – I know it may be 18 months before they settle down and we get some definitive indications.

Meanwhile we're not holding back but are busily planning an overseas trip in the Fall thanks to the confidence the folks at the Seattle Prostate Institute have given me. What a team – such professionalism, such dedication, such empathy. I couldn't ask for anything more.