

Active Surveillance. It all started with life insurance in March of 2009.

I wanted to change to a lower cost life insurance policy and being the healthy guy I was, I figured this was a slam dunk. After enduring the normal amount of grilling over the phone the insurance representative set up an appointment for the examiner to come by and run some routine tests. Piece of cake, my last physical came out good even though my cholesterol was a little high.

About two weeks later I received a letter from the insurance company turning me down! The reason given for my rejection was because the tests showed elevated AST, ALT and GGT. These test results have to do with liver enzymes. I found out taking certain medications, including ones I was taking at the time for a respiratory issue could elevate them. And oh yeah, and I had a PSA of 4.33 – cutoff was 4.00.

Not willing to accept the rejection I went to my HMO, explained what happened and they agreed to re-test me. I was done with the medication so again; it would be a slam dunk.

Sure enough test results came back, which I checked on line, and all three enzyme tests had gone down well below the cutoff. However, the PSA was missing, so I had to call in for the results. What I heard stopped me in my tracks – my PSA was HIGHER. A lot higher, as in 6.08. Little did I know what that would unleash.

I was referred immediately to an Urologist who scheduled a biopsy. It wasn't long before I got the results and it wasn't good. When my wife came home that evening and asked about the results, it was as though I had slapped her in the face. The look of astonishment, the "this-can't be-true look".

I explained that they only found a very small amount and we would go in for a consultation with the urologist soon. I continued on about the first options offered, either surgery or radiation. It was mentioned that there were other treatments, but my HMO didn't do or endorse them. Oh yes, you could also do this thing called "watchful waiting".

Even though watchful waiting was explained and sounded to me like a possibility, as far as my wife was concerned that wasn't an option. This wasn't something to play around with. Isn't your life more important than some stupid little gland in your crotch I was asked? I said yes, but we didn't really have enough information yet. She reluctantly went along provided I agreed to dive into this headfirst and find out everything I could and follow whatever the recommendations were religiously. I agreed.

First we saw the urologist who explained in detail about what was going on and how the "treatments" were administered. The biopsy resulted in a Gleason score of 3+3=6 Stage T1c. with 5% cancer cells found in one of twelve samples. The right side of the prostate gland I was told had the cancer while the left side "looked suspicious" but they wouldn't call it cancer. (I later found out how wide open the word suspicious was.) The doctor did admit the test results showed such a low level of cancer that "watchful waiting" was an option. However, because of the ambiguous results of PSA's, biopsies etc they, the doctors, couldn't really tell me 100% where I was at any given time. In other words, there was risk. Of course there was also risk with surgery, risk with radiation, risk of side effects. It came down to which risk door you wanted to go through.

The Prostate Cancer Manager at my HMO was very helpful and suggested my attending their group meetings held twice a month. As part of my program I started attending the meetings and was very impressed by the fact there were so many men there, that they were so open and a lot of good information was exchanged. It was all over the map. It ranged from men who had various treatments

to people like me to one individual who admitted that after finding out he had prostate cancer it took him about 3 seconds to decide on surgery. Even though his was not life threatening, actually closer to my situation, he couldn't live with the thought that this DISEASE was inside of him and he wanted it GONE. I heard from the facilitator that this was common. Even my urologist pointed out that if you decide against treatment that you have to be able to live with your decision 24/7. If that's going to drive you crazy, then you better not wait. Made sense to me. I also heard from a man who had been on watchful waiting for over 10 years. So there you have it, all the way from yank it to watch it.

My wife and I met with the surgeon. Very informative, I was told I was a "great candidate" and he could get me in a couple of months. This was accompanied by the obligatory oh and by the way here are the many things that can go wrong...

I was 70 % of the way toward a final decision when I was told about another support group from a member at my HMO. They said they met up in La Jolla and offered "other courses of action". The support group acknowledged their existence, but obviously wasn't endorsing them. I wondered, what could be the big deal? Was there a big deal? Did they advocate voodoo? Magic potions? Howling at the moon? Figured I better check it out.

Meanwhile I ordered another PSA. My urologist questioned why and I informed him I had read that there were a number of reasons for an elevated PSA that could have nothing to do with cancer. After all, he had also diagnosed me with BPH so why not? He agreed and the next one came back 4.49. Music to my ears. This was the kind of breathing room I wanted and now it was off to the other group.

My first meeting was in Sept 09. I was immediately impressed by the attendance. It appeared to be 60 or 70 people, mostly men. I was greeted by a gentlemen name Gene Van Vleet who took down my info and said he'd follow up later which he did. The talk was informative but one of the most impressive moments was listening to another gentlemen named Lyle LaRosh. To say that Lyle was forceful in his sweeping assessments of the current state of prostate cancer treatment would be an understatement. Since I was strongly considering watchful waiting, which I was also told was now called "active surveillance", this was a great resource.

Over the coming weeks I learned about the color doplar ultrasound and how it had helped, maybe saved a few of the men in the group. After getting my wife's vote of approval I scheduled an appointment in Ventura to see the well respected Prostate Specialist, Dr. Duke Bahn. In late Oct. I had my visit and exam. The results were good and I now had my second opinion from Dr. Bahn. - it was I was OK with active surveillance and I should come see him again in six months. I found the closest restaurant and ordered up a beer.

Since learning in June 09 about my cancer, in addition to the meetings, I started on a crash course of reading and researching. One of the consistent threads that emerged was that there appeared to a correlation between animal fat and cancer, particularly red meat. Good enough for me. The red meat was swapped for tofu and veggies. We already ate that way occasionally but now it was a lot. Oh yes - no dairy. That I've been doing for the past 30 years. Who knows, if I hadn't maybe I'd be telling a much different story.

I went in for my physical in Dec 09 and my primary doctor was a bit shocked. In the last year my cholesterol had dropped from 206 (once was 237) to 190. I had been changing my diet well before the diagnosis but it had never been that low. My blood pressure had dropped AND I lost 15 pounds. She asked what I had been doing different. I said one thing; same exercising, same sleep, maybe more

stress since 2009 was a bitch, still limited alcohol; it was the red meat substitute. She was flabbergasted. Now why should a doctor be so surprised? Oh and my PSA was 4.6.

I followed up in March 2010 with another visit to Dr. Bahn. He tested me again with the color ultrasound and the results were the same. In fact his comment was I had advanced BPH with evidence of chronic prostatitis. A lot of other details followed by “the known cancer still appears too small to be seen and may be clinically insignificant at this time.” I had another PSA test at his office and now it had dropped to 3.8! He also ordered a PCA3 urine test just to add to our portfolio and it came back negative also. He stressed continued PSA monitoring and watch for any consistent trends up over time, at least 3 tests.

Summarizing this I now had multiple pieces of evidence showing that for now and maybe for the next 3, 5, 10 years this might stay under control, particularly with my lifestyle changes. It also meant something else; if I had followed the urologist/surgeon/radiologist preference, I would no longer have a prostate and might have a whole lot of other problems. Doesn't mean I might not have to do that some day but I DEFINITELY didn't have to do it right now.

So from here on out I have a life long course to fulfill. Health-wise I haven't felt this good in a long time. Mentally I don't dwell on the “C” word, only that I improving and reinforcing my bodies immune system and even if I can't reverse what's happened, though I don't think that's impossible, I will at least stop it. If I can offer any help to someone going through the same turmoil I did in the beginning then I will be happy.

Update 2011: several more PSA's and still below 5.