

305. Prostate Cancer for Dummies.doc, 8 pages

The nurse put her hand on my shoulder, a warm compassionate touch that made me finally accept the fact that I had... prostate cancer!

"Give him one of those books," the doctor said hurriedly at the billing counter, as though he had just shown me a line of refrigerators and I had to go home and decide which one to take.

Until now I had convinced myself that I was still indestructible, these seventy seven years, that the biopsy I had taken on Christmas Eve would be negative.

"Here's where the cells are," the doctor had said in his office, pointing to an X-ray-like design.

I was sure he was looking at a teaching model of some kind, that he would conclude by saying I was OK , just do your regular testing.

"You're at Stage Two,' he went on, as though analyzing an engine block, "you're about to go into Stage Three."

I didn't know anything yet about "Stages", I still knew I was going to be OK, especially since the doctor was in a hurry, that this he had to get to those other guys in the waiting room, the ones with serious problems.

"With a Gleason score of 8, and a PSA of 13.5 you should move quickly," he continued, "I recommend cryosurgery, but we can do radiation, if you like. You don't have too many options at your age and cancer status." I was too old (77), to sustain prostatectomy.

"Give him one of those books..."

That's when the nurse put her hand on my shoulder, and I knew I wasn't going to be OK

"Prostate Cancer." That was the title of the book the nurse gave me.  
KLUNK!

I raced through it for the words Gleason and PSA. In the next week I read everything I could find on the subject but the book that seemed to fit my status most accurately was "Prostate Cancer For Dummies"\* , not only because it summed up everything quite lucidly but also because I had relied entirely on my general practitioner. I had to ask him three times to check out everything, well you know, DOWN THERE.

I talked to two other urologists. One pushed radiation and the other two suggested cryosurgery. I decided on the later, ironically because I had watched my wife go through two years of chemo and radiation for breast cancer and its resultant debilitating fatigue. With cryosurgery, the literature said, you spend one night in the hospital, a week at home, and then you can be back at work. Cryosurgery is a ten year old procedure that freezes the cancer cells in the prostate. The probes used are heat protected to avoid as much as possible danger to adjacent organs. Unlike radiation, if it doesn't work, it can be repeated.

I had watched my wife endure two years of radiation along with chemo for breast cancer, (albeit successful), I chose cryosurgery because it offered a quick fix. Earlier I went through two years of open heart surgery rehabilitation, pretty dismaying but nowhere near the fatigue of low testosterone. I've learned, after the fact of course, that there is growing research that some cardiac problems develop from low testosterone, making various organs work harder. This fact bewilders me still: Why my urologist didn't do a testosterone test in advance of the surgery, as a general awareness, and certainly before introducing the Viadur implant.

Seeds. The two urologists with whom I consulted before choosing which process to use never mentioned the seeds approach. I don't recall why I apparently ruled it out. A had third consultation with a radiology expert. Because I had already favored cryosurgery for the above reasons I didn't pay a lot of attention to his lecture delivered by a very knowledgeable nurse.

In January of 2008 I took a Viadur implant in my shoulder, a Lupron testosterone-inhibiting device that was to last for one year. I learned after the fact that its manufacturer, Bayer, took it off the market three months later. Nor did I know that for older patients the duration of the implant can extend the time indefinitely for the pituitary gland to re-trigger its testosterone.

The hormone blockade. Unnoticeable. Perhaps because there were so many other expected after-surgery symptoms, sweats, runs, muscle pain, etc. I was virtually unaware of it until about six months after surgery, nine months after the implant insertion, when the other symptoms began to decrease. That's when my urologist should have stepped up to the plate and told me what was going on. Either he was oblivious in his craft or he hoped in his greater wisdom that I would "pull through" and should not be burdened with the Low T status .

'JESUS!' I screamed. It wasn't a prayer. But it wasn't a curse either. I thought at the time how amazing it is that some of us invoke the various names of Jesus at moments of extremity - when someone cuts us off in traffic, or overcharges, or whatever, often accompanying it with an illogical sequel of some fornicating action or defecating aftermath.

"CHRIST," I pleaded again. Here in the after-surgery room. I still wasn't cursing, I hope. "We already gave you three morphine shots," a nurse from outer space called down to me. "Is the pain in your stomach or your penis?"

"JESUS!" This time it was a curse, forgive me Father. Where the hell do you think it is. Didn't they just...

I woke up the next morning to see the face of the nurse looking down at me...compassionately. These nurses! Who are they? Nightingales, for sure. Unsung. Angels where doctors don't care to tread. "You're going to be OK," she said, a slight Hispanic accent. God, how I loved that Hispanic note, I loved her. Instantly. "You can go home today, as soon as the doctor comes in."

The doctor! I called him several times after I got home, two days later, three days, maybe he was ...busy. I wanted to ask him about this cabbage effect down there, a swollen jam of genitalia, that the younger generation at the airport screenings refer to as "my junk", that we referred to pretty reverently as "the family jewels." It looked up, challenging me to figure out from what particular angle the urine would come this time. If it ever came again.

I recalled the nurse's voice; "You're going to be OK" Compassion! It goes a long way, I think. Bedside manner from the doctor? Maybe Medicare doesn't cover it.

.02 ! ALL CLEAR! My first PSA report after three months. June, 2008

I thanked the doctor and then particularly the surgeon. Wasn't it wonderful they had studied so hard at medical school and been able to save my life. And this cryosurgery that I had brilliantly selected, wasn't it magnificent?

JESUS! This time it was definitely a prayer! "But why do I feel so tired?" I asked the doctor. He didn't answer. His brow seemed to infer: Well of course.

And who was I to complain about feeling a little tired? Compared to those guys out in the waiting room. It was always full, like a barber shop, except they didn't read the sports pages and no one was talking. Several had withdrawn sallow faces. Their prognosis couldn't be good. And besides, I was able to get back to work at the small business I still ran out of the house.

I made three more quarterly visits, each trumpeting out my continued cure, a relentless PSA of .02, but each accompanied by my growing fatigue and varied reactions from the doctor. His first response was to give me the name of a general practitioner, who scheduled a series of neurology, osteopathy, and intestinal tests, consuming the next three months. All negative, mostly. "What kind of cancer did you say you had?" he asked distractedly on two different visits. Ultimately he fell back on the last refuge of uninterested physicians: "Does your family have any history of depression..."

I knew now I had to be the master of my prostate, and the captain of my soul, so to speak. I went back to the books and the unschooled logic of a layman, eventually coming up with something that these two doctors wanted to ignore ---maybe it would just go away--- or just didn't think of . It was on my PSA report.

"What is my testosterone level?" I phoned the doctor. "It's a little low."  
"How low?" "I don't have it in front of me." What!

I had started a swimming program at the Y --the literature recommended vigorous exercise to fire up the endorphins. Even though the resultant exhilaration doesn't last, its better than nothing and cumulatively it can help. My wife had accepted a call from the Department of Defense at Fort

Dix, so my dialogue was restricted pretty much to Spot, who tried to be pretty understanding but didn't have any answers either. She seemed a little dismayed also because I can't walk her now more than one block because of muscle pains and sheer fatigue. Getting to the supermarket is a challenge. I can't read more than three paragraphs of any paper work. I don't analyze any bill; just pay the damn things. My social life stops totally at 3;30 PM and I've become a prisoner of Law and Order, falling desperately and un-requited in love with Detective Mariska Hargitay. The other expected side effects of the surgery? Muscle pains, the sweats, the nightly runs to the bathroom and more during the day – sometimes I don't make it, and I'll never be invited back to the waiting line at Dunkin' Donuts. Overall it's like the Flu ----one minute I'm afraid I will die; the next minute I'm afraid I won't.

"How low is 63 for a testosterone count?" I asked the doctor on what turned out to be my final visit. The Viadur implant had been removed after one year. But this time I had gone back to the testing lab to get a copy of the test. It's mine, isn't it? Captain of my soul. He looked up from writing his report, surprised. "What can be done about it?" I asked, not waiting for his answer. "Nothing. You have to wait for it to come back on its own. How long does that take?" "Three months after the implant is removed, six months; a year maybe. For some it's two years. Sometimes it doesn't come back at all. You can take a Testosterone patch, but that can sometimes bring back the cancer." "What was my testosterone level before the surgery?" "It wasn't tested."

There! He seemed to say, initialing the final Medicare form. My fifteen minutes were up. "Listen," he said then, "if you want, I can start you on the testosterone patch right now. It's easy to apply, you just..." "Take the patch," someone else in the office said then, "if the cancer comes back, you can just take another implant."

I went back to the internet. Testosterone! This mercury of life that until now I took for granted I learned that at this tender age of 78 I might expect to have a T-level of about 350, or so, that back at my bestial best, say around 39, it was probably 1,000 or so. I could find nothing, however, about older guys who had come through the same thing, no studies, zilch. .

Then I discovered US TOO. Al Coldon, the chairman at two chapters, nailed me the minute I arrived, introduced me around, and asked me to

tell my story to the groups at the Hackensack and Valley meetings. At a subsequent meeting I polled the attendance, about twenty-five guys, - did any have low testosterone? Two said they did, but as it turned out, they didn't. One said he had a 350 score. I would have given my right arm for that level. They didn't understand the significance of 63. In fact even my friends didn't - I could see their eyes wander when I tried to explain it; there were too many guys around who had real cancer problems. I looked healthy, and I was still standing. Besides, how long do you expect to live, you old coot Quality of life, that's what it's all about, isn't it? Take the damn patch; live a little. If the cancer comes back, so what? These were my words as well as theirs, but on two occasions at new doctors' offices when I was ready to take the patch, a contrariness surfaced and I left without it. The hell with it, I said - at least the devil I know, the fatigue but not the cancer.

One of the leaders of the chapter, a Peter Gerrone, gave me a note on Tai Chi therapy. Two other guys joined in to tell me it had helped them. In fact the nurse at the dentist's office gave me a book on it. Nurses! They're always at it, God bless them.

I started the classes but had to quit after a few weeks because my back "kicked out" from something else. But at the same time a dear friend sent me a book entitled "Tong Ren Therapy", a Chi discipline that focuses on the acupuncture points of the body. It can be administered in group session or even on the phone! The author, Rick Kuethe, a disciple of its originator Tom Tam, and a Master himself, was able to cure his wife of lymph cancer, Hodgkins Disease.

WHAT! What did I have to lose. I started the program and got immediate results, feeling an exhilaration after each session with Master Kuethe, enough to continue but not to raise the T-level. I kept at it however; I had nothing else.

I wrote to every prostate cancer expert I could find, in every research group, and every medical school college. A few responded, mostly inferring in one way or another that it's better to wait. Then I received a response from Dr. Larry Lipschultz at Baylor College of Medicine in Houston, Texas \*, along with a survey that partially covered this very subject. It indicated that about 15% of older prostate cancer survivors suffer from longer periods for their testosterone to re-trigger. The

information was vital to me, but his taking time to listen and respond was even more encouraging. .

15% ! There have to be other old guys out there in the same situation. Where are they? Did they gamble on the testosterone booster, did the cancer come back. If it didn't, how long did it take on its own?

I called Bayer, the Viadur manufacturer, who had given me an embossed application to join the Viadur Club. I didn't join because I knew I was already cured. The Viadur personnel didn't know anything about the Club, and they couldn't give me any data on customers. Somehow I could hear the wagons circling. I went to the internet to discover Viadur had been taken off the market three months after I had received it. I also noted a few class actions against Viadur. Then I received two follow up calls from Bayer, voices that had an unmistakable legal overtone. The first caller asked for my symptoms, lawyer-like, making no comment; she had no interest in my question about older patients. When the second one called, I answered his questions with questions of my own.

By now I had consulted with four urologists and an endocrinologist. Two urologists had patients in my situation but would not reveal any data and certainly not their names for me to talk to. I did my own survey to one hundred local urologists asking the same questions, offering of course to share any results. Three responded, wanting to make me their patient.

Hey, Doc! Name your price. How 'bout five bucks a head? Wa'da'ya say. I don't need no names. I don't wanna' date 'em I jus' wanna ask 'em how long did it take, you know whad I'm sayin'. OK, tell ya' what, ten bucks, no make it fifteen, dat's my final offer, alright twenty five. Com 'on, Doc, gimme' a break, you name it. Hey, Buddy, how 'bout a hundred? I'm desperate.

The word "covet" came to mind, but I didn't say it; then the word, "hoard". Yo! What about the Hypocratic Oath, and science for science sake, and Madame Curie and Dr. DeBakey, and...

Hey, there's 360,000 prostate cancer patients surfacing every year, according to the Wall Street Journal. There's gotta' be some guys like me, right? Am I out here alone? 15% of 360,000 is 55,000, ain't it? Times a few years of the past.!

The dog was beginning to wonder about my shorter walks; the sweats and hurried toilet trips decreased, but even Detective Mariska Hargitay seemed to be losing interest. It was now twenty one months since the Viadur device had been removed. I had to do something. OK, one final attempt. I emailed forty five chairmen of the US TOO chapters who represented the largest population states, asking if they knew anyone like me. Within an amazing thirty six hour period I was overwhelmed with thirty six responses and eleven more arriving in the next two weeks. In the mix were SIX patients in similar circumstances. I talked to all six and hope to form a group, LOTS, with available data that might help other old coots in my circumstance, or young ones.

And then something else happened! About October 15, 2010, I started to feel better. My PSA test that happened to come four days later showed that the testosterone went from an abysmal 63 way up to an astounding 120! WHOOPEE ain't the word! "Get down on your knees, Lad, and thank God" is more like it. And an enormous thanks to US TOO people for listening, caring, and answering.

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\*Prostate Cancer For Dummies, Paul H Lnage, MD Wiley Publishing, Inc  
909 Third Ave NY, NY 10022 Wiley.com

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"Kinetics of Serum Androgen Normalization and Factors Associated With  
Testosterone Reserve After Limited Androgen- Deprivation Therapy In  
Nonmetastatic Prostate Cancer." James L Gulley, et al. HIH Public Access  
(National Institute of Health)