

Personal Experience
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I am a seven year survivor of prostate cancer. My history might be useful for learning about things not to do in making decisions about the treatment of prostate cancer (PCa). I will sprinkle "I wish I had known" comments as I go along.

If you have done any research about the disease you are likely overloaded with studies and statistics that talk about many types of treatment, their success rates, identifying the seriousness of the disease and prejudiced opinions on what you should do. One of the most difficult issues with PCa is to find out where you fit into the statistics. Are you in the high percentage of "not-to-worry" or the lower percentage of "get your affairs in order"? This is the most difficult question to answer about our disease.

Beginning at the age of 59 and for a period of about 3 years I dealt with BPH (enlarged prostate). BPH is not usually a precursor to cancer but should be an alert to regular PSA testing—annually at least. Late in 2002, during a routine exam which included a digital rectal exam (DRE) my doctor felt an unusual lump in my prostate and referred me to a urologist for further examination. The urologist performed another DRE as well as an ultra sound test which resulted in a recommendation to do a biopsy. "I wish I had known" about color doppler ultrasound which likely would have been a more accurate assessment of my cancer and certainly would have been less painful. To explain, a biopsy is a procedure of firing a number of needles from a device inserted into the rectum that fires, mostly at random, needles into the prostate in order to take samples which can be analyzed by a pathologist. A color doppler ultrasound procedure not only identifies more precisely the area and size of a tumor, but can be used to guide the biopsy process if a biopsy is deemed necessary.

My PSA was 1.8 when I began dealing with BPH in 1999 at the age of 60 and had risen to 4.7 at the time of the biopsy in 2002. The biopsy resulted in a Gleason score of 3+4=7 Stage T1c. I began researching treatment options none of which could overcome my overwhelming sense that I needed to get that cancer out of my body. Also, being raised in the Midwest and in a generation in which doctor's analyses were considered next to gospel, I relied on what the urologist said. To compound this even though I thought I was being diligent in asking for a second opinion, I was unaware that the referred second urologist was a member of the same team as the first. Of course his opinion was the same. "I wish I had known" that removing the prostate was not necessarily a cure. I saw the statistics that showed that a high percentage of surgeries were successful and discounted the negative possibilities of impotence and incontinence. Unfortunately most of us tend to believe we will be one of the successful ones in the higher percentages and focus too little on the negative aspects. In my opinion as you continue to look at studies and statistics you unknowingly are searching for ones that satisfy your wishes. I believe that my initial conclusion to have a radical prostatectomy could not have been overcome unless I had the benefit of the knowledge and experiences of men who have been through it like you get from our support group. "I wish I had known" about our group beforehand.

I had a radical prostatectomy in January, 2003. The surgical process (not robotic) was unremarkable. I was out of the hospital in 3 days and used a catheter for bladder drainage for 3 weeks. I was back at work in 2 weeks. AAH! SWEET SUCCESS—I THOUGHT. Following the surgery I experienced lessening degrees of impotence for about 3 months and thereafter I experimented with Viagra and tri-mix injection, either being effective for me. Of course Viagra is

more convenient although its side effects were objectionable to me. Regardless of the mental stigma of a needle in the penis it really is not very painful. I discontinued injections because of the inconvenience and used Viagra when necessary. I have a slight degree of incontinence that requires me to wear a light pad to catch an occasional unexpected drip or squirt.

OOPS! After the surgery, my PSA went to $<.01$ and stayed for about a year then began to slowly rise until it reached 0.4 in May, 2005. I underwent pelvic MRI's and CT scans to determine if there was any evidence of metastasis, all with negative results. The urologist then recommended external beam radiation which would radiate the prostate bed and hopefully destroy any remaining cancer. I underwent 33 treatments, going 5 days a week from June to August, 2005. This was the now old fashioned external beam radiation without the focusing capabilities of the modern techniques. Following this treatment my PSA dropped to 0.1. "I wish I had known" that this was a futile and needless procedure which I now know as salvation radiation that rarely resolves any problems. Radiation leaves scarring and possibilities of future ramifications. Unlucky me, in May 2006 I ended up in the hospital for 5 days with a serious bladder infection, being aspirated every 15 minutes and twice having larger catheters inserted under anesthesia in order to expel clots and fluids. The urologist denied that this was a result of any radiation scarring! My PSA began to rise again and reached 4.3 in January 2007. My urologist's only suggestion was to see an oncologist.

Fate finally smiled on me when, through a casual acquaintance, I heard of Lyle LaRosh and the support group he heads up—Informed Prostate Cancer Support Group (IPCSCG). I called Lyle and had a very eye-opening and comforting discussion about prostate cancer treatment possibilities. Prior to this, I was convinced I was headed toward a short term existence. He convinced me otherwise. I went to my first meeting in February, 2007. Through the group I learned about a more extensive insurance program that would allow me to leave the HMO program I had so that I could broaden my treatment capabilities. I learned about the positive aspects of diet, nutrition and exercise to help fight my cancer. I settled on a Mediterranean diet and began an exercise routine of 45 minutes 6 days a week. Having been raised in a rural community in the mid-west, I had a diet extremely high in meat and milk products. I read The China Study that is highly recommended reading by IPCSCG which tells about the effect of diet on cancer. I lost 50 pounds very rapidly and brought my cholesterol and HDL within acceptable limits for the first time in many years.

Also, through the Group I learned of Prostate Oncology Specialists who focus only on the prostate. Surprisingly there are only about 100 such specialists in the United States and none in San Diego County. If the transmission on your car is broken you wouldn't take it to a general mechanic. Why would you have a different attitude with your body? Take it to an expert on the problem! I became a patient of Dr. Lam who put me through the most extensive examination of my medical history and relevant CT and heart scans than I had ever had. Not only did he want to help with my cancer he wanted to improve my general health as well. After discussions about possible treatment alternatives, I decided on hormonal therapy consisting of 150mg Casodex daily, .5mg Avodart daily and 2.5mg Femara every other day. Casodex and Avodart help to keep cancer cells from feeding and growing on dihydrotestosterone and Femara helps lessen the possibility of breast tenderness/enlargement which is common in most such therapies. I began this therapy in February 2007 at which time my PSA had reached 8.9. By June my PSA had dropped to .9 and I was having no noticeable side effects of the medications. My PSA reached its low point of .286 in October 2008. In February 2009 I took a holiday from Casodex as is customary in hormone therapy. Unfortunately, my PSA began to rise rapidly again and reached 11.8 in Jun 2009. I began taking Casodex again and my PSA dropped to 0.671 by September, 2009. And is 0.843 at this writing. This time, I developed breast tenderness and

slight enlargement. To overcome this I underwent 5 sessions of prophylactic radiation with Dr. A.J. Mundt of UCSD Radiation Oncology here in San Diego. The problem has subsided.

Since the low point or nadir of my PSA score is higher than it was the first time around, it may indicate I am developing resistance to the drug. We will monitor it as well as research alternative drugs. There are newer treatments appearing on the horizon all the time so it is important to continue research and communication with your doctor to achieve the most beneficial treatment choices.

In summary, here are some of the important things I have come to understand since my involvement with IPCSG

1. The PSA score is not an indicator of the aggressiveness of prostate cancer but rather should be used to monitor the disease. A high or increasing PSA score should be monitored closely by you and your doctor---hopefully one skilled in prostate oncology.
2. A color doppler ultrasound procedure is highly recommended before taking a biopsy. No one in San Diego performs this procedure. Dr. Duke Bahn, <http://www.pioa.org/bahn.html>, is the leading expert on this procedure and he trained Dr. Mark Scholz and Dr. Richard Lam of Prostate Oncology Specialists, www.prostateoncology.com. If the color doppler ultrasound indicates serious involvement of cancer in the prostate, a biopsy might then be needed.
3. Be your own case manager. Do not let a doctor dictate what treatment is best for you. Get as much information as you can from research and networking with others with the disease to make decisions best for you. This is the value of the Informed Prostate Cancer Support Group.
4. Once a treatment choice has been made continue to monitor your condition. Too many find that their disease appears again after they thought they were "cured"

Since discovering IPCSG, I have volunteered my efforts to the group and have derived the highest degree of satisfaction from it as anything I have done before.

Respectfully submitted,

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