

Lessons I Learned along the Way

Ivan Misner, Ph.D.

Being a patient is not a passive role. For better care, a patient has to find quality professionals and collaborate with them. Ivan Misner, Ph.D., a friend of the PCRI and New York Times bestselling author shares his experience as a prostate cancer patient and shares a few important points he learned along the way.

Since my own prostate cancer diagnosis, I have had the chance to speak to several men immediately after they have heard the same words from their urologist that I heard in March 2012. I hope my experience and the many things I learned along the way can be helpful to you or someone you love who is starting out on this journey.

Please understand that I'm writing this from a patient's perspective. I am not a medical doctor. I am not giving you advice or addressing your particular situation. You must do your research, and consult with your doctor before making any decisions about what is best for you!

Right after I received my diagnosis, I spoke to five men and came away from these conversations knowing five ways I did NOT want to approach my own situation. But the conversations I had with all of them were invaluable. They also put the fear of God in me because of the side effects they told me about. I found the motivation I needed to put into effect the total and complete dietary and lifestyle changes I made.

Not long after receiving my diagnosis, I attended the Prostate Cancer Research Institute's annual conference in Los Angeles. I learned so much there from doctors who are at the cutting edge (no pun intended) of the emerging trends in prostate cancer diagnosis and treatment. →

The Top 8 Lessons I Learned:

1 Your PSA doubling time is important. Many times the PSA (a blood test which measures Prostate Specific Antigen) can begin to rise one or two points over a period of time due to age or other factors, but your PSA doubling time is more important when cancer is suspected by your clinician. I found it helpful to keep a graph chart of my PSA tests, so that I could really keep an eye on the amount of time it was taking for the count to rise. In my case, my PSA had not even doubled in any one year when my doctor said he wanted to take a look at why my number was going up. He went through the order of screening and diagnostic tests mentioned below. And, of special importance to me, when I made dietary changes after my diagnosis, the slowly rising number stopped and actually began to drop.

2 There are many types of screening and diagnostic tests you can do, ranging from less invasive to more invasive. For example, going from an elevated PSA to a biopsy may be going a bit too far, too fast, unless you and your doctor have other reasons for concern. There are many things which can cause a PSA test to come back elevated: bicycle riding, having used the hot tub prior to having your blood drawn, intimacy prior to the test, or prostate infection (prostatitis). I am surprised that most of the men I have talked to have not been made aware of these factors which could be the cause of elevated PSA results.

Remember, this is your experience. You have the right to request the types of tests you wish to have performed. If you feel your doctor is rushing from a slightly elevated PSA to a biopsy, do your own research, ask your own questions, and consider a second opinion.

One of the first things my general practitioner did after my annual PSA came back slightly higher than the prior year's test was to run the test again. When that one was also elevated, he recommended a course of antibiotics to rule out a prostate infection (prostatitis). When my PSA remained elevated, he then began to move into the following cancer-diagnostic procedures. He did a digital exam and then referred me to my urologist for an ultrasound.

3 A high-definition, color Doppler ultrasound or a multi-parametric MRI (mp-MRI) can be the next diagnostic step to take if the digital exam reveals an abnormality in the prostate gland. The ultrasound I had revealed the lesion. A high-definition, color Doppler ultrasound or an mp-MRI is especially important when you are doing active surveillance (point eight below).

Proper imaging can help you and your doctor tell when the tumor is preparing to grow or is actively growing. Angiogenesis, or excess blood flow, can increase to the lesion as the cancer cells begin to move into a more active phase. If there is no angiogenesis present, active surveillance may be one of your options. Color Doppler ultrasound is designed to show this blood flow. A mp-MRI can help detect this as well,

4 A PCA3 test can help give an indication of the presence of prostate cancer. The PCA3 test is a urine test that measures the prostate cancer gene 3. My first PCA3 result was after my diagnosis, and came in at 26 (my urologist estimates that it would have been just under 50 at the time of my biopsy), while subsequent tests have been 17 and now 13, considered negative for cancer. Numbers below 25 are considered "negative" and those above 25 are "positive."



Ivan Misner, Ph.D. is a New York Times bestselling author. He is the Founder and Chairman of BNI (www.BNI.com), the world's largest business networking organization. His book, *Networking Like a Pro*, can be viewed at www.IvanMisner.com. Dr. Misner is also the Sr. Partner for the Referral Institute (www.ReferralInstitute.com), an international referral training company.

5 Regarding your scans and other tests, request copies of everything, including written reports. Most of your doctors will be glad to make copies of the reports and even the imaging scans. I started a notebook in which I put my PSA graph chart, all my PSA blood test results, the ultrasound imaging reports and the biopsy results (pathology) report. Having this notebook gave me valuable information to keep a handle on where I was in the process, and it also was extremely helpful to the members of my medical team. Overall, it kept me in the position of captain of my "game."

If you ask for the imaging scans: the DVD you will get has an embedded program you need to install before you can open the images. Most doctors already have this program on their computers, whereas I did not. It took a few tries to view my scans before I realized I needed to install the program! Ask the radiologist about this before taking your DVD. You can also ask for copies of the written report.

6 Be aware of the after effects of a biopsy. Since there are bundles of nerve fibers encasing the prostate gland, the biopsy needle can nick them and cause temporary to permanent side effects, such as incontinence and impotence. These nerves can regenerate but it is a very delicate procedure. Please be sure you go to someone who has done hundreds and hundreds of these procedures. You don't want to be part of a learning curve for the new guy! After the biopsy you may urinate and ejaculate blood for a time. That can be painful, not to mention completely unsettling, even when you are aware it will happen.

If your biopsy returns positive for cancer, find out how many core samples were taken and how many of them were positive for cancer. This will be on your pathology report. This information will help you determine your risk category. PCRI has a great website into which you can plug all these factors to learn your "SHADE" on the risk spectrum. This tool can be found on their Blue Community website: www.pcribc.org

7 Another piece of information to come away from your diagnosis with is your Gleason score. This score is made up of two numbers called "Gleason grades". Adding the two numbers together gives you your score, but the order in which the numbers are added gives you information, too. If the lower number is given first, then the higher number (for example, 3+4), your risk is somewhat lower. If the higher number is first, then the lower (4+3), your risk is higher, even though both scores are a 7 on the Gleason scale. 3 + 3 = 6 is the lowest risk, and 5 + 5 = 10 is the highest.

Knowing my risk category helped me decide how I wanted to approach my treatment. My numbers all placed me in the low to intermediate risk category. Having all the diagnostic information I had helped me determine what I was going to do. It wasn't a case of the doctor diagnosing cancer and scheduling me for surgery a few months later! →

Patient PSA Tests Biopsy Risk Scans Treatment Learned Doctor Side Effects

Lesson I Learned, continued from pg. 9:

8 Consider active surveillance, if appropriate for your stage of prostate cancer. Urologists and oncologists used to refer to a time of “watchful waiting” related to prostate cancer. Watchful waiting is now being referred to by many doctors and patients as “active surveillance”, which has a slightly different definition. Think of the word active as being active in getting your tests, the color Doppler or mp-MRI scans, and active in keeping an eye on the situation so you know when it is the right time to intervene medically. Active surveillance gave me the time and the space to make the lifestyle changes I made to see if they would give my body what it needed to repair the damaged cells. I had monthly PSA tests, regular HD color Doppler ultrasounds and saw my urologist every six to nine months to evaluate all my numbers. Even now that I’ve been told I am in remission, I will continue active surveillance.

I learned that a radical prostatectomy was NOT my option if at all possible! The side effects are common and often permanent. If I had a fast-growing malignancy, I might have responded differently.

I recommend a couple of books to read if you have been diagnosed with prostate cancer. The first is *Invasion of the Prostate Snatchers*, written by Dr. Mark Scholz, the founder of the PCRI. He has co-authored this book with one of his patients, and I found it extremely informative and comforting. Dr. Scholz is an oncologist, not a urologist, so surgery is not his first reaction to a prostate cancer diagnosis, as it is for most urologists.

The second is *Love, Medicine and Miracles* by Dr. Bernie Siegel. This book reveals the incredible power the mind has over the medical conditions of our bodies. Since hearing those words in March 2012 – “you have cancer” – I have come to believe more deeply just how integrated our mind and bodies are when it comes to healing from conditions like cancer.

Remember that you are “the captain” of your experience as a patient. Knowledge gives you the opportunity to make choices. Get as much information from sources you trust, and then do what YOU feel is best for you. It is your diagnosis. Treatment protocols need to be your choices – not someone else’s. □