

ACTIVE SURVEILLANCE: A PATIENT'S JOURNEY



Mark Lichty
Prostate Cancer Patient

Note: This article is written from an active surveillance patient's perspective, and should not be considered actual medical advice or the opinions of PCRI. Please consult with your doctor(s) before making choices about treatment.

It has been more than two years since I shared my active surveillance journey in the March 2010 issue of *PCRI Insights*. In that article, I wrote that my father's over-treatment for prostate cancer resulted in a vastly decreased quality of life in his last year. His experience inspired me to opt for active surveillance (AS) when I was first diagnosed in 2005.

In the US Too Inspire online support network, I often read about men who have had intervention and are now dealing with the consequences, such as incontinence, erectile dysfunction and other uncomfortable side effects. Hearing about these experiences has reaffirmed active surveillance (AS) as a legitimate route for me.

My AS journey has taken me down many trails, and introduced me to a brotherhood of those similarly affected by prostate cancer. This is an update of that journey. I don't have all the answers for you about how to approach your cancer, but perhaps my experiences over the last seven years on AS may inform you in some way.

I have been encouraged by recent progress made by the medical community in accepting AS as a legitimate alternative to immediate intervention. Seven years ago, my choice of "watchful waiting" was viewed with skepticism and disapproval by my doctors and loved ones alike. Watching and waiting seemed passive to all of us, merely waiting for the cancer to do its dirty work. But when watchful waiting morphed into active surveillance - a minimum of intervention with a maximum of surveillance - I was all in. Now, AS is featured prominently on both the US TOO and PCRI websites as an alternative. Seven years ago, there was little mention of active surveillance as an option. As recently as two years ago, AS was not even mentioned on a nationally televised program that featured famous PC survivors such as John McEnroe. This reinforces the need for such progressive organizations as PCRI to carry the torch.

One of the greatest challenges for patients on active surveillance is finding support groups that cater to us. To their credit, PCRI has offered AS support groups at its annual conference, but I have found no such support groups on the East Coast. I recall chairing a PCRI support group when one man, nearly in tears, asked: "Where was this AS support group before I had my intervention?"

Us Too has developed an online support group, Team Inspire, where I have posted some questions and received thoughtful responses. Similarly, the PCRI Blue Community offers online forums for patients to discuss various treatment options with one another, including active surveillance.

The most significant event for me in the last two years has been the excruciatingly painful experience of not being able to urinate. Initially, my doctor suspected a urinary tract infection (UTI) and put me immediately on antibiotics. When the tests came back negative for a UTI, I was catheterized, resulting in a painful couple of days. It's interesting how our plumbing, which we take for granted most of our lives, awakens in our late 50s or so and says emphatically, like a spurned wife, *you know you have taken me for granted for all of these years, now I demand your attention.*

With this inability to pee, I was faced with a choice: I had to have either TURP or Green Light therapy. I prefer to avoid intervention whenever possible, but here I had no other option. My wife even suggested I get the prostate removed to eliminate potential problems and any risk of future cancer.

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I gave this notion a passing thought, but was still concerned about side effects. In addition, I have a sort of warped attachment to that troublesome little walnut. Removal didn't fit into my overall minimalist philosophy.

My research at the time focused on how many years the Green Light fix lasted, and initially it appeared to last about the same length of time as a TURP. Subsequently, I heard that the TURP may have a longer life span. I prefer outpatient procedures, and with the TURP I would have had to stay overnight, so I opted for the Green light. I still wake up several times a night to urinate. I have a bottle by the bedside so that I no longer disturb my wife by getting out of bed. Once one enters the brotherhood of the prostate, the simple act of urinating unexpectedly becomes a topic of much significance.

In retrospect, had I continued Avodart as my doctor advised, my prostate would have been smaller, and this whole incident may have been avoided. I had taken Avodart, but felt that it affected my sex drive and perhaps even my emotional state, so I discontinued. Was this a case where I relied too much on my own intuition? Should I have listened to the doctor? I will never know, but I am always cautious with drugs, as they have effects beyond what they are intended for - we call them side effects, but I prefer to drop the word "side."

The over-treatment epidemic is created by a variety of factors, including a legal/economic climate that nurtures this over-treatment (an issue which is discussed at length in the book *Invasion of the Prostate Snatchers* by Dr. Mark Scholz). So we have government agencies making recommendations not based on root cause analysis, but rather, on the notion that too much data is more than we can handle.

This points out the need for genuine participatory medicine. Both the patient and the doctor must step up to the plate.

In a New York Times article, Dr. Pauline Chen cites Dominick Frosch, lead author of a study on this subject, who stated, "Systemic changes to increase shared decision-making must be addressed... doctors' practices must be restructured to allow more in-depth conversation." When I was CEO of a corporation, I learned that infusing the air with my own ideas and prejudices would not empower those around me. We need to find ways to create these open vessels of caring conversation where empowerment can occur.

As I write about this notion of caring conversation, I think of my own conversation with my urologist seven years ago. I respect the man and count him as a friend. However, in a caring conversation context, I would have preferred that he step out from behind the desk, sit close by, take the clinical hat off, and after he shares with me that I have cancer, if he doesn't have time to spend with me, send me on to his nurse who would spend the necessary time providing me information about support groups, treatment options and other relevant information.

Of course, the conversation today would be quite different than it was seven years ago. At that time, I thought cancer was cancer. I didn't realize that some prostate cancers are slow-growing, and therefore may not be life-threatening.

Once our PSA starts to double or rise, the next step in the medical protocol is to undergo biopsy. There is an emerging PSA test, the Prostate Health Index (PHI), that may give us more information than the current PSA test. It combines 3 PSA's together – Total PSA, Free PSA, and 2Pro PSA. It has been used in Europe for several years, and may help AS patients in their surveillance process. PHI was cleared by the FDA in late June, but we are awaiting availability in the US. You can find more info at www.prostatehealthindex.org.

Rather than using biopsies, I have been monitoring my cancer with color Doppler and Magnetic Resonance Spectroscopic Imaging (MRSI). I was in a MRSI study at UCSF until funding dried up. My last MRSI indicated no cancer, but somehow a little voice in me believes that maybe it missed something. Unfortunately, MRSIs are expensive and not covered by insurance.

My experience has taken me to shamans, prayer, support groups and on many interesting journeys. It has been a synthesis of the East and West. I have shifted to a living food diet (primarily vegetarian).

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The vegetables alkalize my body, the theory being that cancer grows only in an anaerobic environment. I still believe that sugar feeds cancer, and I am in good company with folks like Dr. Lewis Cantley of the Harvard Medical School. My discipline on diet has faded with time, and my sons still get on my case about eating cake (or whatever sugary morsel tempts me). I am far from perfect, but I guess that makes me human. Cancer forced me to follow a diet that I might not otherwise have stuck to, and now my health, energy level and mood seem more consistent.

As I mentioned in my previous article, I have created a small online support group. One member, Paul, moved from a Gleason 6 to a Gleason 8 on AS and subsequently had radiation and hormonal therapy, moving through it with remarkable strength. He ran and exercised regularly during the entire course of therapy, which I believe was key to the grace with which he glided through that challenge.

Exercise is important for those of us on AS, but I admit that I am remiss here. I have done yoga for about 40 years, but could do more aerobics. I believe Paul is glad that he waited, as in the intervening 5 years from his diagnosis, options for therapy had improved. In fact, that is in part a motivation for many of us on AS to pursue it as we witness technological progress in medicine. This man's elegant handling of his transition from AS to intervention was an inspiration for me, and should be noted as a case study in how to transition from AS to intervention with faith.

Thus, my lesson from these past 7 years is that for low-grade prostate cancer, we can do active surveillance successfully and fearlessly. Support groups are a critical part of this journey, whether they are online or in person. Don't overreact to minor changes in your PSA. If you don't think you can make life changes such as diet, and exercise, intervention may be the choice for you. Once diagnosed, take your time, be patient with the process, do your research, and be at peace with your final decision, whatever it may be.

Tonight I listened to Steve Jobs' cancer story, and heard some criticism levied against him for not following more traditional medical protocol. I wonder if perhaps my loved ones may criticize me in the same way if my gamble doesn't pay off. In the end, I will know whatever happens, I did it my way.

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