

A Woman's Struggle with Misdiagnosis and Bladder Cancer

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I wrote this very personal account of my experience for publication to inform everyone - particularly women - about bladder cancer. If you see blood when you urinate or if reports of microscopic blood is seen during a routine urine test at your primary care physician's or Gynecologist's office go to a urologist and have a cystoscopy to check if there is a tumor growing in your bladder.

If the tumor becomes invasive, a complete hysterectomy and bladder removal has to be done. If a man sees blood in his urine, he becomes immediately alarmed and seeks proper medical attention. I know of many men on the bladder cancer web café discussion group, who went immediately to the emergency room after seeing blood in their urine. Women are accustomed to seeing blood, and so are not immediately concerned. That lack of concern along with most physicians believing bladder cancer is an old man's disease, further complicates proper diagnosis. Many younger men and woman have undiagnosed bladder cancer.

My story

In May 2000, after having blood in my urine on and off for three or four years, a four cm tumor was seen on a CAT scan

that was ordered by a urologist, who finally did a cystoscopy check of my bladder.

There were many errors in the medical field up to that point, as I kept having checkups for the bleeding without being directed to an urologist. I was given antibiotics and it would stop. I was diagnosed with cystitis. I had a clear sonogram. Even the urologist to whom I was first referred in December 1999 diagnosed me as having passed a stone.

Just prior to that, I was also feeling blockage and pain when trying to urinate. He did not do a cystoscopy check on me. I went for a second opinion. That urologist did a cystoscopy check by inserting a small catheter with a

camera through my urethra to view my bladder.

He showed me on a monitor the actual view of the tumor in my bladder. It was not very "beastly"; looking to me. Ironically, it was a rather whimsical flowery swaying growth. I was very traumatized at being pronounced having a malignant tumor that could be invasive and being told that I may have to have my bladder taken out.

This second urologist told me the disturbing prospect prior to removal of the growth and pathology report. I was able to search the Internet and found much information particularly through the Web site bladder cancer web café: <http://www.blcwebcafe.org>.

I then asked the second urologist many questions and discussed concerns. I became very dissatisfied at his lack of addressing

my concerns. He even discouraged me from probing further into these unanswered questions.

A friend referred me to a third urologist. He was professor of urology at a university affiliated medical center one and half hour away, in Dallas, TX. I have since learned it is best to be treated for cancer at a university affiliated medical center.

His check-up of me was so much more thorough than the others. Not only did he do the cystoscopy and show it to me on the monitor, but also took pictures, gave me a pelvic and anal exam to check for tumor invasion. He told me afterward that he could not feel any protrusions or invasions elsewhere and "we probably lucked out with this just being a superficial tumor."

He also said it was probably so large because it had been in there so long. He explained to me why a TURB—a minimally invasive surgery to remove the growth and send to pathology—needed to be done and what they would learn from it. I had the surgery three days later with him at the University affiliated hospital.

Although all three urologists said it would be an outpatient procedure, I was kept overnight at the hospital. Later in the day, the doctor came in and said he was a bit concerned about the size of the stalk. The stalk may have invaded the bladder wall. He may have to remove my bladder and do a complete hysterectomy. I was very angry and shouted "that is not going to happen."

I was released from the hospital the next morning but had to wait five days for the pathology report. It was an agonizing five days. The report showed no muscle invasion. I could keep my bladder and other female organs. What a relief!

I was then told of follow through check ups and immune stimulating treatments that would be done. The way to beat cancer is to have a strong immune system. I ran across a very convincing medical test trial about an immune stimulate called Maitake d-fraction that could be bought at health food stores. I took this along with my BCG treatments. I had no ill effects from the treatments.

Superficial bladder cancer will not bring death. It does recur quite often and could become invasive if not closely monitored. I have had two minor recurrences in five years.

I have accepted the fact that this will be long-term surveillance and treatment but feel blessed that treatment is available. I had been a smoker. My doctor told me the 112 chemicals in a cigarette mix with the urine and cause abnormal growth. Certain jobs that bring you in touch with chemicals regularly are also cited as a cause of bladder cancer. Hydration and regular urination is important and therapeutic.

Prior to having bladder cancer, I did not drink much water and held my urine too long often times because I was so busy doing something else. I now take more time for myself and am enjoying my home in Lake Land or in Caroline County.