

## **Gary Porter**

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Gary and Dee live in Viola, Kansas, USA. Gary was 66 when he was diagnosed in March 2004. His initial PSA was 105 ng/ml, his Gleason Score was 8 and he was staged T3b. His choice of treatment was Androgen Deprivation Therapy followed by Surgery and Radiation. Here is his story:

At the age of 66, after working four decades as a TV Broadcast Engineer, I decided to retire. After a couple of months of doing absolutely nothing, I decided to start a small business that could be operated from my home. About the time I was ready to launch the business, my wife suggested I have a physical, since I had not had one for at least six years.

A blood test was scheduled prior to my appointment, and early March 2004, I met with my doctor for the results, and a DRE (Digital Rectal Examination). You can't imagine how surprised I was to find my PSA was 105ng/ml, and the doctor was not very happy with the results of the DRE. An appointment was scheduled two weeks later with a urologist.

The urologist confirmed the PSA, DRE results, and scheduled a TRUS and biopsy. The results were devastating to hear. A total of 13 cores were removed from both sides of the prostate and seminal vesicles. The Gleason Score was determined to be 4+4 (8) and it was staged at T3c, which meant the seminal vesicles were also involved. CT and bone scans were negative.

The urologist immediately started Hormone Therapy with a 3 month depot of Lupron, and wanted to schedule surgery within 3 weeks. I knew nothing about prostate cancer and put my trust totally in the hands of the urologist. The surgery was postponed until mid May, due to a death in my family, but then on the 17th of May, 2004, I had a retropubic radical prostatectomy.

During the first stage of surgery, biopsies were taken of several lymph nodes, to determine the extent of the escape of the tumour from the prostate gland. Because the nodes were clear, the surgery was completed. Both nerve bundles were not spared, and the urologist said he thought he was able to leave clear margins, however, he could not guarantee it 100%. The post pathology report indicated that the gland weighed 66 grams, and that the

Gleason Score was 9 (4+5). Staging was analyzed at T3b, pNO, MX, lymph nodes ck'd negative.

After a short stay in the hospital, I started my recovery at home with the urinary catheter and after about 10 days it was removed. I had what might be considered a normal bout of incontinence, and after hundreds of Kegels, and several months, the leakage slowly improved to a point of not requiring any protection.

One month after surgery, my PSA was 0.1 ng/ml and two and a half months post surgery, it was <0.10 ng/ml. I received another depot of Lupron (4 months) and was scheduled to start 40 treatments (7200 cGy total) of seven-field, three-dimensional conformal radiation therapy, the last of October, 2004.

A month after surgery, I was invited to attend our local Us TOO support group, and was starting to become very involved with researching my disease and treatments. I was beginning to find out that there is much more to this disease than what I was being told by my doctors. For example, I was beginning to question my doctors about bone loss due to the ADT (Hormone Treatment) and was not getting anywhere with that. There were other blood tests that should have been done prior to surgery, but due to my ignorance at the time, many base line numbers were not obtained before treatment. So now I was playing catch up with what I should or should not be doing.

In any event, I proceeded with the Radiation Therapy and managed to get thru it with minimum damage. During the last week of treatments, I was beginning to have some rectal pain, but the doctor said that would not be out of the ordinary, and that the damage should heal in a couple of weeks. It actually was a couple of months before I felt that it had healed.

The first of December, 04, my PSA was still <0.10 ng/ml and after much arm twisting, I received my first testosterone result, which was 26. I had another Lupron injection (3 months) and at the end of Feb 05, my PSA was still at <0.10 ng/ml and my T (testosterone) level was <20.

I was still trying to get my doctor to talk about bone loss and finally I was able to convince him that I should have a QCT bone density test. The last of February the test was scheduled and I was not surprised to learn that my bone mass was 79 and that I had osteoporosis.

After consulting with others of the Us TOO group, an oncologist was recommended, who after reviewing my case, immediately started me on 70mg Fosamax, weekly.

One year post surgery, I received another 4 month Lupron injection and my PSA was still holding at <0.10 ng/ml, and I hoped it would remain the same after my next test in August, 05.

I am very grateful that I had a support group available. If I have learned anything at all, is that you are putting your life on the line, if you blindly trust the information that you receive from most of the medical community. Those of us who spend endless hours researching prostate cancer are far more knowledgeable than most doctors (except the true artists who care) and this information must be presented to them before treatments. It is our choice, and is not to be dictated by anyone, regardless the fact that he has a MD after his name, or an insurance company who will only pay for what they decide is proper.

I now spend most of my free time as chairman of our local Us TOO group, and my goal is to make our support group more visible so others have the opportunity to educate themselves, to be able to make the correct choices, because their lives are going to be changed. This needs to be in a positive direction, and not one that one will regret for the rest of his life.

UPDATED December 2005:  
December 5, 2005, I was able to convince my doctor that my PSA should be checked by the ultra test and I was very pleased to see that my last PSA test results were <0.00. One cannot ask for anything better than that.

I hope to discuss with my oncologist in January, the possibility of taking a Lupron holiday, after being on that program for 21 months.

UPDATED January 2007  
In March of 2006, my PSA was still undetectable at <0.01 and I asked my Oncologist if he might consider the option of dropping the ADT for a period of time, however, he wanted to wait a few more months before considering it, and I received another 4 month depot of Lupron.

In July, 2006, I was retested and my PSA was still undetectable at <0.01 and my Testosterone was 34. Since I had a good record of being undetectable and low level of Testosterone, he agreed to stop the Lupron treatments.



8/11 PSA 0.64 T 337 Vit D 48.0

My Oncologist stated during my last visit that he thought we would wait a bit longer before there is any resumption of ADT. Zometa was also being considered as a replacement for the Fosamax that I have been taking for the past 6 years. Will continue testing every 4 months.