

306 unexpected journey.doc

Synopsis:

A newly diagnosed patient with a near doubling of PSA was advised to have a biopsy. The pathology report was borderline problematic. He resisted urological advice to choose a treatment within six months, reinforced by his cancer-knowledgeable partner. He chose Active Surveillance, including vigorous exercise and Mediterranean diet. He is most thankful for his current quality of life, “safe” PSA numbers, and the lifting of the cancer curse. Life is good!

UNEXPECTED JOURNEY, 5 pages

- 5/06 What started out at age as a routine yearly physical exam turned into a life changing experience. My PSA reading which had been between 2.2 and 2.7 for 6 years jumped to 3.84. My GP said I needed to talk to a Urologist and I made an appointment for early June.
- 6/06 I met with the Urologist and he explained to me that the significant jump in the PSA was concerning and may be an indication that I had Prostate Cancer. When he said the “C” word I almost fainted. How could someone who has no health issues, eats the “right” foods and exercises regularly have this happen. He said I should have a biopsy and I should schedule it ASAP. I scheduled it for early July.
- 7/06 I had a 12 core biopsy and then a follow up meeting with a second Urologist from the same group to review the results. My meeting with the Urologist was a life changing experience. When he “confirmed” I indeed had Prostate Cancer I probably turned white as a sheet. Even though he said prostate cancer was not life threatening and I could take some time-up to 6 months-to decide what I wanted to do he made it clear I needed to have some form of “treatment”. Upon further discussion I established that what he meant by treatment was surgery or radiation-the same as the first Urologist. After giving me a book to read which described my “treatment options” he told me to take some time and get back to him and we could set a date and the type of treatment.

I started spending about 12-15 hours a week surfing the internet, reading several books and starting to ask questions of any one I could about Prostate Cancer. I also found information on cancer support groups in Cincinnati on the internet-since no information was given to me by either Urologist. I started attending both the large and small Prostate Cancer support group meetings at the Wellness Community in Blue Ash. I found these meetings to be both moral support and a good source of information. The small group at the time could be from 5-10 people while occasionally having 12-13. The large group would be 20-30 with sometimes having more. Listening to the discussions in these groups I started to realize that virtually everyone had had treatment BEFORE they started attending the meetings.

By the end of August my mind set was that I needed to decide which method of treatment I was going to have and how long I was going to wait before I had it. I scheduled robotic surgery for early February in 2007. Little did I know how my life was going to take yet another turn that I totally didn't see coming.

9/06 One night while on the internet I received an inquiry from someone on Match.com. which I had been using to meet people for several years since I worked 70 hours a week and really had no time to "go out". This initial "meeting" has led to me being with my partner for nearly 6 years. Not only has the relationship been great but she works in the field of cancer risk assessment and the insight and education she has provided for me has been invaluable.

After meeting her I started reevaluating whether or not I should have treatment or pursue what was at the time called watchful waiting. Given my life style, quality of life was probably more important to me than most and just living for a long time to be alive had no appeal to me AT ALL. I race cars, scuba dive, have sky dived, am relatively young looking for my age and the thought of incontinence and ED did not appeal to me.

We embarked upon an aggressive pursuit of a doctor with whom I was comfortable and who was supportive of what was starting to be called "Active Surveillance". We went to 2 more doctors in Cin. and neither was any more receptive to the approach than the first two. We decided to go outside Cin and drove to Baltimore to John Hopkins. The experience was better; I was accepted into a clinical trial for people on AS but I was still not comfortable with the doctors I had met. We continued our research.

11/06 In Nov there was a panel discussion on cancer at The UC campus. I decided to go and at the last minute convinced my partner to go with me-that decision changed everything. One of the doctors on the panel, Dr. Charles "Snuffy" Myers, a medical oncologist and Prostate Cancer survivor, turned out to be one of the best known and most forward thinking doctors in the field of prostate cancer treatment. After talking to him after the workshop, he said I should come see him at his office in Virginia and discuss a plan for dealing with my "prognosis" which did not include radiation or surgery. The next day I scheduled an appointment with Dr. Myers for March 2007.

12/06 My partner and I discussed with each other what Dr. Myers had discussed with us after the workshop. We decided that his approach of Active Surveillance was where I wanted to go and I would cancel my surgery at least until we had met with him in March. My Gleason score of 3+3, PSA of 4.4, Free PSA of 32% and 3 positive cores out of 12 all with less than 5% invasion were good enough for me to feel comfortable taking some

additional time to make a decision which could cause me to have side effects I would have to deal with the rest of my life. I cancelled the surgery and continued my pursuit of information about Pca.

2/07 Dr. Myers had also told me to see Dr. Fred Lee in Detroit, Mich. before I came to see him in Mar. Dr Lee-also a Prostate cancer survivor- was the inventor of the Color Doppler Ultrasound. In short, the process uses the same type probe as traditional ultrasound but the image on the screen-which is viewed by the patient at the same time as it is viewed by the doctor-is in color just as you would view the radar screen on the local weather channel. Blood flow is shown in red and the other areas are primarily green and yellow. The greater the blood flow in an area the more red you see on the screen. Since cancer is hyper active cells with high blood flow areas with elevated cancer activity can be identified.

The key to this process is for the doctor to know what levels of blood flow are “normal” and what levels are “of concern”. The activity in my prostate showed very small areas of some elevated activity but according to Dr. Lee the activity was “clinically insignificant”. I was told to come back in one year unless my PSA began to rise before then.

Dr. Myers requested I have some blood work done before I see him in March. The results from the blood work showed that my PSA was down to 3.4, my Free PSA was 33, my Vitamin D level was 22 and my DHT level was 54.

3/07 Dr. Myers explained to me that my high Free PSA combined with a PSA that was falling without any medication was a sign that I may have had some inflammation causing the spike on my prior reading. The Vitamin D level was normal for someone my age not taking a D supplement and for general health I should start taking a D supplement until my reading was up around 60. He also said my DHT (Dihydrotestosterone) level needed to be brought down to <5 because testosterone is converted into food for cancer by DHT. I was put on one Proscar capsule per day. Finally Dr. Myer said that given the results of the Color Doppler Ultrasound his prognosis was that I did not need active treatment and there was a high probability that I could stay on active surveillance (AS) the rest of my life but we would just have to take things one day at a time.

I left Dr. Myer's office feeling like the weight of the world had been lifted from my shoulders. I knew nothing was definite but I also knew I had temporarily postponed having to deal with the probable side effects of treatment. I also had taken control of my destiny by committing to change my diet, exercise more and do everything possible to prevent having to have surgery or radiation at some point in time. I also knew that worst case I would have several years before I would have to have treatment. I also knew I may never have to have treatment and the side effects that go with it.

4/07 After leaving Dr. Myer's office I set out on the journey which I am still traveling today and hopefully will be for many years to come. The last 8 months had shaken my life to it's roots, created tremendous anxiety, caused me to go thru intense fear-anger-frustration-determination and resolve pretty much in that order. I think it is worth taking a few minutes at this point to share what my perspective is in hindsight on what occurred.

When I first heard the "C" word I was in disbelief. I had never had a health issue, exercised regularly and watched what I ate. Next I was scared I was going to die soon no matter what I did. Next I was very mad because I had tried so hard to be healthy. After doing some research and finding out about AS I was very frustrated; no doctors in Cin would talk to me about that approach. It was sheer determination and my "never give up" mind set that allowed me to find Dr. Myers. If I had not met him that day at UC I would have kept looking until I found him or someone else who would help me with my journey.

These are the basics of my program and although they will be fine-tuned over the years they will probably stay about where they are today.

My diet is not a low fat diet but a Mediterranean diet which means 4-6 portions of fruits and vegetables (preferably green) per day.

About 40% of my calories are from heart healthy fat such as almonds and pistachios, olive oil, Omega-3 fish oil found in fish such as salmon and tuna.

Ideally no red meat, egg yolks (which have the same Omega-6 as red meat) or dairy products. In small quantities these items can be eaten as a "treat".

Currently the supplements I take are Omega-3, Vitamin-D, Curcumin, Pomegranate, and resveritrol.

I exercise vigorously 4-5 hours a week during the cold months and 7-8 during the warmer months. I started doing running and biking events and have run marathons and several duathlons.

I continue to educate my self on what is happening in the area of PCa treatment so I have knowledge of what is available if I ever have to have radical treatment.

I have blood work done every 3 months to monitor my PSA, Free PSA, Vit-D, DHT, and testosterone.

2/11 Fast forward to Feb. 2011. It has been nearly 5 years since I first heard that “C” word. I have spent hundreds of hours trying to educate myself about what the most advanced treatment procedures are and what is “down the road”. There are a few things that I can say about my journey to this point.

First and foremost I have zero second thoughts about what I have done. I have had 5 years of living my life to the fullest-no ED or incontinence to deal with, no limitations on what I do and when I do it and if I were to have to have treatment now or in the future I have more options and the high probability of better results with less side effects than if I had had treatment 5 years ago. There is even speculation by some that in 5 years prostate cancer of all kinds will have a cure.

I thank God every day that I had someone come into my life that challenged me to think about the trade offs between quality of life and quantity of life. I decided if I lived 15 good years that was better than 25 so-so years. By the time I decided to cancel my surgery I was convince that given the low grade of my cancer the worst case was that I would live 15-20 years which would make me in my late 70’s. I want to live as long as I can still do the things I enjoy doing. Sitting in a rocker watching TV to me is not living. When I can’t be active most of the day, drive myself around (even if I can’t race cars), and at least walk 3-4 miles a day I am willing to pack it in and say “I had a good run”.

I’m sure many people will say,”Wait until you are that age and you won’t feel that way”. I guess I will just have to see because I am going to work hard at staying healthy so I can play hard and enjoy life. Where will it all ends up, only time will tell. Right now I would give you pretty good odds that I will live a long and healthy life. Why? I will eat the right foods, I will exercise strenuously, I will keep my mind fresh, I will relax and I will continue to nurture my spiritual beliefs in God who will make the ultimate decision when it is time for me to physically leave this world. Until that time I am going to grab for all the gusto I can.