

Don Walker's story

I'm a very active guy. I've always worked hard and played hard, with more hobbies and interests than I could cram into several lifetimes. But...there is not much I enjoy more than riding my Harley, whether cross country or just for the afternoon. So, when a friend of mine suggested we go on a Poker Run sometime in Late 2004 my wife and I readily agreed. The tickets were a bit pricey for our budget, but we were told the food at the end would be good and there would be some sort of grand prize for the winner of the poker hand, which didn't really matter because I've never won anything in my life.

One full house later I was stunned to be told we had won a week in Honolulu for 2 including airfare! I remember listening to a gentleman on stage going on about Prostate Cancer research, and I was surprised to hear that he had PC, as he looked so healthy. I wasn't even sure what a Prostate was, but Lyle LaRosh brought me up to the stage and presented me with the grand prize. Over the next few months I had several conversations with Lyle, squared away the logistics of our trip and he even paid for the airfare for my youngest daughter to accompany us on what ended up being the vacation of a lifetime!

I don't like doctors or hospitals and avoid them like the plague. I go to the docs when I can't stop the bleeding or a bone is sticking out. My wife had a new doctor at Kaiser Permanente whom she really liked, and had been trying to get me to have some sort of physical since I turned 50 in April of 2005. I didn't have time. A buddy and I were taking an 8000 mile bike ride to the East Coast and back in August and then I was going to climb Mt Whitney in September. But I caved in, and in January 2007 I had my cholesterol checked. I don't remember what the results were, but I do remember that something called PSA was a little elevated. PSA 6, should be below 3. Nothing to worry about, but an appointment was made to see a urologist 6 weeks later.

I packed my gym bag and kept my appointment with the urologist, telling a friend I might be a few minutes late for our racquetball game but he could warm up without me. The doc asked me all kinds of questions, did I have any problems urinating or any other symptoms? No, I felt normal, sometimes I got up once at night to pee, sometimes I didn't. Ok, time for the Digital Rectal Exam. I wasn't looking at my watch, but he sure seemed to prod and poke down there for a long time and I was relieved when it was finished. I cleaned up and sat back down in the chair waiting for his assessment. I cracked some joke about him feeling a lot of guys, and how did I compare? His answer caught me off guard. "Don, your Prostate feels abnormal". This was not expected, and a chill went down my back. "How abnormal" I asked, trying to sound nonchalant.

"Very" was the answer. "Do I have cancer?" Probably, but we won't know for sure until we do a biopsy" BIOPSY??? ME??? Nope, there must be some mistake. "Ok, on the off chance that I DO have Prostate Cancer, it is one of the slowest growing and most treatable, right?" "Yes, but let's wait for the biopsy". I didn't play racquetball on the way home.

The biopsy wasn't comfortable, but I was prepared to be a bit tender, and ready for rectal bleeding, and a week later my wife and I were in the doctors' office preparing to listen to the results. They were not good. Gleason 9 (4 + 5). This indicated a very aggressive cancer that included Neuro-Endocryn features. A CTScan would be scheduled, along with a bone scan to see how far the cancer had spread. The meeting remains fuzzy in my mind, but I clearly remember asking the Doc how long I had to live. His answer is burned into my brain. "Do you REALLY want to know? Think about it before I answer." "Yes" I choked. "2 years if you don't do anything." Ok, how long before I have symptoms and pain?" "I don't know, but the first thing

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you will lose is your appetite, you'll start losing weight and continue getting sicker." Trust me, at that moment I didn't think I would ever have an appetite again.

He went over my options, but strongly suggested that with my stage of cancer he leaned strongly toward surgery, feeling that I had a better chance than with radiation. I agreed, radiation just didn't sound like it was good for the body. I went home and started diving into studying PC. I've never studied harder for anything, made college seem like a cakewalk. My CTScan showed possible involvement with a seminal vesicle, more bad news as I knew what it meant to escape the capsule. Next stop, bone scan.

The technician explained the procedure for the scan, that it would take about 20 minutes and would be painless. About half way through, he re-enters the room and said, "Mr. Walker, don't move, but there are a few questions I have to ask you. First, are you in any pain?" "What? I thought this procedure is supposed to be painless." "I don't mean now, I meant when you came in." Well, yes, my neck hurts since I ran into the wall playing racquetball about 6 months ago." He laughed, seemed very relieved and replied "Mr. Walker, do you know you have a broken neck?" He suggested I see a doc soon after the bone scan. The bone scan came back clear, and we scheduled a meeting for Pre-op for surgery.

I continued studying everything I could get my hands on, and the more I researched the more confused I became. I had lots of questions for the urologist, but he never returned my phone calls or emails. I came to know one of his nurses well, who did a much better job of answering my questions, and reassured me that if he needed a urologic procedure, there is no one else he would prefer. Still, I had reservations. The pre-op meeting answered more of my questions, but still there was this nagging feeling that something wasn't quite right. 48 hours before surgery I left a strong message for the urologist requesting that he give me assurances that we at least had a fighting chance of getting it all. I finally received my call back 24 hours before I was scheduled to go under the knife. 7:30 in the evening in April 2007 he said he decided not to operate on me, that he would damage my rectum if he tried and that he was sending me to the Experts at Kaiser Sunset in LA who handled the "difficult" cases. Great...

Dr. Jon Kaswick has impressive credentials and a good bedside manner. He seemed very confident that I wasn't going to be dying in the next few months. I liked him. He introduced me to his protégé, Dr. Williams whom I liked equally as well. They took charge, seemed confident and had a plan. I was to get Lupron to stop the testicles from producing Testosterone in an attempt to shrink the tumors before they operated. I had done my homework, knew the side effects of the Lupron shots and the Flutamide pills used to avoid a Testosterone "bloom" with the first Lupron injection. Best of all, I now had TIME. Time where nothing had to be done right away, and time to do a LOT more research.

Lupron is an interesting drug. A chemical castration, it has been given to sexual offenders. I had just turned 52, and had a normal sex drive and relations with my wife of 30 years. Even though I studied the drug side effects I wasn't really prepared for them. I was sick for 3 days after the injection, and within a week my sex drive was gone. Completely, just like turning off a light switch. I could watch some sweet thing in a bikini, appreciate the nice shape but no sexual interest at all. Wow! It wasn't really too bad for me because if you don't want it you don't miss it, but I felt sorry for my wife. I'm a very confident guy, but having your libido disappear really affects the way you view yourself. If my wife wasn't so wonderful and understanding this part of

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the treatment would have been brutal. As it turned out for me, the mood swings were the roughest part. I immediately went into Menopause, complete with nasty hot flashes and serious mood swings. Attending my daughter's graduation from MIT was going to be an emotional experience, but I was not prepared for the unstoppable flood of tears and emotional mood swings. My wife explained that women have learned to deal with them all of their lives, but now I had the emotions dumped on me all at once without the benefit of years of practice. Whew...no more menopause jokes for me!

The hormone blockade worked. For about 3 months. My PSA which had reached 10 had settled down to 2.5, but then by the fourth month it started climbing quickly again, rising up to 7 in a couple of months. I told Dr. Williams (who Dr. Kaswick decided would be my primary doc) that surgery was no longer an option, that I had learned enough to know that there was no way surgery was going to cure me. I wanted a referral to see an oncologist and radiologist. Dr. Williams explained that there were no medical oncologists that specialized in PC in the Kaiser network, gave me a couple of names outside the network and would work on getting me a referral. Then he dropped me like a hot potato. I called regularly and left messages, did my due diligence and found suitable medical oncologists and asked for referrals. Still no response. Months went by. During this time I contacted Lyle for the first time, attended my first IPCSG meeting. In the meantime I confirmed with my Primary care physician at Kaiser that Dr Williams had indeed received all of my phone calls and emails, but still had not responded to me at all. A certified letter threatening litigation finally resulted in a phone call and apology, saying he thought someone else was treating me. Hmmm...

Lyle recommended I speak with Dr. AJ Mundt at UCSD med center. I called and to my complete and utter surprise I received a phone call from Dr. Mundt at 7:30 in the evening. We must have spent half an hour on the phone, he answered my questions clearly and concisely. I asked him to send me the bill or he could use a credit card, and I was stunned when he said no charge, he was glad to help! Wow, I wasn't even a patient yet! I made an appointment to see him, did the background check and was absolutely confident that I was dealing with the very best radiologist and oncologist on the West coast as well as the best facilities. My appointment confirmed my feelings that I was in the best possible hands. I was ready to go on January 1, 2008 when we changed from Kaiser to Aetna.

By January 2008 I was paying to see Dr. Lam, who took me off of Flutamide and put me on Casodex and back on monthly Lupron injections. He suggested chemotherapy, using Taxotere (a primarily breast cancer drug) in order to try to shrink the tumors before trying radiation treatments. I could not afford the chemo through his office, and had to wait 2 months until the first of the year to change insurance companies.

It was around this time that I had an epiphany. Dr Lam recommended a couple of books to read, about nutrition. I had already been reading everything I could get my hands on about PC and didn't need to study nutrition. I KNEW what was good for me, the only problem was actually doing it. Or so I thought. My mom was a health nut, exercised a lot, played tennis several hours every day, ran small marathons and races, didn't drink alcohol or eat red meat. She died of breast cancer at age 57, although there was no history in her family. I grew up on salad sandwiches, fresh veggies from her garden and constant lectures about nutrition. She (and I) drank NONFAT milk (you know, no fat, lots of Calcium and good stuff) and when we had meat always had lean cuts. I exercised, have always been very active and eat lots of veggies and fruits, along with my

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gallon per week of nonfat milk, cottage cheese and yoghurt. So, no need for me to waste my time on nutrition books, I would just eat better than I had been and spend my time studying PC. My wife got the books at the library, and half way through the first INSISTED that I read it. "The China Study" by Colin Campbell. I was astounded and shocked by what I read, and frankly felt that in my emotional state was willing to believe anything. I bought the book for my daughter who had just graduated from MIT where many of the studies in the book were referenced. Cindy pulled up the studies and confirmed they were scientific and legitimate. I changed my lifestyle (as did my wife, my daughter, her fiancée and a variety of other people I have given the book to)

Dr. Lam and Dr. Mundt agreed that a full course of chemotherapy should be undertaken prior to radiation in an attempt to shrink the tumors, which by this time had invaded my rectum and bladder as well as possible involvement in some lymph nodes. Unfortunately, Dr. Lam was not covered by Aetna, and again, we could not afford chemo. The doctors recommended a Dr. Vicario down here who IS covered to actually administer the chemo. Here I had my great team working for me and had to change doctors again! No worries, the referral was great and I would highly recommend Dr Vicario at the San Diego Cancer Center. He is open to new ideas, and is willing to work with me even when my approach may be contraindicated. Dr. V explained that I did not fit the "norm" of age, aggressiveness and type of PC and there was no clear definitive answer as to what exactly would work the best. With the neuroendocryn features of my cancer he felt that rather than using Taxotere as Dr Lam suggested, a combination of Carboplatin and VP16 might be better. I understood his logic and the first week of January 2008 I started on my chemo regimen. Five hours a day, four days a week for 5 months. I learned that doctors don't want to tell you about all of the side effects as people don't get them ALL. After just one course my tinnitus (ringing in my ears) increased and became permanent. It seems the Cisplatin can cause hearing loss among other things and they changed the drug to Carboplatin. I found it is critical to fully understand ALL of the possible drug reactions and take full responsibility for your own healthcare. I had many of the typical reactions to chemo. I became very close to the porcelain god, lost all of my hair, had sores in my mouth, food tasted funny and sometimes was not edible. Even though I had a hard time keeping food down I gained 25 pounds during chemo because of the powerful steroids given along with the chemo drugs to keep some of the reactions down. I continued to work at my job, had good weeks and bad and managed to take several long vacations and motorcycle trips during this time. In April the doc ordered a CTScan to see how well the chemo was working. Results? It wasn't. It beat me up, but did not shrink the cancer at all. However, a necrotic "hole" had developed in the center of the large tumor. Chemo should work from the outside in and neither Dr Lam nor Dr. Vicario had any explanation. The center of the cancer had died. Could this be from the diet change? No way to prove it, but I am convinced.

I started radiation May 5, my PSA was 4.73. Five days a week for 6 weeks. While radiation has its own set of side effects, in my case they were a piece of cake compared to chemo. The most difficult was the constant fatigue. I was ALWAYS exhausted, kind of lived in a fog but I continued to work and tried to live as normal as possible. I made a unilateral decision on June 1 to stop taking Lupron. I didn't feel that it was working, and that the side effects of no Testosterone carried too large a risk of heart attack and osteoporosis. Dr. Vicario did not agree, but let me drop Lupron and triple the amount of Casodex. I also started on Avodart and Femara (to lessen the side effects of the hormone blockade) Testosterone should be between 200 and 800, mine had dropped to less than 5. I had my last Lupron shot June 1.

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By June 1, while still on Radiation treatments my PSA had dropped to 1.63 from 4.73 a month earlier! It seemed that I was responding to the treatments!! My radiation was over at the end of July and I was stressing over my decision to stop taking Lupron. PC is supposed to be hormone dependent, and increasing my Testosterone is contraindicated. I was feeling much better so I could tell my T was increasing, but what effect would it have on my cancer? Dr. Mundt said to ignore any PSA tests for at least 3 months after stopping radiation as the values could be all over the board. Me? Ignore a test? Hardly.

My next test was August 14. As suspected, my Testosterone had increased from less than 5 to 416. And... my PSA had dropped to .3, along with a corresponding drop in my cancer markers. By September 4 my PSA had dropped to .1 I was thrilled! Done with radiation, done with treatments, now just wait to see if I am Cured!!

A visit with Dr Lam set me straight again. In his opinion there was a 90% chance of the cancer recurring. He suggested another full course of chemo, which would increase my odds to 75% to 80% chance of it recurring. Not great odds, and I debated long and hard with myself whether the POSSIBLE improved odds were worth the definite damage the chemo does to the body. My hair was back, I was feeling and looking great. The thought of going back to poisoning myself again was just devastating. Dr. Lam's own brother opted NOT to have chemo to treat his PC, but again, everyone is a different case. With serious discussions with family I decided to start the chemo, this time using Taxotere as originally recommended by Dr Lam. I had my first infusion on Sept 4. No sickness this time but in two weeks like clockwork my hair came out again. Just in time for winter! Other than hair loss, the side effects of the Taxotere are much milder than the previous drugs. Fatigue is a problem again as the white and red blood cells get killed off. Neulasta is a drug given along with the chemo to help increase blood cell production in the blood marrow, and this time I had 2 days where EVERYTHING hurt, my teeth, fingernails, toenails, and every joint in my body. But, it only lasted a few days. Fifteen more weeks and I'm done! (I hope).

To sum it up, in my specific case I'm convinced that a combination of very aggressive treatments was required due to the extreme aggressiveness of my cancer. I have no doubt that it will come back unless I keep it in check with my change in diet. Nothing extreme here, not even a COMPLETE vegetarian. But, I have eliminated all milk products, and drastically cut down on animal protein. I have continued with lots of vegetables as I have all of my life, but have introduced many more grains and nuts. I continue to study everything that I can and will continue to learn more for the rest of my life. I have found that the doctors really don't know that much, and that if you don't take charge of your own healthcare, you may as well give up. Ask lots of questions and if the doc doesn't like you asking, change doctors. (I have had consultations with more doctors than I can remember)

If any of my experience of knowledge can be of help to anyone please let me know. I will never forget how devastated I was, nor how helpless I felt. A great guy who became a friend in San Francisco helped me through some very hard times and I am deeply indebted to him. Another friend literally saved my life when I was considering ending it. I had no idea that he had a different cancer, far more serious than mine and he verbally "kicked my butt" all over the place and made me stop feeling sorry for myself.

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So, if you see me at an IPCSG meeting, or anywhere for that matter and have any questions, please don't hesitate. I'll answer anything you ask, no question is too personal. I check email regularly, madhatter@nethere.net or feel free to phone ANYTIME (619) 445-3318. If there is any way I can lend a little help to anyone I would be honored.

Don Walker "EVERYONE DIES, NOT EVERYONE LIVES"