



Spirit Lake Tiyospaye

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What I Learned from Cancer

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Those of you who know me and/or read my blog know that I have prostate cancer that has spread to my lymph nodes. When prostate cancer spreads outside the prostate, it is also called metastatic cancer. This article is to inform people who are curious as to how I am doing, but are too polite to come right out and ask. It is an in-depth look at my personal battle with prostate cancer.

Special Issue!

This month, we have a special issue in which Dr. Longie discusses his on-going battle with cancer and what it has taught him.

In early 2008, before I was diagnosed with cancer, I was traveling home from Grand Forks, N.D. It was morning -- around eleven -- when I noticed what looked like a large deer crossing the road up ahead. It was right after I passed the Larimore rest area. *This is odd, I thought. Deer are not usually active at eleven in the morning.*

As I came closer to the deer, I noticed it was not a deer at all. Instead, it looked like a large dog. Finally, when I drew abreast of it, I saw it wasn't a dog, either. It was a wolf.

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It had stopped on the other side of the ditch, and had turned and looked back at me. I was excited. It was the first time I had seen a wolf in the wild. I immediately told family and friends about it when I returned home.

A couple months later, I went on a trip to South Dakota with a cousin. On the way down, I told him about seeing a wolf. My cousin is a traditional sort of person, and he immediately told me that it was a good sign that I had seen a wolf. I agreed with him. I was sure that it was a good sign.

Months later, several weeks after discovering I had cancer and somewhat discouraged by the tenacity of the disease, my thoughts returned to seeing the wolf. Feeling sorry for myself, I thought, "Boy, did we misinterpret the sign of seeing that wolf!"

However, after months of battling, living with and accepting my cancer, I realize we did not misinterpret it -- seeing the wolf was a good sign. A wolf is known for his courage and ferocity in

battle, his perseverance, his endurance in bringing down prey he needs to live and his strong will to survive. These are exactly the characteristics I need to win my battle with cancer.

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I believe my experience with cancer started several years ago. One cold winter evening in 2000, around ten o'clock, I was sitting in front of my computer when I felt the flu coming on. Forty-five minutes later, much to my surprise, I was lying on my couch, flat on my back, so sick I could barely move. I never had flu symptoms progress so rapidly.

Over the next few years, my flu-like symptoms became more common and more frequent. Finally, after two weeks of feeling great in the morning, but horrible in the evening, I decided to go to the doctor. The doctor ran several tests. One of them was a prostate-specific antigen (PSA) test, a test used to screen for prostate cancer.

The PSA test came back and the measurement was seven nanograms per milliliter (ng/mL) of blood, a fairly low measure.



“The results came back positive. It was cancer.”

Dr. Erich Longie

The doctor told me I had a prostate infection -- not cancer - and he prescribed strong antibiotics. The antibiotics worked fine at first, but my symptoms kept recurring. Over time, I found the antibiotics were less and less effective, and my PSA number kept rising. (A rising PSA number is a sign of an infection or something worse, such as cancer.)

Prostate-specific antigen is a protein produced by prostate gland cells. A PSA test measures the level of this protein in the blood. When cancer or other disease is present, the level of this protein often rises. Because the body produces PSA and its level is affected by the presence of disease, it is sometimes called a biological marker, or tumor marker.

Finally -- after a couple of years on antibiotics (seven years after that first episode of flu symptoms) -- the doctor ordered a biopsy. The biopsy for prostate cancer was performed, and the results came back negative. The doctor did explain to me that although the results were negative, it did not mean that I was cancer-free.

“We only tested parts of your prostate,” he told me.

I continued to take medication for my prostate until September 2008, when I needed an annual prescription renewed. Prior to filling the prescription, doctors took another PSA test. This time, the number came back at 26.8 ng/mL. My doctor immediately ordered another biopsy.

The results came back positive. It was cancer.

(continued)

From that moment, my life changed forever.

I was shocked to say the least. I enjoyed good health all my life. I could not comprehend why I would get cancer. Wow! I thought. *What happens next?*

After my initial shock, I recalled what I knew about prostate cancer. When my prostate problem would not go away, I did a considerable amount of research on prostate problems. I had learned about benign prostatic hyperplasia (BPH), also known as an enlarged prostate, which is the growth of the prostate gland to an unhealthy size. I also read up on prostate cancer, so I knew prostate cancer is highly curable when caught in its early stage. However, I also knew the side effects from the treatment for early prostate cancer (which includes an operation to remove the prostate) and absolutely did not want to experience them.

The hardest part was telling my children. I called them together and told them the bad news. Although I told them many men survived cancer and that I probably would too, they still took it hard. I hugged each of them in turn as they cried.

My mother passed away in 1987. At first, I made periodic visits to her grave bringing her a can of pop and a candy bar, something I had done often during the last couple of years of her life. As these visits became less frequent, I only went to her grave when some thing catastrophe happened in my life. The last time I had gone to visit her grave specifically was when my son Joel died in 2001.

I visit my son's grave frequently (I put a rose on his grave the first of every month.). And as he and my mom are buried next to each other, I indirectly visit her grave as well. However, the weekend after I found out I had cancer, I went to the graveyard with the purpose of visiting my mom's grave. While I was there, I was overcome with self-pity and cried for a while.

When I finished crying, I made a promise that, for the sake of my children, I would never cry again no matter how sorry I felt for myself. I then asked my mom and my son for strength and left their graves. I felt surprising good the rest of the weekend.

When news of my cancer got out, I wasn't surprised by the amount of support I received from my family, relatives and friends. After all, Indians are the most generous and helpful of all people and they rush to help someone in need. After being asked, "How are you doing?" so many times, I wrote a blog entitled *How Are You Doing?* When someone would ask me how I was doing, we would talk about it for a little bit and I would refer him or her to my Web site, which had a lot of information.

My three children -- Angela, Marshall and Ryan -- came with me to Grand Forks when I was to undergo the operation to remove my prostate. During the operation, the doctor tested several lymph nodes. They came back with microscopic traces of cancer.

The cancer had spread.

He immediately stopped the operation, did not remove the prostate, and sewed me back up. Apparently if the cancer has spread, removing the prostate does no good. In other words, the method of treating prostate cancer changes if the cancer has spread.

I recall, right before I woke up in the operating room, my son Joel, who went to the spirit world several years ago, came walking up to me. He looked older. When I woke up, I felt really good, because I had seen my son. That's why it came as a real surprise when the doctors told me my cancer had spread. My daughter cried, and my sons, Marshall and Ryan, were extremely saddened by the news.

I know my children were bewildered by my seemingly calm acceptance upon hearing the bad news. There were several reasons why I did not show any reaction. First and foremost, I did not want to appear weak and/or scared in front of my children. Second, my son Joel's "visits" are few and far between. When he does pay me a visit, my happiness of "visiting" with him is so great that it pushes everything else (in

this case, the bad news that my cancer had spread) to the back of my mind. Lastly, at that point, I was convinced I would win my battle with cancer and the news that it had spread just meant my battle became a little tougher – that's all.

After my operation, I was sent to the Altru Cancer Center to undergo radiation treatment. I met with Dr. Winchester and he told me I would have to undergo 37 radiation treatments. In preparation for my treatments, I had my body literally tattooed (among other things) and mapped so the technicians would know what area of my body to expose to radiation. My radiation treatments started November 17, 2008, and ended January 9, 2009. Because I resided out of town (the treatments were done in

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Grand Forks), Dr. Winchester helped make the process easier on me by letting me pick the times of the 15-minute treatments.

Every day, when I walked into the Altru Cancer Center, I saw these words on the wall:

"Life is measured in years, but when you live with cancer, it's divided into moments."

At first, I did not see the wisdom in these words. However, by the third or fourth week of treatment, when the side effects from the radiation began to rack my body, when I became tired of receiving treatments every day, when I lost my appetite and had to force myself to eat, when my constant diarrhea and bladder issues made it important to be near a bathroom all the time, when I saw many other cancer patients much worse than me, when insomnia kept me awake all night, when the cruel reality of having cancer began to sink in, then the wisdom in these words slowly became apparent.



This newfound wisdom led me to focus on whatever particular activities I was doing. It pushed me to enjoy those activities without letting myself become distracted by other issues. Whether it was playing pool, visiting with friends, shopping, eating, sleeping, working, or the weekends I spent with my children and grandchildren, each activity was special.

There have been many poignant moments in my life since I finished my radiation treatment, too many to put in this newsletter. But I will list a few that were the most memorable:

- On the day I received my last radiation treatment, I attended the North Dakota State Pool Tournament in Minot. Pool players are the biggest liars. They are bigger liars than poker players, fishermen; you name them, pool players could out-fib any of them. Pool players are also notoriously self-centered. They only pretend to listen to someone, and then they talk about themselves as long as anyone is in the vicinity to listen. In spite of these character flaws, several pool players made it a point to come sit by me, ask questions, listen to my story and offer me encouragement. I was humbled by their generosity with their time and their willingness to set aside their own egos to come and give me support. The conversations I had with them lifted my spirit when I needed it most. (Coincidentally, I won 1st place in the Men's B Division.)
- One day, I received a call from my 5-year-old granddaughter Ashlynn. I did not know she was my grandchild until a year or so ago. But from the first moment I saw her, I knew she was my

grandchild. We bonded immediately. I go visit Ashlynn every now and then and take her out to eat and to buy her toys, clothes and stuff. She also calls me occasionally and asks me how I am doing.

She called me one day, and after talking with her for a while I thought we were finished talking, so I said goodbye to her and hung up. She called me right back up and gave me hell for hanging up on her.

Apparently, I hung up before she was done talking to me. Then she asked me, "Are you a good Grandpa or a bad Grandpa?" She was teasing me because I always ask her if she is a good girl or a bad girl. Finally she said, "Grandpa everyone is saying you are sick. I keep telling them you're not. Grandpa everyone says you are sick..." Her unspoken question, "You're not sick are you Grandpa?" hung in the air. I could tell by the way her voice sounded she was mad at everyone for saying I was sick.

Not knowing what to say I kept quiet for a while. Not wanting to lie to her even though she is was only five years old, I finally said, "Grandpa has cancer granddaughter, but I will be all right." There was a pause and then she said brightly, "OK Grandpa, bye."

I didn't know whether to cry for her because she is so sweet and innocent and accepted my assurance I was "alright" without question; or to smile and feel happy because her unconditional love for me prompted her to get mad when "everyone" said I was sick. So I did both.

This past February, six weeks after my radiation treatment, I went back to the doctor and he measured my PSA. It was 0.5 ng/mL, which is not bad but is right at the borderline. At that time, the doctor told me my cancer would eventually find a way around the cancer-suppressing drug I was taking. This would be indicated by a rising PSA level. Finally, he told me I had approximately five years to live. I did not press the issue at the time because I was sort of in shock. I never once believed cancer would get me. Now the doctor was telling me I had five years left? Wow! He gave me another shot of the cancer-suppressing drug and made a follow-up appointment for July 9, 2009.

When I left the doctor's

office that Friday my mind was in turmoil. I just couldn't accept the fact that I had only five years to live. It was a horrible weekend. I seriously considered not telling my children the truth because I did not want to see them cry for me again. But, I soon realized I would be committing a gross act of disrespect if I were not honest with them so I told them. I am glad I was honest. It is much easier facing my cancer together.

There was yet another incident during this time that helped me accept my cancer. One evening when I was alone and feeling low, my thoughts turned to my son (Joel) in the Spirit World. As memories of him went through my mind, I had a sense that he "was in the room with me."

The feeling became stronger, and although I did not physically feel, hear or see him, I swear he and my mother gave me a hug. I immediately felt better. After this incident, I soon came to terms with the idea that I had five years (maybe) left to live and I put my

depression behind me.

I have a true friend, the kind that only few people are lucky enough to have. Her name is Dr. Carol Davis and she's from Turtle Mountain, N.D. She is the kind of person who will steadfastly stand by her friends under any circumstances. Her kindness and compassion helped me tremendously when I my son Joel departed for the Spirit World. She is such a strong person that some of her strength and courage would stay with me long after I would visit her to talk about Joel.

Now she is constantly encouraging me to remain strong. So when I had a dream that really bothered me, I wrote it down and e-mailed it to her. She e-mailed me back with a really tough question:

Do you think you are doing everything you can in your fight against cancer?

I told her I honestly didn't know. I went on to say how helpless I felt at times because I had done a lot of research on prostate cancer and all the information says the same thing – prostate cancer is highly curable if treated early but once it spreads there are very few options. I went on to talk about how hard it is to keep negative thoughts out of my mind 100 percent of the time and that my life would be a lot less stressful if I "just accepted" the inevitability of death from my cancer and didn't worry about my cancer until it got me -- after all, we're all going to die at some point. I also told her that waiting until each checkup to see if the cancer has spread is stressful. I told her I have a "get it over with" mentality at times. Finally I told her if I just accept my situation, I can start preparing to go to the Spirit World and will not have to worry about check ups, new cures, etcetera.

As my July 9 appointment date drew near, I begin to worry that the checkup would reveal bad news. At my last checkup, the doctor told me I had approximately five years to live. What bad news would he tell me this time? I was also becoming increasingly tired of the side effects from the drug I was taking to help suppress my cancer. A couple of months ago, I read a study about pomegranate juice and its positive effect on prostate cancer. The studies indicated by drinking eight ounces of pomegranate juice every day men with advanced prostate cancer were able to keep their PSA level low for almost five years. The brand of juice used in the study was called POM Wonderful Pomegranate Juice. I went to a health food store in Grand Forks and ordered a case of it. If the juice were to work for me, it would double my life expectancy.

When July 9 rolled around, I had made up my mind. I was going to inform the doctor that, for the sake of my children and my grandchildren, I would take the cancer-suppressing drug one more time. If cancer was going to get me anyway, there was no sense in suffering from the side effects anymore. If cancer was going to get me anyway, there was no sense in suffering from the side effects anymore. I would quit taking the drug, and I would depend on pomegranate juice to extend my life.

Part of my checkup is to have my blood drawn to measure my PSA. However, I was so convinced that my PSA had risen that I did not wait to hear the result of my PSA test. Instead, I told the doctor of my intention to stop the cancer-suppressing drug. Naturally, the doctor strongly advised me to continue taking the drug, but my mind was made up. We talked about how he would help me get into clinical trial for men with prostate cancer. When we finished talking (We debate the Fighting Sioux Logo every visit.), he ordered the nurse to give me a shot of cancer suppressing drug and I left.

A couple of hours later, I checked my messages and there was one from my doctor.

“Erich, your PSA results came back and it was 0.09,” he said. “That’s excellent, the radiation and cancer-suppressing drug worked.”

He made sure he stressed the cancer-suppressing drug. I was stunned. I could hardly believe it. I quickly calculated what that meant in years and I knew I was going to live five more years -- with a good possibility of living several years beyond that.

In spite of how I felt before my July 9 appointment, I just cannot and will not let cancer get me so easily. I am a stubborn guy and I will not let cancer get me just because it is known as terminal illness. In addition, I feel I can overcome anything once I put my mind to it, cancer is no different.

Although my PSA count is low, I know the battle has just begun. As much as I can be, I am prepared emotionally, physically and psychologically to fight this battle. I concur with a young girl I saw on TV who had cancer. She said, "I know this sounds strange but having cancer has given me a positive frame of mind".

The doctors tell me once you have had cancer, you are always a cancer patient. If cancer is not present, you are in remission, not cured. This is something I will have to live with the rest of my life. It changes you -- in some ways, maybe for the better.

Maybe that was the significance of seeing that wolf so long ago. Maybe it was a sign that life was going to change for me, and it would be for the better. Maybe my son Joel was trying to tell me everything would be all right and not to worry. I don't know. Time will tell.

Right now, I have a "do not sweat the small stuff" attitude and my cancer does not scare me any more. I changed my diet somewhat. I exercise an hour-an-a-half a day, four days week. I am drinking pomegranate juice every day (I order a case at a time.). I have more energy now than I had in a long time. And I will continue to try to get into a clinical trial some place. Right now, I have no doubt that I will be in the 44 percent of men with metastatic prostate cancer that live 10 years and that I will go on to be among the 19 percent that live 15 years.

What it comes down to is not asking the Creator to win this battle for me, I have seen too many cancer patients much worse off than me so it is hard for me to ask the Creator for help, instead I ask him for the courage to put up a good fight. The outcome will take care of itself.

I think we all know that our bodies grow old and deteriorate over time. Sometimes, cancer is a part of that process; sometimes, the process is driven by something else (heart disease, diabetes, dementia). No matter the cause, we know we will one day die, and that is not necessarily a bad thing. When I die, I will be with my son, Joel, again. Eventually, we will all be together in the Spirit World. I look forward to that day. Dying is part of life.

But while we are alive, we can live each day fully. I am still alive in this world, and there is much to do and much to enjoy: spending time with my children and my grandchildren; places to visit; pool tournaments to win; good food to eat; more proposals to write with another very good friend and business associate Dr. Annmaria De Mars; and most of all, the visits with my friend Dr. Carol Davis, where we repeat all gossip we've heard since the last time we visited. When we run out of gossip, we make up stories and tell each other little lies -- like we think the other one doesn't know.

NEW COURSE NOW RELEASED: Courageous and Ethical Managers

The first session of the Courageous and Ethical Managers course was taught last month on the Turtle Mountain Reservation. Based on the strong response, we are offering two other sessions:

Friday, August 14 – Spirit Lake Nation

This all-day workshop will be taught at Cankdeska Cikana Community College, beginning at 9 a.m.

Friday, August 21- Turtle Mountain Reservation

This all-day workshop will be taught at Turtle Mountain Community College beginning at 9 a.m.

Courageous and Ethical Managers course is also available on-line FREE for the next 60 days.

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