

302.Epiphany: My Proton Photon Prostate Cancer Journey
302.epiphany.doc, 17 pages

1. Cancer diagnosis out-of-the blue at age 59

When my urologist informed my wife and I that I had prostate cancer, the news came out of nowhere. That famous image of Indiana Jones being chased down the tunnel in the temple by an enormous round boulder that suddenly appears out of nowhere came to mind. That was us. Unfortunately, bad news is often delivered like a large boulder coming right at you out of nowhere. My biopsy found cancer in both lobes in 6 of 12 samples. At nearly 59 years of age, I had led a highly active, healthy, and illness-free life up to that point. Illnesses were extremely rare. Missing a day of work was something that happened once every three or four years. Doctor visits were rare because I always felt great. Why would I have to worry about prostate cancer when an occasional cold was as sick as I ever got? If the doctor hadn't told me that I had an illness, I never would have known.

The meeting with my urologist was preceded by a PSA test performed by my family physician during a routine physical a few months before. My GP had detected a rise from 2.0 score two prior to 6.8. My family doctor recommended the urologist who in turn said a biopsy was in order, which he performed in early December 2008. Due to the holidays, we agreed to discuss the biopsy results in person after the first of the year.

2. An enlightened urologist urges research before decision

Towards the end of the bad news meeting in early January 2009, my urologist recommended that I do something that I have come to learn was extremely rare for urologists to do: he suggested I research prostate cancer and the different

treatments. He said that the cancer definitely needed to be treated and that surgery (prostatectomy), internal radiation (brachytherapy) or external radiation (several options) each offered the potential to cure me. He told me, "You need to get your head inside this issue and figure what you think is best for you. We'll meet again in six or seven weeks and discuss what you've learned." He handed me a book about prostate cancer along with a few brochures. I asked him if he knew of a way to get in touch with other patients and he referred me to the Wellness Community Center in Blue Ash. As my wife and I drove home that evening, she was shocked and I was bewildered and moving toward anger.

3. Networking at Wellness Community

I came to realize the wisdom of my urologist's approach as I heard the prostate cancer stories of other patients two days later at the Wellness Community Center and through networking with other patients around the country. It still amazes me when I hear a patient say that his doctor informed him that he had prostate cancer and then told him to schedule surgery as soon as possible. No research. No options. No patient involvement whatsoever. Patient involvement, as I learned through my research, increases the chances of a successful cure. Patient involvement also brings a "qualitative" perspective to the problem while doctors tend to be more "quantitative." Avoiding impotence and incontinence may be high on your list while saving your life may be the sole item on your doctor's list. The anger that I had over learning that I had prostate cancer was channeled into researching prostate cancer, which I did with total abandon.

The next morning following the evening meeting with my urologist, I started researching prostate cancer beginning with the book he'd given me. It was general in scope, but a fair starting point. I also began visiting websites. Late in the

morning I visited the Wellness Center and spoke with a few people who worked there, but weren't prostate patients. I learned that a group meeting for prostate cancer patients and survivors would take place the next evening and I decided to attend.

The meeting lasted two hours. My hope was to hear the successful stories of other patients. In fact, the meeting focused on the problems of post-treatment survivors. Those in the meeting seemed to be in more need of help than me at that point and I said to myself that I needed to look elsewhere to find men who had successfully survived prostate cancer. The meeting did increase my resolve to find a successful treatment even though it was not evident among that group that night.

4. Plan needed before telling family about my disease.

One of my first issues was how to handle the news with family and friends. My wife and I have two grown children who live away from home, and I was worried most about how to break the news to them. What I decided to do was to tell them nothing of my cancer until I had a clear plan of treatment defined. My reasoning was that I didn't want to simply "dump" my problem on other people without a positive outcome in sight. Telling people prematurely struck me as "emotional littering" because simply passing my problem to someone else meant neither of us knew what to do about it. As an executive in business, I always asked people who worked for me to look for problems AND solutions. When someone walked in my office and said, "We have a problem," my first response was always, "Thanks for catching the problem. What do you propose to fix it?" I followed my own approach from business and decided to nail down the solution before sharing the news. I waited until I decided on a treatment and knew the start and completion dates. This approach made it extremely easy for me to tell

my children, my relatives, and my friends. Keeping it under wraps before releasing the news was difficult for both my wife and me, but I was glad we handled it the way we did. The emotions of our family and friends weren't wasted by the fear of the unknown. We told them exactly what was going to happen and when.

5. An epiphany leads me to important attitude adjustment.

Another initial problem was my attitude. At first I was bewildered, then angry, and then overwhelmed. I felt that I was thrown into a situation requiring years of medical education and I was totally unprepared. I didn't believe that I could render a successful medical decision that would save me from prostate cancer. During this time I was swimming daily and had an epiphany or moment of clarity while doing laps. The thought was this: you need to take the attitude that you will definitely beat prostate cancer because others have certainly done it before you. Once I adopted that attitude and declared victory, it was a matter of developing the winning battle plan. That change in attitude restored my clear thinking, bolstered my confidence, and set me on a path I felt good about. I know this little story about adopting the right attitude sounds corny and something that Dale Carnegie might have written, but it's true. A different attitude was a critical juncture in my prostate cancer journey.

6. 110% effort to become professional patient.

I had the good fortune to be self-employed, which meant that if I deemed prostate cancer the most important issue in my life that I would commit to solving it with 110% of my daily efforts. For nearly seven weeks, ten to twelve hours a day, I worked at becoming a professional prostate cancer patient. I used books, the Internet, and networking with

patients and doctors to get an education on prostate cancer and treatments. If I read a clinical research study and had questions, I would track down the doctor and try to talk to him or her. For example, I came across the name of a cancer patient in Knoxville who had posted a letter on a New York Times prostate cancer blog. I tracked him down and spoke with him and received helpful information. Sometimes I was successful reaching resources that way. Sometimes I wasn't.

Although I knew that I could select only one form of treatment, I kept my options open. I didn't know where the research would lead, but I wanted my final decision to be the right one for me.

7. First major problem: PCa data not aggregated

Early in my research I uncovered two major problems. The first is that the data on prostate cancer is not aggregated. It is in ten thousand bits and pieces in a variety of clinical studies and anecdotal stories. I was searching for The Big Picture of Prostate Treatments that would help lead me closer to a decision. As I stepped back from the research I was doing, I felt that given the small number of variables (data points) across the prostate cancer landscape such as age, PSA test levels, T scores, general health, morbidity, morbundity, incontinence, velocity, impotence, treatment choice, and possibly a few more, that the overriding picture of prostate cancer must exist somewhere. Certainly some organization has assembled this. I looked for it everywhere, but didn't find it. While discussing my frustration over my research with a radiologist, a doctor who I met with for a third opinion, he somewhat smiled and told me the Holy Grail of Prostate Cancer Research doesn't exist. He agreed with me that the data had not been aggregated and should be. He went on to tell me that once cardiology pulled it's data together to determine what worked and what didn't, heart

attack deaths were cut in half. Unfortunately, this has yet to happen with prostate cancer treatment. It's shameful that it hasn't. I realized at that point that I was left to cobble together pieces of research to form my own picture based on my needs.

8. Second major problem: data reliability

The second problem I encountered was reliability of the data. I became suspicious of the data for two reasons. The first was that many of the clinical studies, which I was able to access online, had small sample sizes, universes of under 200 men in some cases. This is common in medicine I learned. Since I was used to relying on marketing research in my work, sample sizes of 400 to 800 were considered minimums for reliability. For example, I came across an advertising message of a prostate cancer treatment that claimed quantified superior results (10% better!) over another treatment. I checked the footnote, found the clinical study, read it, and learned that the study included only 187 men. Small research study. Big advertising claim. The second reason was that the research subjects, i.e., middle-aged and older men, were unlikely to be forthcoming, candid, and honest about their conditions and side effects. How many men would volunteer that they were now impotent, incontinent, unhappy, and depressed? Even some of those who survived successfully probably didn't want to discuss their personal prostate cancer experiences. Many probably chose to move on with their lives and simply not think about it.

9. I wasn't a doctor but became one hell of a patient!

Despite these two undermining conditions of prostate cancer data, I continued my research in hopes of getting a clearer picture of my options and then selecting the best option for

me. I came to the conclusion that the available data could give me a general direction of what made sense. For the specifics, I relied on the anecdotal stories and personal experiences of survivors. It is a hit-and-miss approach because I was relying on contacts of other patients, but it's all that I had.

Within a few weeks I found that I had learned a substantial amount about prostate cancer. The more I learned, the more I was able to learn. More and more of the research made sense to me even if I didn't always agree with it. My conversations with doctors and patients across the country grew longer and more beneficial. I reached a point that I could hold a meaningful, productive conversation with doctors about my treatment options. I was beginning to feel that I had a grip on the situation. I wasn't a doctor, but I was becoming one hell of a patient. My anger was replaced with the confidence that I would find the best treatment for me.

10. Awoke to conclusion: medicine all about precision.

After four weeks of research, I was leaning towards proton radiation treatment, but had yet to make a final decision. One night I woke at 3:00 a.m. with the thought, "It's all about precision." Medicine is about precision. For me, the most precise treatment was definitely proton radiation. It was more precise than brachytherapy and surgery. A list of other reasons also entered into my final decision, but the thought about precision was critical in my decision process. If my prostate cancer was a page from a coloring book and I was searching for box of Crayolas, most of my options were cans of spray paint. I wanted something more precise.

11. Sharing thoughts brought backlash from doctors.

As I met and spoke with other doctors to get additional opinions and points of view, I would wait until they felt our consultation was over and then I would ask if I could run my thoughts by them. Usually, they would say, "you're healthy so just have surgery." When I said that I was leaning towards proton radiation, I was met with strong backlashes on two occasions. One was an urologist, who went on a rant about Medicare costs and proton treatment for prostate cancer. He was talking about national healthcare policy and I was looking for a personal cure. During his rant, he revealed inadvertently that he didn't know as much about proton radiation as he thought he did. Another doctor, a radiologist, likened my possible treatment to a cult, something akin to the Stockholm Syndrome. Neither doctor was able to speak about the medical reasons why they felt proton radiation was inferior, but both opposed it. It helped confirm my growing opinion that everyone is an expert on only one sliver of the prostate cancer treatment spectrum. When they took one step away from their field of expertise, they were amateurs like many of the rest of us.

12. I want a doctor with large volume in my treatment.

One point of view I developed while keeping all my options open was that the doctor, hospital, or institute that delivered the treatment had to be a high volume operation. If I decided on surgery, I didn't want a surgeon who had performed 500 procedures. Instead, I wanted a surgeon who had performed thousands. The same went for whatever treatment I chose. I wanted a treatment provider that had a broad and extensive background of experience in case my situation developed some rare issues.

13. My final decision: proton therapy

What I chose was proton radiation therapy. I chose proton radiation for the precision that I mentioned earlier. Another reason is that it's fractionalized. In other words, treatments are performed a fraction at a time, such as 39 treatments in my case. I liked that approach because a mistake on any single day wouldn't affect the outcome dramatically. By comparison, a mistake on the day of a prostatectomy or seed implants could be life-changing.

As I held conversations with people across the country, I noticed that prostate cancer survivors who had undergone proton radiation were far more enthusiastic about their treatment and their stories were consistent. They didn't suffer from incontinence, impotence, or other side effects. Proton radiation seemed to be the only treatment with a fan club. Why didn't my research on other treatments lead me to groups of men who felt strongly that they had "dodged the bullet" and wanted to share their success with others? I'm sure that they're out there, but I didn't find many of them. At least, not in the quantity I found in proton radiation treatment.

14. Revisiting my urologist seven weeks later

My wife and I met my urologist in mid-February seven weeks after our initial meeting to discuss my research. He asked me if I had made a decision and I told him that I had: proton radiation. To be sure that I had done my research, he politely grilled me on the other options he had suggested and my reasoning for selecting the treatment I did as well as the reasons for rejecting the other ones. He seemed genuinely surprised that I didn't select brachytherapy, but supported my selection of proton radiation by saying that it would definitely get the job done.

During that meeting, he suggested that given the location of some of my cancer near the prostate capsule, I should consider a testosterone suppressant called Lupron to keep the cancer from growing until I could receive treatment. This is called adjunctive therapy, a supportive therapy to the primary therapy. I told him that I would consider it, but wanted to be sure that it wouldn't interfere with my proton treatment. A few days later I spoke with a proton radiation oncologist and received the green light to get a four-month shot of Lupron.

15. Choosing a proton treatment center; prepping

Another reason I chose proton radiation was the minimal disruption of my life. Because treatments take about an hour a day, the rest of the day was mine. Without side effects, I could continue to work and play. The biggest inconvenience of proton radiation was that there were only four locations in the U.S. offering treatment at that time. (The number of locations is now seven and growing.) Of the four choices, the University of Florida Proton Therapy Institute in Jacksonville offered the best combination for me of experience and convenience.

In late February 2009, I sent in a patient application with my medical records, DVDs of scans, and insurance information to the Institute. The Institute called during this time to let me know that Anthem Blue Cross/Blue Shield had declined to pay for the treatment based on the rationale that it was experimental. It was a bluff and I had learned from other proton patients that it might happen. The Proton Institute filed a challenge and Anthem backed down. In my hip pocket were the names of other proton patients who had their treatment paid by Anthem, but I didn't need to use them.

In early March, I was scheduled for a prep visit, which consisted of a physical, consultation with a doctor, a site tour, another biopsy, custom fitting for a pod, and installation of fiducial markers. The markers are small gold pins about the size of a ball from a ballpoint pen installed in the prostate to identify the exact location of the prostate during treatment during medical imaging. Markers are jokingly referred to as "prostate bling."

The prep sessions lasted three days but jumped across a weekend and required just a few hours each day. During the down time, I visited the beach, toured apartments, and became familiar with Jacksonville.

16. Second biopsy throws a curveball before Jacksonville

After I returned to Cincinnati and was one week from beginning treatment in Jacksonville, I received a phone call from my doctor at the Proton Institute. The biopsy performed in Jacksonville confirmed that some of the cancer was at the edge of the capsule. I had a one in five chance that the cancer had jumped the capsule over into my lymph nodes. If the cancer had metastasized, the precision of proton radiation might not be enough to cure me. My previous Gleason score of seven (four over three) had been elevated to a score of eight (four over four). The recommendation was to undergo a combination treatment of photon (standard X-ray radiation) and proton. Proton radiation would be used on my prostate. Photon would be used on my prostate and the surrounding lymph nodes. This was a late development that I was not happy to learn about. I felt I had everything wrapped up and now it was coming unraveled. Up to this point, I had made many of the decisions about my care. Now I had to rely heavily on the advice of a doctor. In talking with my doctor, I came to realize what an uncomfortable situation he was in. He was in the position of delivering bad news a week before I was to

begin treatment. If he didn't believe in what he was telling me, it would have been easier for him to let the entire matter slide and proceed with proton radiation only. After a lengthy discussion with the doctor, I came to agree with his recommendation to go with proton and photon. In hindsight, the decision was the right one and I'm glad I listened closely to my doctor at this point in my journey. My confidence in my treatment was high. I would tell family and friends that I wasn't out of the woods, but I was on the path there.

17. Proton photon "radiation vacation" in Jacksonville.

Proton treatment patients refer to their time at the Institute as the "radiation vacation." My wife and I found a beautiful furnished apartment in a gated community that looked out on a swimming pool. We were permitted by the apartment management to have our dog, which we couldn't leave behind. We lived about 20 minutes from the Institute. Our apartment was close to a highway so the commute to and from the Institute was easy. We were less than ten minutes from the beach and just a few minutes from the University of North Florida swimming pool where we swam daily as well as within a mile of great restaurants and shopping. Throughout our stay we socialized with other patients over lunch, dinner, concerts, or day trips. We continue to remain in contact with some of them.

A typical treatment took about an hour from time I arrived. Radiation is delivered in a "gantry" of which there are three. A radiation technician would walk into the waiting room, find me, and escort me back to the gantry. I would enter a private changing room, remove my clothes below my waist, don a surgical gown, and proceed to into the gantry. My special customized pod, contoured to my head, back and hips would be placed on the gantry table. I would lie on the pod while three medical radiation technicians positioned me. Once I was in position, they would leave the gantry and go

next door to an office to monitor my treatment. The gantry table would swing into the hole of a large doughnut three stories high, which would rotate to adjust the position and angle of the radiation beam. After 20 minutes, my session would be complete.

Throughout the proton portion of my treatment, I never had any side effects. I used to joke with other patients that I felt like Brer Rabbit being thrown in the briar patch. If this was cancer treatment, it was a piece of cake.

The proton treatments lasted for 16 days. Up to this point, I experienced no side effects. The Lupron, however, began to work on my memory. I have always had a strong memory and my recall is somewhat legendary among my family and friends. Suddenly that changed. At times I had difficulty coming up with names of relatives that should have been a snap, but I struggled with them. Months later as the Lupron dissipated, my memory returned in full.

18. 16 days proton followed by 23 photon treatments

The final 23 treatments were photon. Although the procedures were much the same as proton, the radiation was delivered using entirely different equipment. While undergoing photon radiation, I experienced two side effects. The first was diarrhea and the second was stomach pain. Both lasted about two weeks, but neither was in any way debilitating. For each I took an over-the-counter medicine, which was sufficient.

As I came close to completing my treatment in the latter half of May 2009, I looked back at how I had felt in early January and how I felt now. What looked to be a "car wreck" back in January had been downgraded to a "flat tire" in May. I would soon be back on the road in the same shape I was before receiving my diagnosis.

19. Looking back eighteen months post-op.

One month after completing my treatment in May 2009, I received a one-month Lupron shot based on my oncologist's recommendation to continue this adjunctive treatment although I had reservations about it. My urologist agreed with my reservations, and we decided to go with a one-month shot and then get me off the Lupron. After the Lupron dissipated, I expected my PSA scores to exhibit a rollercoaster effect, but they didn't. My PSA tests, which I've done every three months, have been low and consistent: 0.36, 0.32, 0.39, and 0.62. I have not had any side effects from the radiation treatments. I am neither incontinent nor impotent. I do not take any pills such as Viagra, Cialis, or Flowmax. For several months I experienced some fatigue, but short naps and occasional electrolyte drinks helped.

Through a loose-knit network of prostate cancer patients across the country, I receive one or two calls a week from men who were recently diagnosed and are looking to talk about their situation. I'm always glad to take the calls and offer as much time as the man needs. I began my prostate cancer journey looking for men who had received treatment successfully. Now that I am one of those men and grateful for it, I'm honored to help others on their journeys.

As I write this, I am close to 18 months since completion of my treatment. My attitude about my prostate cancer is that I want to make it a footnote to my life story, not a chapter title. I have more important things to think about and more important things to do than worry about cancer. I have a life to live without cancer and that's the way I'm doing it.

20. Learnings about the complexity of prostate cancer.

A. Be cautious about anyone who pushes you too hard and too fast to get a cure. That includes medical professionals, prostate cancer survivors, friends, wives, and relatives. More than once I've heard stories about wives who insist that their husbands get the cancer cut out immediately. You can't wait forever, but you certainly have the time to conduct research for a few weeks and make a decision based on what's right for you.

B. Everyone is different. If I had been seven or eight years older, I probably would have chosen a different treatment. Don't assume that what is right for one guy will deliver the same results for you. Even when I was undergoing radiation treatment, I was amazed how each patient was treated differently than other patients. Each of us received variations of the same treatment, but none of us received exactly the same treatment. I believe this is true across all prostate cancer cases and treatments. Proponents of surgery often describe prostatectomies as "The Gold Standard" as though it is the only cure and no one should dare challenge it. The only Gold Standard is what is best for you and not necessarily someone else.

C. Research, analyze, and synthesize. Research, analyze, and synthesize. Yes, it's worth repeating. The "secret decoder ring" for what is best for you is your brain. Use it. Gather information, think about it deeply, and draw conclusions on your own. The result will be decisions you have confidence in. The alternative is living with the decisions of others for which you will always have doubts.

D. Assume that everyone involved with prostate cancer – both doctors and patients – lives in a silo. The points of view you'll read or listen to are very narrow. Everyone has a bias. Surgeons recommend surgery. Radiologists recommend radiation. Patients who receive seed implants recommend them. Patients who receive prostatectomies recommend them. Patients who receive radiation recommend it. All groups are quick to undermine those treatments outside their area of expertise or personal experience. The old adage "if you're a hammer, everything looks like a nail" applies heavily to prostate cancer treatments.

E. Don't get pushed into making concessions about impotence or incontinence. I'm amazed at how many patients are quick to cave in on this. If you're not impotent or incontinent now, then why can't you expect to enjoy the same level of good health following your procedure? Many men negotiate these away during discussions with their doctor because they think they have to. You don't. Stand up and fight for all your health.

F. Expect the unexpected. One of my collateral effects of prostate cancer was my diminished self-confidence in my body. Throughout my life, I've asked some extraordinary things of my body and it has always delivered. I've been in world-class competitions and knew my body could handle what I trained for it to do. Suddenly, that has changed and I felt like I had let my body down. I simply didn't see it coming. My confidence in this area is still rebuilding and it will take some time.

21. My expectations for a PCa future and quality of life.

My general view of prostate cancer treatments is that whatever you choose, it gives you a five-year "hall pass." If you come through your treatment, regardless of what it is, in healthy fashion you have an excellent chance of five cancer-free years. If the procedure was exact and thorough you may be cancer-free for the rest of your life. If your procedure missed some of the cancer, it will begin showing up between five and ten years. Depending on the location of the cancer in your prostate, size of the tumor, the velocity, your general health, stress levels, and a few other factors, reoccurrence may be an issue or it may not.

I find it fascinating that about two of three men in the U.S. have prostate cancer when they die. Only about one in thirty, however, dies from prostate cancer. To me that suggests that men who are treated have pretty darn good odds of living long, healthy lives without prostate cancer undermining the quality of it. That's what I expect and that's how I plan on living my life.