

Approaching Cancer Aggressively *One Member's Case Study*

In December of 2006 I was diagnosed with a serious case of prostate cancer. Serious because it was graded on a Gleason Scale, (which measures the level of aggressiveness of the cancer cells,) as a 9 out of a possible 10. My conscious choice at that time was to “keep it quiet,” as I didn’t want anyone “hanging crepe,” showering sympathy, or any of the other most common reactions. In retrospect, I would call that a somewhat self-serving decision, as there was probably some benefit my friends could derive from knowing about my case; how did I get cancer, and how was I going to pursue it? Looking at it more closely, it would be very accurate to say that at that early stage I knew next to nothing about the answers to either of those questions. Now, sixteen months after that diagnosis, I know a lot more, and I believe that knowledge will significantly benefit not only my friends, but also, hopefully, many people whom I’ve never met, which is my purpose in writing this. I hope that the list of friends I initially send this to will pass it on to their friends so that what I’ve learned will be of some help to as many people as possible.

My view from inside this situation has radically changed the way I view and interact with the healthcare system, and I believe the readjustment of my thinking has positively affected the benefits I derive from that system. The experience has also taught me that there are more productive ways to approach dealing with a serious, life-threatening disease than the usual “three D’s,” Denial, Despair, and Delegation. I hope that reading this will help you to impact your own life more positively if/when you are also facing the same kind of threat.

If there’s one overriding message I’d like to get across here it’s this; if you are hit with a serious disease, you are your own case manager. If you aren’t your own case manager, chances are you don’t have one. No one has more to gain or lose by the decisions that will be made about your diagnosis and treatment than you do. While “the system” may appoint a case manager, two minutes after you leave that case manager’s office he/she has gone on to the next patient and your case has been reduced to the progress notes hastily scrawled on your chart. I don’t state that fact with anything less than the deepest respect for the people who have worked so diligently to help me beat this disease, but rather just as the reality we all have to deal with. I am not the only patient they’re working with, there will be dozens more today alone, and while they do the best they can with the time they have, I am not their only concern and you won’t be, either.

Your job as case manager is to understand as much about your disease as you are able, with as many of the questions as possible at your fingertips even though you know you are probably not going to be the one to come up with the answers. You will need to know as much as you can learn about the various treatment options that are available to you, and you will need to have absorbed the advantages and disadvantages of each. (I’ll explain more about the reasons for that later.) Last but definitely not least, you will need to select and hire those healthcare professionals whom you feel are best qualified to deal effectively with your disease, and while you will rely heavily on their skill and dedication, you must never lose sight of the fact that you are the one whose life will be affected, (or possibly ended,) by the decisions that are made, so the decisions must be yours. You may be surprised to find that the doctors you are working with would wholeheartedly approve of this position. They recognize that many of the decisions that are made

will be a “best guess.” That’s why they still call it “the practice” of medicine, and they prefer that you are part of the final decisions in your treatment choices. Yes, you will rely heavily on their experience, input and the application of their accumulated skills, but you are the one who ultimately calls the shots.

While my experience is limited to my own case of prostate cancer, I feel quite certain that what I’ve learned will be of some help to you not only in the event that you also experience prostate problems, but no matter what serious healthcare issue inserts itself into your life. The principles won’t change much. That said, let’s get into talking prostate, and please understand that a great deal of the following advice comes originally from my wife, Angela, a Certified Urological Registered Nurse who after over thirty years of treating prostate cancer found herself in a situation where her favorite...and probably most difficult...patient was her husband. Her experience has been invaluable to me as I worked through each of the decisions that ultimately determined, and continue to influence, my treatment.

Let me frame this discussion by giving you a capsule account of my own case, as it will help to illustrate the reasoning behind the points I hope to make.

After years of annual exams which showed no unusual change in my PSA readings, (the generally accepted indicator of prostate disease, which we’ll discuss in more depth later,) and annual digital rectal exams by my family physician that turned up nothing alarming, I began to exhibit what are called “lower urinary tract symptoms,” or “LUTS.” Those symptoms generally include frequent urination, (especially at night,) urgency, (I not only had to urinate, I needed to do it NOW,) and a narrowing of the urinary stream. While LUTS are most likely to indicate nothing more serious than an inflamed prostate or a urinary tract infection, they are always a signal that should send you to your friendly local urologist.

My urologist did a digital rectal exam like no other I had ever had previously, found a hard spot on the least accessible surface of the prostate, and because of that decided a biopsy was necessary to get a more dependable indication of the condition of my prostate. I agreed, and the biopsy was performed about a week later. Thirteen cores were taken, all thirteen were positive for cancer. (My PSA at the time was a very normal 1.4.) Not only were there cancer cells in each core, but a pathology report indicated that the cells were of a very aggressive type.

The next week was a time of intense adjustment. Suddenly, after a lifetime of virtually disease free health I was faced with a disease that was life threatening and which forced me to confront the fact of my mortality. I did a few days of feeling sorry for myself, and then took a more sensible position; at the tender age of 73, it was time to accept the inevitability that at some point in the not very distant future nature would take its course. It was time to be grateful for a life I can only describe as full, happy, interesting, challenging, and seasoned with the love of a very fine lady. I had told my friends for several years that “if I cash out tomorrow, this life doesn’t owe me a nickel! It’s been a great trip.” Now that the possibility of that life ending sooner rather than later was upon me, the realization that I had been given the gift of a truly enjoyable time on the planet helped me to accept the reality of the situation.

The next response was, now that I've accepted the possible downside, let's see what we can do to change the odds.

Various rough spots in my life taught me long ago that the devil you know is easier to deal with than the devil you don't, and my standard operating procedure when faced with a serious problem is to find out as much about that problem as I possibly can. At the very minimum, know what the questions are, even if you haven't yet got the answers. So I began to read....voraciously. The Internet became my second home for weeks, and proved an invaluable source of both very dependable and totally superfluous information. As I got further into my research it became easier to identify the reliable and authoritative sources and avoid the "quack shops." In a very short time, I became quite knowledgeable about a very narrow range of the human condition...prostate cancer. I'm firmly convinced that knowledge has extended my life, both in terms of quantity and quality, by guiding my search for the "right" decisions as we've progressed through the diagnosis and treatment of this disease.

The diagnosis made by my urologist led to an appointment with a radiologist for several body scans, which further illuminated the extent of the problem. It appeared that I had a couple of metastases to the pelvic bone, which is the way prostate cancer cells typically spread. A consult with a robotic surgeon (Dr. Carol Salem, who strikes me as a fine physician and surgeon,) brought her opinion that removing the prostate would not be a good choice, as the cancer had already spread to the bone. It's worth cautioning here that the opinion of a specialist that his/her specialty is not necessarily the best way to go is not nearly as common as it ought to be. This is one of those areas where your job as case manager is getting as many opinions as necessary to convince you that you have all the information necessary to make an informed decision, and then you make it.

I was then referred to a "medical oncologist," a physician who treats cancer using chemotherapy and/or other non-invasive, medical approaches. He put me on Luprolide, which is an androgen blocking agent that suppresses the prostate's production of testosterone. Prostate cancer (PC) depends on testosterone for its progress, so cutting the supply is part of the treatment. My second trip to the oncologist's office was probably the most formative of my experiences with the medical system, and the one that radically changed my perception of where I fit into the picture and what my job was from there on. I'll describe it for you so you won't necessarily have to wait that long before you come to the same acceptance of your role in the process.

My PSA, which had risen from 1.4 to 2.0, (still not a level that would trigger alarm in either your family physician or urologist,) had dropped to .9 on the Luprolide treatment. While that was encouraging, all the reading I had been doing led me to think that Luprolide alone was inadequate to the job. First, while the prostate is the primary source of testosterone, the adrenals also produce a small amount. Secondly, the truly harmful agent is dihydrotestosterone, which is a derivative of testosterone. A more aggressive treatment called the triple androgen blockade uses two medical agents to block not only the prostate, but also the adrenals from producing testosterone, and uses a third to destroy any stray dihydrotestosterone. In addition, a chemotherapeutic agent is usually used in conjunction with the blockade to attack the existing cancer cells. It seemed to me that my treatment wasn't adequate for the disease, and I asked the oncologist whether we ought not to be using the triple androgen blockade. His reply was "we

don't do that." Mine was "why not?" His comeback? "Because it's not the standard of care." At that point I needed to know just what chance this physician gave me if I settled for the standard of care, so I asked for his prognosis. He hemmed and hawed, but when it was obvious that I wouldn't settle for an evasive answer, he admitted that he felt I had one to two years to live. I again asked him why the triple androgen blockade wasn't an option he'd consider, and his answer was "It's not without risk, you know!" My reply was "you just gave me one to two years...how much am I risking?"

"Standard of Care" is a term you'll encounter often when interfacing with the medical community. To help you be unimpressed with the phrase, let me describe how it was defined for me by another physician. "It's basically what everybody else is doing. Doesn't make any difference if it's dead wrong, if it's the treatment that most doctors are using, it's the standard of care and there's little chance that you can be successfully sued for employing it." So the standard of care, it would seem, is more important to the health of the physician than to the wellbeing of the patient.

My reaction to my oncologist's answer was to take the whole issue to another physician for my first "second opinion." How important is a second opinion? Important enough that Medicare will pay for it, and Medicare doesn't pay for anything unless they deem it to be worthwhile. Taking my case to a longtime personal friend who is the semi-retired Chief of the Urology Department at UCSD, I presented my reasoning for feeling strongly that I didn't have a standard disease, and therefore needed more than standard care. He agreed completely. My next decision had to be whom to use as my medical oncologist. I was completely convinced that my present doc was accurate in suggesting that if I stayed on his treatment I had very little time left to live. This was another point where all of my preliminary research would prove worthwhile. The information I had pulled from the internet established that there were a few...very few...oncologists in the country who made a specialty out of prostate cancer. All the rest were generalists within their specialty. They were as likely to be working with a patient who had breast or pancreatic cancer as one who was fighting PC, and my conviction was that each type of cancer was sufficiently complex that I'd be better served by someone who spent all his time working with prostate cancer. Fortunately, there were two practices in the Los Angeles region which had a long term track record of successfully treating PC exclusively, and I was able to schedule a consultation with Dr. Mark Scholz, in Marina del Rey.

Within days I was on a triple androgen blockade, and a week later was put on the chemotherapeutic agent Taxotere. Once a week treatment in LA required five hours of driving three weeks out of every four, but I felt that the trade-off was a good one. (There are, to the best of my knowledge, no oncologists in San Diego who treat PC exclusively.) Within a little more than a month my PSA had dropped to negligible levels, indicating that generation of testosterone, and therefore dihydrotestosterone, had been halted and that the cancer would have nothing to grow on.

At that point, what we had bought was an opportunity to see if the cancer could be killed using the chemo. We stayed on the treatment regimen for fifteen weeks and then discontinued the Taxotere. If the PSA started to rise again, it would indicate that the cancer was still active and further treatment would be necessary. Within weeks the PSA started to move upward. As Dr.

Scholz put it, “the mother ship will have to be neutralized.” That meant disposing of the prostate gland.

There were again several choices available, cryotherapy, (freezing the gland,) brachytherapy, (implanting radioactive “seeds” within the prostate,) and several flavors of external beam radiation. All had their advantages and disadvantages, which we discussed thoroughly. It was essentially a matter of choosing which of the undesirable side effects would be most acceptable, and I decided I would prefer external beam. Fortunately, a world class piece of equipment had been installed at Moores’ Cancer Center, here in San Diego, and an exceptionally well thought of radiation oncologist, Dr. A.J. Mundt, had been spirited away from the University of Chicago to head the oncological radiology department at Moores. A check with some of Angela’s colleagues in Chicago satisfied us that Dr. Mundt was very highly respected, and I chose to be treated at Moores using the Varian Trilogy machine.

A few weeks after starting the treatment, Dr. Mundt did another set of scans of the pelvic area which revealed that the previously mentioned bone metastases appeared to have calcified over, indicating that they were no longer a threat. His comment at that point was that “thinking in terms of a complete cure isn’t out of the question.” Not a promise, but one whole heckuva lot better sounding than “one to two years.”

Nine weeks of daily radiation treatments later, I’m back on a different chemo agent, Ketoconazole, and the procedure will be the same as previously...stay on this regimen until about November, discontinue the chemo, and see whether the PSA stays low.

What are the points to take away from this rather long winded account?

- 1) Have your PSA checked every year, but understand that the result is not necessarily definitive. Therefore you also want a digital rectal exam each year, performed by a urologist, because the most aggressive cancers don’t secrete PSA cells.
- 2) If you’re diagnosed with PC, take responsibility for your disease and its treatment. *You* are the case manager.
- 3) Learn all you can about your disease. Know what the questions are.
- 4) Find the most highly qualified expert professionals in each field in which you will require treatment, and hire them.
- 5) Ask them every question that will help you make a more intelligent decision. (They’ll appreciate your interest in a successful outcome.)
- 6) Evaluate each of your options on a risk-reward basis. Make the decision that seems most sensible.
- 7) Never quit.

Oh, one more thing. If you’ve got lousy healthcare insurance, change it now. The best insurance isn’t going to be the one with the lowest premium, and if you find yourself in the situation I’ve just described you’re going to feel like a nitwit if you’ve scrimped on your healthcare plan.

How can you give yourself the best chance of avoiding prostate cancer? It appears to be largely a lifestyle disease. Eat red meat and your chances of contracting PC are eight times greater than if you’re a vegetarian. Same thing for whole eggs. (Beef, pork, and egg yokes all contain heavy

rations of arachidonic acid, which PC really thrives on.) Dairy products like milk and cheese increase your odds by 600% over a veggie diet. All cancers feed on sugar. And incidentally, pretty much the same caveats apply to breast cancer, so there's good reason for your spouse to sign on to this lifestyle change. Do what you will with this information...it's your body and your life.

What do you do if you have symptoms of prostate problems, such as painful urination, difficult urination, or other LUTS? Go to a urologist, not a GP. Most men find a digital rectal exam (DRE) a bit uncomfortable. Not wishing to lose a patient just to do a thorough exam, and also because they do only a few DREs, the average GP isn't going to give you as aggressive an exam as a urologist who does several DREs each day. You want the talented finger of an experienced urologist, because you want an accurate evaluation of the condition of your prostate.

And if you find that you're one of the quarter million men who will be diagnosed with PC this year, remember that it's your disease and it's your life. Immediately find and join your local prostate cancer support group, where you'll meet a group of other men with the same problem and varying levels of experience with the disease and its treatment, all of whom can be helpful to you as you wade into the decision making process. And never, never forget...you're the case manager.

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