

Cancer Treatment Advice May 12, 2016

Overview:

- Based on my experience over the last five years with Stage IV lung cancer, I believe it takes at least seven elements, together, to survive the most severe forms of cancer. They are, in no particular order:
 - A desire and the perseverance to survive which includes learning about options and seeking out the very best treatments and physicians regardless of proximity and convenience
 - Immediate action
 - An outstanding caregiver and circle of friends (Either a caregiver or you must understand the treatment modalities, risks, side-effects and prognoses)
 - State of the art technology and front line physicians
 - An outstanding nursing staff that cares about you and is open with you
 - A spiritual network of friends, family and even people you've never met sending their well wishes, kind thoughts, and prayers
 - Faith, belief and a positive mental attitude

Diet, exercise, maintaining one's lifestyle as best as possible and documenting one's treatment and health status are also very important, but I believe these seven to be of paramount and equal importance, because the absence of one could prove disastrous.

Immediate Action:

- The first decisions are usually the most critical... and from what I've seen are often the worst ones. See a physician at the first sign of a problem. Don't wait, hoping it will go away. If you can't get in to see your preferred physician in the immediate future, find another. I wish I had. Time is critical. Cancer can spread at an alarming rate. Inconvenience at the outset can spare you months of treatment misery or worse.
- Do not delay, not even a single day!!! Had I waited two days before trying to get a second opinion, I'd have not received the treatment I did and I'd probably not be writing this. Seek a second opinion from a renowned expert as soon as possible. It's amazing how well our friends and family can help us to not only identify, but also help us to gain appointments, with such experts.
- We want to believe that our nearby hospitals and cancer centers are excellent health care providers. They assure us that they are, they believe that they can provide excellent care. That may be true, but it's unlikely that they are world class. That is especially true for a hospital that is not devoted to cancer treatment. If nothing else, they do not offer clinical trial options or have state of the art radiation equipment (which *does* make a huge difference, if not immediately, then down the road). If you're going to endure cancer treatment, why not receive the best from the best, or at least get the very best opinions. Do so especially if you're

given no hope. Over four years ago I was given weeks to months to live... by a pulmonologist, no less! And distance need not be a concern. Cancer Treatment Centers of America flies a surprising number of patients across the country free of charge every day and covers the majority of the food and lodging expenses.

- I am a huge proponent of clinical trials. I have participated in two of them and have greatly benefitted from both. The enrollment requirements are stringent; often mandating failed previous treatments. It is desirable to enter into Phase III clinical trials – the safety and dosage of the treatment have already been established. This phase with its large number of patients identifies how the new treatment compares with standard treatments. (The first trial I participated in was in Phase I. It was worth it.) Blinded trials in which you might receive a placebo are the very lowest option in my opinion. Clinical trials are so well designed and require so much pre-clinical testing that patients are not guinea pigs, rather they are receiving state of the art care. Pharmaceutical companies invest enormous sums of money in the development of new drugs; they do not jeopardize their investments, nor their reputations, with shoddy practices. Plus, their practices are highly regulated by the FDA. Not all drugs fulfill their initial promise, patients do not respond in the same manner. But that is precisely why clinical trials are performed.
- Ask for and accept help. In my case, I had to send a broad work-related email because I had to cancel an extensive trip around the world and it wasn't fair to ask anyone else to try to explain. Though I dreaded sending such a message to so many people, the sharing of my diagnosis and grim prognosis served as a request for help, which dramatically altered my course of treatment. Let everyone know.

The First Few Days:

- Take charge of your care. Regardless of the level of health care that you're receiving, you're still but one of many patients. Take daily notes of your condition, get copies of your records, double check on your treatment, write down and ask every question that you have, record every answer, insist on explanations if you suspect something is not right. Be responsible for own treatment.
- Stay off the internet except to read up on your drugs and treatment. Every cancer, every reaction to every cancer, every treatment response, every patient is different. Most of the items on the internet are depressing and demotivating.
- Ensure that your oncologist will submit biopsied tissue for a full battery of genomic testing. The best treatment can be prescribed by knowing the specific mutation of the tumor(s).
- If drug treatment is warranted, determine if you qualify for immunotherapy. This treatment does not poison the cancer. In my case, immunotherapy with a checkpoint inhibitor reduced a very large tumor by 80-90% within 8 weeks! With no side effects whatsoever! The drug removed the protein layer surrounding the tumor, an invisibility cloak if you will, thereby allowing my immune system to recognize the tumor and go to work. No poison, no burning, no effect on healthy cells, no side effects. Immunotherapy options also exist for blood-borne cancers.

Multiple forms of immunotherapy treatment are available, including some that have achieved FDA marketing approval. As I said, mine was a checkpoint

inhibitor. Other modalities include therapeutic vaccines, monoclonal antibodies and cytokines. Bear in mind that in order to qualify for some, if not all, of these immunotherapy options you may have to have undergone previous conventional treatments. Plus, chemotherapy may be coupled with immunotherapy; combination therapies tend to achieve superior results. For more information see: <http://www.fightcancerwithimmunotherapy.com/ImmunotherapyAndCancer/TypesOfCancerImmunotherapy.aspx>

- Read up on your infusion drugs. Chemocare.com offers concise, easy to understand synopses of drugs and their side effects.
- Pull out all stops when it comes to your care. Eastern medicine has value, too. All the things you do to help yourself also help in maintaining a positive attitude. Medicinal mushrooms have been shown to be effective. (e.g., Turkey Tail mushroom and MyCommunity capsules; fungiperfecti.com.) Each practice offers its own hope.
- Learn to accept the diagnosis as soon as possible so that you can focus on healing. Elisabeth Kübler-Ross's seminal book entitled, *On Death and Dying*, introduced the concept of stages of the grieving process. She explained that we must undergo certain reactions, in sequence, in order to finally achieve acceptance of the loss. Others have subsequently slightly modified the steps in order to more generally apply them to the acceptance of any loss. Cancer patients and those close to them also go through these stages. The basic steps are:
 1. shock/denial
 2. anger/depression [blame, bargain]
 3. understanding/acceptance [find solution]

The first two steps involve alternating behaviors. For instance, during the first step, we vacillate between shock and denial. Most importantly, we must proceed through each step in the proper sequence in order to accept the loss. If we skip a step, we're fated to return to that step and still follow the subsequent steps in order to find closure. The usefulness of this model lies in explaining to others that it's not only natural, but is actually healthy, to express denial and anger and blame in response to a loss. Further, the model can be used to track one's progress in the healing process.

Many people get hung up on asking, "Why me?" It might help to recognize that as of October 2014, one half and one third of American men and women, respectively, develop cancer.

Knowledge diminishes fear. Bombard your health care professionals with questions. They really don't mind; the best ones appreciate that you're doing your part to get well.

- Ask about every adverse side effect of treatment that you experience. There are many remedies, but you have to ask.

For instance, there are special compounds that contain Lidocaine available for treating mouth sores; dab with Q-tips, don't swish – the stuff is foul.

Claritin in the morning in combination with Aleve morning and night eliminate the bone pain associated with Neulasta. This information was not offered to me until I asked.

In my experience, 600 mg daily of over the counter Alpha Lipoic Acid was initially remarkably effective in reducing neuropathy associated with chemotherapy. (It's far cheaper through Drugstore.com.) 1000µg/day of Vitamin B-12 (or perhaps better, B-complex + B-6) is alternatively recommended for the treatment of neuropathy. Lyrica, a prescription drug, apparently works very well addressing the pain associated with neuropathy, as does Gabapentin, another prescription drug. Both, however, can present significant adverse side effects. I've learned that SENSUS Pain Management System and Quell (available by prescription and over the counter, respectively) are electrotherapy devices that are worn around the arm or leg to reduce pain. Acupuncture and electro-acupuncture are also viable alternatives. I can attest to the efficacy of the latter treatment. My neuropathy has been dramatically reduced even after being left untreated for over two years. I have observed that my left hand/fingers and left foot/toes were far less affected than those on my right side. I'm left-handed and concluded that the increased use of my left side thwarted the advance of the neuropathy. Therefore, I suggest at least the frequent use, if not the exercise of, the arms and legs.

And should you be taking a Tarceva pill for treatment, what they call skin rashes will hopefully arise. I say hopefully because generally the more pronounced the rash and other side effects, the greater the response to the targeted cancer drug. The rash looks exactly like a severe case of zits, but it isn't. Typical treatments for teenage skin problems don't work. The "rash" is actually a manifestation of infection. Over the counter Cetaphil soap and lotion help a bit. Clobetasol Propionate USP, 0.05% (steroid) cream and/or lotion in combination with Erythromycin Topical (antibiotic) Gel USP, 2% work wonders. (I've heard that the more expensive Aclovate topical steroid cream and Clinamycin antibiotic solution or lotion are also effective.) If these topical drugs don't do the job then a Doxycycline Monohydrate 100 mg (antibiotic) capsule taken twice daily is your ticket. But you don't want to take it for extended periods of time if you can help it.

Request a prescription of 2.5% Lidocaine – 2.5% Prilocaine cream (EMLA) to apply to the skin to eliminate pain when the port is accessed. (Ensure that you receive a PowerPort, the state of the art venous access port that can withstand the pressures associated with the power-injection of contrast dyes that are infused as part of routine CT scans. Otherwise, an IV line is typically required. Slow dye infusion is viable with a standard port, but if for some reason the injection is high flow [e.g., because the tech wasn't informed], the port can rupture causing very serious problems. Some nurses recommend against taking that chance.)

Apply a radiation burn cream to the affected areas. They work. The treatment unit may provide it free of charge. Mine did (MPM RadiaPlexRx Gel). Calendula cream is a highly recommended over-the-counter alternative.

Ongoing:

- Without a positive attitude you are doomed. Hang on to your faith. Continue to practice yoga, meditation or any other modality you may prefer. Acupuncture is

reported to alleviate the side effects, too. Look inside a cancer clinic and you can immediately tell who is working to survive. Be positive and find reasons to be positive. (As a side note, later, in speaking with a cancer patient I was finally able to articulate how I felt about facing cancer. I never liked characterizing it as a fight. I much prefer describing it as seducing it into submission [or, at least, into remission].)

- A number of non-pharmaceutical options are available to manage pain. Chiropractic treatment can address many forms of nerve pain, beyond just neck and back pain. Acupuncture, especially electro-acupuncture, is yet another viable option. Medical marijuana has proven pain-relieving benefits. I recommend the ingestion of edible forms. (Gummy Bear forms are especially cute and effective.) I have also heard that Bowen Therapy is an unusual, but highly effective, holistic approach to pain management and healing.

Self-treatment in a virtual healing room is yet another viable modality. To create such a room, begin by learning to relax in an imagined perfect spot in nature. First, lie down, making sure to avoid any distracting pressure points. Relax your fingers until you cannot feel them, then do the same with your hands and up your arms, and so on down the length of your body until you have no feeling. Then imagine a perfect spot in nature that you can enjoy. Once you become successful in repeatedly achieving the resultant theta brain wave state, you can begin to create your healing room where you can diagnose and treat others and yourself.

You next create a subterranean portal in your perfect spot in nature. You descend twelve stairs, getting deeper into a relaxed theta state with each step. At the bottom you need to create a protective curtain that only you can pass through. Once inside, you can begin to create and stock a room. First, create a treatment table then add whatever furniture, tools, appliances you feel you might need. You can always add, remove, modify, and rearrange items at any time. You should also create a male and female helper to assist you in any way that you desire. Last, construct a secure entrance only to be used by invited visitors.

You next can learn to diagnose by imagining your journey through at least some of the major systems of the body, such as the circulatory, respiratory, musculoskeletal, nervous, and endocrine systems. The intent is to identify any possible abnormalities. You heal others by using a Reiki-like technique of holding your hands over the affected areas in order to treat them. For self-treatment, one of your helpers can do this for you or you can simply will yourself well.

- Honor your caregivers. It's harder on them in many ways.
- Have something to look forward to... a vacation, a significant personal event, a holiday, attending the Phillies game when they win the World Series (a goal that may keep me alive for many years to come).

(I booked a river trip down the Colorado River through the Grand Canyon in August, 2014 when my breathing was diminishing and I had yet to receive further treatment. I was determined to participate in that adventure. In August, 2015 I was able to fulfill that dream despite the appearance of a rogue tumor in March and the fact that I could not have made the trip any of the previous 4

- Augusts. I'm certain that having that goal had a lot to do with my improved health.)
- Maintain your lifestyle as best you can. Keep pursuing your hobbies and your work. I've noticed many survivors doing just that, even when they were exhausted and in pain.
 - Build on positive responses to your treatment. Celebrating your progress makes the side effects far more tolerable.
 - Do not assume that the docs are on top of your treatment. They're human and tend to generalize diagnosis, prognosis and treatment. Surprisingly true. Find a great doc who inspires trust, not quick answers with little input. It's critical to do all the tests to be certain of the type of cancer. Many docs ignore the low percentage types of cancer. And don't assume docs are communicating to one another or that the nurses are passing on all of the information that you provide them.
 - I've been told by oncologists and oncology nurses that major advances in the treatment of cancers and the side effects of chemotherapy occur about every two years. So, if and when the cancer reappears, there will likely be a new treatment modality available. Use this knowledge to help maintain a positive attitude even in the face of disappointment.
 - Good friends always offer to help in any way they can. But their offers are rarely acted upon. Why? Because if you ask for help on a specific matter, the volunteer may feel obligated to oblige even if he/she has no desire to do so. Or, there may be reluctance to ask for assistance out loud. I learned of a creative way to accept the offers. Create list of things that others could do to help. It can include anything, such as meals from a favorite restaurant, magazines for the reception area, delivering flowers, performing errands, helping with minor house repairs, lifting heavy objects, sending cards, and so on. We would have created such a list had I thought of it. Instead, I silently turned down many offers that, in hindsight, I wished I hadn't. Remember, people are delighted to help. If they offer, they mean it. Alternatively, Katie Couric had this advice, "[Don't] say, 'Please let me know if there's something I can do.' Say, 'Can I take the kids for the day to the playground? Can I mow your lawn? Hey, my friends and I are going to clean the house today.' The worst that could happen is a person could say no. And even the mere gesture means so much."

MTV reality star Diem Brown, 32, died of cancer in November 2014. She was first diagnosed with ovarian cancer at age 23. It recurred in 2012 and in August she was diagnosed with cancer throughout her body. She wonderfully created MedGift.com – a registry for ill people and their friends and family that operates just like a bridal registry. A simple, creative, enduring endeavor. "MedGift is the complete resource tool for those facing a health related hardship or need. MS, Cancer, Elderly, Autism, Memorials... whatever your health related hardship or need might be, MedGift is here to help support you through your journey ... Financially, Physically and Emotionally with our free online support tools." (excerpted from the website)

- I implore everyone to always pass on good news to your health care providers. And thank them. If fame motivates you, then do so because you'll become a hero. They rarely hear the good news, just the bad news and the complaints. I became

popular in Scottsdale simply because I thanked them profusely, and deservedly, along the way. And I mean all of them, starting with the receptionists, and including the pharmacists and volunteers. They seek to help and they do help and they rarely hear the good news from cheery survivors.

- A remarkably gutsy and strong cancer survivor friend offered this sagely advice: “Live each day to the fullest and appreciate what you have and control what you can and forget about what you can't control.”
- Follow all of this advice if the cancer returns. Especially getting the second opinion. I almost didn't the first recurrence, knowing I'd need more regular chemo, but the second opinion landed me in a clinical study that has been remarkably effective, devoid of the worst side effects from the initial treatment. (It's good to follow one's own advice.) You can search all of the ongoing U.S. clinical studies at <http://clinicaltrials.gov/>.

My best summary of the advice is this: Embrace, as soon as possible, the mantra “it is what it is” and face the challenges head on, without delay. And if I had to condense my advice to a single word, that word would be immunotherapy.

ADDENDUM

What causes that first cell to change?

A wonderful friend from forever ago asked me this tough and *great* question. Obviously, I'm no expert, not at all. But, as I am wont to do, I have formed opinions. After 5 years I should have some thoughts, right? I answered her mostly by digging up passages from what I have read.

- All of our bodies possess oncogenes that have the potential to induce a normal cell to become cancerous.
- A cancer cell must acquire six characteristics as it develops: “It must acquire the ability to stimulate its own growth and to ignore signals admonishing it to slow down. That is where the oncogenes and tumor suppressors come in. It must learn to circumvent the safeguard of programmed cell death and to defeat the internal encounters – the telomeres – that normally limit the number of times a cell is allowed to divide. It must learn to initiate angiogenesis – the sprouting of its own blood vessels – and finally to eat into surrounding tissue and to metastasize.” [per Douglas Hanahan & Robert Weinberg, *The Hallmarks of Cancer*, 2000, excerpted from George Johnson's *The Cancer Chronicles Unlocking Medicine's Deepest Mystery*]

Along with smoking and obesity, the greatest risk factors are old age and entropy. Environment, genetics, and diet play a role, but a very small role in comparison. Every day, our cells are wildly mutating as they divide. As we live longer, the mutant cells have a greater chance of meeting the six requirements and forming tumors. And once formed,

they are very adept at adapting to challenges to their survival. Sheesh, even dinosaurs had cancer!

“The infectious diseases we have defeated were each caused by a single agent – an identifiable enemy that could be killed or vaccinated against. With cancer we would have to seize control of a whole slew of factors, including the mishmash of symptoms arising from imbalances in energy metabolism. And the biggest risks will always lie beyond our grip: old age and entropy. Cancer is not a disease. It is a phenomenon.”

The author also made the case for how different cancer is from other maladies. Unlike the diseases that have been conquered in the past, there won't be a single vaccine or a single antibiotic to vanquish cancer. Cancers vary greatly; it's highly unlikely there will ever be a single panacea.

[George Johnson, *The Cancer Chronicles: Unlocking Medicine's Deepest Mystery*]

□ A Johns Hopkins news release from January 1, 2015 stated, “Scientists from the Johns Hopkins Kimmel Cancer Center have created a statistical model that measures the proportion of cancer incidence, across many tissue types, caused mainly by random mutations that occur when stem cells divide. By their measure, two-thirds of adult cancer incidence across tissues can be explained primarily by ‘bad luck,’ when these random mutations occur in genes that can drive cancer growth, while the remaining third are due to environmental factors and inherited genes.” And, of course, the random mutations accumulate as we age, which isn't bad luck, but we are taking our chances.

□ 1 in 2 American males develop cancer, 1 in 4 die from it (mostly lung/bronchus and prostate). 1 in 3 American women develop cancer, 1 in 5 die from it (mostly breast, lung/bronchus, and colon/rectal). [as of 10/1/14]

[<http://www.cancer.org/cancer/cancerbasics/lifetime-probability-of-developing-or-dying-from-cancer>]

My conclusions... Cancer is prevalent, far more so than you may think. There are three major risk factors. We can increase our risk by smoking and becoming obese. The third major factor is living longer. For this reason, we are almost predisposed to develop cancer. The mutations accumulate with time; the longer we live, the higher the risk. The randomness of mutations, combined with the ingenuity and resiliency of cancer cells, make this disease so exceptionally difficult to conquer.