

## SPIRITUALITY AND LIVING WITH CANCER: *MY CANCER – A BLESSING OR A CURSE?*

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October 25, 2009

Three things, right off the bat... One, a lot of my thinking over the past 4 ½ years has been influenced by two authors whose works have resonated deeply in me – Richard Carlson, the author of *Don't Sweat the Small Stuff* and many other books about finding happiness and contentment in life, and M. Scott Peck, the author of the *Road Less Traveled*, its two sequels, and several other books. Second, this talk has been a work in progress for just over 4 ½ years. This point was made ever so clear to me just yesterday. I thought I had this talk "nailed" months ago when I had first written it. I made some minor changes since then and re-read it two days ago. It was OK, but seemed somehow incomplete, yet I couldn't figure out what was missing. I awoke yesterday with what Carlson refers to as "wisdom", where without actively trying to think about an idea or seek the knowledge, it just comes from somewhere deep inside in an unexplainable almost miraculous manner. I immediately sat down at my computer and made major revisions to this. And third, cancer can be a horrible disease. I lost my Mom suddenly to an aggressive lymphoma when she was 72. I'm unable to look at her cancer in the same way that I look at mine. My talk today is very personal; it is not about cancer in general, it is about my specific cancer. Many cancers are indeed horrible and it is not my intent to generalize my experience to the many people who have suffered far worse than I.

Peck, in his "The Road Less Traveled" makes no distinction between spirituality and the workings of the mind. An important point, since a lot of what I'll be talking about has to do with work that I've had to do to strengthen my mind, which has thus enhanced my spirituality.

In the summer of 2004, I began experiencing severe pains in the areas around my joints. There was really no explanation for the pain or rhyme or reason. The pains traveled around and I never knew where I would be hurting from one day to the next. The explanations offered by my doctors were unsatisfactory to me and I was very persistent in obtaining referrals to different specialists and getting orders for various diagnostic tests. By the spring of 2005 a diagnosis of Waldenstrom's Macroglobulinemia, a rare type of Lymphoma was confirmed.

Bad news, Waldenstrom's is an incurable cancer. Good news, it is indolent (slow growing) and manageable with treatment and that I would most likely die WITH it, not OF it. Someone on my online Waldenstrom's support talklist once said something like, "Ours is the Cadillac of cancers. Many cancers give people time to learn to die with grace and dignity; ours gives us time to learn to live with grace and dignity."

Very late the night after my diagnosis, I was lying in bed unable to sleep. Afraid that my overwhelming sadness might make me a bit crazy, I rolled over and held my wife, Nancy. I began to focus on how much I know she loves me and will always be there for me - this helped reduce the anxiety I was feeling. I thought about my sons, Brian, Eric, and Matthew, and remembered how much joy and happiness they have brought into my life. I

thought about my job as an accounting professor at Montgomery College knowing that I have been so very fortunate to have had a job that I not only enjoyed, but one that afforded me a great deal of time off to enjoy my many other interests and hobbies.

I got out of bed and began writing this all down in a document I titled "Please Read At My Memorial". As I wrote, I was flooded with memories and a sense of deep appreciation for my family members and my friends. I began to realize what a wonderful life I have led.

In my "memorial" letter one paragraph said: "Religion hasn't played much of a part in my life since I was a teenager, so I don't know what lies ahead for me. If there's nothing after this life, I'm OK with that - the idea of eternal sleep and unawareness seems somehow restful. I sort of believe that if you keep me in your mind and heart and think of me from time to time, that's one way of living on. If there is something else - and so many times in my life it has seemed that I've had a guardian angel or some force watching over me, it makes me think that there could be - I'm hoping that I'll be OK. I think overall that I've been a good person and have generally tried to do the right thing."

As I read this today, all these years later, it seems like the writing of an agnostic, one who freely admits that he doesn't know, but is unwilling to deny the possibility of God's existence.

Anyway, first order of business involved 20 radiation treatments to get rid of a solid tumor that had metastasized into my thoracic spine (a rare occurrence itself since Waldenstrom's is a blood cancer that 99% of the time stays confined to the bone marrow). The radiation did not do anything for the pain in my joint areas and I had to plead with my oncologist for about a year to get him to treat me with Rituxan (today's frontline chemotherapy drug). My oncologist wasn't certain that my joint area pains had anything to do with my Waldenstrom's and since he had just had a patient die from Rituxan, he was very gun-shy about giving it to me. Anyway with persistence, a year later I received Rituxan. I obviously did not die from it and finally got relief from the pain in my joints.

This period was obviously a stressful time in my life and fortuitously I discovered and read Calson's *Don't Sweat the Small Stuff* and several of his other books where he develops his ideas significantly deeper. I began to put some of his suggestions to work to start living a less stressed out life. Besides helping me to develop an attitude of "it is what it is" and "if it won't matter a year from now, than it's not worth stressing about", three concepts resonated strongly in me... (1) The importance of "living in the present moment", (2) the idea that your thoughts play a major role in how you feel at any particular point in time (and that one can choose to hold onto a thought or "let it go"), and (3) the idea of trusting your inner wisdom, i.e., when the analytical part of your mind fails you, rather than continuously struggling for a solution to the problem, it's better to walk away from it and the solution will often make itself known without conscious effort on your part.

Flash forward to the summer of 2007. I'm retired on disability enjoying a relatively stress-free retirement in Middlesex County, Virginia, far away from the Washington, D.C. beltway area where I had spent most of my adult life. My symptoms have improved over the last three years with treatment, but my cancer has nonetheless become more aggressive and I entered a clinical trial using an experimental drug called Perifosine. It was not the miracle cure I had hoped for - I experienced so much back pain, knee and feet pain and swelling (I had large amounts of fluid removed from my left knee twice) during the Perifosine trial that I was unable to walk without crutches during much of the trial period. I was on many different pain meds to which I was having adverse reactions, developed insomnia, and ended up having three psychotic breaks within five days that ended in my being committed to the psych ward of Rappahannock General Hospital (RGH). Three days after my first psychotic break, I had what I felt was my very first truly religious experience. Racked with pain and confusion, I was in my hot tub outside, long after Nancy had gone to bed. As I looked into the sky that beautiful evening I was awe struck by the vastness and wonder of the universe and the fact that it has existed forever, I guess. There was a beautiful full moon that evening and as I gazed at that wondrous moon I truly felt I was gazing into God's face. Wow, at 60 years of age I had found God!

Anyway, these psychotic breaks caused me to totally lose touch with reality... the best way I know to explain them is that I left my conscious mind and dwelt in the vast realm of my unconscious mind. In my unconscious mind I found a myriad of things. I found fear and violence within me like I've never known. Two of these breaks occurred in hospitals where I became convinced that everyone trying to help me were demons in disguise trying to pull me into hell (most likely leftover remnants of my childhood Catholic upbringing) and I had to resist them at all costs by professing my faith in my newfound God. I punched a hospital minister (a demon in my mind). I knocked the glasses of my wife's minister (another demon) to the floor, breaking them beyond repair. During my last and worst episode, I actually escaped from the "holding room" into the hospital attic and proceeded to crawl to a different part of the hospital. The police were called; I put up a good fight, but with the help of a tazer, I was finally put in restraints and loaded up with drugs.

Three days later, a hearing was held to determine if I should be committed. I was appointed a lawyer to represent me. I was no longer violent and, in my deluded mind, totally ready to be released. In preparation for my initial meeting with my lawyer, I wrote down on a yellow sheet of paper some "facts" that would help him help me. I still have that paper. It starts out somewhat coherently wherein I explain about my cancer and the clinical trial that brought me to all of this. The final paragraph is intriguing...

"Meanwhile, a biggie, I find God in my life and am dealing with concepts of heaven, hell, immortal soul, etc. I don't currently feel that I'm insane but am being held against my will by the devil's gang (who is ever so tricky), E.G., I did not want a shot prior to meeting Bill Nunn (my lawyer) since I felt clear headed, but was forced a shot in my left hip to calm me down, which quickly made me fuzzy. I will be going to Lower United Methodist Church, if I make it back home, for spiritual guidance and hopefully salvation."

Obviously, at my hearing before the county magistrate, these written words did not serve me as I had intended and I ended up spending 11 days at RGH before being released. It took a good year before I completely recovered from this experience and much of what follows I now realize was me functioning partly in my conscious mind, but still partly in my unconscious mind as well. I came home from RGH a changed person. I was more loving to my wife, sons, sisters, and friends than I had ever been. I even felt affection for my wife's dog, Randy, whom I had always disliked and resented. I was extremely fearful, however. It took a long while before I could go into our bedroom, where I had previously spent weeks and weeks lying in pain. I could not watch anything on television that had any hints of violence or scariness. Being that it was close to Christmas, I watched a lot of Charlie Brown shows. I was very afraid of losing my mind again. One of the things that helped get me through this was what I had learned from Richard Carlson...to "live in the moment" and "to let go of my negative thoughts". When I found my mind wandering to places I didn't want to go, I would focus intently on what I was doing at the moment, E.G., if I were brushing my teeth, I would think to myself that I was brushing my teeth and I would concentrate on the sensation of the toothbrush as it brushed across my teeth and gums. This helped a lot to distract me from my negative thoughts and allowed me to let them go. Things that I could previously do without difficulty – like driving a car and performing home repairs – were a bit strange and difficult for me. With my newfound belief in God, I began going to the Methodist church with my wife, Nancy. For her this was truly an answered prayer. I even revised my "Please Read at My Memorial" document by adding the following paragraph: "I'm happy to say that God revealed himself to me this past year and helped me find the way to a lovely church. There, I've been helped to feel God's love and I have regained and strengthened my faith. I have become less afraid of dying and I pray when that time comes, that God will welcome me by his side in heaven."

As time passed, I slowly began to get my old self back – driving was no longer difficult, I regained my carpentry, electrical, and plumbing skills and was able to finish remodeling a bathroom that I had started before the clinical trial. I lost my fearfulness. However, along with these positive signs of recovery, I became somewhat less loving and even starting resenting my wife's dog Randy again. I was having serious doubts about my newfound faith. Nancy and my brother-in-law, Bob, encouraged me to attend devotional Bible study classes at the Methodist church. They were sure that would restore my Christian faith. Over the next year, I attended three Bible study classes at the church... an introduction to the Old Testament, an introduction to the New Testament, and an in-depth study of Daniel's apocryphal book in the Old Testament. Nancy and Bob's plan backfired - the more I read the Bible, the less I believed that these writings were the inspired inerrant word of God. I became convinced that the Bible was a holy, but very human book containing stories written by ordinary humans. I found myself unable to believe in my heart in Jesus' divinity and resurrection, the key tenants of Christianity. I also began to feel more and more conflicted when attending church services. I found myself regularly and routinely mouthing words and listening to proclamations of faith that I didn't truly believe in my heart.

That's when I sought out and discovered the Unitarian Universalist Fellowship of the Rappahannock (UUFRR) in White Stone and that's when my spiritual journey went into high gear. I began reading books dealing with religion and spirituality. The first few dealt with the history of Christianity. These books along with Bart Ehrman's *Jesus, Interrupted: Revealing the Hidden Contradictions in the Bible* soon solidified in my mind that I was not going to find the answers to my spiritual questions in the Bible. Since then I've read books written by believers, agnostics, and atheists and have become a fairly deep thinker. I have found the website [SBNR.org](http://SBNR.org) (Spiritual But Not Religious) particularly inspirational. Most recently I read Peck's *The Road Less Traveled*, the sequel *Further Along the Road Less Traveled*, and am currently reading *The Road Less Traveled and Beyond*. What resonates particularly well in me in Peck's books is his treatment of Grace. He gets into some issues that I've actually been thinking about for quite a while now, E.G., why so many of us (myself included) have been so blessed and fortunate in life. I've struggled with whether my many blessings have been simply blind luck or have been what Peck refers to as the miracle of serendipity. Webster's dictionary defines serendipity as "the gift of finding valuable or agreeable things not sought for". Peck develops this concept quite well, albeit in a manner that I would not have been able to fathom or accept a few years ago. Although I don't have the time to fully do the topic justice here, I can say that he has opened me more than ever before to the idea that Grace or God resides within me, that my life's many blessings, including this spiritual journey that I am on, are a gift - part of the miracle of serendipity. There is a sentence from his book that intrigues me... "The mind, which sometimes presumes to believe that there is no such thing as a miracle, is itself a miracle".

In closing, I'll reiterate that very first question "is my cancer a blessing or a curse?" I should mention that with treatment, my cancer has stabilized over the last two years. I do struggle with neuropathy in both feet and with chronic, but improved anemia, but I have tolerated my treatments well and enjoy a good quality of life. I wouldn't wish Waldenstrom's on anyone, but I will say that if I could go back in time and change my initial cancer diagnosis into a diagnosis of a simple bacterial infection, curable by an antibiotic, I doubt that I would do that. My cancer has given me an appreciation for life, unlike anything that I've known before. It has also led me to a newfound spirituality that has added enrichment to my life that I never dreamed of or thought I deserved.