

“GNAWING ON A ROCK” – A Man’s Long Journey Living With Prostate Cancer

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This appears to be the appropriate title regarding my life as a husband, father, grandfather managing being the “rock” my family considered me, while coping with the ravages I have experienced with surgery, radiation, then over two decades of hormone medications drawing testosterone (aka androgen) out of my body - the life sustenance of men but, adversely, the fuel to cancer growth and proliferation - *because Prostate Cancer was gnawing within my “rock” body!*

This story of my life with cancer begins and ends with Hope and Faith its cornerstones. Importantly, living with cancer depends on what patients contribute to their own survival.

I was diagnosed with Prostate Cancer in November 1992, Gleason Score 3+4/7, PSA (Prostate-specific antigen) blood level 6.3ng/ml, with subsequent treatment over the years of initially radical

prostatectomy (open surgical removal of the prostate gland and associated organs) followed by external beam radiation to the prostatic bed and periphery as a safeguard, three years apparent remission with PSA less than ($<$) 0.1ng/ml, then return of slow rise PSA to 0.81ng/ml by November 1996 indicating prostate cancer cells were still active within my body.

From 1996 to 2018 I had been able to control growth and manage my cancer with Androgen Deprivation Therapy (ADT) (the suppression of testicular production of testosterone) and variety of medications subsequently prescribed, but the consequences of this necessary protocol came with difficult to tolerate side effects.

I mention 2018 because it was in that year a new isotope for imaging – fluciclovine/Axumin - came available at the University of Kansas Medical Center Department of Nuclear Radiology. I had F19 PETCT imaging from top of head to pelvis following injection of this new isotope in July 2018 and the cancer cell activity was finally identified as 1cm of activity in the area of the anastomosis (where

the urethra is reattached to the bladder neck after surgical removal of the prostate). Head, chest, and lower pelvic area were clear of activity. Back home in Wichita, Kansas I received CT imaging then MRI to set up appropriate direction for targeted radiation, then with the EDGE Radiosurgery System my treatment was successful with those remaining active cancer cells eradicated. Unfortunately, despite the radiation having been targeted as closely as possible to those cancer cells, the radiation spread caused scar tissue to form in that bladder neck/urethra location as well as weakening muscles in the rectum associated with bowel movement. The scar tissue, though weakening the flow of urine out of the bladder, was causing little concern for a couple years, but then had developed to close and shut off all flow out of the bladder. With any scar tissue closing and pressure of urine from the bladder on that scar tissue, nerves that extended to the head of the penis would react with very discomforting pain. For a brief time insertion of a urethral catheter through the penis (urethra) to the bladder provided relief with urine flow during and after that catheter removal, but eventually the scar tissue had built up wherein a catheter change had to be relocated for

urine flow to exit to a urine collection leg-attached or overnight bag via an opening in the stomach near the umbilicus (commonly known as the belly button) where a suprapubic catheter is wended a couple centimeters into the bladder. Urine build-up in the bladder, despite eventual exit through the suprapubic catheter, continues to this day to pressure the scar tissue sufficiently that consequent nerve pain to the head of the penis has become a constant discomfort I have had to tolerate and accept; there appears no remedy. This has become my continued life- long management of urine control.

The consequences of the foregoing and protocols necessary to have prolonged my life have included medications oral, injected, or infused that if not closely monitored and dose controlled can be toxic to different organs in the body; a weakening of muscles; an effect on bone mineral density and bone mass decreases requiring yet additional medications; infusions, and regular imaging; sleep deprivation; general discomfort from other effects within my system; and over long term in my case, left me with chronic anemia and despite these drugs stopped following targeted radiation in 2018, my testosterone

never returning; chronic fatigue from these issues; and a resulting conclusion that unless I continue to set my mind to survival and tolerating these issues despite constant discomfort, my life now in my 90s, will rapidly decline. Hope and faith have carried me this far and continue to be my cornerstones of survival.

One's life can be drastically changed with the diagnosis of any cancer. The important very necessary way of survival and controlling your own destiny is researching and learning all you can about that cancer so that with at least even minimal knowledge, you can work more closely with your treating physician(s) to insure you are receiving the most appropriate treatment for your condition. Research and study of my cancer began the day in 1996 I learned my cancer was still present in my body and will continue to my demise. It has been the wealth of knowledge then gained, regular counsel with physicians specializing in prostate cancer, and involvement in prostate cancer research and treatment that has enabled this long and continuing survival.

Be mentally strong, set your mind to do everything necessary to control and manage your cancer, be open and willing to seek counsel from others dealing with your or other cancers to learn methods of self-management of your cancer.

Never give up hope, no matter how challenging your life has changed. Hope can prolong your life for years, wherein giving in to those challenges will not only affect your reasonable well-being, but rather hasten your demise.

My daily prayers are that all diagnosed with life-threatening cancers will maintain the hope and faith that I have to strengthen their resolve to survive. Hope accompanied by prayer and faith are known to work wonders.

I care and am available online to anyone seeking someone to understand and hopefully assist in addressing their concerns.