

## BEATING THE ALTERNATIVE

By Gary S. Lachman

Dedicated to the memory of Richard Raphael

### *I'm a different person*

Many people feared the end of the world as we know it would occur at the Millennium. Massive power outages, computer network crashes, natural disasters, geopolitical crises and other mortal blows to humankind were all predicted; yet none came to pass. Except for me.

I'm a different person than I was in February of 2000. Throughout this ordeal, many people asked me if I felt I had changed at all. At first, I wondered what they were talking about. Later, in the deepest darkness of my despair, I suspected that I had undergone some fundamental psychological and spiritual changes. Many of these turned out to be nothing more than the offspring of temporary depression. But now I truly know. Although I don't fully understand the actual metamorphosis of spirit, I know I've somehow changed. I imagine it's akin to a tadpole losing its tail and sprouting arms and legs. It certainly doesn't know that it's a frog, but somehow it must feel that it isn't a tadpole anymore. There's something different about me – my thinking, my feelings, and my values. Sometimes, with a clue just beyond the horizon, I almost think I understand the changes. But most of the time, like the frog, I just blindly exist as I now am.

There is both a physical and a psychological dimension to cancer. Both of these dimensions of the disease have their own distinct cycles. If you have the misfortune of receiving a diagnosis of cancer, you will experience firsthand the circle of your own life; a circle that doesn't quite complete itself at the same place it started. For example, from a cerebral standpoint, it begins with denial. After all, it shouldn't be surprising that the human brain simply can't immediately process the entire weight of the thought that it may imminently cease to exist. Not on all levels, anyway.

Now, at the end of a yearlong nightmare, I have finally arrived at a point where I can talk honestly about my experience. It took a phone call from a stranger who had recently received a diagnosis of cancer and wanted someone to talk to about what he could expect. A mutual friend had referred him to me. I met with him and we immediately hit it off. This was a man who didn't want anything sugarcoated, and I therefore agreed not to pull any punches. The opportunity to provide him with a first hand account of what lay in store for him carried the promise of a catharsis for me. It also raised the flag of my greatest fear - the future receipt of another diagnosis of cancer.

*A chink in the armor*

As I piloted my BMW through the dark curves of the GW Memorial Parkway one evening in early February of 2000, I was lost in reverie over a recently closed deal for the U.S. Department of State. Suddenly there was smoke and flying debris ahead. Cars were careening wildly off onto the grassy shoulder and smashing into one another in domino-like fashion. Acting purely on instinct, I downshifted and steered my way through the maze of twisted metal and broken glass. A tree had fallen across the left lane, almost completely blocking the remaining right lane. With the uppermost branches raking against my windshield and driver's side door, I barely squeezed through a narrow gap between the tree and the grassy shoulder.

Looking at the wreckage in my rearview mirror as I shot through that gauntlet, I breathed a sigh of relief. I had made it. Pulling over to a scenic overlook so that I could safely call the police from my cell phone I thought, "YES!!! I am invincible! Indestructible!"

The next day at my office, I received a call from the office of the Gastroenterologist that I had recently seen for a colonoscopy. They wanted me to come in that day for a consultation about the results. A small chink began to form in the armor I thought I always wore.

So it is now slightly over seven years from the date I heard those unreal words from the Gastroenterologist: "We found a moderate-sized lesion in the wall of your colon..." How many times a day, in how many places around the world are words to this effect spoken? And how can I offer hope, encouragement, and advice to those who are hearing them? Perhaps it is by opening some windows on the experience for those who are afflicted as well as those who are along for the ride. The first window that should be opened is labeled *Anger*.

It's typical for a cancer patient to experience the highs and lows from hope to despair or fear. But the more significant emotional pendulum swings between joy and anger. Joy at receiving good news, joy at the return of your appetite, being able to take a shower and not freezing when you emerge, watching a good movie that completely distracts you from your pain, pleasure at receiving love from concerned family and friends. All of these experiences are taken for granted when you are healthy. They are welcome gifts when one is suffering. This basis of joy is also the launching platform for anger.

The first seeds of anger are sown at the moment of understanding you have a life-threatening disease. There is anger turned inward at your body for betraying you; the childlike belief that you are indeed invulnerable is suddenly shattered when mortality is

confronted. Then a more generalized feeling of anger is experienced. It is directed outward, non-specifically at external influences and conditions.

“Why me?” you ask. “Was it my diet? My genes? My environment? My destiny?” But no one can provide the answers you seek. The doctors simply don’t know. The precipitating factors are unclear; the prognosis is expressed in unsettling percentages.

I asked each of the doctors I consulted, “Was it because I don’t eat many vegetables? Or because I put a lot of Equal and powdered, non-dairy creamer in my coffee? Maybe the result of a high stress job?” Nobody knew. No one had any answers.

I felt like I was the victim of the ultimate irony. I had always tried to take extremely good care of my body. Despite the fact that I had been relatively hard on the old corpus, subjecting it to many insults and injuries from self-destructive sports, I was in excellent shape. I had been working out with a personal trainer for years and had put countless miles on the treadmill and exercise bike. I had broken my shoulder, ruptured my spleen, broken my nose on numerous occasions, shattered my jaw, and torn up my knees, but considered those painful experiences as the price paid for fun and adventure. So what was this cancer all about? I hadn’t asked for trouble here. This couldn’t be right.

What I couldn’t come to grips with was the fact that maybe I wasn’t as invulnerable as I felt that night on the GW Parkway when I avoided that fallen tree. In retrospect, I suppose I always saw myself as larger than life. I played football in high school on an undefeated team. I was an accomplished skier. I had conquered many of the 14,000 foot peaks in the Colorado Rockies and climbed the Mont Blanc in the Alps. I earned my Pinks with two foxhunts and played high-goal polo at several clubs in the U.S., as well as in Mexico, Argentina, and South Africa. I was the proverbial legend in my own mind.

Colorectal Cancer. It was like one of those brainteasers: “What’s Wrong With This Picture?” Living legends just didn’t get such an unglamorous disease. I couldn’t accept it. I didn’t want to accept it. It didn’t make any sense to me. I couldn’t figure out what had happened to the Golden Boy.

But one thing was for damn sure - I had a right to be angry with my primary care physician. When I noticed bleeding with my bowel movements, he examined me and prescribed suppositories for hemorrhoids. When the bleeding got much worse, he examined me again. Maintaining it was still a case of hemorrhoids, he refused my request for a colonoscopy. Only when I vehemently argued against his diagnosis and demanded a referral for a colonoscopy did he finally relent, perhaps just to pacify me. Sadly, he hasn’t spoken a word to me since the day I received the diagnosis of cancer.

I also still harbor feelings of anger at his predecessor, a sweet man who had been my internist for about twelve years. This doctor always expressed a sincere concern for me

because of my then inordinately stressful occupation as a homebuilder. Yet for all his concern, he absolutely blew a flexible sigmoidoscopy less than two years before. He apparently pushed the sigmoidoscope right past the polyp that was steadily growing into a cancerous lesion less than 7 centimeters from the anus, pronouncing me in possession of a perfectly clean colon. This was later deduced from that fact that colon cancer always starts with a polyp that takes many years to develop into a cancerous tumor. There was no way I could have a lesion that was 23 cm. in diameter in February of 2000, that wasn't in evidence as, at the very least, a noticeable polyp in March of 1998.

Unfortunately, the tumor hadn't just been resting on its laurels; it had grown completely through the wall of the colon and was dangerously close (if not actually into) the surrounding lymph nodes. I was told that this was an advanced stage two, or very possibly a stage three, lesion. The tumor encompassed approximately 20% of the circumference of the rectum and was less than the length of an average size index finger up from my anus. It was inconceivable that the two internists had failed to notice it.

The punch line came in February of 2001, when I found out the possible reason the first internist had missed the polyp/tumor in 1998. The doctor was practicing medicine while allegedly suffering from Alzheimer's disease. It was the opinion of another in his field that he should have retired from his practice long before this missed diagnosis. If a polyp had been detected from a properly performed sigmoidoscopy, it could have been removed with a simple wire snare – an outpatient procedure.

Was this cause for anger? You bet your life it was.

So there I was - angry with my body that had betrayed me, angry with a doctor who thought it was just a case of pesky hemorrhoids (at the time I didn't know about the Alzheimer's or the negligently performed sigmoidoscopy), angry at the hand fate had dealt me – yet I didn't know I was angry. Go figure. It all made sense to me a year later. Unfortunately all that unrecognized anger had serious repercussions come that summer.

After the first waves of anger have washed over you, a new phase begins. This is a period when it seems you are engaged in many activities that are related to your diagnosis, but at the same time keep you focused away from it. This ensuing denial phase just acts to provide an incubation period for the feelings of anger to further germinate. When I learned that I had cancer it was like being presented with a new and challenging deal. At least that was the way I apparently chose to hear it. This reaction was probably the result of my being an inveterate deal junkie. It became an opportunity to phone and fly around the country seeking the best surgeon and the optimal hospital care.

Donald, a close family friend had offered to put his plane at my disposal for visiting far-flung cancer centers. So on a brilliantly clear winter's day my good friend Howard and I

flew out to the Mayo Clinic to meet with a renowned colorectal surgeon. Although he was a “white knuckle” flyer, Howard wasn’t about to let me take that journey alone. I remembered his nervous grip on my shoulder when we once hit some turbulence on a commercial airliner, so flying in Donald’s fast but noisy Merlin took an extreme act of friendship.

I exchanged e-mails and calls with Izzet, a best friend in Istanbul who had experience with colorectal surgeons in New York. I visited Johns Hopkins and Duke Medical Center. Doctors at the Lombardi Cancer Center at Georgetown University Hospital examined me. I surfed the web for any information I could find on my disease and current treatments. I met with a guy at the EPA who had survived the same form of cancer and was living a successful life. I ordered visual imagery audiotapes on the Internet. Was I really performing my characteristic due diligence, or was I just avoiding reality and postponing the inevitable?

The best thing I did was to take my two children to Vail for a week of skiing. My son and daughter have been my winter travel companions since they could walk, and I felt we needed what was going to be the last shared holiday for awhile. Maybe forever. They went to ski school in the mornings and alternately skied with me in the afternoons. We went to fun restaurants for dinner and rode the gondola up to Adventure Ridge for tubing and snowmobiling at night. The last day of the vacation the three of us covered almost the entire mountain together. The weather was good, the snow was great, and I can’t say how many times when my suffering was at its worst that I would remember those moments.

I returned home having made the decision to be treated by Dr. Patricia Conrad-Rizzo, then an oncologist at Georgetown, with the surgery to be performed by Dr. Kirk Ludwig at Duke. An Interventional Radiologist at Georgetown installed a Mediport, and radiation and continuous infusion chemotherapy commenced immediately. This is when things began to get interesting.

First of all, cancer treatment is a seemingly endless series of indignations to be suffered by both mind and body. Some people feel overwhelmed by fear and just numbly go along with the program. Others are thrilled to be receiving so much attention and act like this is all some great adventure or privilege. For me, the deal junkie, it was the time for getting down to business.

## *Smart bombs*

Despite the cheerful attitude of the casually attired staff, the Interventional Radiology Department at the Georgetown University Hospital is a grim place. Cloistered in the basement of the sprawling red brick medical center, the Radiation Unit treats all manners of cancer by blasting the afflicted area with massive doses of cell-burning rays. Throughout this story, I will avoid the clinical explanation of treatments and describe what occurs in layman's terms. One reason for this is that I certainly am not qualified to lecture on these esoteric medical procedures. Another is that I think that the technical jargon depersonalizes and desensitizes one from what is really happening to the body. That kind of pabulum is the last thing I need to dispense.

At the inception of a regimen of chemotherapy and radiation treatment, you are physically prepared to receive the poisons that are designed to kill and/or stunt the growth of the cancer cells. In my case, a device called a MediPort was installed just under the skin above my right pectoral muscle. A long catheter is snaked through the tissue into the jugular vein, so that the chemicals injected into the port have a direct route to the heart. They are then pumped throughout the body, but somehow know to head right to the tumor. Kind of like the smart bombs we all saw on television during the Gulf War. And hopefully with more accurate effect than the missile that slammed into the Chinese Embassy in Belgrade.

This is a good warm-up procedure to experience. You know something tangible has been done to fight the cancer. You can feel it, and are comforted in the knowledge that a gateway has been established that will open the tumor to attack by fearsome chemical forces. It also doesn't hurt. I was out cold for the installation, and the removal was performed a year later under local anesthetic. Somewhat uncomfortable, but no big deal. I was happy that finally something was really happening that would put me on the road to recovery. I would wear a cool, black leather fanny pack (rotated around to rest just over my belt) that would hide a small pump about the size of a Walkman. This pump would continuously deliver measured doses of the cancer fighting cocktail 5 FU (fluorouracil) with Lucovorin to the site of the tumor.

The day before the Mediport was slipped under the skin of my chest, I spent an hour in the radiation lab. There, the technicians isolated the site that would be subjected to the radiation treatments. The procedure involved my lying motionless on a cold steel table for about 45 minutes while, after receiving four pin-sized tattoos to set the physical parameters of the site, the technicians zoomed the x-ray focus in and out on the target. This is no day at the beach. After about ten minutes on your stomach, skin to cold metal, you begin to sense that this must be what it's like to be a corpse at the morgue. Except

you can feel the cold of the table's metal surface, and the cramping from being in an unnatural position.

The purpose of this rather uncomfortable exercise is to program a computer that will control the field and duration of the radiation. The good news is that you only have to go through this one time. Once the field is established, it's merely a matter of coming in every day, flattening out on the table for about five minutes, and having this big, white x-ray machine rotate around you, bombarding the tumor from several different angles with cell destroying radiation.

So now you're good to go with the chemo and radiation treatments. Your daily radiation appointments have been scheduled, arrangements have been made for a travelling nurse to visit your home once a week to refresh the chemo bag for the Mediport infusion, and you've been advised by the doctors about the possible side effects. And now the fun starts.

Everybody reacts a little differently to chemo and radiation. Some lucky bastards sail through the treatments without so much as a hiccup, but that's rare. On the other end of the spectrum are those unfortunate souls who suffer with violent nausea, skin burns, mouth sores, hair loss, impotence, and debilitating fatigue. At least for this first six week course of treatment, my experience fell somewhere in the middle of these two extremes.

For the first month, everyday at 8:15 a.m., I happily went down to the basement of Georgetown Hospital for my radiation sessions. After catching up on the ACC scores with my technician – he a Maryland fan, me a Dukie – I'd stretch out on the table, my chest and legs supported by a foam pad with the section under my gut cut out. Although this had the effect of pushing my bare butt up for all to see, I soon adjusted and learned to relax. I would visualize the powerful rays zapping these evil little beings, much like Pac Man eating up the dots. I don't know if that technique had any positive effect, as claimed by proponents of Visualization Therapy, but it gave me something to do while I lay there, the machine rotating around me.

Dr. Cindy, the Radiologist, was the spitting image of a college friend I once had. Slim build, medium height, straight, shoulder length hair, a formidable intelligence burning in her eyes. Her casual demeanor, almost like a "hippie chick" in her thirty-somethings, belied her subtle professionalism. It was almost spooky every time I saw her. I could barely resist the impulse to drop that old line about, "y'know, you look just like..." Likewise, her staff was so nice that the deadly serious nature of the treatment was softened by their collective attitude. But despite their comforting personalities, the effects of the radiation eventually began to manifest themselves on my unprotected posterior. I can't say I wasn't given fair warning. The best way to describe the condition of my butt after a month of radiation is to have you imagine being staked out in the

desert, bare-ass naked, stomach down, with your butt cheeks spread to receive the full brunt of the Saharan sun for several days of exposure.

Going to the bathroom became an ordeal. It was tortuous whenever I took a shower and the water ran down into the cracks and fissures of my rectal region. And in the midst of the radiation burn period, I lost my appetite for normal food. A craving for Little Debbie Strawberry Shortcake rolls took hold. I'd go through nearly a dozen a day, driving my wife crazy with demands to stock up on boxes of this sweet treat so that I would never face the desperation of running on empty.

This was really bizarre. Being lactose intolerant limited my ability to indulge in typical desserts that would assuage a sweet tooth. No hot fudge sundaes, white frosted birthday cake, Crispy Crème donuts, or strawberry milkshakes for this boy. But thank God for those Little Debbies. I would have starved without them.

Such cravings apparently are not all that unusual when one is under the influence of chemo and radiation. I'll get into this later, but trust me when I tell you that these treatments make you a little crazy. Weird things happen not only to your appetite, but your taste in many other things undergoes a change. Movies, books, TV shows, colors, and attitudes – all are subject to the influence of the rays and chemicals. And your dreams get strange, as well. But I'll get back to that.

The last two weeks of treatment were difficult. The anal fissures and burns didn't respond to the salves and creams that Dr. Cindy prescribed. My appetite continued to wane. I counted off the days until the six weeks would be over. This was my first brush with an overriding sense of waiting. This feeling of waiting became even more prevalent over the next 9 months. I always seemed to be waiting: waiting not to be nauseous; waiting to be able to wipe my butt without wincing in pain; waiting to be able to take a comfortable shower without the sting of soapy water in an open wound; waiting for chemotherapy treatments to be over; waiting for my strength to come back after surgery; and waiting for an end to the innumerable blood tests.

I had almost forgotten the blood tests. These weekly invasions of my veins were necessary to monitor my T-cell counts to determine whether the chemo was reducing my resistance to infection, a common side effect of the chemicals. I'm the first to admit that I'm a big baby. I dreaded those arm sticks. I learned the hard way that there is an art to taking blood. It's more than just wrapping an elastic tourniquet around the arm, squeezing on a rubber ball, letting a vein pop out, and then puncturing it with a needle.

For one thing, there are different size needles. Since this is a procedure that is going to be repeated more times than you want to know, always ask for the pediatric size needles. It only makes sense: smaller needle = smaller hole in the vein. For some reason, it doesn't effect the extraction of blood. As long as you're still alive, the blood will flow

into the syringe. So if you want to avoid looking like a late-stage heroin addict, go for the baby needles, find an infusionist with a delicate touch, and put really hard pressure on the puncture site when the needle is withdrawn.

I found a bona-fide saint in the blood lab at Georgetown Hospital. My veins were never bruised, and despite my driving her batty with my constant unnecessary reminders for the pediatric needles, she maintained a gentle patience with me that I was truly thankful for. Serena never failed to ask about my kids, my job, my wife, and my parents. Every week she'd pick up the conversation where we had left off the previous visit. I don't know how she did it. She must have seen more than twenty-five patients a day, five days a week. Her mind worked like an ultimate soap opera database.

I never let anyone else get near my arms except once, when Serena was away on vacation. Although nothing evil befell me, that was a really stressful experience. And that's what I mean about the chemicals making you a little crazy. You really get into the ritual of all the little actions that have been newly introduced into your days and weeks. Things that are designed to test you, make you feel better, fight the cancer, repair the damage to your body. If they're repetitive, they evolve into ritual, and you resist changes to them to an absurd degree.

### *A slick black leather fanny pack*

I mentioned earlier that during the first six weeks of treatment, I was attached to a miniaturized pump that pushed the chemo-cocktail directly into my jugular vein. Carrying the pump in a slick little black leather fanny pack, I doubt most people even perceived it for what it really was. In fact, during that period of time, I usually wore clothes, belts and shoes that coordinated with the pack, making it look more like a fashion accessory than a poison injection system.

Did you ever notice how once you've acquired something you then begin to see others with the same product, condition, or interest? Green Toyotas, Oakley sunglasses, college decals, political bumper stickers, whatever. Then it's not surprising that I now see many others with the telltale fanny pack with the clear tube running out of the bag and under their shirt. Obviously they were around before. I just never noticed them since I couldn't relate in even the remotest sense.

In the middle of March, 2000 I had the opportunity to go to an early evening fund-raiser for then-candidate Bush that was being held at a large hotel in Baltimore. I left Washington while it was still daylight, but had to stop in a rest area along I-95 to take a brief nap. The driving was making me tired even though the trip was less than an hour. This is typical of the kind of fatigue you'll experience. One minute you're fine, the next you're desperate for a catnap.

After a twenty-minute snooze, I resumed my journey, arriving about thirty minutes before the event was to begin. I cruised around the hotel, checking out the pins, t-shirts, posters, and other Bush memorabilia that was for sale, and waited for a friend to arrive. We found each other in due course and proceeded into the huge ballroom. A photo opportunity with the candidate was being organized and scores of supporters were entering a roped off room to wait in line for his arrival. My friend and I entered the room, passing through a metal detector and several security guards.

Well, you can imagine what hell broke loose when I set off the alarms and was grabbed by a guard who wanted to forcibly remove the fanny pack from my body. After a brief struggle, I was allowed to demonstrate the infusion system concealed in the leather bag. The guards were so unnerved by the experience that a real assassin could have probably walked right in behind me with a shoulder mounted Stinger missile. So much for security.

Candidate Bush finally arrived and we had our picture taken, shaking hands with confident expressions on our faces. I don't think he ever even noticed the fanny pack. If he did, he was too cool to say anything about it. That fund-raiser was the last public

appearance I was to make where I felt halfway normal for many months. The chemo was beginning to take hold, and it was insidious.

I began to squirrel all kinds of little things away in my leather pouch. I kept it turned around to the front, so it was easier to sit down in a chair, as well as to get at the things I had stashed in there. It began with my reading glasses. Then my wallet found its way inside the bag. Then pills, keys, and loose change. Then pens and notes and other office supplies. What started out as a slim, non-descript accoutrement was growing into marsupial proportions. Lucky for me that it was only a six-week ordeal with the little pump. I'd have parked my Bimmer in there if I thought it would fit.

It was during that time that my wife and the kids went to Colorado while I stayed behind to continue with the daily radiation treatments and weekly chemo bag replacements. Their departure was a little disquieting for me, but no big deal. I was still feeling fairly normal, going to work every day, and had good friends around to keep me company. But the next time they were to leave me behind, I had a major meltdown.

During this period, however, I was comfortable being alone in the house with our German Shepherd, Emma. Whenever I was home, Emma followed me from room to room. It was like we were attached at the hip. At night, she would crawl up into the bed with me; her years pricking up every time the infusion pump made its little cycling noise. I don't know if she was just lonely for the wife and kids, or she somehow perceived that I was the walking wounded. Either way, it was a great comfort having her around. Lately, there have been many articles and television newscasts on the subject of the value of pet therapy. I believe that there is a lot of truth to this. There was something comforting about having this beautiful big dog padding along behind me, watching every move I made with eyes filled with canine compassion. Some people are comfortable being alone; I am not one of them. I like a full house – full of friends and family.

Since I couldn't be with my family, my time with Emma was elevated to almost human significance. I also began to perceive that my friends fell into three categories. The first category includes all the people that were more acquaintances than friends. Some of those acquaintances actually became elevated to friend status, by virtue of their reaching out to me and offering support. The second category is comprised of those friends who, for some reason, were uncomfortable with my being sick. I got the feeling that my having cancer reminded them of their own mortality. As a consequence, I didn't hear much from them while I was fighting the disease. After I regained my health, some made their way back into my life. Some didn't, and that's OK. No hard feelings. There were enough people that fell into the third category to make up for their lapse of attention.

This third category is comprised of people that I called the "true friends". I hope that anybody who has to suffer through the indignation of cancer has at least a few of these people around. True friends fill in the gap that family cannot be expected to fill, either by

reason of geographic remoteness, personal time constraints, or on the other hand, simply being too close to the situation. In addition to providing love and support, true friends supply a sense of objectivity and humor. The true friend is able to do this effortlessly, so you never feel that they are even trying.

Sometimes you find these people performing acts of kindness that are way above and beyond the call. Sometimes they are just...there. Whatever the case, you will be wise to accept everything they have to offer. It is doubtful that at any other time in your life you will be so rewarded and indulged. During the course of my battle with cancer, I learned that I am a very fortunate man. I had always known that I was blessed with a wonderful family, but now I know that I am also rich in true friends.

Scott was probably my best true friend at the time. In addition to having remarkably similar backgrounds and living nearby, our wives and children were good friends with each other. Several years before, Scott and I began working out with a personal trainer. I had an extensive exercise and weight room in my basement, so it was like having our own private health club. When the reality of my impending surgery hit home, I resolved to train for this ordeal like a warrior preparing for battle.

Despite having the MediPort imbedded in my chest, the infusion pump strapped around my waist, a sorely burned ass, and feeling the first fatigue from the chemotherapy, I forced myself to ratchet up my training regimen. Scott and our trainer, Chin Le, offered me no quarter, pushing me to higher reps and heavier weights. About 3 years before, I ruptured my spleen in a fox hunting accident. I therefore had experience with having my abdominal muscles sliced open for surgery. I was acutely aware of what lay in store for me.

There's no getting around it; abdominal surgery is a bitch. It's amazing how many little movements of the body involve the stomach muscles. And that goes beyond the involuntary actions such as sneezing and coughing. When just sitting up in bed becomes a major effort, you know you have your work cut out for you. I don't know which is worse, the actual surgery, or the business of rehabilitating those muscles. I worked as hard as any professional athlete on my middle aged six-pack. Even when Scott and Chinh weren't around to encourage me, I'd go downstairs and crank out hundreds of gut crunches and knee raises. By the time Spring was coming to a close, and my date with the surgeon arrived, I was in top form.

## *Homecoming*

I rendezvoused with my parents down at Duke University on May 23<sup>rd</sup>; My wife and the kids would come down on Friday after the surgery. My dad is a hefty former athlete who just turned 80, with a shock of baby fine, white hair and sparkling blue eyes. He doesn't so much walk, as lumbers. If you send him to stand on line for anything, by the time he gets to the end, he's made a dozen new friends for life. My mother is a year younger, more cerebral and reserved than my dad, and able to play hours of tennis in the hot Florida sun. Blond and trim, she is a perpetual motion machine.

As difficult a time as this was for me, it was even more stressful for my folks. On one hand, they were in their element. This was exactly the kind of thing they were prepared for. They had both served on the Duke University Medical Center Board of Visitors for many years, making numerous friends among the doctors and supporters of the hospital. At the same time, it was still their kid who was suffering from a potentially lethal disease and facing major surgery, the outcome of which would determine the length and quality of his life. As far as they were concerned, this was the best set of circumstances for a bad situation.

I was also on somewhat familiar ground. Although the hospital had expanded exponentially since my days as a Duke student, there was something of the homecoming to it. No pep rallies, football games, or quad parties - just being able to look out the window and see the brown and gray stonework of the gothic architecture must have had the effect of returning me to a simpler time in my life. A time when my priorities were studying for the next exam, going to rock concerts and basketball games in Cameron Indoor Stadium, and driving down to Myrtle Beach for a carefree weekend of partying and surfing.

I had reserved connecting rooms at the Washington Duke Inn & Golf Club. Although the "Wash-Duke" hotel had not existed when I was a student, I had stayed there before, and enjoyed being able to look out on the fairways I had played, often accompanied by my Labrador Retriever, many years before.

The eve of the surgery passed quietly. I wasn't allowed to eat anything, only drinking concoctions designed to clean out the bowels. I watched a movie on television with my dad to pass the time. I listened to my mom talking on the phone in the next room. I was their kid again. They were in control, giving me the sense of security that had always been present, but often rejected and rebelled against, when I was younger. Now that I was a grown man, I could address the support they had always offered, and appreciate it for its true value. I only hope I was able to communicate my understanding of what genuinely fine parents they had been, despite all the brain damage I had given them. My

dad told me that I shouldn't worry about it. Although he was still pissed at some of the bonehead moves I pulled when I was younger (for which no pardon was deserved) this episode wasn't my fault. Therefore, my rescue was a matter of love and necessity - not exasperation and indulgence.

In this respect I was a truly lucky guy. I couldn't imagine going through an experience like this without my parents' incredible support as well as the love from my wife, kids, and true friends. Actually, I could. It would be terrible and almost unbearably frightening. I suppose that's the main reason I'm telling this story and baring my soul. If you know what's in store, try it on for size mentally, and gain some familiarity with the highs and the lows, the reality becomes less daunting. Anyone can triumph over adversity like this. You can't avoid the suffering, the anguish, the frustration, and the fear, but it sure beats the alternative.

That night, my old college pal, Peter, called to see how I was holding up. Peter was one of my closest friends during the four years I lived in the Durham area. Since our graduation from Duke, Peter had acquired a small agricultural tract, which he named Down Yonder Farm. He restored the century old farmhouse, and built several outbuildings, including a large music hall. He and his wife raised two fine daughters, countless sheep, horses, dogs, and chickens and developed the farm into a refuge for writers, artists, and musicians to focus on their crafts.

Peter is also a social worker and drug counselor, employed by the County to aid the less fortunate members of this newly affluent area. His natural talent for connecting with anyone, and communicating calm, realistic, and appropriate advice is prodigious. Over the course of the next several months he would have ample opportunity to subtly monitor and influence my soon to be fragile ego. This experience must have been fascinating for Peter, if for no other reason than clinical. He had known me as a brash, materialistic, spoiled kid, then as an aggressive, ambitious professional. Always the ego had been strong, large, out-there.

With major surgery imminent, the chink in the armor had expanded into a noticeable crack; one that would grow dangerously wide in the upcoming months. I just didn't know it at the time. On the eve of my surgery I was still, to most outward appearances, pretty much the same guy I had always been. I would only watch movies with violence and sex aplenty. The same went for my taste in reading. Formalistic drivel, my brother Bill would call these action movies and "beach books". His entreaties for me to sample *cinema verite* and modern literature were scorned.

That night, I dreamed of trying to buy a Morgan Plus 4 sports car. You will learn in the following pages that dreams play an important part in the cancer cycle. Whatever dreams you have when your are healthy are supplanted by really unusual, complex parodies or metaphors for the cancer patient's life during treatment and recuperation. Sometimes

they are easy to interpret - the symbolism being obvious, and the fears being transparent. Other times the dreams come in the form of dark allegories, replete with the somnambulist equivalents of dungeons and dragons. You'll see what I mean.

This was one of those frustration dreams. I was calling endless lists of ads in the papers, finally giving up and going from dealership to dealership. (That alone is a joke, since you could probably count all the places Morgans are sold in the U.S. on one hand.) Each time I arrived to see a car; it would be gone for one reason or another. Finally, just before I was ready to give up, a gorgeous blond drove up in a red Morgan, parked, and handed me the keys. I slid behind the wheel as she walked away. I noticed she was wearing a nurse's uniform. I turned the keys in the ignition, shifted into first, and woke up.

Even though all of the terrors of surgery and post-op were literally only hours away, I was steadfastly trying to maintain my bravado, both for my sake as well as that of my family's. I was obviously trying to convince myself that I still held the keys to the car. That I was driving this baby, I was in control, and I was confidently driving away from the nurse and the hospitalization she represented, despite how attractive she was. As have most coins, this one had two sides. One was my denial of the cancer by nonchalantly driving away from it in the sexy red sports car. The other was not that I was laughing in the face of adversity, but rather fleeing from it with all possible speed.

## *The anal part*

For obvious reasons, I don't remember much about the day of my first surgery. One thing I do recall is talking to the anesthesiologist, Dr. Gene Moretti, about my aversion to pain. I related to him my experience with the immediate aftermath of abdominal surgery. He told me he would compliment the general anesthesia with an epidural that would remain in place for several days after the operation. As it turned out, this was an excellent idea, because it completely numbed-out my gut area during those critically painful days after surgery.

Anyone who has had major surgery can tell you that one of the most annoying things you are subjected to immediately post-op, is the nurse constantly harping at you to suck on a clear plastic tube that looks like a pot smoking bong. The idea is to pull enough air into the contraption to lift a yellow plastic ball to a certain level and maintain it there for several seconds. This is supposed to help keep your lungs from getting congested while you are laid out on your back. The problem is, if you've just had your gut sliced open, the last thing you want to do is sneeze, cough, or forcibly suck plastic balls around. It hurts tremendously. The epidural was like a cheater. I could suck my brains out, with nary a twinge of pain.

The actual surgical procedure that I had undergone was called a low anterior resection with colonic j-pouch to anal anastomosis. Sounds pretty impressive, doesn't it? Except for the anal part. And speaking of the anal part, mine was temporarily disconnected. Perhaps the weirdest part about waking up after the surgery was that I had a new appendage – an opaque plastic bag that was attached to the lower right side of my belly. By the time I had sufficiently regained my wits, it was already starting to fill with small amounts of nasty looking, brownish stuff. Since my colon had just undergone some major cutting and splicing, it was probably a wise idea that this objectionable material was being diverted from the fresh wounds. That was the idea behind my temporary ileostomy, anyway.

I was worried that the plastic bag would fill and burst, flooding the room and bathing me in the vilest, most foul deluge imaginable. I was reassured that the ostomy nurse would be by to instruct me on how to handle this apparatus before such a problem arose. As the hours dragged on, my mind began to imagine wild incarnations of this almost mythical ostomy nurse. Even the appellation, "ostomy nurse" sounded fantastic. It was difficult to imagine what kind of person would devote their life's work to teaching patients how to live with a bag.

Begging the pardon of all those wonderful people who have chosen this career path, the images fashioned by my drug influenced mind were not exactly savory. Attila the Hun

was closer to the picture than Florence Nightingale. Much to my relief, Eileen was actually a lovely and kind woman. Technically called an enterostomal therapy nurse clinician, she patiently walked me through the care and feeding of this new part of me. The surgeon had created what looked like a large nipple (or small finger, if you prefer that analogy) from a piece of the ileum he had pulled through my lower abdomen. An adhesive ring fitted over this and attached to the bag. The bag had a plastic clamp on the back end of it that could be opened to let the liquid poop drain out. Every few days the adhesive ring, bag, and clamp were replaced to maintain a good seal and hygienic apparatus.

I'll apologize now, if this discussion gets too scatological for you, but after all, this was where the cancer chose to attack. After going through this experience, you get a whole new appreciation for the digestive process. Before cancer, or B.C. as I'll call that time, I never gave a moment's thought to going to the bathroom. A.C. (you can figure that one out) it becomes a major part of life. Just before I was to undergo the operation, the doctor gave me a videotape about colostomies. The target audience was people not only suffering from colorectal cancer, but those afflicted with other disease and devastating damage to the lower bowel. And I must admit, that tape did a hell of a sales pitch. By the time it had finished, I was ready to go out and proselytize the masses to have their colons removed so they too could enjoy the benefits of having an ostomy bag.

The reality was somewhat less than the tape promised. As I now know, many people live out perfectly normal lives with ostomy bags. For many, the bag is a welcome relief after suffering for years with colitis or irritable bowel syndrome. In my case, this was a temporary stop along the path to wellness. It would allow my bowel to heal without the danger of infection from leakage of the anastomosis into the pelvic cavity. If you think I was worried about leakage onto my clothes (this never happened), believe me I was far more worried about leakage into my pelvic cavity. An infection resulting from that could be fatal.

Dealing with emptying the bag became routine. As time passed and I became more adept with it, I learned little tricks that made it all a little more tolerable. I'm sure everyone has his or her own idiosyncratic methods, and I imagine you will develop your own. The thing to remember is; whatever works, do it. But let's get back to the hospital room in the days immediately after the surgery.

I slowly but surely began to emerge from the haze of general anesthesia. The epidural helped a lot, since I didn't have to keep hitting a morphine button and getting drugged-out. I remember watching a lot of television during the late evening hours after my family had gone back to the Wash-Duke for the night. I have no recollection of any specific shows, but I'm sure I missed the Sopranos a few times. I think I saw the movie, *Mystery, Alaska*. I remember something about hockey in that film.

On Saturday, May 27<sup>th</sup> I answered the phone to find my friend Csaba Magassy on the line. A noted Washington plastic surgeon, I knew him from my fox hunting days when we would spend long hours dashing across the open fields of western Montgomery County and hacking leisurely back to the trailer. I had also been Csaba's patient, after a polo accident left me with a badly broken face. He was one of those peripatetic folks who was either riding a bike or a horse, running, surgically turning sow's ears into silk purses, heli-skiing, elk hunting, giving lectures on the benefits of cosmetic surgery, or flying about the mid-Atlantic visiting patients in far-flung locales.

Csaba and I had connected right from the start. I think Csaba saw me as a cross between a son, a brother, and a friend. I was honored to be any or all of them. I am best friends with his twin sons, Matt and Steve.

Anyway, there was Csaba on the line, asking how I was doing and inquiring about the weather. Now how the hell was I supposed to know what was happening with the weather? After all, I was laid up in a hospital room – a virtually hermetically sealed environment. I did have a small view out the window, and I was able to relate that it looked cloudy but that was about it.

“How cloudy?” he asked.

“Christ, I don't know... Cloudy. Ya' know, gray sky cloudy,” I replied.

“Is it raining?”

“I don't think so. But I can only see *up* from here. I can't see the pathways below to tell if they are dark and wet. But it doesn't look like it's pouring or anything.”

“Have you heard a weather report?”

“Csaba, give me a break. Why would I pay any attention to a weather report? It's not like I'm going anywhere today.”

He finally gave up on this line of questioning. After a few more minutes of generalized banter he said goodbye. I drifted off to sleep.

I don't know how much later I heard a gentle knocking on the door. I opened one eye. Two grinning faces were peering around the corner at me. It was Csaba and his wife, Junior! They had flown Csaba's plane down to Raleigh-Durham airport and taken a taxi over to the hospital. They brought a huge history of the world type book as a gift (big enough to put legs on and use as a coffee table *a la* Kramer from *Seinfeld*) and ample amounts of good cheer. Now this is what I mean about true friends. They blew my mind showing up like that; and ended up having to make an instrument landing to boot. The weather had been worse than I thought.

## *The Pain Team*

If you've had any surgery in the past twenty years, you know that in addition to sucking on the bong with the yellow ball, the other torture they inflict is the walkabout. No matter how devastating the operation, be it open-heart surgery, thoracic trauma, or cancer, it's up'n at 'em as soon as you regain consciousness. Pitifully trailing your I.V. stand, you're forced to shuffle around the corridors surrounding your room. Depending on your perspective, and how deviant your sense of humor may be, this can be an entertaining activity. You get to sneak peeks into the other rooms and check out the old lady who's been screaming bloody murder, the man who's been cursing at his relatives, the sheik with the retinue of traditionally wrapped wives and unrestrained children, and the local politician with the never-ending line of supplicants.

Sometimes you encounter another patient making the same rounds. I was always tempted to propose a race. The first one to the finish line gets a new catheter. Or maybe that should be the last one to the finish line gets a new catheter.

I had an unexpected honor immediately following my surgery. Dr. Ralph Snyderman, the Chancellor of the Duke Medical Center at the time, paid me a visit and accompanied me on my first walk. This really elevated my status in the eyes of the hospital staff. As nice and attentive as they had been before, after this little promenade they were literally falling all over themselves to ensure that I was comfortable.

Before I knew it, a week had passed and I was ready for discharge. The epidural spinal catheter had been removed and sensation was beginning to return to my abdomen. I had met with the "Pain Team" and was armed with a portfolio of prescriptions designed to alleviate any continuing discomfort. The leader of this group, who practiced what is currently known as Palliative Medicine, was a kindly, grey-maned doctor who reminded me of the Wizard of Oz. We had discussed how best to address my post-op pain and my dad was ready to run over to the pharmacy to fill the prescriptions so that I wouldn't have to suffer even a moment's discomfort. I believe this was when my drug and equipment anxieties started.

When you are in the hospital, the attending nurses provide all of your medicines on a somewhat fixed schedule. You never even consider that a hospital could run out of medicine. When you are discharged, this becomes your responsibility. For whatever reason, I became progressively more obsessed with having sufficient amounts of medication available. When amounts dropped to a ten-day supply, I became nervous. When they dropped to a week's worth, I began to panic. I drove my wife to distraction with this anxiety. I know it was ridiculous, but I couldn't help it. To this day, I still take what are perhaps somewhat excessive precautions not to get caught short.

If you find this happening to you, recognize it for what it is. You have been subjected to intense pain, or at the very least, the possibility of intense pain. You know that the only thing standing between you and that pain is a little pill. It stands to reason that you want to avoid suffering. If you were a soldier in the infantry, you would feel the same way about your supply of ammunition when you were on patrol in enemy territory.

I was given Oxycontin (a pill) for long-term pain control and Roxycodon (an elixir) for short-term pain control. The pain that I was endeavoring to control was along the vertical incision on my stomach, as well as lower down around my rectum where the real surgical business had taken place. I started off taking the long-term pill every morning and evening, and the shorter-acting syrup on an as-needed basis.

I was concerned about the possibility of becoming addicted to these opiate-based drugs. Although the doctors – both the Dukies and the Palliative Medicine Team at Georgetown – reassured me that as long as I was really treating pain and not enjoying the medicine recreationally, I had nothing to worry about, I'm not so sure it was as simple as that. None of them could understand exactly how the pain medication would interact, chemically or psychologically, with the chemo, once that started up again.

I went directly from the hospital to the Washington Duke Inn & Golf Club. My family had returned home and I was installed in the room they had occupied. The kids actually had a pretty good time during their stay. After dutifully making their visits to their walking wounded dad, accompanying me on my cruises through the labyrinth, they enjoyed hanging out with Peter. In addition to spending some time at Down Yonder Farm, Peter took them to what they thought was the coolest store they had ever been to – the dollar store. This was amazing to them - an entire store where you could choose from thousands of interesting knick knacks, all for a dollar or less.

My then eight-year-old son, got a big kick out of the fact that I was wearing cargo pants identical to those that he favored. You see, I had been warned about the logistical difficulties of wearing belted pants with an ostomy bag attached to your lower belly. A fellow I had spoken with who wears a bag on a permanent basis told me that he always wore suspenders to accommodate having a stoma at belt level. So I bought a couple of sets of braces and had several pairs of trousers fitted with suspender buttons. But I also wanted something a little more casual to wear in lieu of blue jeans. The baggy, elastic waist cargo pants sold at The Gap fit the bill. I bought a pair of the clip-on type suspenders to hold them up, since I couldn't really tighten up the waistbands without having a tourniquet-like effect on the middle of the ostomy bag.

During my week at the Wash-Duke I must have watched twenty-five movies with my dad. Most of these were videos that he would rent by the boatload, but a few were on

HBO. Towards the end of our stay, we went to the cinema. Sitting here today, I can't say I remember any of them.

I had brought my laptop along and was able to connect to the Internet via a port in the hotel phone. I kept in touch with my friends back in Washington, as well as around the world. I enjoyed swapping jokes and assuring them that I was very much alive. Twice a day, I would take a walk along a path that encircled the golf course. Although I certainly wasn't in any condition to make the entire 3.5 mile circuit through this section of the Duke Forest, every day I tried to go a little further, eventually working my way up to about 1 ½ miles.

The path winds its way through thick stands of old pines, sugar maples, and live oaks, at times kissing the fairway rough, at others veering away into forest primeval. Joggers steadily pound along the trails, as do parents towing young children and babies, and students with their dogs. The sun filters through the canopy of needles in a fine spray of light; just enough to remove any feeling of dread but not too much that it becomes oppressive. Only the occasional "fore!!" after the whoosh – crack of club meeting ball, reminds you that you are on the periphery of a beautifully manicured golf course, and not in the midst of the Smokey Mountains.

When I was a student, I would often take my dog for walks through the Duke Forest, not around the golf course, but further down the road and deeper in, where a small creek meandered through the mixed growth of trees. Even though this path was in a different section of the Forest, the smell was the same. It brought back memories of minor adventures, former friends, and my Labrador - Buffalo Gal. As my parents and I shuffled along (actually I was the only one shuffling) we revisited those times: a simpler era before the complications of profession, family, and most recently, disease.

We took most of our meals in the hotel room. We had a couple of small refrigerators that my folks kept stocked with juices and fruit. The room service menu only offered a few choices that I could handle, but they were well prepared and delivered with good cheer. So basically, my days consisted of the walks along the wooded path, room service meals, sending a few e-mails, and innumerable movies. The long period of waiting that had begun back in March with the first course of chemo and radiation therapy was now in full force and effect.

## *Circuit Training*

By the time I returned home in the second week of June, Washington was in the vice-like grip of summer. We had a slate patio behind the house that during the early morning and late afternoon hours received partial shade from an ancient black oak. The back yard ran several hundred feet out to a white, three-board fence that defined the boundary with Hunt View Farm, 160 acres of pasture that about thirty horses called home.

We had temporarily inherited a vinyl-clad metal chaise lounge that belonged to Scott and his wife, Holly. We were keeping it until her parents moved into their new townhouse and would have a need for it. A hunter green cloth-covered mattress stretched across it and it was really pretty comfortable, except for the ragged end of the left arm rest where one of Scott's dogs had chewed on it.

There was a certain angle that I could place the chaise at that afforded me a particularly pastoral view through a pair of oak trees to the horse pasture and red barns beyond. Emma the German Shepherd would often sit outside with me, stationed beneath the shade of the black oak, staring out at the lackadaisical movements of the horses in the fields nearby. She seemed to sense that I was in this waiting mode, and she was perfectly happy to be my patient sentry.

Every few hours, I would rise from my chair and do my "circuit training". Unlike the exercise regimen that term implies in a modern gym, my circuit was along the flagstone path that ran around the outside of my house. Four hundred and twenty feet, more or less, approximately two hundred abbreviated paces, Emma always at my side. We would occasionally stop to inspect the flowerbeds or to allow Emma to playfully jump at a meandering butterfly. If a car drove down our little lane, she would fiercely bark and charge, stopping just short of the Invisible Fence that ran around the perimeter of our property. Every day this scene was repeated, me counting my steps, Emma playing the part of the Palace Guard.

I would hold court back there on the patio. Although those June weeks were basically long stretches of boredom, the visit of a friend would serve to dispel any accumulated gloom. I would rise to the occasion, believing the friends who told me how good I looked despite my having lost nearly 20% of my body weight and almost all of my muscle mass. I had, in fact, never had that much excess weight to spare. Therefore, losing almost forty pounds was devastating. My butt had literally disappeared. I couldn't even stand to sit on the thatch seat kitchen chairs without a cushion under me.

This was a tough time. I didn't have an appetite. Not even the Little Debbies were palatable. My strangely altered sense of taste only permitted me to eat chicken tenders

and microwave chicken and beef flautas – and these only in small amounts. My craving for the Little Debbie's was replaced by a penchant for Famous Amos vanilla crème cookies. I went through a package of these every few days. I kept losing weight. I was really worried about what would happen to me once the chemotherapy started up again.

In retrospect, I think part of the problem was the ileostomy. Whatever nutritional extraction that normally took place in the large bowel was obviously not happening. It seemed that whatever small amount of food I was able to consume was rapidly passed out into the bag as brown goop. Sometimes it was liquefied; sometimes it was more like oatmeal in consistency. The surgeon had told me that this was tied to what I was eating, and the effect it had on my digestion. I don't know. There never seemed to be any rhyme or reason to the way it came out. I just learned that the more watery it was, the more careful I had to be when emptying out the bag. [Hint: if your pants are down around your ankles when you are on the pot, tuck your feet way back against the base of the toilet. It will save your trousers from any backsplash.]

Like I said, I always rose to the occasion whenever a visitor came a calling. My true friend Andy was particularly good at calling and coming by to check up on me. The same can be said for Mark, who knew all about the tedium of recuperation from major surgery. Unfortunately, his experience occurred before we met, so I didn't have the opportunity of helping him through his difficult stretch. Also, unlike me, he didn't have a strong support group of family and friends. It was heart-rending to hear him talk of having to place an ad in the paper for convalescent company.

This reminds me of an important point. It is critical for you to have someone with you when leaving intensive care for your hospital room. Even if you are fortunate enough to be able to afford a private duty nurse for the first several days after surgery, nothing can take the place of a concerned friend or family member to watch your back for you. I have heard innumerable horror stories about incorrect medication, unnoticed bleeding, unsanitary conditions, and patient disorientation, even in the finest medical centers. Almost all of these disasters would have been preventable if someone had been around with their eyes open. Don't think you can handle it alone. The effects of general anesthesia take awhile to wear off, you're under the influence of pain medication, you're in a strange place, and your wake-sleep cycle is thrown out of whack. There's no way you are in control.

Anyway, back to Mark. He was one of the only friends I had who had actually experienced the lingering effects of multiple major surgeries. I'd have to say that he came the closest to being able to convey to me the psychological as well as the physical demands that are foisted upon a patient. I had so many questions for him, which he answered as best as he could. But time is the rival of painful memories. Mercifully for him, Mark couldn't remember all that he had suffered through and how he dealt with his

darkest moments. That's why I'm thankful for this opportunity of writing this all down for you, before I forget.

Another favorite visitor was my gal pal, Holly. She took me down to the C & O Canal towpath that runs parallel to the Potomac River. After three weeks, I had made the transition from circling my house and accompanied my wife on a few short walks along the towpath, she jogging ahead for a mile or so and then jogging back to me as I slowly moved along. Holly and I walked for a longer time than I had previously accomplished, stopping frequently to sit on a log and rest. I was able to confide in her just how fragile I was feeling. We covered a lot of interesting subjects, mainly talking about relationships. I like talking to certain women, and Holly was one of those. My wife was just too close to the whole situation, dealing with my myriad problems on a day-by-day basis. Her response to my whining was a dismissive, "Cowboy up!"

I needed a fresh female perspective. Although Holly was certainly not one to coddle, at least I received a small measure of sympathy. But hanging out with a woman discussing interpersonal relationships was uncharacteristic for me. In fact, when I was in law school, I got dumped by a girlfriend for not being interested in talking about feelings and relationships. Even though I didn't perceive it at the time, this was a not so subtle hint that I was changing. If you had known me B.C., this would have shocked you. It's not that I ever had any problem having relationships of varying kinds with women (after all, I was married almost 20 years then), it's just that I had never enjoyed talking about them. Even more amazing, is that later in the summer when my wife and the kids went to England without me, Holly, my brother, and I went to see the movie, *The Dao of Steve*. This was an entire film about a guy who had problems with relationships. And I actually enjoyed it!

In early July, another woman friend came down from New York for a two-day visit. Laurie actually lived in Istanbul, Turkey with her husband, Metin, and two young sons. I had met her there while working on the acquisition of land for a new consulate. Despite the geographical differences, we had a lot of interests in common and had forged a strong friendship over several trips I had taken to that city. Her parents lived on Long Island, and she came for an extended visit every summer with the two little boys. It was really special that she took the time to fly down to Washington to see how I was getting by.

Among other things, Laurie and I also went down to the towpath for a walk. We entered at Great Falls Park, a beautifully scenic stretch of the Potomac River, with walkways and bridges over the rapids. It was a wonderful, albeit strenuous, day for me. We also talked about relationships and spiritual subjects, interspersed with real estate deals and projects in the red hot Istanbul property market. I suppose there is always some emotional component to a land deal that can be appreciated in its aftermath.

As the hot and humid days of July slowly passed, I knew I had a date with the oncologist approaching. I was scheduled to begin another regimen of chemotherapy on the six-week anniversary of my surgery. This time, the chemo was to be infused through the MediPort just once a week, during a three-hour appointment in a Georgetown Hospital outpatient clinic. I was apprehensive about starting this course of treatment, because I was still suffering from constant nausea and a limited appetite. I thought I knew what to expect, and it wasn't good. I had been struggling with various types of anti-nausea drugs, including one called Kytril that cost nearly \$100 per dose. Nothing seemed to be working all that effectively. Nothing could have prepared me for what was to come.

## *Major Meltdown*

For a number of reasons I elected to have my chemotherapy at an outpatient clinic of Georgetown Hospital that was located in the Ballston section of Arlington. This decision had been made back when I was in heavy denial that fighting cancer was anything that would require my full strength and concentration. Since this facility was only about ten minutes from my office, I had innocently believed that I could go to work, get infused with chemo, and then return to work. Hah!

As I learned more about the whole chemo program, I became glad that I had chosen the Arlington location, anyway. It was a smaller, more comfortable, and less institutional setting in which to spend over three hours once a week. My Oncologist, Dr. Rizzo, was there nearly every day. The nurses, Susie and Mary, blended a mixture of compassion and professionalism that made the best of a bad situation. Six reclining chairs were scattered about the room, each paired with an IV stand. Patients were reading or dozing, connected to drip lines that ran between their bodies and the chemo bags.

Some people came alone, others with friends or families to keep them company. My wife was my usual companion, except for five or six times that my dad did the chemo duty. I quickly figured out that the place to be was not in a chair, but rather in a sectioned-off treatment room that sported a bed and a door that could be closed for privacy. I don't know about you, but unless I'm watching a helluva good movie or an exciting ballgame, three hours is an unbearably long time to sit in a chair – even if it does recline.

Before I had the opportunity to make the move from chair to bed though, I had the major meltdown that I mentioned earlier. I had received one treatment of the chemo, and a day or two had passed without too much excitement. But then I started feeling really awful. My stomach ached, the nausea increased exponentially, and I started twitching like crazy. I felt like I was literally jumping out of my skin.

I called my Oncologist, and she arranged an emergency appointment with a Gastroenterologist. My wife loaded me into her car and sped over to the doctor's office in Fairfax. People shrank back from me in the waiting room; I must have looked like the walking dead. The doctor took one look and called over to have me admitted to Georgetown Hospital. He couldn't say *what* was wrong, just that something definitely *was* wrong. So it was back in the car for the trip over to the hospital.

In the admitting office, we were told that a room would not be ready for several hours and we might as well go home and wait for a telephone call. Upon hearing that, I actually lay down on the floor and curled into a fetal ball, saying that I wasn't leaving. I was twitching and shaking uncontrollably, with a few well-timed moans thrown in for

good measure. I was sicker than I had ever been in my life. Within twenty minutes, I was taken in a wheelchair to a private room on the internal medicine floor.

The room wasn't as well decorated as the wood paneled Duke Hospital digs, but I was in no shape to complain. It had a window that looked out at another wall of the red brick building and from my vantage point on the bed I could see a patch of sky; the same basic view as from the Duke room, but with different masonry. It was about half the size of the Duke room, so I obviously wouldn't be entertaining lavishly. It had your basic hospital issue television suspended from the ceiling that received about four channels, a private bathroom, one of those tray tables on wheels, and one visitor's chair. Everything was off-white.

For the next seven days I would undergo every medical test known to man, as the concerned staff endeavored to determine what was wrong with me. Sometimes these tests were administered during normal business hours, and I had to wait in crowded rooms with other patients from outside the hospital. At other times I was awakened in the wee hours long after midnight, and wheeled down empty corridors for scans and x-rays that were performed by young doctors and nurses working the night shift.

There was a constant parade of senior doctors, residents, interns, medical students, and nurses trooping into my room and asking me batteries of questions. This is one of the drawbacks to being a patient in a major teaching hospital. You become everyone's case study. I literally had to make a scorecard to keep track of all the doctors that would pay me daily visits. I was an enigma. It was easy to see that I was very sick, but it was proving extremely difficult to figure out why.

My parents came up to Washington to help with the kids while my wife would visit me in the hospital. Then they would switch, and my folks would replace her on Gary watch. A small television from home with a built-in VCR was brought in to my room. We watched whatever videos that could be found that I hadn't already seen. I remember one about a remote lagoon. Some young Americans had heard about it while travelling someplace in the Far East (Thailand?) and built a makeshift raft to journey to some island that was controlled by a tribe of drug farmers. It was like Gilligan's Island meets Lord of the Flies.

A few friends from work dropped by since the hospital was just across the river from my office. My devastated appearance probably scared them. This was one time that I couldn't rise to the occasion. My friend Mark stopped in, having learned my whereabouts from my wife when he had called the house to ask after me. Likewise my old polo buddy Jack, a stockbroker with an office in nearby Foggy Bottom. These days were a blur – long stretches of waiting interspersed with short periods of frenetic tests, studies, and consultations. Although the doctors still didn't know what was wrong with me, for some reason as the days dragged on I was getting better.

One of the first teams of doctors that paid me a visit was the Palliative Medicine Group. Remember my telling you about the doctor at Duke who reminded me of the Wizard of Oz? Well, this was Georgetown's answer to the Pain Team. Doctor Ursula, on temporary loan from a medical center in Germany became my personal pharmaceutical guru. She mapped out all the medication I had been on, listened to my complaints about nausea, pain, and fatigue, researched the side effects of the 5 FU with Luovorin chemo cocktail, and began to retool my medications. There was a single, extremely uncomfortable, misstep with something called Atavan (it made me bounce off the walls). Other than that, almost everything was replaced with something else that was more effective without side effects.

I was taken off the expensive and unproductive anti-nausea pills, and given older, tried and true medications called Phenergan and Reglan. The liquid and pills I had been taking for post-surgical pain were replaced with a single less powerful tablet. I was told to take a two-week break from chemotherapy to give everything a chance to settle down.

The thing to understand is that people react to different drugs differently, and the combination of different drugs, differently. So what combined to create Frankenstein's monster in me might be a panacea for you. Conversely, what finally worked out for me might be worthless for you. The moral of the story is that there are many choices available to the doctors that are caring for you. Don't be afraid to push them into fine-tuning your meds. I slowly began to emerge from the unbelievable physical discomfort to which I had been subjected. Unfortunately, I didn't know until several weeks later that this was only half of the battle.

## *You feel better now?*

Ever since my crash and resulting hospitalization at Georgetown, my parents had stayed in our house in Potomac and helped support my wife with her day-to-day responsibilities. One of the therapies recommended by Georgetown's Pain Team that I decided to try was acupuncture. Through my State Department Asian grapevine, I found a certified doctor of acupuncture that was located in Rockville, working out of her home. My father drove me over there twice per week for appointments that lasted approximately thirty minutes.

I was still in pretty bad shape. Due to the pain medication and the anti-nausea drugs (that made me sleepy) I wasn't allowed to drive. In fact, I hadn't been behind the wheel of a car for over two months. It was like being a kid again; always depending on an adult to take me wherever I needed to go. This lack of being in control had a greater effect on me than I was aware of. I definitely felt physically fragile and vulnerable, but I didn't realize that I was gradually taking on many of the characteristics of a child's psyche.

Leaving our shoes by the door and donning bedroom slippers that had been left for our use by the Chinese acupuncturist and her husband, we would make our way down to a basement rec room. Dad would bring along whatever spy novel he was currently digesting, and I would lie on a narrow table in the next room and have very thin needles pushed into critical points in my body. I had described my feeling of constant nausea and surgical site pain to the doctor, and she showed me a male anatomical chart that indicated all of the nerve junctures in the body that could be influenced by the acupuncture needles. I was surprised to see several needle sites located on and around the penis. I didn't even want to think about what those were for.

Triggering her index finger with her thumb, the acupuncturist would give me a little thwack, and then quickly slip the needle in the targeted site. A total of about forty needles were inserted, everywhere from my ears down to my feet. After she had pushed the needle in, she rotated it slightly until I felt a tingling sensation. It never really hurt. It was just...weird.

The doctor would then attach electrodes and wires to about a dozen of the needles. Electric current was turned on and gradually increased until I cried "Uncle". After getting really zapped a few times, I may have had her keep the voltage lower than that which I could really tolerate, but I wasn't taking any more chances. When we had the electric current adjusted to a compromised level, the lights were turned off and I had to lie absolutely still for about twenty minutes.

The doctor was a small, slim woman with deft hands and a compassionate expression on her face. After each treatment she would ask, "You feel better now?" with such sincerity

that I felt obliged to answer affirmatively no matter what. It took her scant seconds to pull all of the needles and wires out at the end of the allotted time.

While I would be lying there, my mouth would get incredibly dry. Once I tried having the doctor pour water from a plastic bottle into my mouth, but I ended up choking and sitting up reflexively. This had the unfortunate effect of causing the tiny electric wires to pull loose and make contact with other needles in my body.

The effect was immediate. My arms and legs started jerking like a spastic marionette until she was able to get me unplugged. So that wasn't such a great idea. In the future I would just bring a couple of Starburst hard fruit candies to suck on. The problem with that was I always felt that I might doze off and choke on the damn thing. Believe me when I tell you these minor annoyances took on major implications. I truly fretted about this choking potential.

And so another ritual was born: driving with my dad to the modest home in Rockville; taking off the shoes just inside the house; choosing a pair of slippers from the dozen or so pairs that were neatly arranged by the door; walking downstairs to the sparsely furnished basement; and laying down on the table while my old man read in the next room. I can't say that I relished these appointments, but I wanted to believe that they were helping me. And because they had risen to ritual status, I was loath to make any changes.

I actually went for twenty of these acupuncture treatments. Did they help assuage the pain and nausea? I can't honestly say, but by the end of the course of treatment I was definitely feeling better. You will remember that we had changed the medications I was taking after my Georgetown stay, so that must have had a lot to do with it. But the acupuncture may have helped as well. I can say unequivocally that they didn't hurt, except for the little episode with the loose wires.

.....

Shortly after the completion of the acupuncture my parents departed for their summer home in Vancouver, Canada. My daughter accompanied them to collect my niece, and then fly over the pole to England. This was a very special trip that both girls as well as their grandparents had really been looking forward to for almost a year. No matter how much of a basket case I was, they were going, and going with my blessings.

There was a logistical dilemma of how to get my daughter back to Washington when the trip was over with my parents and niece destined for Vancouver. My wife deciding to take our son, over to London for a week solved this. But then the issue of who would take care of me raised its head. I was very needy. I couldn't drive and couldn't stand to be left alone for a minute. I had become a very different person from the self-conceived legend that lived back in early February. I was not only vulnerable to a life threatening

disease that wasn't a result of my typically reckless behavior; I was feeling afraid without knowing why.

Now let's take time out for a reality check.

At this point in time, I had survived the major surgery with the cancerous lesion having been completely removed. The lymph nodes that were taken out along with a substantial length of the large bowel had tested negative for any metastasis. That means, as far as the pathologists could tell, there hadn't been spread of the disease. My blood tests were all normal – no indication of cancer anywhere else. When I was hospitalized in July at Georgetown, they had given me a CT scan with barium enema and iodine dye IV and hadn't found anything abnormal. All the other esoteric tests I had been subjected to came back negative for any cancer; or anything else unusual, for that matter. I was receiving weekly doses of cancer-killing chemo. Other than facing the second surgery to reconnect my ileum in September, I had nothing to be worried about in the immediate future.

I was, however, seriously underweight. The thirty eight pounds I had lost within a few weeks after the surgery were stubbornly refusing to return. My butt consisted of some sharp bones with skin stretched over them. No matter how padded the seat, it was uncomfortable to sit in one position for more than a few minutes. In fact, I was generally uncomfortable most of the time. This discomfort was probably twenty percent psychological, but that didn't make it any less real; the result being that I was still waiting. Waiting to feel better. And waiting for my fear to abate.

The fear I was experiencing was non-specific. Sure, there is always the possibility that the cancer could mysteriously reappear sometime, either in the next few years (some possibility) or much later in life (as it could with anyone), but I don't think that was it. I was afraid in general, like a seriously wimpy type of person – a panphobic, to coin a new term. So I was panicked at the thought of everyone leaving me high and dry.

Now you should be hearing rapidly approaching hoof beats. The cavalryman reins his horse, amidst a cloud of dust. The white steed rears skyward with a loud neigh. As the dust settles we can see the face of the pale rider. It's...it's....

Brother Bill!!!!!!!!!!!!!!!!!!!!!!

This time he rode to my rescue as sure as the Lone Ranger ever rescued a damsel in distress. Once again, I give thanks for my close and supportive family. It had been arranged that on the same day that my wife and son departed to rendezvous with our daughter and my parents in London, Bill would fly to Washington from Vancouver. But man, did I sweat those five and a half hours that I was alone with only Emma for company.

Bill is five years my junior. We were very different people. We still are, although in not so many ways as before. Bill was always the sensitive one; although he was often brash, selfish, outrageous, and materialistic – he was always sensitive. Although we share many of the same obnoxious characteristics, I have to admit, sensitivity wasn't one of my strong points. Over the last twenty five years, Bill has gone from being an over-age kid to acting as the official caretaker and manager of the family: both the business and the people. He works for our dad and handles all the day-to-day operations with aplomb. He is the ultimate combination valet and concierge for our parents, be they in Florida or Canada. Without having to question me or say a word, Bill understood what was going on inside of me. And he magically knew how to deal with it.

## *Reach for the rope*

Just after I received my diagnosis of colorectal cancer, I bumped into a long time acquaintance at the Starbucks in Potomac Village. I told Rick the truth when he automatically asked, “How are you?”

He told me that he was feeling a little low because his favorite cousin had just died from breast cancer. Being a psychologist, he was comfortable with his introspection on the subject, and had made the offhand remark that he would be pleased to sit down with me if and when I felt I needed someone to talk to. Nothing formal - just a receptive ear and some friendly advice. At the time, I hadn't given the matter much thought. I was still in the living legend mode, only beginning to get the hint that I was damaged goods. Plus, although I had taken several Psych courses in college, I was much more at home with analyzing the problems of anybody other than myself.

When I was in 7<sup>th</sup> Grade, I had read Freud's *General Introduction to Psychoanalysis*. This might sound intellectually impressive until you consider that my sole motivation was to gain popularity with some of the prettier but terminally spoiled girls in my class. After I had analyzed their problems I would confidently declare that everything was their parents' fault. This experience, as well as learning first-hand that some of my Psych profs at Duke were more deviant than the subjects of the cases we studied, gave me a jaundiced eye toward that profession. I had filed my friend's offer of help away in the back of my head, pretty much in the same category as holistic/alternative cancer treatments.

Within about five minutes of arriving that August, my sensitive brother Bill told me that I was acting depressed and should definitely be seeing a shrink to help me deal with my mortality issues. Initially, I recoiled at the thought. But after an aborted attempt to sit through a movie that fit my usual genre, I gave the suggestion some serious thought.

The day after Bill came to take over my care we went to see a new film at the Kentlands movie complex, a state of the art multiplex with stadium seating. The movie was a surrealistic tale about trying to save the victim of a serial killer by entering the psychopath's mind and learning where he had hidden her. I lasted about five minutes and then had to walk out. The colors were too exaggerated, the sound too loud, the cinematography too edgy – I just couldn't handle it. It was making me feel like I would jump out of my skin if I stayed another minute.

Not wanting to call the trip a total waste, we walked into another theatre showing a scene where an obese African-American woman sits down on a toilet and begins to let 'em rip. Pardon the pun, but it blew me right outta there. It was too....gross. The other movies in

the 8-plex cinema were either bloodier than the first or more stupid than the second. We had to leave.

Bill became really worried about me. I was acting even more sensitive than even he could be at his most absurd. My brother was witnessing a role reversal that he was unprepared for. All of our lives I had been the one to defend him, both physically and verbally. When we were little kids, I came upon an older boy repeatedly hitting Billy in the face. I threw the boy off of a small cliff. Miraculously, despite hitting his head on a rock at the bottom, he didn't die. Another time when we were riding the school bus together, a bigger kid had pounded on Billy and threatened to throw his shoes out the window. I pushed the kid's head out the window and ratcheted it closed, trapping his neck. The unfortunate bully had to ride all the way to school with his head stuck outside the bus.

When we lived in Colorado, I coerced Bill into climbing some of the 14,000' mountains with me. I always climbed in the lead and then protectively belayed him on the technical pitches. So imagine his shock at finding me so out of character. Now it was my turn to reach for the rope.

To Bill's credit, he managed to handle me with kid gloves, getting me home from the movie theatre and settled down with *My Fair Lady* on cable TV. Here's the clincher. At the end of the movie, when Dr. Higgins realizes that he's in love with Eliza Doolittle, I started crying! I was overcome by emotion. To this day, I can't believe that I had become such a blubbering idiot. Watching the tears roll down my cheeks as that old classic ended, Bill confronted me with my serious need for some outside guidance, I remembered Rick.

I called him at home, and we arranged to meet at a restaurant in nearby Chevy Chase. My brother would give me a ride over, and then leave to do some shopping. This was good neutral ground for me – I think I would have felt too weird to go to his office. We began our conversation talking about Rick's feelings over the death of his cousin. This was tough for both of us: him because he had truly loved her; me because it was hitting close to home. It was easy for me to imagine someone in my family sitting around with a pal talking about my death.

What emerged was an appreciation on my part that Rick could truly empathize as well as understand what I was feeling and going through. What may have been sacrificed in professional objectivity was more than made up for in candid conversation. We decided to continue our talks on a weekly basis whenever we could find mutually convenient times and venues. He understood how fragile I was feeling, and showed me the respect not to just deliver a bunch of clichés designed to make me feel better. He recognized that I wasn't the same guy he had been acquainted with for so many years, and assured me that we could work together to pull ourselves out of our respective funks.

Bill returned from his shopping spree and took me back in tow. He had telephoned my true friend Howard, the fellow who had flown out to the Mayo Clinic with me, and arranged for him to come over for dinner. Howard's wife and daughters were at the beach for the summer, and he spent the week in Washington running his advertising agency. This would be a cancer patient's version of boys' night out.

The combination of Bill and Howard did much for my sagging spirits. We grilled a medley of fish and meat on the patio and swapped lies; the two of them sampling a vast array of beers Bill had bought at the local liquor store and wine Howard had brought from his cellar. It was such a success in terms of improving my mood that Bill lined up dinner joint ventures with Scott and his wife Holly, as well as neighbors Beez and Angela.

These dinners were of much greater significance to me than you could imagine. I've explained how I was plagued with this constant feeling of waiting. Usually, I would just be waiting to feel better. The dinners gave me a goal to wait for. Being together with good friends who had known me B.C. was important because I didn't have to be "onstage". These were people that knew what I was all about; there was no need to try and impress them. If I felt like curling up for thirty minutes on a couch and not participating in the discussion, that was alright. If I felt like complaining about something, that was all right too. Since I didn't have an appetite, the dinners were not about food. They were about being with friends.

Maybe I'm just a particularly friend-oriented person, but frankly, I don't see how you can get through a cancer experience without friends. A close family helps enormously, but what makes the love from family members so wonderful, also it makes it stressful. Parents, spouses, children, – they all love you so much that they can't help but suffer right along with you. Sure, they're not actually feeling the surgical pain, nausea, fatigue, and digestive distress that you are going through. But family members that are around you day by day, minute by minute, are hurting from watching you hurt.

Since we've been talking about dinners, I'll give you a food analogy. Although it's difficult for family to understand, their suffering is like gravy on the mashed potatoes of pain you are experiencing.

Friends, on the other hand, may love you and sincerely care about how you are getting along. They may even be shocked and distressed at how awful you look. But generally, they will try to make the best of a bad situation, and after giving you all the opportunity you need to tell them how you are feeling, attempt to move things on to more positive subjects. They know how to distract you and help you have a good time, to the extent that is possible. Then, unlike immediate family, you each go back to your respective homes and you can feel that the pressure is off them.

Just so we're clear here, what I'm saying is that you need both. Family to help with the daily grind – all the little chores that you can't do by yourself and might feel uncomfortable imposing upon friends, no matter how close. Friends to help you escape from your present circumstances – to hear what's going on in the non-cancer world and let you feel like you're participating in your old life. Even if it's just a few hours every week, this escape becomes really important.

So what do you do if you don't have as wonderful an assemblage of friends and family as I've described? You manufacture it. You get involved with support groups. They exist for everything, including people with temporary ostomy bags. You ask your doctors if they know of any former patients who might be willing to help you along. You ask the people you work with if they know anyone who would be available to help you take care of yourself. You check the Internet for organizations that provide support to post-surgical and cancer patients. You put up notices on message boards seeking help or companionship. This is the time for serious networking. Don't be shy.

## *I still felt the funk*

Time slowly dragged on. Despite my informal therapy sessions with Rick, I still felt the funk. I wasn't putting on any weight. I still hadn't found my appetite. I still couldn't drive myself anywhere because I was on low doses of pain medication and the anti-nausea drugs made me a little sleepy. I had worked out an arrangement with my boss whereby I was able to engage in some work by telecommuting, but I sorely missed the human interaction of physically being in the office. I only now appreciate what a serious effect this isolation had on me. Having recently taken a Myers-Briggs Type Indicator, I learned that I am an off-the-charts extrovert. If you've ever had the opportunity to have your type determined by this method, you know what I mean. No wonder I was so down in the mouth.

I had a strange dream. I was inside a huge indoor arena. I was racing up and down the painted concrete ramps and hallways searching for a way back to my seat. I was desperate because I was missing the event I had come to watch. At one point, I approached the outside of a special tented area that had been set up to service a private party. I was offered some refreshment, but not allowed to pass through the tent to reach the interior of the arena. I left the restricted area and found myself climbing down a vertical steel ladder through a narrow concrete shaft. It ended several levels below ground to another series of long hallways.

I eventually came to a dark, cavernous room that was hosting an all-night rave party. House music was blaring: the beat strong and steady. I felt incredibly uncomfortable, not because I was older than the partygoers, but because I was so anxious about missing the event being staged in the main arena. I climbed back up the steel ladder and found myself outside in a vast parking lot without a car. It doesn't take a PhD in psychology to analyze this one. It was a REM stage representation of how I felt while awake.

Despite its rather transparent symbolism, Rick and I talked about this dream, as well as several others of particular note that I recalled. During our meetings, we covered a lot of ground; sometimes superficially, other times delving as deep as I felt comfortable with. He never pushed or pried. Sometimes he would give me a little nudge, though. Just enough to get me to confront an issue that he thought I shouldn't simply sweep under the cerebral rug.

It was a fine line that we walked. In fact we even talked about it. I wasn't your run of the mill patient with issues concerning parents, substance abuse, spousal problems, or other non-life-threatening subjects. I had started out as an overly confident, optimistic guy and was now a diametric opposite of my former self. Add to that the fact that I was feeling fragile as hell. So he therefore refrained from being as tough as he could have

been on me. Instead, Rick confirmed that I had every reason to feel depressed. This gave me reassurance and confidence. He would remind me that the combined fabric of the chemo and opiate-based drugs, the surgery, the fatigue, the pain, and the cloud of uncertainty about a reoccurrence of the disease made a heavy cloak to wear. It was fine that I was trying to work out these issues in my sleep through the employ of dreams, but I had to deal with this reality while conscious, too.

Hopefully, you can find a Rick type person you can talk to. Try to identify a trained professional who has some personal experience with cancer. Any kind of cancer experience will do, so long as it involved surgery and chemo. Then go see that person before you sink as low as I did. I still can't believe that I let things get so out of control for so long before I went to talk to Rick.

*This sure beats the alternative*

My wife returned with the kids from London, and we got them lined out for the new school year. Before I knew it, the time had come for me to return to Duke for the “reconnect surgery.” This was something I had been looking forward to with a mixture of excitement and dread. I certainly wouldn’t miss the ostomy bag. On the other hand, any surgery that requires general anesthesia isn’t something to be taken lightly.

Once again, my parents would be meeting me in Durham to help with all of the arrangements. Plans were made for my wife and the kids to come down over the weekend following the surgery. Everyone was telling me that this surgery was nothing. No pain, little discomfort, quick recovery, etc. I had my old room back in the Duke Hospital, and even some of the original nurses were on hand. This time, the preparations for surgery were simple – nothing to eat after midnight. For obvious reasons, I didn’t have to worry about purging my bowels and Fleet enemas. I had a strange feeling of déjà vu as I checked into the surgical center early in the morning on the day of the surgery.

The next thing I knew I was waking up in the hospital room. But wait a minute. I was in pain. That wasn’t supposed to happen, because we had employed the epidural procedure again. Unfortunately, as I learned from the Anesthesiologist, epidurals aren’t effective 100% of the time. Apparently, this one had slipped out, and because of some anti-coagulant that had been administered, they were afraid to reinsert the catheter. So I had to cowboy-up and tough it out. I had one of those morphine buttons, but trust me it wasn’t nearly as effective as an epidural would have been.

I was kept on a liquid and soft diet for a couple of days. My first trip to the bathroom was almost anticlimactic. As I had been warned, there was some blood, but otherwise, nothing surprising. The surgeon had also advised me that it would take between a year and eighteen months for things to return to normal. I wasn’t quite sure what that meant, but I would soon find out.

I was in the hospital for five days and four nights before I just had to escape. Once again, I met with the Pain Team, and the Wizard of Oz reviewed the medications that I would be leaving with. I beat a hasty retreat for the Wash-Duke and settled into my old room there with my family. Although the pain was considerably greater at first than I had experienced immediately after the original surgery, it quickly abated having been brought under control with Dilaudid. I had learned the hard way to stay away from the twin harpies Oxycontin and Roxycondon. The Wizard had advised me to keep the pain medication to a minimum, since it had a constipating effect. It took me a while to figure out the significance of this instruction.

What ensued for the next few months was a maddening metronome swing of constipation to diarrhea. I remember lying around the house watching the Olympics from morning to night, alternatively suffering from one or the other. I was damned if I did and damned if I didn't. Going to the bathroom became an ordeal. Often I would be up and down for two hours and seven or eight trips before everything was moved out. And when I was finally finished, my rectum felt like an army had marched through it. It hurt so badly that I couldn't stand or walk without taking some Dilaudid. But that started the constipation again. One minute I was swilling Paragoric to stop the cramps, the next I was swallowing Senekot to get things started.

My greatest fear was that I would mess in my pants. I was afraid to go anywhere there wasn't a bathroom within a few seconds walk. This was awful. Everywhere I went I made sure that I had a spare pair of underwear, a bottle of Paragoric, and four tablets of Imodium. I almost started to believe the message of that colostomy video. This was a problem that was to continue for many months after the surgery had faded from my memory. I had to keep reminding myself, "This sure beats the alternative."

Three weeks after I returned home, the chemotherapy started up again. Fortunately, this time I didn't knock me for such a loop. I also didn't have the same problems as before with nausea because I was already taking Phenergan and Reglan. Slowly but surely I started putting on some weight. As the surgical wound began to heal, I started light exercise with my friend Scott. But when it comes to colon cancer, nothing comes easy. I was to undergo two six-week courses of chemo with a two-week break in between. I found that the further along I got in the regimen, the more I had a feeling like a wet blanket had been thrown over my brain. I wasn't depressed or dopey, I was just...cloudy. It was akin to the feeling of seeing the world through goggles. Some unseen force was restricting my cerebral equivalent of peripheral vision. I wasn't really able to perceive this until about a month after I was finished with all of the chemotherapy. It took that long for it to begin to dissipate from my body.

Time dragged slowly along. My wife chaperoned me to the chemo sessions at the Georgetown outpatient clinic. It was excruciatingly boring for both of us. She would work on her photo albums while I would try to sleep. I began to go into the office a few days a week. My co-workers were surprised to see me up and about. You'll know what I mean when I say you get tired of people asking how you are doing.

The good thing about the passage of time is that it truly does heal all wounds. Eventually I was able to cut out the painkillers and resume driving. I began driving myself to see Rick wherever we decided to meet.

At first, each trip involved meticulous planning and timing with bathroom visits. Later, as I gained more comfort with my intestines' schedule (such as it was) I didn't angst as

much over each journey. What initially seemed like major expeditions gradually resolved into mere jaunts. As my bowels began to resolve themselves – the pendulum swings growing less extreme - my mood began to improve. I began looking forward to a trip we had planned nearly a year ago with my extended family to Cancun, Mexico. This was a vacation I seriously didn't think I would make only months before.

Due to this trip to Cancun, I was looking at either taking a two-week break from the last course of chemo, or simply bailing out on the last couple of infusions. I consulted with both my Oncologist and my surgeon and all agreed I could forego the last two treatments.

Besides the ongoing issue with bowel movements, there was a nagging infection at the site of the second surgery. Both my Oncologist and my friend, Csaba, had cultured the thing and had confirmed that it was due to a staph infection. I learned that this type of infection is endemic to virtually all hospitals, so I had probably been carrying it around since the second surgery in September. Csaba tried repeatedly to clear it up with anti-bacterial creams and finally by re-opening and cleaning the former stoma site. He eventually found the culprit. It was a suture that hadn't dissolved from the second surgery. He cut it out, cauterized the wound, and advised me that while it would be fine to swim in the ocean, I should avoid the pool.

The Christmas weather in Cancun was less than optimal for a tropical vacation. Nevertheless, it was far better on the Yucatan peninsula than back in Washington, so complaints were kept to a minimum. My brother and I even managed to get a morning of scuba diving in. Although we signed up for two dives, I was only able to complete one tank. And I managed to consume that in nearly twenty five percent less time than under normal conditions. But it was wonderful. The water was warmer than the air, the aquatic life abundant, the current not too strong, and the seas were fairly calm. I felt tired at the completion of the dive, but satisfied that here it was only a little over three months from my second surgery and I was swimming around fifty feet under the blue-green waters of the Gulf of Mexico.

I returned from Cancun and resumed work on a full-time basis. I was assigned a new portfolio of diplomatic missions that included some of my original Southern European posts, as well as Scandinavia and Iceland. Some changes had occurred in the way tasks were assigned and we would eventually also receive a new Director who would alter the culture of our Bureau in fundamental ways. I was a changed person, as well. Instead of working my usual ten or eleven hour days, I made a concerted effort to leave the office as close to 5:00 as possible so I could have dinner with my kids before they started their homework.

This would be a wonderful point at which to end this story. I was cancer free, it having been so determined from a CT scan, an exam by my surgeon, and blood tests. I had enjoyed a wonderful vacation with my family, and I was happily back at work.

Unfortunately, there was a strange bulge in my abdomen, about 1 ½ inches above my navel and about three inches wide. I went back down to Duke to have the surgeon take a look. Hernia, he said. The abdominal wall had pulled apart along the incision line and my intestines were pressing through the hole. Apparently, this was not uncommon.

I went to a local surgeon at Sibley Memorial Hospital in Washington. He confirmed the Duke surgeon's diagnosis and we discussed my options. Both doctors said that it would be okay to take a couple of previously planned ski trips to Colorado with my kids, but not to delay the repair surgery for too long. I was told that this would be fairly major surgery: somewhere between my two earlier surgeries in severity. This was a terrible cloud to have hanging over me.

## *Subcutaneous shining armor*

The day of my scheduled hernia repair surgery arrived. Dr. Gray, Chief of Surgery at Sibley Memorial - a local area hospital with a stellar reputation, would perform the operation. My parents, having previously scheduled a trip to Washington this particular week to see the grandchildren, easily transitioned into "son-in-hospital mode." I was admitted early on a Friday morning and the operation was expected to take approximately 1 ½ hours. I wasn't scared, just appropriately apprehensive. My concern was over pain, more than anything else. I was now a veteran of abdominal incisions. I knew what to expect when it came to post-surgical sneezing, coughing, laughing, or even rolling over in bed.

I had been advised by the surgeon that a piece of carbon fiber mesh would be installed to act as a base for reattachment of the weakened tissue and muscle. I somehow developed this mental image of high-tech chain mail girding my abdomen. Like a modern-day knight with subcutaneous shining armor I should be stronger than ever, able to crunch out hundreds of sit-ups without rest, right?

Wrong. Unfortunately things are never quite good as new when it comes to the human body. The last thing I remember before succumbing to unconsciousness was a quip from Dr. Beauregard the anesthesiologist (my friend Scott's next door neighbor) that our mutual friend would now and forever best me in heavy lifting.

The next thing I knew, I was awake and chatting with complete lucidity in the recovery room. This was amazing: no post-anesthesia fog or nausea. Dr. Beauregard had done an excellent job. He had managed to knock me out for over an hour's worth of surgery, and then gently pulled me back into consciousness without the slightest hiccup. With a seven inch incision running between my belly button and sternum, even the thought of a dry heave was enough to send shivers down my spine. I clearly remember a smooth ride up to a hospital room and transfer to a regular hospital bed.

Dr. Beauregard and I had decided to roll the dice again with inserting an epidural to control post-operative pain. As with the second Duke surgery, this time it wasn't effective, either. I suppose every instance with an epidural can be different. A continuous infusion of pain medication was supposed to be administered via the epidural. The push button operated pain control device (called a "PCA" by hospital staff) was likewise connected to the epidural catheter. Great care had to be taken with respect to the insertion of the epidural because of the obvious danger of having the pain medication misrouted to my lungs and diaphragm.

Unfortunately, the bulk of the medications went directly to my perfectly sound left thigh. My abdomen, unfortunately, felt like it had just been sliced open and stapled up. (No surprise there.) The more I pressed that little PCA button in an attempt to assuage the pain in my stomach, the number my left leg became. The worst was getting in and out of bed; something the medical staff requires the day after surgery. I remember getting stuck in a position half in, half out of the bed. The pain was incredible whichever way I moved, so I simply froze in place. My nurse, frightened by my grimaces and groans, was likewise petrified. Finally a nurse more prone to decisive action than the woman who had been attending me, came in from the hall, grabbed my ankles and flipped them up onto the mattress. The relief was instantaneous.

We finally gave up on this futile exercise and switched to oral pain meds. The effect of the change was remarkable.

What didn't surprise me this time around were constant visits from my friend Dr. Csaba Magassy, as well as his wife and children. Not only had Csaba recommended both my surgeon and Sibley Memorial, his mother was then currently a patient in a room across the hall from me. I became a third party beneficiary of this wonderful family's devotion to their matriarch.

I was recovering remarkably well and was able to return home that Sunday afternoon. Moving in slow motion, I carefully ascended the curved staircase to the second level of our home and lowered myself into bed. For the next several days it was a *déjà vu* of watching endless movies and drifting on and off into a light doze. Except this time, there were no Olympics to help pass the time. Only Michael and Julia, my precious children were there to provide the best entertainment of all. It was probably a good time for them as well, since for the duration of my recuperation the "fighting and biting" was kept at a minimum by the siblings. I especially enjoyed their competition to see who could be the most compassionate and helpful to the wounded dad. Even though I knew that they were getting really tired of seeing me so weak, and were constantly worried about why I had to keep returning to the hospital for surgery, they were so brave and inspiring for me. The good news was they made me laugh a lot. The bad news was that they made me laugh a lot – laughing really hurt my incision area. But it was a good hurt, so that was ok with me.

"Dad," my son asked before going to bed one night during the week following the hernia surgery, "can I see the operation?"

I pulled up my shirt for him to see.

"Whoa! Dad! It looks like you've got a zipper up your stomach!" he exclaimed.

Were that it was so. With twenty silver staples running in a line from naval to sternum it did look grotesquely like a zipper.

The oral pain medication was very effective, but I dreaded becoming dependant upon it. I was acutely aware of the possibility of experiencing an onslaught of depression. These drugs are incredibly dangerous, and their allure insidious. I can see how people become easily so addicted to them. Nasty, nasty, things. Both the surgeon and the anesthesiologist had warned me to be wary of the symptoms. After last summer's debacle with my pharmacopoeia, I was leery of becoming over-medicated. Since I had already experienced so much abdominal pain, I concentrated on differentiating between the uncomfortable feeling of tightness in the area of the surgery and actual pain. For it felt like I had a steel girdle under my skin, laced very tightly with unyielding wire. Occasionally, pure unadulterated pain would slice through this tightness like a scalpel. That was the only feeling I allowed myself to medicate against. I measured success as a 12-hour period without taking a pill for pain.

That Friday, exactly a week after the surgery, Dr. Gray removed the staples. Now the passage of time would heal this hopefully last intrusion into my body. My pelt of fur would doubtlessly grow back, covering the ragged scar from three surgeries. That, as well as the tightness in my abdomen from the fiber mesh, and the small pucker of a scar from the temporary ileostomy, would be the only physical reminders of more than a year spent in hell.

My anger towards the first and second internists hasn't dissipated. I will never excuse them for their lack of caring or their incompetence. And although I may feel some sympathy for the first internist and his battle with Alzheimer's disease, I have nothing but contempt for his successor who repeatedly misdiagnosed my colorectal cancer and gave me such a hard time about wanting a colonoscopy. His failure to communicate with me in any way after I received the cancer diagnosis, even just to express his concern for my survival is inexcusable. He is a pitiful excuse for a doctor.

Rather than spending my time in the rather negative pursuit of some type of revenge, I revel in the precious details of my life. I really looked at my children - as if trying to fix their appearances and personalities as they were right then, forever in my mind. My son's sweaty boy smell and flushed cheeks in the aftermath of a winning soccer game. My daughter's ear-to-ear smile as she playfully shocks a friend with her monkey-tail skink balanced on her head.

Frequently, when engaged in a family activity, I find myself channeling the experience through all five senses as if to create a reality-gram for my memory. I learned the hard way about the value of having a full mental scrapbook of pleasurable experiences that can be recalled in great detail. This is a most effective method for dealing with pain, and I always want to have a well stocked selection should the need ever arise again.

I see my friends in a whole new light. My true friends who gave so much of themselves and were along for this gruesome roller coaster ride, my colleagues at work who were so supportive, and my worldwide array of acquaintances that checked in to provide encouragement and laughs. They have taught me much about what it means to be a friend. Friendship requires some level of constant attention and responsibility. These aspects can be ratcheted up or down depending on the circumstances surrounding the relationship at any given stage, but the participants should always be sensitive to the needs of each other as they move through their respective lives. You can't be a true friend to everyone with whom you are acquainted, the commitment is simply too great. But you can be a kind of a personal SWAT team to any level of friend, ready to mobilize if and when the need arises. You can always tailor the response to the degree of intimacy you're comfortable with.

I am told that with each year that passes without reoccurrence, my prognosis for survival improves. I will have to closely monitor my colon and related areas for signs of cancer, be they polyps, changes in blood counts, or other indicia. It's akin to going through life like you've betrayed a member of the mafia - always looking over your shoulder. But instead of wasting too much energy worrying about what could happen, I've chosen to take a more positive path. One that focuses on the gifts life has provided me with, taking pleasure in my family and friends, looking for ways I can be of help to others who receive this frightening diagnosis, and smelling every single rose along the way.

© Gary S. Lachman 2001