

That's Not What I Expected – Cancer, Chemo and Surgery

Sitting across from the urologist, my wife, Gwen, and I listened as he said “you’ve got cancer”. This was the meeting to review the latest in a series of test results because I thought I was dealing with a kidney stone.

I said I feel great and asked what that means if I don’t do anything. He said “you’ll die”. So much for the bedside manner.

That meeting started a journey that no one ever wants to take. And while life is full of choices, in this case, you are not given a choice. You must find a way to get through it.

After many consultations with the urologist and the oncologist and their attendant nurses plus the ETs, I faced the first of many choices. What is the best approach to get rid of this vile disease? And how am I going to live normally with a major change to my plumbing?

It was evident that the experts recommended chemo before the surgery and then the removal of the bladder and possibly two other organs, prostate and urethra, depending on how far the cancer had spread.

My first visit to CancerCare featured the soon to be typical registration and waiting process. Once in the comfy chair the entire chemotherapy process was described. I have given blood some 37 times so the needles didn’t bother me. And I got all the water, juice and coffee/tea that I wanted...with table (or chair, as it were) service!

After nearly 7 hours I was able to leave. My wife picked me up as we were not sure what shape I was going to be in after treatment. For some reason I had minimal side effects. In fact, after the second treatment the following week I could drive myself to treatment and back home.

Three full cycles provides a lot of time for reflection. I met some very interesting people and we had lively discussions. One of the chemotherapy nurses worked for me in a previous role, and we had a glorious time catching up on how much the kids had grown and what they were doing now.

As well as I did on chemo (gained 20 pounds) my heart broke watching the children endure the treatments. I believed I had lived a great life so far, but for these youngsters that haven’t even seen their 16th birthday yet, well that tears you apart. There is not much you can do other than support them and maybe make them smile. Forget the “tough football player” image where he still plays with a twisted knee or some other ailment. These kids are the truly tough ones that are in a battle for their life.

And I also had weekly, or more frequent, meetings with the doctors and nurses. The focus and professionalism was outstanding. I really felt like they had my best interests at heart. And they answered all my questions. They even laughed at my corny “old man humour (as my sons call it).

And for 10 weeks of treatment, the clock kept ticking towards the surgery.

I never had surgery before. In fact, even with sprains, slight tears, concussions and assorted bumps and bruises from many years of football and rugby, I had never been in the hospital overnight. Let alone have surgery that required a two week recovery period. I knew I wasn't looking forward to hospital food.

Throughout this process leading up to the surgery I told no one about my diagnosis. I am a Certified Management Consultant and none of my clients knew what I was going through because I wasn't impacted by the disease or the treatments. Our two sons were at university in Bismarck, North Dakota. The oldest was a junior and the youngest was a freshman. I didn't want them to worry from over 600 KM away.

I was also coaching with the University of Manitoba Bisons football team and it was the first season in the Investors Group Field. I knew that if anyone was aware of my situation all I would get at practice every day was "how are you doing coach?" I didn't want to be a distraction to the excitement the team was generating.

And this was hard for me because generally I enjoy being the center of attention and have never met a microphone or stage I didn't like!

For some reason I didn't want to let people in on my situation. Other than the medical professionals and my wife no one knew. We didn't tell our sons until two weeks before the surgery. And I didn't tell my friends until after the surgery when Gwen sent an email I wrote before the surgery. You know, just in case...

After the surgery, the urologist visited me almost every day. What was a very matter of fact and non-emotional approach during the treatment and preparation period turned into a wonderful relationship. He was still very candid, which I always appreciated, and yet we spoke like old friends as we discussed football, hockey and dogs. He did have a wonderful bedside manner after all.

I was keen to get up and get moving as soon as possible. This turned out to be harder than I thought. With the encouragement of the nurses, I was walking regularly around the ward and visiting with people at other stations as much as I was allowed to leave my room.

I wanted to get out of the hospital clothes as soon as possible. I had my "Operation" game and "I've got gas" sleeping pants that certainly caused a few double takes as I strolled the corridors.

The food? Let's just say it wasn't close to home cooked or even a one star restaurant. Although this was good for me as I needed to drop some weight.

Visits from friends and families were most welcome. What made me feel the best was the fact that everyone said I looked the same. And you need to know that my family and close friends are very honest about this.

Gwen visited every day during a winter of extreme cold and severe wind chill. It was a minimum 45 minute drive each way every day. She was there for my first lesson on how to

change the ostomy bag and it was pretty funny. You see, I also think I don't have to read instructions. In this case I am glad I listened to the ET. With some practice I was able to do it myself in pretty short order. I needed to be independent. I just don't want to have to rely on someone more than I believe I have to.

I was off the pain killers in short order, too. Not because I was trying to be a tough guy, but because I had no pain. This relatively quick recovery allowed me to leave the hospital a day early. Oh happy day! Until I stepped outside into the minus 30+ wind chill. It almost made me want to crawl back into my hospital bed. I said "almost".

And my dear wife asked what I wanted for my first meal back. She makes terrific spaghetti and the sauce and meatballs did not disappoint! After a lovely meal I went for a nap. It was great to be home.

Next issue, I'll tell you about the past three years and living as a new ostomate.

Life as an Ostomate – Finding my New Way

The first night in my own bed after two weeks in the hospital was absolute heaven. It is a good thing I sleep on my back because I was connected to my night drainage system, and I didn't have to worry about rolling around and getting the hose tangled.

I did learn about one important and unforeseen positive side effect. I went to sleep and didn't have to wake up at all to go to the bathroom. This must be too good to be true so I had to investigate further on night two. A couple of glasses of water before bed and, yep, slept right through.

This revelation was part of my "new normal". I began to learn more about what changes in lifestyle and regular activities I would have to make to manage life with my appliance.

Courage is important when you are facing a challenge. I learned this from the start of my journey with the initial cancer diagnosis. Building a personal level of mental and physical toughness is more than winning a bar fight. This is a different fight and definitely not a fair fight.

I learned quickly that I would not be exactly the same person leading the same life as I did prior to the surgery. While I needed courage to face the situation and demonstrate some "toughness" I was baffled at a situation where I could not defeat the foe without major changes in the day to day business and habits of being "me."

The real test would be the impact on my psyche. And I had some searching and thinking to do about this aspect of life. I had seen my parents and several aunts and uncles fight cancer, with

most of them eventually losing the battle. My Mom survived for a few decades after breast cancer and resulting double mastectomy. My Dad had three different cancers before the third took him. Both parents lived into their 80s. Considering their struggles in light of my own revealed their quiet toughness and resilience in the face of the daily challenges these life saving interventions throw at us.

I felt really good during my first week home. Our sons would be home soon from University in the U.S. for Christmas break and I wanted them to see that I was OK. And really I was.

I dropped 24 pounds in the hospital. Now that is a diet plan – hospital food!

My pants fit again. Well, almost. Now that I had my urostomy pouch I had to be careful about how tight my pants were and how much liquid could be held. Determining how pants, shirts and suits fit and looked were all part of the learning experience. As a result, I wore sweats a lot when I was at home.

One tremendous benefit we receive in our health care system is home care. The professional nurses that visit to see how we are managing are courteous and respectful while they help you learn to live in your drastically altered physical state. They were knowledgeable and really worked hard to get to know me, my lifestyle and how I live. While this home care situation was new for me, my wife would say (correctly) that she has been providing home care to me for the 27 plus years we've been married. I digress...

The home care nurses knew what to look for as I got more and more comfortable at home. They showed me better ways to apply the seal to the pouch. And provided tips on getting out into the real world. Their care and genuine interest caused me to be very mindful of everything I did and needed to know. I wanted to be as independent and “normal” as possible. I always had a list of questions for their next visit.

I was never in a hospital overnight in my life before this. And to now have a nurse visiting a couple of times each week to check on me was a bit unnerving at first. I wasn't used to being an invalid.

Poor Tim.

Enough! I wasn't about to let this keep me down. I needed to rethink my approach and determine how I could become “old Tim” in the “new Tim” body.

The key would be resilience. The dictionary definition is that an object returns to its original shape. Like a ball when it bounces.

Humans do not return to their original physical shape after this type of event. However, new Tim's body still contained old Tim's spirit. We have to adjust the way we get through every day and that puts our emotional and spiritual lives through the wringer as well. Moving forward meant constantly remembering: It is not what happens to us. It is how we react to the event.

A good friend asked how I kept a positive attitude. I responded that I had two options. One, curl up in the corner and think life is over. Two, get fired up and back at living. I chose door

number 2. There were many moments where door number one was a tempting choice. Both doors create self-feeding loops of positive or negative energy or spirit or whatever you choose to believe in.

I joke about getting kicked out of CancerCare. My oncologist was a terrific doctor and was so pleased with my recovery that in short order after getting home he said he needed the space for really sick people and that my regular doctor and the surgeon would take over from there. I was grateful for his sense of humour and his expert advice.

I believe that everyone has a story and their own challenges to face. Courage helps prepare you to meet these challenges. Resilience helps you return to a good state so you can keep on moving forward.

It was a happy and sad day when the home care nurses said I didn't need them anymore. We had a friendship that was very important to my overall recovery. And their advice and guidance were extremely helpful.

I learned how to accommodate my new body and carry on as old Tim. I had created a little emergency backpack that I took with me when I went anywhere. Even when I had a business meeting, I wanted to be prepared in case of an accident.

Yes, I had a couple of wardrobe malfunctions in business meetings. Fortunately, in both cases, my clients knew about my surgery and ostomy and we were able to maneuver around the leakage. It actually became a bit of a joke, and in hindsight, it was kind of funny. The other people in the meetings never knew what happened.

The worst part of the early recovery period was that I developed a blood clot. Man, that was painful, inconvenient and a real nuisance. I needed to give blood three times a week to get the correct blood thinner dosage to balance my INR. Not fun but it sure worked and six months later I was clear.

Back to my new normal.

I had started to get busy in my management consulting practice and this was another test to see how I would manage working with this appliance. Other than those two malfunctions, I was getting the hang of it.

I had to use a dryer in the morning to dry my bag completely. I had to empty before meetings, at every break and when I left. I made more daily pit stops than a driver at the Indy 500.

Everybody is different. I am a big person and enjoy eating. I have to be mindful of portion size and amount of liquid to balance my bag capacity. The extra time in the morning, during the day and at night means my time management has had to improve dramatically.

I was known for being chronically late for most of my life. I have to be more aware now about early preparations in order to be on time. Thankfully, my wife can snap me into reality better than anyone. She reminds me, correctly, that it has to do with respecting the person(s) I am going to meet. Be on time!

Live and learn...live and learn... live and learn...

Part 3 in this story will be up to the present time, everything I have learned in the past three years and how I joined the Winnipeg Ostomy Association.

The final chapter in my story, not my life

We had to say good bye to our golden retriever of almost fourteen years, Trax, shortly after I was diagnosed with cancer. This may help you understand why I didn't want to tell our sons, Tylar and Turnar, about my diagnosis. They needed proper time to grieve about their hairy brother that grew up with them. They did not need to worry about their Dad, too.

Fast forward to the spring of 2014, six months after my surgery and we got our new dog, Trappar. In my mind he was a therapy dog for an important reason. I knew I had to walk him at least twice a day given the energy that goldens have. This would help make me more conscious of my physical condition since we were well past surgery.

Yes, this was like having a young child again. My wife, Gwen, was also keen on a new dog and we quickly had to remember all the tricks and tips that we learned from our time with Trax. Having Turnar home for the summer was another big help as he and I could manage "puppy-sitting" while the other worked away from the house. Now, it was not always easy and I sure lost my temper far too often. Apparently, I forgot what it was like to train a puppy. Heck, it was practice for me to learn to be patient, again!

This process mirrored my ongoing learning about life as an ostomate. Reinforce the positive moments. Learn from each experience, whether good or bad. Keep close track of little tips and tricks that helped with the pouch change or other care of my appliance.

In particular, I went through a period of leaks on almost every pouch change. This was frustrating. I even had to reschedule some business meetings because I couldn't get a proper seal. This anxiety resulted in more frustration for me.

Can you picture this gorgeous golden retriever pup staring with his head turning and his ears perking up trying to make sense of my cussing as I had to change or adjust another pouch well before the regular time? There must have been times when he thought I was talking to him. Fortunately pups have a short attention span and I'm sure he forgot all about my babbling.

Hmm, a short attention span. This is something else you need to have as an ostomate as you keep moving forward from wardrobe malfunctions and the like. Don't dwell on those unfortunate situations.

I needed to do something. The obvious answer was to phone my ET, Mary, and ask for a consult. Sure enough, talking with her and showing the inconsistent adherence I was achieving with the pouch changes, resulted in her recommendation to use a different type of appliance.

Apparently, I was not walking enough with Trappar and my belly had expanded a bit too much. This became another wakeup call as I needed to start on a more consistent active living plan to stop the weight gain. With the new appliance working very well, Trappar and I began our now regular walking program.

Up at 6 AM, and out the door shortly after, we would walk for 45 to 60 minutes depending on conditions. We would then have another lengthy walk in the evening. Trappar also got lots of training and really lived up to his breed of retriever. Plenty of fetch occurred in our back yard.

When he was close to a year old, I started taking him to an off leash dog park on the weekend. We soon met a few early morning regulars and established a routine. This was a lot of fun and Trappar and I both made new friends. This was a bit tougher on Gwen as she wasn't always able to sleep in on weekends. Sorry, dear.

My weekend regulars were two RCMP officers and a music teacher. We covered all sorts of topics, and we continue this weekend and holiday routine to this day.

I learned a bit more about appliance capacity, adhesive strength and my "look", especially in the summer when we were in shorts and t-shirts. I consciously tried not to put anyone in a difficult situation where they might say "hey, what's that sticking out of your shirt"?

The more work I conducted directly with clients, in addition to our trips to the U. S. to watch our sons play football, resulted in more overall awareness. I needed to be mindful of when I had to change my pouch, when I had to have my emergency back pack with me and some new tricks to stop leaks. For instance, I kept a roll of clear medical tape that I could stick to the edge of the appliance if it was starting to loosen and I wasn't in a place to perform a change.

This tip was from my doctor who suggested it when I "sprung a leak" during an exam. She wasn't fussed about it and calmly showed me what to do. I had to buy some extra rolls of tape and put them in my briefcase, sports bags and in a few spots at home.

During a change, I apply some powder before placing the pouch. Gwen suggested using an old makeup brush to apply the stomahesive powder. Works like a charm.

I was still coaching with the Bisons football team at this point. All the coaches were aware of my situation and, fortunately, didn't treat me any differently. I got the same abuse as before and dished it out as well. Treating me the same way was what I expected from these good friends and it helped me realize that I really had adjusted to my new lifestyle.

I started to play basketball with my senior men's team, Old School. And I started to skate regularly with my Friday night pickup hockey group that had been together for over 20 years. Not everyone knows what I went through and it doesn't matter one bit.

In fact, my close friends in town and across the country, and business associates that knew of

my adjustment, also treated me the same way. Without them realizing what they were doing, they were really helping me understand that this was only another chapter in my life and not the end of the story.

One great friend and confidant asked me if my disease diagnosis and subsequent procedure had changed me. I thought about that and responded that if it took something like this to make me smell the roses, then maybe I hadn't lived such a good life after all.

Fortunately, I believe that I had been doing alright in the life department before this event. And I am far from perfect. I did become more aware of a few things in regular life now and appreciated a broader type of books, learning and topics of discussion than I had in the past.

As a man of faith, I believe that the Good Lord has a plan for me. My ability to progress through this situation into a new life style means that I am here for a reason.

Thanks to the WOA, I have been able to share my journey. I would like to think that if my story invigorates one person to choose a positive approach to their situation then I will feel humbly grateful to have helped. However, I can't do it for everyone. You have to work through your particular situation. And there is help if needed.

Writing about my journey has also helped me realize the importance of the WOA. We really are "Ostomates helping Ostomates". An old adage that seems appropriate here is "those who can should". I am also trained as a visitor. And after sharing my story I now want to share others' stories, too.

I really don't consider myself the most courageous or toughest that has had to make lifestyle adjustments due to major diversion surgery. Younger people that will require their appliance for a longer period than me have to be even more resilient. Older folks that have to adjust for a shorter period need to be more resilient, so they can enjoy a great quality of life in their remaining years.

I have been blessed to have the most wonderful family. Gwen, Tylar, Turnar and Trappar keep me grounded and inspired. My sisters Cheryl and Jodi, and brother Ted, and all my nieces and nephews, also make certain I am the Tim they grew up with. My friends are from all parts of my life and their ability to treat me like they did before has probably done the most to help me realize I really haven't changed my attitude. And my clients and professional colleagues have allowed me to do the work that I love. They have high expectations, too, and I cannot let this disease and resulting surgery allow me to provide anything less than my best professional work.

Well, Trappar has his ball and is ready to go for a walk and play fetch so it's time for me to sign off. Where have the past three years gone?

Time flies when you're having fun!