

## Narrative of Jeff's UC odyssey

Starting in very late October or very early November 2005, I started to get diarrhea. A lot of it. It shortly became the only type of BM I had.

In mid-December, I followed my wife's recommendation, and made an appointment with my Internist, Dr. James West. During several appointments with him in January, in which I had bloodwork, stool test, ultrasound of my abdomen, he told me that I needed to go to a gastro-internist doctor.

Following a recommendation by my mother-in-law and seconded by several other family members, I made an appointment with Dr. Randy Yanda. In late April 2006, I got a colonoscopy done. The results showed small to moderate amounts of Ulcerative Colitis in the large intestine.

He recommended several drugs, like Asacol, Pentasa and Colozol. I went through the Asacol and Colozol without effect.

On the morning of July 4<sup>th</sup>, I ran the Peachtree Road Race, for which my time reflected the lack of training, but I did not have any UC-related problems before, during or after. Thank God.

The evening of Thursday, July 13, as I was on Pentasa, I met my best friend for dinner at Longhorn Steakhouse. At about 2:30 AM on that Friday morning, I had to poop. While on the throne, I noticed some pain in my abdomen, similar to that of hunger pains. I tried to sleep, but the pain kept getting stronger. I had a 10:00 appt with Dr. Yanda that morning, and I asked myself if I could hold out.

As I had gotten up and was walking about, I looked at my abdomen. It was very swollen about two inches below the sternum and very painful to the touch. At that point, I asked my wife to take me to Piedmont Hospital.

It was about 4:30-5:00 AM by the time we got there. The hospital staff admitted us to an ER room after verifying my insurance, of course. In the ER room, they took blood tests that showed I had pancreatitis. By this time, I was in a lot of pain, grimacing and moaning with each exhalation. They

hooked me up with Dilatid, and when it kicked in, I was so glad-no pain. No other sensation common to painkillers, but no pain.

Dr. Yanda's PA came in shortly, asking questions and taking notes. I called my sister-in-law, who works at Piedmont. I called my boss to let her know what was happening and my tennis captain, as I was scheduled to play that following Saturday. I was admitted shortly afterwards, and through Blynnsa's efforts, was put into a suite instead of the standard room.

The standard treatment for pancreatitis is to not take any food or water for 24 hours, then very gradually start introducing bland foods over the next several days.

That first day, I had only IV fluids, but was not hungry at all. Connie left in the late morning, if I remember right. Would have been very boring for her, and she had been up with me since about 2:30 AM. I am sure it was a long day for her, having to go into work afterwards. I had a nice long nap.

The next day, Saturday, I was allowed the starvation diet plan, of which the main thing that was edible was grits. On Saturday, an ultrasound of my gallbladder showed negative. Connie brought a goodie bag from the house for me-some books, toiletry stuff, glasses.

At some point, I received a Remicade infusion. It was preceded by a shot of liquid Benedril. I felt the wonderful effects of that in about 2 seconds. Great sensation of a wonderful drug, and then sleep.

Was finally discharged at about 11:30 AM on Tuesday, July 18. For the next two weeks, I was on a low fiber/low residue diet. Ick. It took a lot of discipline to adhere to it.

Dr. Yanda thought the pancreatitis could have been caused by a reaction to the Pentasa. The other major cause of pancreatitis is alcohol. Not a worry there. He took me off of Pentasa, and put me in 6mp.

Wednesday, July 19. I made the mistake of going in to work the day after I got out of the hospital. I should have stayed home. I left after 6 hours, feeling very tired and sluggish. I was worn out.

The next day, I left after about 6 hours again with a headache.

Monday, July 31, we received a bill from Piedmont for \$22,000. We were not amused. On August 11, we received an EOB showing our portion was \$414. That was nice.

Had another Remicade infusion on Wednesday, August 16 at the Infusion Room at Piedmont and another on Wednesday, August 30. Both took about 3-4 hours, and both appointments were in the morning. So I had great naps, and brought along a book to read.

On Labor Day, Sept 4, I ran the US 10K Classic. I had major misgivings with doing so. Porta potty lines suck, but I was able to go across the street from Cumberland Mall to the Galleria and found an open door in the back. I used the bathroom several times there prior to the race. During the race, I had to stop at Dunkin Donuts and Pep Boys to poop. Pisser. Rotten time, walking 2/3s of the race as I could not train properly for it.

On Friday, Oct. 13, we left for vacation at Amelia Island Plantation. I had some reservations about the drive-no problems. On Sunday morning, we went for a kayaking excursion in the marshes. I was scared to death, as there are no bathrooms in a kayak. I did very well, and three hours later, while back at the dock, I used the porta potty there. Whew.

Friday morning, October 20 at about 2:30 AM, I had the same pain and symptoms of pancreatitis as I had back in July. So, another trip to the ER at Piedmont, another diagnosis of pancreatitis. Another five-day vacation at Piedmont Hospital. Got discharged on Tuesday, Oct. 24 at about noon, with another two-week regimen of a low fiber/low residue diet. We were both thankful this happened when we were back home instead of on Amelia Island.

I learned (to a limited degree) about working following a hospital stay, and so only worked 4 hours the next day. The next day, Thursday, I worked 6 hours and on Friday, was back to full days.

On Wednesday, Nov. 8, I got a second opinion on the recommended colon surgery. Went to Dr. Brandenburg at St. Joseph's Hospital. He saw that I was about at the end of the treatment regimen for UC, but mentioned several clinical trials that he knew about. Neither seemed a possibility.

On Monday, Nov. 27, Connie and I met with Dr, Jay Singh, the surgeon recommended by Dr. Yanda. We agreed to the colectomy surgery on Wednesday, Dec. 27.

On Tuesday, Dec. 12, I tried to give blood to bank for my surgery. I had the bag 2/3 full, then told the attendant that I was about to pass out, so they unplugged me. Bummer. I do not remember the needle hurting like that during the previous times I have given blood. It hurt badly the whole time.

At some point around this time, I had my preop hospital appointment. I weighed 203 pounds. Damn prednisone.

In the afternoon of Wednesday, Dec. 27, I had my large intestine removed at Piedmont Hospital. I was told it took about 7 hours and that Dr, Singh had very little room for error in that the small intestine designated for the j-pouch almost did not reach. I remember very little of the following Thursday and Friday, but I remember Mom spending the night each night. I remember two nurses giving me a sponge bath on Friday morning. Guys tend to remember things like that. Each day following, I gave myself a sponge bath. Even if I did not feel like it, I knew it was important to do so. Shaving was optional. Deodorant was not.

Saturday was the first day I started feeling anywhere near human. As the anesthesia worked its way out of my body, I had the male equivalent of hot flashes over the next few days. There were times I was burning up, and sweating. I kept the thermostat to around 67, which I think was the lowest setting. As it was January anyway, I had a blanket on me as well. What I call a blanket and what the hospital calls a blanket are two different things.

My legs were hooked up to some mechanical massager to help prevent blood clots. While I liked it during the day, at night it got to be a pain. I had to call the nurse each time I had to empty my bag, go to the bathroom or go for a walk. That got to be a pain, so at some point over the next day or two they brought me some of those tight calf-length socks to do the same thing. I wore the gray hospital socks, the ones with rubber strips to prevent sliding, over the white socks. After a day or two, they caused my legs to itch like crazy. So I stopped wearing them.

As they wanted to measure my output, I had to drain the bag into a beaker.

One doctor told me first thing today-he woke me up, is that if I felt like I had to go to the bathroom, to go and listen to my body. The first few times I went, I pooped out a lot of blood. I was told this was normal, and I would pass mucous-like poop.

One thing that was a lifesaver the first night or two was the beaker they gave me to pee into at night so I would not have to get out of bed. That took a few attempts but I got the knack of what position to be in to best use it. They measured that output as well.

Sunday afternoon, Dec. 31, 2006,. While Connie was with me, a nurse from the Wound/Ostomy Care Center showed us how to drain and also how to change the bag. Major yuck factor involved in each. At about 2:30 AM later that night, New Years Eve, I woke up, knowing something was wrong. When I turned on the light I saw that the bag was full and leaking like a sieve. I was a mess, the bed was a mess and soon parts of the floor were a mess. This is not how I wanted to wake up.

I made the conscious decision to not panic or freak, thinking that if I could change the bag under difficult circumstances, it would only help me in the future. So I got up, went to the bathroom and drained the bag. I started to clean myself up, and then changed the bag. Afterwards, I finished cleaning myself, and then had to call the nurses station and let them know what happened. They brought me a new gown as well.

By the time I got back into bed, it was about 4:30 AM, and I was exhausted, embarrassed and frustrated. I then threw a pity party, and cried like I had not cried in years. All the frustration, all the stress of dealing with the UC, all the worry of the next several months, came out. Then I did the smarter thing, and started praying like I had not prayed in years. I told God that I needed Him-He already knew that. I told him I knew whose footprints those were in the sand-His. He knew that too. I prayed for several more minutes and felt instantly when the weight of the world started to leave my shoulders. The weight kept getting lifted. I knew who was doing that, and that He was better able to carry that burden than I ever could.

That thought has comforted me a lot since, but sometimes I place some weight on my shoulders through habit.

Naturally, I felt poorly today and did not feel too great on that Tuesday either. When Dr. Singh saw me on Tuesday morning, he thought I was not ready to leave-did not look like I was ready.

On one particular day during my stay, I got a call from my mom that Blynnsa, my sister-in-law who works at Piedmont, was in the Emergency Room. So without thinking about it, I got my robe and trekked down there. The way they have the doors arranged from the main corridor to the ER, you can not open them from the corridor. So I walked through the parking lot, rolling my IV pole in front of me. When I entered the Emergency Room lobby, I ran into my brother, and we walked out of the ER lobby back to the individual ER rooms. No hospital employee said anything to me, which I found to be hilarious. I must have presented quite a sight walking through the parking lot!

Blynnsa was sitting in a chair in one of the corridors and was not happy to see me. Being the nurse she is, she fussed at me, saying I did not need to be there with my having gone through my surgery and the damage to my immune system. I have to admit she was right. I stayed a minute or two later to wish her well. From the Emergency Room, I entered the main corridor through the one way doors and went back to my room. Still no hospital employee said anything to me.

I got discharged about 4 o'clock on Wednesday, Jan. 3, 2007. We left with a very bad taste in our mouths. The staff wanted us to meet with the home health people who could visit us at home if needed. The lady was delayed, and we waited over three hours. Major pisser.

At some point, we noticed a leak, and spent 30 minutes changing it. The lady came during this time, and did not want to wait for us, so she just left a brochure. I wanted to wring her neck.

Miscellaneous thoughts on my hospital stay:

1. I had to curtail my watching of South Park due to my abdomen hurting while laughing. I had to stop watching the movie Airplane during the cockpit scene when they started their routine of, "What's the vector, Victor"...Laughing too hard again. I rented this movie from Blockbuster a month later.

2. Take as many naps as possible during the day. I was not able to sleep very well at night due to the frequent blood pressure, temp and pulse readings taken.
3. Go for 4-5 walks a day, but do not overdo it.
4. Learn to like sponge baths.
5. Being positive and thinking long term will get you through the day.
6. Visitors are great to have, but if you need to sleep, sleep. Try to go for a walk with them.

For the ride home, I sat in the back seat with a pillow between my abdomen and the seatbelt-great suggestion from Connie, and I hated every bump we hit on the way home.

We stopped at Eckerd on the way home and the pharmacy tech somehow thought there was a problem with the pain prescription. Thirty minute delay there. The script was properly filled out. Incredibly aggravating. Thank God they had seats for me to sit on.

Got home around 6:30 PM.

So glad to be home. Some of the preparations we had made were to get a mattress protector in case of a leak. We had done some grocery shopping in advance, knowing I needed a low-fiber/low residue diet.

When we left Piedmont, they gave us a number of items for later use. Among them were surgical gloves and a large pad, 1.5 foot by 2.5 foot or so. We used this on the couch in case of a leak. The surgical gloves were to be used when I changed the bag. I tried them for several days, but decided that I needed the dexterity of going glove-less.

On Friday, Jan. 5, I started walking from one end of the house to the other. Walking from one end of the house never seemed like a chore before, but I felt like it was. I hope I never take good health for granted again.

I soon noticed I was up several times a night, draining the bag. I never wanted the bag to get too full, so it was common to drain it at 1/3 to 1/2 full.

On Saturday, Jan. 6, Connie went with me for a walk outside, just to the end of the driveway and back, several times. Felt great being outside.

I developed the habit of going for a brief walk after breakfast, followed by a nap. Mid morning naps are wonderful. I felt like a cat.

For a few days afterwards, we walked down to the cove and up the hill, and called it a day.

At some point, we named my stoma Rosie, in honor of Rosie O'Donnell. This was shortly after her spat with Trump. My stoma reminded me of her, always spewing and full of crap.

On Wednesday, Jan. 10, I had an appt. at the Wound/Ostomy Care Center. The nurse took out my stitches and removed a glass rod that propped up the stoma. This hurt like crap, and she then changed my bag. This was followed with an appointment with the surgeon, Dr. Jay Singh. He told us of an impending procedure to test the integrity of the pouch, scientifically called a pouchagram.

On the next day, my bag started to leak. If the WOC people could not last longer than two days, I did not feel so bad. I could not do any better.

I soon learned that taking a shower loosened the wafer. So I started to take sponge baths each day, and washed my hair in the kitchen sink. I took showers only when I knew I would be changing my bag immediately afterwards.

On Jan. 13, I noticed that I was getting some good sleep until about 3:00 AM, then my lower back and hips started to ache badly. Nothing I could do would increase the comfort level. I did not want to sleep on either side because of the bag, so I was stuck sleeping on my back, and ached at night. This was miserable.

Sunday Jan. 14-felt strong enough to get out with Connie and go to Kroger and Blockbuster-she drove. I was glad to get out somewhere. I walked very slowly, and was hunched somewhat over the buggy.

At some point I realized to start changing my bag, if possible, only when I had not eaten for several hours. The times I tried to change it after eating only led to frustration and wasted bags because Rosie was more active.

Monday, Jan. 15, I had a bad day. While trying to change the bag, I got frustrated and Connie had to help. After a minute or two, I began to feel weak and got dizzy. I went to bed bagless and Connie had to put it on while I was in bed. Rosie was very active the whole time. I think I succumbed to the ick factor and somehow Connie had the patience and ability to get through that and put a new bag on me.

Thursday, Jan 18- I am was doing my best to take one step at a time and to stay positive. But I am getting frustrated with my inability to have a bag last longer then two days. We did a few errands-Kroger, credit union, Blockbuster

Friday, Jan. 19, I went for the longest walk yet; a walk to the subdivision entrance and back, about one mile.

Monday, Jan. 22, Connie went back to work. I got stir crazy and went to Chick-Fil-A and read the paper, had some sweet tea, then went to the library and the credit union.

With Connie back at work, I knew that I needed to be as independent as possible, more so than before but I failed at this occasionally. Connie was a great help with Byram and getting my account set up and supplies ordered.

Connie's office had a church deliver a lasagne dinner. What a treat.

Tuesday, Jan. 23-did fairly well during the day, but got bored easily, which I remedied with a late morning and mid afternoon nap. I felt like a cat. Again..

I noticed with my diet, I was able to handle any food I ate, with the exception of soup-that went straight to the pouch. Lots of output for not much substance, so I stopped the soup. Juices went straight to the pouch. I stopped drinking apple and grape juice, but kept with the orange juice, just not as much, as I wanted the nutrition.

I usually drink a lot of Ensure.

Wednesday Jan. 24, I met Mom and Dad for lunch at our favorite barbeque restaurant, Old South. I enjoyed getting out and meeting them. I was able to handle barbeque, which was a step in the right direction.

Had a rotten night sleep that night, but had a great nap this afternoon.

Thursday, Jan. 25-went to Chick-Fil-A again, for sweet tea and to read the paper. Felt great just getting out of the house and going somewhere. Went to Borders Bookstore afterwards and bought a Johnny Cash CD.

Had a rotten evening. Had three leaks, finishing with the last one after midnight. Was very frustrated.

Friday, Jan. 26-ordered more supplies from Byrum. I had a great fear of running out of supplies. It helped knowing we lived about 13 miles from their Georgia retail store, for if I ran out, I would not have to wait on the mail or have to request an overnight package.

Chick-Fil-A again. Got a haircut.

Saturday, Jan. 27-watched television and read most of the day. Had pizza for dinner. Handled it well.

Had a bag hold up for two days. Wow. Almost a record.

Sunday, Jan. 28

We went to Kroger and I was again glad to get out. Had cold pizza for breakfast, and again handled it well.

Connie fixed a wonderful fire tonight. She had a good coach.

Monday, Jan. 29-Ordered more supplies.

Chick-Fil-A again.

Our computer was acting up. Again.

On Wednesday, Jan. 31, I felt well enough to go out and do a bunch of errands: Sports Authority, Kroger, Borders Bookstore, Blockbuster. Also stopped by Byram.

Chick-Fil-A again.

Thursday, Feb 1. Had the threat of an ice storm last night that luckily never materialized. Connie was able to go in to work.

Dreary day. It is easy to be positive when the weather is wonderful, a lot harder when it is overcast and nasty.

Started working on our tax stuff.

Sunday, Feb. 3-went to Connie's tennis match.

Monday, Feb. 5-started taking Connie to and from work. Connie likes not having to drive, we like the extra time together and it gets me out of the house.

Chick-Fil-A again, and went to Cumberland Mall for some shopping.

I went to Chick-Fil-A many more times than indicated in this narrative, if only to get out of the house. It is isolating enough being sick or recovering from surgery, but getting out even if just to read the paper really helped my outlook.

Wednesday, Feb. 7-met a friend for dinner at Longhorn Steakhouse. I was not brave enough for a steak, but they have good salmon.

Saturday, Feb. 10-saw a movie, Letters from Iwo Jima, at the theater. It must have tired me out, because I later took a two hour nap.

Monday, Feb. 12-we had an early Valentine's dinner-sushi. Handled it well, but at the restaurant, I noticed a leak. It was a small one, so I did not replace it there, waiting until I got home. By the time we got home, it was a major leak. I was a bit of a mess.

Wednesday, Feb. 14-had a pouchagram test at Piedmont to test the viability of the j-pouch. From Piedmont, I took Connie to work, and had lunch at the Varsity. Handled it with no problems. The extra grease may have helped.

Thursday, Feb. 15-set a record. My bag has not leaked since Monday-4 days.

Friday, Feb. 16-had an interview. Was extremely worried about the bag. Drained it right before I left.

Had pizza again for dinner. No problems.

Saturday, Feb 17-Crappy morning. Had to change the bag, and had two replacements leaked immediately. Pisser. The third one worked. My frustration from the first one leaking contributed to the second one leaking. Impatience is not a good thing.

Saw a movie. Handled popcorn well, but made sure I chewed it well. Afterwards, we ate at the Varsity and window shopped at the mall.

Thursday, Feb. 22-Went for a long walk on the Silver Comet Trail. I'm trying to incorporate long scenic walks instead of just walking in the neighborhood. Plus it is a great way to spend an hour or two.

Friday, Feb. 23-still not sleeping very well.

Sunday, Feb. 25-Beautiful day, and we went for a long walk, and also walked at the nearby lake. I had not been around that lake in 20 years.

Saturday, March 3-We went to Connie's mom's to help her out with some cleaning. I replaced the guts of one of her toilets, but in the twisting and bending I did, my bag sprung a leak. Replaced it there.

Saturday, March 17-had a tennis get-together/celebration for our mixed doubles team winning the bag tag. I had several slices of pizza-no problems. I had an in-depth conversation with a teammate who has Chrons disease. He was very interested in what happened to me. He had previously had some of his large intestine removed, but retained most of it. Afterwards, they went out for bowling, which I passed on. I did not want to torque my abdomen. That was the first time I ever considered bowling to have some physical effect on someone.

Tuesday, March 20-Went to an all day HR seminar. I was extremely worried, but the bag held up nicely. One woman I knew told me that her mom had died of pancreatitis. That was a dose of reality.

Stopped by the Varsity on the way to pick up Connie. Discovered that a chocolate milkshake goes straight to the pouch. Glad I checked before I left-it was full. At the downtown Varsity, there is a row of 4 to 5 toilets that do

not have much, if any, privacy. There is one for handicapped customers that is enclosed. I am very thankful it was available. Having to drain it in view of others would have been very embarrassing.

Saturday, March 24-I am getting nervous about my upcoming resection but look forward to life without a bag.

Wednesday, March 28-Had my preop blood work done. I did not even contemplate banking a pint of blood.

Tuesday, April 10-Resection surgery at Piedmont. Screw up on the arrival time. Our paperwork showed an 11:00 arrival time; theirs showed 1:00. Pisser, but glad the times was not reversed.

Had a lengthy delay in Recovery. I was awake during much of this time and was surprised I was lucid as well. I think Blynnsa used some clout to get me a room sooner. Got up in the room at about 9:00 PM.. As the techs were about to move me from the transport to the hospital bed, I reminded them at the last second about the catheter bag. That would have hurt badly had they moved me and that bag had stayed in place. Dumb.

Wednesday, April 11. Made it through the day, but had a crappy night. Lots of liquid bms, on top of the standard hospital procedure of denying a full night's sleep with the repeated blood pressure, temp and oxygen checks.

They brought me a beaker in which to go without getting up. They wanted to measure my urine output. I told the Care Practitioner that if I was peeing, I was having to poop. If I was having to poop, I was on the toilet. If I was on the toilet, it was difficult to use the beaker.

Thursday April 12-a decent day and a better night. Got upgraded past the starvation diet.

Friday, April 13-best day so far. Dad called, saying that they were in the emergency room at Piedmont, that Mom had fallen and hit her head when they were at their broker's office. He specifically told me to not come down to the emergency room, knowing what I had done several months ago.

They came by several long hours later-no concussion and a negative CT scan.

Got put on an even better diet; Dr. Singh wanted to see how my body handled it.

Saturday, April 14-Got discharged at about 10:30 AM. Great way to start a day. Among the supplies I received were some long q-tip thingies, sterile water and a lot of gauze bandages. For the next week or so, I would have to clean the site where the stoma was. It was an open hole. To clean it, I poured some of the sterile water on to a gauze pad, and used the wooden end of the long q-tip to pack the gauze into the stoma hole. Then I put another bandage over the stoma hole. I think I did this several times a day. It is not for the faint-hearted. After a week or two, it closed up by itself.

Sunday, April 15-Had a so-so day. I could not sleep well last night until 3 or 4.

This has been hard on Connie. She had a two hour nap this afternoon and I think she needs to catch up on a lot more sleep.

Wednesday, April 18-Went out to the library, Home Depot and Target. Felt great to be out without the bag.

Friday, April 20-Crappy night sleep last night. Great 2 hour nap.

For my first week post-resection, I think I have done well. My energy level is OK, appetite reasonable. The quality of my sleep is poor, with a high number of bms.

Saturday, April 21-Connie spent the day with her mom. Did not have much of an appetite, and had several naps.

Sunday, April 22-Went to watch Connie's tennis match at North Fulton. I got very tired and laid down on the lawn to take a nap. Thank God the temperature was warm, but I was not ready to come out to watch her match. My stamina was lower than I had hoped for.

Monday April 23-Started to get bad gas pains, about 15-20 an hour. The pain reminded me of the pancreatitis pain. No appetite at all. I remember being on the computer at about 5 AM, trying to force myself to eat some Ritz crackers and peanut butter. I laid in bed most of the day and slept.

Connie had the day off for Confederate Memorial Day. She was sick too-lots of diarrhea with one upchucking. She laid in bed with me most of the afternoon. Misery loves company.

I think we both had a stomach bug.

My bms were still very watery/diarrhea-like.

Tuesday, April 24-Another bad day. Both of us were still sick. Connie is still having diarrhea, but no upchucking.

About 1 PM, I noticed blood in my bms. Each bm, of which there were multiple, until about 9 PM had some blood in it.

Still no appetite. My weight is down to 169, which I have not weighed in 20 years. At some point over the next several days, I hit 163. I had lost 40 pounds since my preop appointment in mid December. Wow.

Wednesday, April 25-Feeling better, but still have some queasiness in my abdomen with diarrhea-like bms.

Had a doctor's appointment with Dr. Singh. Told him of the last few days. He said I am progressing well.

While at Piedmont, I dropped off my leftover ostomy supplies at the Wound/Ostomy Care Center.

I felt well enough to go afterwards to both Whole Foods and Publix. We were getting low on edibles.

Thursday, April 26-Better day for both of us. I took Connie to work at 11:30, stopping by Chick-Fil-A afterwards for some chicken soup and sweet tea.

I am definitely feeling better but still do not have much of an appetite.

Had soup for dinner, but made the mistake of having ice cream afterwards. I upchucked.

Friday, April 27-Rotten night last night. Multiple bms, leaving me exhausted, frustrated and cranky. I ended up sleeping on the couch trying to get a change of scenery and to avoid disturbing Connie so much. I think sleeping in a semi-erect position using propped-up pillows helps somewhat.

Saturday, April 28-Feeling much better. Connie felt well enough to see a movie with her mom.

Sunday, April 29-I knew better than to go to watch Connie's match.

Monday April 30-started driving Connie to and from work again.

Sunday, May 6-For the first time, I felt like I was walking in a normal manner. My speed was improved as well. So glad.

Thursday, May 10-Bad night's sleep last night. Still trying to get used to this j-pouch. Sometimes I have to go 3 to 4 times in a row to get one full bm. I know something is in there but does not want to come out.

This pattern of multiple attempts at a full bm will be an ongoing pain for a long time.

Monday, May 14-started a short term HR assignment at ADAM Software. I felt well enough to work but had some misgivings on the number of times I would have to go to the bathroom. It did not cause as much of a problem as I thought. But there were times the cleaning crew had closed the bathroom for cleaning. I was not a happy camper, but had to go one or two floors up to go to the bathroom. My boss had last seen me back in mid-December when I was above 200 pounds. When he saw me, I could tell he was very surprised by my appearance, down to 163 at my lowest.

Friday, May 18-end of the first week of work. I am tired but getting my confidence back up.

Saturday, May 19-did some light yard work. The yard was overdue.

Thursday, May 31-Had a flex-sigmoid scope done. They found a stricture in my j-pouch. This is a narrowing of the small intestine, formed as Dr. Singh had to jump through hoops to form the j-pouch. He almost did not have enough room.

I have been having way too many bms with very low output. This has left me very frustrated.

Saturday, June 2-started Mesalamine, a suppository/anti-inflammatory to help with my stricture.

Had a very bad night last night. Lots of bms, little sleep. Got dehydrated. Went to Connie' tennis match. After dropping her off at the courts, I went to a convenience store and got a 32 ounce Gatorade. When I got back to the courts, I finished it quickly, then had several cups more that the home court team had brought. I knew something was wrong shortly afterwards, and tried to get some sleep in the car. The temperature was already hot in mid-morning, and I could not sleep. I still felt miserable. I got out and started talking with the husband of one of Connie's teammates. It was about this time Connie finished her match. A few minutes of talking with Rick, I got dizzy and knelt down on the ground. After the dizziness had passed, Connie brought me home. I drank a boatload of gatorade the rest of the day.

This made me wonder about hydration levels, and what would have happened if I had not had that Gatorade.

Sunday, June 3- Connie had another tennis match. I watched, but felt rotten and exhausted from another bad night.

Wednesday, June 13-Started having abdominal pain at about 2:30 AM. What is it with 2:30 and pain? I thought it was hunger pains, so I got something to eat and drink. I thought about pancreatitis, and although the pain was similar and in the same location, there was no swelling. By 5:30 AM, the pain had increased to the point I woke Connie and asked her to take me to Piedmont. I could tell she was not a happy camper that this may be another bout of pancreatitis. Had there been any swelling, we would have been there much sooner than 5:30. Sure enough, after the blood test, the ER doctor said I had "Rip-roaring pancreatitis."

I called both my bosses to tell them I would not be in. I also called Blynnsa to let her know I would be her guest again. The patient census was very high, and she got me into a room pretty quickly, but about 10:30 AM. Connie went in to work once I was in the room.

Same treatment pattern-starve the pancreas. That first night, they brought into the room a Dilatid pump and hooked it up to my IV. My brother advised me to take a hit or two right before I went to bed. So right before I went to bed, I went for a walk and hit that pump once or twice. The next morning, a lady came into the room, saying she was from the Pain Management section, and said that the pump was placed in my room because a lot of pancreatitis patients evidently are “rolling in pain.” I am very thankful I never got to that point, but, like my friend saying that pancreatitis had killed her mom, it again made me aware of how serious pancreatitis can be. I was lucky.

Same vacation at Piedmont: rotten sleep, blood drawn at 4:00 AM by vampires, blood pressure, temp and pulse readings throughout the night. On one occasion, the care practitioner wheeled in a scale to weigh me. I could not be mad at him as he was just doing what his instructions said to do, but I was pissed.

After listening to advice from both Connie and Blynnsa, I made the decision during this stay to not run the Peachtree Road Race. This would have been my 20<sup>th</sup> time to have ran it, but I had not trained properly for it, and this bout of pancreatitis so close to July 4 proved to me it would not have been smart to do so. It broke my heart to miss it, as it would have been my 19<sup>th</sup> in a row.

Sunday, June 17-Got discharged about 10:45 AM. Beat the rap in 4 days this time, instead of the 5 days the two previous times. I must be getting to be a pro.

Towards the end of June, I mailed my Peachtree Road Race number to the Atlanta Track Club so that I could get a guaranteed number for next year.

Saturday, July 7-first tennis match in a long time. Lost 7-5 (7-2), 5-7, 5-7. It was the most evenly matched tennis match I have ever played. It lasted about 3 and ½ hours. Even though we lost, the fact that my stamina was such that I was able to play quality tennis (at least by my definition) for an extended time was a great confidence boost.

Sunday, July 21-Another three set marathon, but we won. Again, good stamina.

Thursday, July 19-Left work early and headed to the ER at Piedmont. Again. Had a good bit of abdominal pain that came and went for several hours.

There were times it was strong enough to make me wince with pain. Got there about 1:15. Left about 8:15. Had an X-ray, CT scan. All negative. The ER doc said he could not determine what caused that pain.

Friday, July 27-Had more pain, similar to that of the 19<sup>th</sup>. Did not go to the ER, but the pain eventually dissipated.

Sunday, July 29. Another 7 hour bout of abdominal pain.

Thursday, August 2-Had a CT Scan of my abdomen.

Saturday, August 4-Had a 5 minute bout of abdominal pain.

Monday, August 6-The results of the CT scan were negative. No complaint there-that is a good thing, but still no explanation of what caused the pain. Dr. Singh thought it was a kink in the small intestine that eventually worked its way out.

Saturday, August 11-Connie and I ran the Dinosaur Dash, a 5-K. Had no problems.

Monday, Sept. 3-Ran the US 10-K race. Had a few bms pre-race, but avoided porta-potty lines by going to the Galleria again. Would have had some problems otherwise. The lines for the porta potties were huge. No problems during the race, or after. Beat the time from last year by 16 minutes.

Friday, Sept. 14. Dr. appointments with both Yanda and Singh. Still dealing with the stricture. High number of bms, lost of low-outputs, false alarms, back to backs.

Thursday, Oct. 4-left for vacation at Amelia Island Plantation. Had no problems there throughout the vacation. We went on another kayak excursion through the marsh, and other than the kayak having poor back support, had no complaints.

Monday, Oct. 8-On the return trip, stopped by a large sporting goods store just north of Macon. While we were there just an hour. I had to go 4 times. Major pisser.

Friday, Nov. 16-Had a stricturoplasty done at Piedmont. Instead of performing a dilation, he made 4 incisions on the stricture in an attempt to eliminate it. Long day that started early. Had two wonderful afternoon naps. Had no pain at all, very thankful about that.

Saturday, Nov. 17-Still recovering some. I am maybe at 80-90%. I can feel some benefits of the procedure yesterday. Had no straining and all bms had output-none were false alarms or little output. So grateful about that.. I hope it stays that way.

Sunday, Nov. 18-Feeling 100%

Friday, Dec. 21-Think my stricture is returning. Getting the same symptoms as before, just not as pronounced:

Low output bms.

Feeling that there is more that wants to come out during a bm, but can not get it to do so.

High number of bms-10-14 a day

Repeated back-to-back toilet trips

Straining has returned, some hard, often involuntary. Some not.

This still beats living with colitis, but I would have hoped for better results from having the colectomy.

Monday, Dec. 31-Reflected on the year.

This has been a tough year:

Physically- recovery from the colectomy was a butt-kicker, another bout of pancreatitis, several procedures and still dealing with the stricture.

I am tired a lot. Still not getting a solid night's sleep-not since November 2005 have I been able to sleep through the whole night without waking up. I usually take naps every Saturday and Sunday, sometimes two.

Emotionally-dealing with everything has taken a toll on me. Dealing with the recovery and the bag was fairly traumatic.

Financially- Thank God I have been with Flex HR as a consultant. I would have probably been fired from any other position as an employee. Still, I

missed work until the middle of May. I could have returned to work maybe in March, but there were no assignments, and I would have been out for at least two weeks in April anyway. Not a good way to begin an assignment. Being out multiple times, -vacation, procedures, hospital trips, and since my client cut my hours in November, will all combine to not do anything good for my income this year. Still, I am grateful for what I could do.

I also learned a few things:

1. Any day out of the hospital is a damn good day. Remember that fact. Doing so will help you emotionally when you have a bad day. You will have them.
2. Appreciate and be thankful for the little things in life. Even the little aggravations of daily life. At least you are alive to notice them.
3. Appreciate good health and do not jeopardize it.
4. I am so grateful for Connie. She has put up with a lot this year.
5. Always have excellent insurance. PPOs are wonderful. My medical bills have totaled about 150K over the last year and a half and we have paid out of pocket maybe \$4,000. UHC probably hates me.
6. Always have money in the bank in case you have tough times. This has been a lifesaver.

Lessons

1. Drain the bag right before you go to bed.
2. Walk as much as you can stand, without wearing yourself out. Getting your strength back will be a major goal.
3. Listen to your body, and act accordingly. Sleep when your body says sleep- you will need it.
4. After your colonectomy, have someone stay with you for at least two weeks after you get home from the hospital. Connie stayed three weeks, and was an incredible godsend.
5. Byram and their employees are great. Go through their catalog and highlight the supplies you usually get so you do not have to remember what you got last time. You will need to experiment to see which product/bags you like. I ended up liking a convex wafer. I was fine with either a one or two piece bag. I tried to get my account set up so that they would bill my Visa automatically for my part, but never could. When I received a bill, I called them to have them put the balance on my Visa.

6. If you end up using a two piece, make very sure it is fully snapped together. Do not assume it is. And be sure to do so before you put it on. It may be painful to put the bag on the wafer separately if you have to press too hard.
7. Have a bag ready for an emergency trip to the hospital with a toiletry kit, waterless shampoo, pencil for the crossword, pen and notepad to write letters, spare glasses, a book or two ( light reading), extra underwear, robe-makes walks less air conditioned, and bring your cell phone and charger.
8. Think long-term. Staying stuck on the present will drive you crazy. Your goal is to drain the swamp, and get your health back. Remember, the alligators are temporary but are a real bitch at the time.
9. Having the travel bag (comes with your Holister stuff) to keep your ostomy supplies is a great thing to have. Keep it in your car so you do not have to remember to take it with you when you leave the house. Buy a small bag of Kleenex to keep with it. Keep it stocked with 4 or 5 bags, small scissors, a pen and a full tube of paste, not the tiny one that comes with it. Add to it a small washcloth. I never used the mirror that came with the kit. Don't be bashful about taking the travel kit with you. I was lucky in that it was winter and early spring when I had my ostomy, so I was able to keep mine in a coat pocket when I went out. There were several times I had to change it while being away from home. It was nerve-racking to do so, but you get over it.
10. Buy a bag of 10 or so hand towels to help with changing your bag, and keep one or two next to your bed for problems at night.
11. Go to [www.jpouch.org](http://www.jpouch.org). A lot. You are not alone.
12. Buy lots of the softest toilet paper you can find. Buy stock in the manufacturer to get some of your money back. You will use a lot.
13. Before you put on a new bag, make damn sure the new bag is already clamped. If you don't, you will only make this mistake once.
14. Inventory your supplies about once a week. Do not run low.
15. Get out of the house at least once a day. It will help your mood, decrease the feeling of isolation and help with feeling depressed. Even going to Kroger with Connie helped brighten my mood.
16. When you are about to change your bag, have several folded sections of toilet paper already pulled and laid out conveniently for when your stoma gets busy in the middle of changing the bag. This helps save time and helps keep the area cleaner. Keep several pieces ready at all times during this process. Lay some toilet paper in the bowl so splashes can be reduced.
17. In your bathroom, keep your supplies in a shoebox so that you will have everything together. I kept the supply of bags in our dining room on a

counter, but in a shoebox in the bathroom I had a supply of 5-6 bags plus everything else needed to change the bag.

18. Butt burn is nasty. Calmoseptine helps when it kicks in a few minutes later, but can add to the fire until it kicks in. When it happens at night, instead of trying to get through it in bed, get up and do something to try and take your mind off it. I found that if I sit down, it helps minimize the burn. I can be sitting down and not have butt burn, but when I lie back down in bed, it starts again. This pisses me off.

19. Change your bag before you eat. Changing it when your stoma is active after you eat is futile. Be patient.

20. Balneol is wonderful in conjunction with the Calmoseptine.

Residual thoughts as of Feb. 2008

1. I do not like nights anymore. From worries that luckily never came to pass about a massive leak at night to major butt burn post-takedown and the interrupted sleep, I no longer look forward to going to bed for a good night's sleep. A good night's sleep no longer happens.
2. I love naps on the weekend to help catch up on the lack of sleep.
3. I am still dealing with a stricture. High number of bms, with quite a few low outputs, back to back, followed by a gullywasher. Stricturoplasties will not be in the picture because of the threat of too much scar tissue, but balloon dilations will be in the future. If I have to have several each year, so be it. It beats UC or a bag.

March 27, 2008

I have a balloon dilation scheduled for April 4 at 7:30 AM, but we have to be there at 5:30. Lovely.

Connie said she while she realized that the UC and subsequent recovery had taken a lot out of me physically and emotionally, she said she "wants me back."

Me too.

April 4, 2008

Had a balloon dilation done at Piedmont. In being there at 5:30 AM, we had to wake up at 4:15, a God-forsaken time to wake up.

As they were prepping me pre-op, they injected a drug called Versaid(sp). I told the nurse that it was cold as it entered my veins, and Connie said that I fell asleep almost immediately after saying that.

Afterwards, Dr. Singh said that my stricture was less than before, which is good news. Didn't make what I went through any different.

We were homeward bound by 10:30 AM. I knew I had a bandage taped to my butt, but after eating soup for lunch, I did not know that my butt was still numb. I found out as I was about to sit on the toilet. Made a mess. I got in the shower to clean off and to take off the bandage.

I got another set of sweats and it happened again shortly after that.

I followed Connie's advice and with another set of sweats, used a hand towel like a pad inside my underwear.

Luckily, I started to get more control, and was more attuned to my body. I had no more accidents.

Both of us took about a 4 hour nap in the afternoon, and I had another one in the early evening.

Sunday, April 6, 2008

Dr. Singh had given me a prescription for Percoset, but as of Sunday evening, I have had no pain, so have not filled it.

The number of bms has stayed about the same. Tried to take a nap yesterday afternoon and this afternoon, but could not. Had bms about one an hour as I tried to sleep.

Have had some blood in the stool, not much though. Some bms have had a reddish hue to them, as some tp at times.

Monday, April 7

I noticed several big differences post-dilation: I do not have to tighten my abdomen drastically to restrain the urge to poop. My notice that I need a bm is more normal and natural now. Pre-dilation, I was having to drastically tighten my abdomen multiple times a day to avoid an accidental poop, and it was much easier to do so sitting down than when I was standing up. The last few days, I have only had one or two a day.

The other big difference is that butt burn is really bad.

I like the first change, hate the second, but still need the numbers down.

Wednesday, April 16, 2008

The changes mentioned above are still prevalent, but the numbers of bms has not been reduced. This has been very disappointing. The quality of my sleep still is poor.

Thursday, April 17, 2008

Had a post-procedure appointment with Dr. Singh. I told him of the positives and negatives of what I have experienced since the dilation.

He recommended I:

1. Take 2 Immodium before I go to bed.
2. Take Flora-Q probiotics
3. Use Balneol with a baby wipe to cut down butt burn
4. Again recommended a Hegar dilator. These are hard to find.
5. Make an appt when I have the dilator.

He said the J-pouch was in very good shape, with no sign of pouchitis or inflammation. That was a relief.

April 23, 2008

Wonderful night's sleep last night. Only up once! I could really tell the difference at work today, after having a good night sleep. Felt great.

April 24, 2008

I received the Hegar Dilator I ordered from Thompson Medical. Not looking forward to using it.

Crappy night's sleep. Maybe 2 hours total. At about 5, Ruth at work told me I looked tired. It must have really showed.

April 25, 2008

Made an appointment with Dr. Singh for next Wednesday.

April 26, 2008

Had a late morning nap, followed by a late afternoon nap. Thank God for weekends.

April 27, 2008

Had a long three hour nap. Dreary, rainy morning.

I think my dilation from the 4<sup>th</sup> is holding rather well. My numbers are still higher than I want, but all other symptoms are ok.

It will be interesting if using the dilator helps long term.

April 28, 2009

Found a good article on jpouch.org:

<http://www.ucsfhealth.org/adult/edu/jpouch/index.html>

Tuesday, May 20, 2008

I tried to do the self-dilation with the hegar dilator. I laid down a towel on the bed, not knowing how my butt would do with lidocaine.

I used two gloves left over from last year, and spread the lidocaine on my butt. I put some ky jelly on my butt and smeared it on the dilator. In it went.

The lidocaine had no effect that I could tell. I got to within an inch of the mark on the dilator for which Dr. Singh had measured for insertion. The

dilator seemed to have hit a brick wall. Stricture. Knowing the pain that I felt when Dr. Singh did this, and not feeling any effect from the lidocaine, I was too much of a wimp to do it to myself.

Connie suggested that I try again. Will do, but won't look forward to it.