My Year with Cancer.

A Patient’s Story.

This was my worst year. I had four surgeries, five cycles of chemotherapy and seven weeks of radiation therapy to fight bladder cancer. I made the treatment choices based on reading technical medical journal articles, listening to advice from many healthcare providers, talking with friends, watching online videos and reading testimonials. What choices did I make and why? How much did all the healthcare cost? More than I thought.

Late September 2017 - First Indications.

I noticed a slightly ruddy color in my urine in late September 2017. I suspected blood in my urine called hematuria but what caused it? At first, I thought the blood was caused by the high dose of turmeric I was taking as an anti-inflammatory supplement. High doses of turmeric can cause blood in the urinary tract. When I stopped taking the turmeric about 1 week later, the bleeding stopped. I thought I was out of the woods, ‘in the clear’, and nothing serious was going on.

7 October 2017 – Second Thoughts.

On 7 October 2017; I noticed the blood in my urine again, called gross hematuria (and it was gross), had returned. I suspected blood leaking out of some organ – a kidney, prostrate, bladder, or somewhere else? Sometimes a clot or clump of blood would pass through my urethra and appear in the toilet bowl. It’s very disconcerting when that happens. Where is that stuff coming from? I started to get worried.

12 October 2017 – Primary Healthcare Provider Appointment.

By 12 October, blood in my urine was very noticeable. Not bright red but more of a good Paso Robles Zinfandel. Paso Robles produces some outrageous full-body Zins. At times, more clots would emerge; small but perceptible given the size of the conduit they pass through. Julie, my wife, said: “Welcome to my world”. I called the front desk of my internal medicine clinic on 16 October and told them I had blood in my urine and would like to see my primary healthcare provider, my GP; they scheduled an appointment promptly on 17 October. The clinic took both a urine sample and blood sample. My GP examined me for distended areas and thumped my back to check for kidney pain. No pain. He said blood in the urine could be caused by a tumor in the bladder or kidney stones. We needed more information to determine the cause like a CT scan.

After the exam my GP directed me to the computerized tomography (CT) office right down the hall in my clinic building. He said we also should have a urologist look at the results. He did not recommend anyone – just that a specialist should look at the results at the urology office in my hospital. It would be reassuring if he recommended someone, but I guess that’s against someone’s rules. No playing favorites. I walked down the hall with my prescription in hand and downstairs to CT office and made the appointment for the scan. The receptionist made the appointment for CT scan on Friday, 19 October. Plus, I got two bottles of barium sulfate to drink. Yum.

19 October 2017 – Computerized Tomography (CT) Scan.

I returned on Thursday, 19 October for the CT scan after drinking only one pint of barium sulfate. After I changed from street clothes into the 'johnnie', the technician, Mary, administered an IV tracer in my right arm and set me up for the CT scan. It took about 15 minutes and five passes through the 'tunnel of love'. That's the big, cream colored, donut shaped machine. Mary said some people experience a faint rush and have a metallic taste in their mouth. I did detect the metallic taste but experienced no rush. Mary said the scan looked 'good'. I tried to talk her up, but she was all business and no chit chat. I don't know what she meant by 'good', but I suspect it only concerns the clarity of the image and has nothing to do with a diagnosis.

After exchanging my clinic gown for my street clothes, I asked for and received a CD of the CT scans. I didn't know what to do with the CD or to whom to give it, but I thought it would be interesting to look at the scans on my computer. The CD had a built-in application executive file that launched when you clicked on it and displayed a torso view and two other images. I couldn't tell what I was looking at, but it looked interesting, I'm sure, to a urologist. Overall, the CT scan was a good experience.

20 October 2017 – Getting an Appointment with a Urologist.

On Thursday, 19 October, (the same day) my GP left a message on my smart phone and asked me to call the front desk at my internal medicine clinic. He said it was not urgent. Imagine, a GP calling me on my private cell phone! I wondered what was up. I called the front desk on Friday, 20 October, and they said he was out that day. I asked them to leave him a message to call me. He called me on Saturday, 21 October, and said the CT scan showed 1 cm kidney stone in my left kidney and a polyp in my urinary bladder. Drink plenty of water was the advice. He said to call the front desk and they would FAX the results to urology office in my hospital. I remember him saying 'looks like we caught it early'. I called the front desk at my clinic and told them to FAX my records to the urology office in my hospital. How difficult could that be?

I got the number for the urology office from my clinic and called them on Monday morning, 9 AM, 23 October, and asked if they had received a FAX from my clinic with my results. Stephanie said they had not received a FAX. I called Stephanie at the urology office again at 10 AM, 25 October, to ask if they had received a FAX from my clinic. No FAX received. I called my clinic and told Mary that the urology office did not receive the FAX. Mary replied, 'A FAX takes time' and told Liz to resend the FAX. My experience told me it takes about a minute but then this is the healthcare system you're dealing with. Is this rocket science? Apparently, it is.

I called Stephanie at the urology office in the PM, 25 October, to make an appointment. Stephanie recommended I call the other urology office since the hospital office didn't have any openings until mid-December. I thought about that and decided to call them again the next day. I called the urology office again at my hospital on 26 October, 10:48 AM and spoke to Linda. Linda said they had an opening on Thursday, 2 November at 1:15 PM for an appointment. That sounded a lot better than 6 weeks later in December, so I took that one. Couldn't someone say: "We know this is important and we'll put you on the critical wait list and you'll get the next appointment. Please call me back in the morning." I guess not. Maybe people in the same hospital office work in different time-space continuums. Persistence is everything.

I called my clinic on 26 October. They had no record of any FAX sent. I told them that whatever they were doing wasn't working after two attempts to send a FAX to the urology office at my hospital. Mary said: 'It takes time to get the information together'. I reminded Mary that supposedly they had sent the same information twice before and urology office did not receive either FAX. I told Mary I was going to help them. Long pause on the line. I told Mary that I would pick up the CT scan report (I had the CD with me) and other transcripts and hand deliver them to the urology office at my hospital which is 3 miles away. Long pause on the phone. Mary said: 'I'll put the materials in an envelope, and you can pick them up at the front desk.' So, I drove over to the clinic then over to the hospital and hand delivered my records.

I get a confirmation email message within one second from Amazon when I order a product; why can't a clinic do the same? My GP and other physicians admit interoperability is a serious problem. I explained the dropped FAX situation to my nephrologist who said: 'It happens all the time.' Now I admit that Amazon is a lot bigger than the entire healthcare medical industry and smarter but why can't healthcare providers transmit, receive and acknowledge a simple FAX? Sure, there are electronic protocols for analog and digital packet transmission and layers of encryption security, but Amazon does it. Why can't healthcare providers send and receive messages with standardized protocols in a secure digital environment? I can't believe it's a HIPAA issue either. I guess it's one of the mysteries of the universe.

I started to think about the problem, determined to help my clinic solve the problems of interoperability. So, for my wellness interview with the clinic, I presented the nurse with a four-page expose' about my experience and how to improve both interoperability and reduce 'human error'. I never heard back about my recommendations.

But then I thought about it some more. Why didn't someone say: 'Gee, we're sorry. We're going to look into the problem. Can you help us?' Then I realized no one goes to a clinic feeling on top of their game. No one steps up to the sliding glass window thinking they're going to buy a ticket to Disneyland when they hand over their insurance card and copay. They really would rather not have someone stick them with a needle, suck out blood and thrust a finger in their private parts. Look at the people working in the clinic office. Do they look like they're having the best day of their lives?

My lesson learned was to always make a confirmation call to the receiving office and ask them if they received a FAX for patient so-and-so from doctor so and so. Obviously, the receiving office has no idea a FAX was sent if it is not received. Don't walk away thinking everything is hunky dory; make the call. I remember asking if my clinic could call (using a phone) the urology office. Their response was they don't answer the phone for routine FAX messages. Maybe it is rocket science.

2 November 2017 – My First Urologist Appointment.

So, finally, I got an appointment to see a urologist at my hospital on 2 November 2017. He was very cool. A physician's physician. Honest with a warped, wicked sense of humor which I appreciated. Julie and I sat in his office at my hospital and listened to him first say, first, you have a cancer tumor in your bladder (polyps bleed, that's what they do) and second, here are the options. He sat right down next to us and spoke to us face to face.

The options ranged from not doing anything to chemotherapy to radical cystectomy to radiation to immunological therapy. Radical cystectomy is where they take out local organs that can become cancerous like your testicles, prostrate, all abdominal lymph nodes, seminal vesicles, and the urinary bladder. I told him: 'I'm not going to be a bag-man for the rest of my life'. I clearly was not going to have parts removed and spend the rest of my life emptying a bag of mucus and urine and carrying around containers of bleach, disinfectant, adhesive, patches, tubes and stuff.

He said I needed a resection of the tumor (scraping the site of the tumor in the urinary bladder). In addition to the tumor, the CT scans found a Filbert nut sized kidney stone in my left kidney. I had no pain in my back or pain 'passing stones'. But the CT scan found it. Amazing! He said his office would make an appointment for the 'procedure'. Really, it's an operation. Julie and I left the office quite satisfied with his assessment, patient skills, interpretation of the CT scan and his professional attitude. Our urologist made an appointment for the operation (to remove the kidney stone and tumor) for 10 November 2017.

So as far as I could determine the first step would be the procedure to remove the tumor and stone. The next step would be thorough biopsies to determine the extent of the cancer. The most likely next step after a biopsy would be chemotherapy. The chemotherapy would take several months. That would give me time to research alternatives and make up my mind about further treatment. After chemotherapy the two alternatives are either radical cystectomy or radiation therapy.

There is a healthcare principle as 'patient prerogative'. This means that the patient can decide what, if any treatment, they prefer. The doctor is responsible for discussing options with the patient, but it is the patient's responsibility to tell the doctor what course of treatment is preferred. A physician acquaintance told me that in 80% of the cases, the patient follows the course prescribed by the doctor. The 20% who don't accept the doctor's advice verbatim are usually engineers and they ask many questions and check the numbers. I was a human factors engineer for 34 years at a major aerospace company. I sure wasn't about to get carved up and left with bags of urine to haul around for the rest of my life. So, in my case, I decided to undergo chemotherapy and then evaluate the results of any biopsies, scans, and research into urinary bladder survival rates based on treatment options.

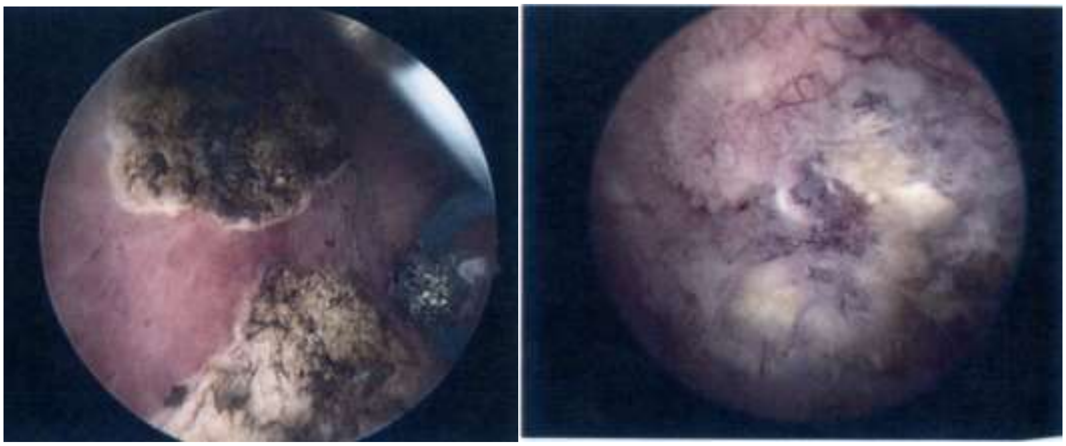
10, 11 November 2017 - First Procedure.

Things are happening a bit faster now. I got a call from Amanda from my hospital for a Friday, 10 November 2017 procedure at 11:30AM. Laurie and Diane at my hospital called to inform me of the admitting protocols and procedures for check in. Very thorough explanations. Shower with Hibiclens, put on clean bed sheets, don't sleep with the dog but you can sleep with your wife. Since the hospital must be flexible, the check in time was updated to 1 PM, Friday, 10 November. I would check in at 11 AM. My urologist would do the procedure.

The procedure is called a TURBT - transurethral resection of bladder tumor. TURBT is the first-line treatment to diagnose, stage, and treat visible tumors. It's a procedure in which bladder tumors can be removed from the bladder wall in the early stage of bladder cancer. During the procedure, a scope with a cutting device mechanism is inserted through the natural channel (in my case penis) into the bladder and then the tumor is removed. The kidney stone is blasted with a laser and the bits are removed with a spring finger flex grabber (or something like that). But only the pathology reports can determine the extent of the cancer. In other words, you may have a visible tumor, but it might be muscle invasive which means it's a Type II or higher type of cancer.

The anesthesiologist would supervise the anesthesia, along with his assistant, Adam. The whole pre-op procedure took about an hour to check in, wait for a pre-op cubicle, sign many forms, change into the hospital gown, etc. Bill, my nurse, was extremely polite, respectful, informative, and pleasant. The anesthesiologist's assistant administered the anesthesia in my left wrist vein. We talked for about a minute and the next thing I remember is waking up in my hospital, room 313. My penis was taped to my left leg with a Foley catheter draining my vital body fluids into a bag I couldn't see. Blue surgical thread protruded from my penis and taped to my 'meatus'. Meatus is a technical term. I felt safe but despondent. Then everyone starts to visit – nurses, doctors, volunteers, wife.

Below are two photos of the kidney stone and urinary bladder tumor. I don't know which the kidney stone and which is the tumor, but they all look very ominous and evil. The lens makes the stone and tumor look like planets in outer space! Nasty looking things!



The nurses who tended to me at my hospital (Lindsey, John, and Kate) were fabulous. The room was private with a large fold out sofa bed and wall-mounted TV. Each nurse signed-in onto the white board so you knew who was on staff. A nurse came in every hour or so to check on the collection of urine – amount, color, viscosity. Very considerate and thoughtful. The staff was extremely professional, respectful, polite, and attentive. Volunteers visited with a magazine rack and a ditty bag with stuff. Not all the right stuff for me but very thoughtful.

While not a travel destination, I enjoyed my visit to my hospital. Thanks to all the nurses, doctors, and assistants: Kate, Lindsey, John, Dante, Asahan, Alexandra, Julie (pre-op), Amy, Melissa (ultra sound tech), the anesthesiologist and Adam (anesthesiology), clean up people, my urologist, Steve (the stick man), Mike (transportation), cafeteria staff, volunteers.

The food was tasty and easy to eat. I had chicken stir fry and vegetable soup for dinner and scrambled eggs and oatmeal for breakfast. The bed was very comfortable with a rather firm mattress. I slumped in the bed because the coefficient of friction between all the layers of linens is low. The slumping is compounded by the Foley catheter sticking out of my dick which makes adjusting the body position a bit difficult and painful. Maybe a briefing by hospital staff about how to painlessly adjust your body using the built-in bed handholds would make the stay more tolerable. Imagine having to learn how to use a hospital bed! I did send the CEO of my hospital a detailed four-page critique of the service, amenities, hospital room arrangements and how to improve any patient's stay at the hospital. Never heard back.

When I woke up in the hospital bed, calf muscle stimulators were squeezing my lower leg muscles to stimulate blood flow. A good idea to prevent thrombosis but it's annoying especially when you try to sleep. Although you might have an exercise physiologist visit you once, why not provide an entertaining, interesting, fun CCTV program that shows some cool movements (not exercises, no one likes to exercise) for the feet, legs, hands and arms. Tell people if you don't do this, then you will die. Why be shy? And have kids and old people in the video; why is everybody so perfect looking in these videos?

It's terribly boring and sometimes lonely laying immobile in a hospital bed with a Foley catheter sticking out of your you-know-what. There's not much to do. Why not have a hospital channel with tours of all the great things going on? Take a video tour of the cancer center, the da Vinci surgical system, the radiation center, diagnostic imaging, a gift center, the cafeteria, cancer support services, an orthopedics center. Meet doctors and nurses and staff. Listen to senior leadership talk about what's important to them at the hospital. This video could be filmed and edited by the local university speech, hearing and communication school. They'd love to contribute something to the local community. They might even do it for a modest contribution. A typical focus area is 'Science, Environmental and Health Communication'.

Hospitals have a captured audience with patients in bed. Give patients something to do and take their mind off their pain. How about some fun stuff like learning how to play a harmonica or how to make an awesome paper airplane? Show how to play the harmonica on your hospital CCTV channel. Include a 50-cent harmonica in the ditty bag. Breathing is very important to prevent lung congestion; learning to play the harmonica in bed will help. Give the patients some paper and a pencil and teach them how to make an awesome paper airplane complete with passengers, pilots, and engines. What else are you going to do? Stare at the door hoping someone comes in? It's terribly lonely at times.

I was discharged from the hospital after an overnight stay to remove the kidney stone and urinary bladder tumor.

12 November 2017 - Side Effects of Surgery and Hospital Stay.

No one tells you how constipated you'll be after general anesthesia, pain medication, and IV antibiotics. Once discharged, I got up every 30 minutes or so at home to pee and walked around the house for two-to-three hours at night for two nights because of the pain. Only after the second day did I take some stool softeners and anti-constipation OTC medicine. It took about 24 hours to finally get rid of the intestinal pain. Maybe the hospital discharge could include some take-away stuff like a couple of packets of MiraLAX.

14 November 2017 – Post operation Urologist Visit.

We met with my urologist on 14 November to remove the stent. I don't know which was more painful – having the tape ripped off my dick that held the surgical thread in place or having the stent thread removed. I huffed and puffed and screamed a bit during the process but much relieved when it was over. The stent thread measured 6 feet from tip through the urethra, bladder, ureter and into the left kidney; at least it felt that long.

28 November 2017 – Urologist Post Procedure Consultation.

On November 28, 2017, Julie and I visited with the urologist to discuss the results of the procedure and the next step. I remember his saying the procedure went well with no complications. He scraped extra amounts of suspect cancerous cells around the main tumor site just to be sure. The kidney stone removal went well. He used a laser to excite energy into the stone to explode it and then used a tiny, tiny basket to remove the parts. Both the tumor and stone would be analyzed for content, cancer type, etc.

It seems I had a small cell, neuroendocrine tumor with blue green cells. Less than one percent of bladder cancers are small cell, neuroendocrine with blue green cells. The rarity did not displace my feeling of uncertainty and doom.

If I heard it once, I heard it a dozen times: “radical cystectomy is the gold standard”. Every doctor said that. Of course, most of the doctors we talked to about treatments were surgical oncologists or urologists. So, that’s what they do – they cut. I’d tell them that I don’t care who’s standard it is, you’re not going to cut me up. They were great about describing the operation complete with diagrams and drawings but not the life changing impact. They don’t talk to you about the downside. One person said if they told you about the downside you might not elect to do the surgery. Why can’t healthcare providers treat patients like adults? Only a substitute radiation nurse told me at one time that radical cystectomy is a life-altering, life-changing, never-be-the-same-again event. I guess like having children, losing your job or dying.

After hours of research reading online medical journal articles and watching many You Tube videos, I understood that the patient has options that can be successful without surgery. Some of my sources were: cancernetwork.com, medicinenet.com, National Center for Biotechnology Information (NCBI), Cambridge University Hospitals, cancer.org, Cancer Council Victoria, National Comprehensive Cancer Network (JNCCN), and hindawi.com. I chose only articles that were published after 2015. I’d read them twice or more to understand them. One conclusion was that for my type and stage of cancer, the survival rate between radical cystectomy and chemo/radiation therapy were within a margin of error of 5%. And no survival rates were projected beyond 3-5 years. Clinical healthcare providers hedge their bets and keep it conservative.

Here is an example of a medical journal article and conclusion about my type of cancer.

“Neuroendocrine tumors rarely occur in the urinary bladder. They can be carcinomatous, subdivided into small cell and large cell pathology. Small cell carcinoma of the bladder is a rarity that may present at an advanced pathologic stage. No treatment regimens have been standardized for local or metastatic disease. Review of the recent literature shows equivalent survival data for localized disease treated with chemoradiotherapy combined with either bladder sparing surgery or radical cystectomy. Patients with significant comorbidities are an additional challenge. We report a case of poorly differentiated neuroendocrine tumor of the bladder, which could not be classified as small or large cell carcinoma, complicated by significant comorbidities. After management with transurethral resection of the tumor, adjuvant chemotherapy, and radiation, the patient is alive and asymptomatic nearly 1 year after initial TURBT with no evidence of disease recurrence.”

Halleluiah. What healthcare providers don’t tell you is that cancer can manifest itself in other sites like the lymph nodes or cerebellum. An annual PET scan for cancer survivors is a better diagnostic and it costs less than the surgery.

5 December 2017 – Deep Biopsy Procedure.

After the procedure to remove the tumor and stone, the next step required performing deep biopsy of sites in the bladder to assess the extent and depth of the cancer. On 5 December 2017, 2:30PM, I signed into my hospital for the procedure. My hospital admissions procedure is well organized. You inform the visitor desk that you're there for a procedure. They check your name and date of birth (heaven forbid you forget when you're born) off the list and one of the volunteers escorts you to the waiting area where another staff person double checks your name and date of birth and checks you off the list. You're invited to take a seat in the waiting room. A nurse assistant calls out your first name (to protect your identity) and escorts you to the assigned bed and cubicle. You have a bag with your 'johnnie' on the bed and instructed to remove all clothing, put on the johnnie and lay down on the gurney bed.

The deep biopsy performed on 6 December required a 3-day (2 nights) stay at my hospital. Their analysis determined that there was no muscle invasion identified. "The muscularis propria is present and negative for tumor". Sounded great. There was marked acute and chronic inflammation (which was expected because my urologist scraped out of my bladder). I remember him saying he went extra wide on the resection because he saw some peripheral areas around the primary tumor that might be cancerous. He was very thorough in his surgery. However, there was a complication caused by the proximity of the biopsies near the opening of the right kidney ureter into the urinary bladder. That swelling blocked the ureter from draining fluid from the kidney into the bladder. My creatine level was elevated, and I was close to renal failure. So, my urologist requested the advice of a consulting physician and a nephrologist. Good idea.

6 December 2017 – Nephrologist Consultation.

A nephrologist was called in to assess the involvement of the kidneys both the one that contained the stone and the right kidney. Since I was near renal failure, the doctors considered puncturing the kidney to allow it to drain until the swelling could be reduced and I'd have to stay an additional day. I was not happy to hear that another operation and perforation of my wretched body might be required. However, my lovely wife, Julie, bought and fetched water bottles so I could avoid it which I did. The anti-inflammatory drugs administered by IV helped, too.

19 December 2017 – Urologist Visit

Another visit with my urologist in his office. One of many.

2 January 2018 -Tumor Board Meeting.

The cancer conference, also called the 'tumor board', met right after New Year's Day. The board is composed of oncologists, nurses, therapists, urologists, technicians, and other doctors. They reviewed my case and based on the hospital pathologist report, they recommended 3 cycles of chemo therapy. Each cycle is 3 days. The first day is Cisplatin plus Etoposide; the following two days are Etoposide only. The platinum-based chemotherapy can be administered either by a ‘port’ on the shoulder or by infusion through a vein in the arm. I chose vein infusion to begin with since I thought it would only be three cycles. You get about 2 liters of fluid pumped into your body. Where it all goes, I don’t know. Each cycle is administered at intervals of three-to-four weeks. I chose infusion by needle rather than port.

9 January 2018 – First Medical Oncologist Visit.

We met with my medical oncologist on 9 January 2018 in my hospital’s Oncology Center. I don’t know how we were paired. Maybe the oncologist attended the Tumor Board and volunteered. Maybe the oncologist was next in line for a patient like when you walk into a car dealership or furniture store. We had a long (45 minute) visit. The oncologist explained emphatically that the only good course of treatment was radical cystectomy. Somehow, I felt the oncologist was jumping to conclusions. One good thing the oncologist said was: “I’m putting you on the launching pad for chemotherapy”. That meant I would get treatment very quickly right there in my hospital’s Cancer Center and I’d have time to consider the alternatives. The oncologist offered a pass for medicinal marijuana, but I declined; I didn’t want to become a doper or even dopier than I was.

It’s a new cancer treatment facility on the first floor of my hospital. It’s easy to navigate with the treatment area right off the main reception area. Several nurses greet you right away. It’s a clean, well-lighted place. The infusion area is open with a central nursing area surrounded by 12 or so individual private booths for infusion. The oncologist ordered a PET scan.

10 January 2018 – First Nephrologist Visit.

My nephrologist, the kidney guy, was very cool. We had a great visit about my condition and how he evaluates patients. He looked at my fingertips for blood flow, tested my reflexes with the ‘thumper’, looked at my outstretched arms for wobbles (which infers something about your filtration system, but I’ve forgotten), and asked me about the color of my urine.

He’s experimenting with using Sherwin-Williams paint color chips in a paired comparison test to evaluate patient’s urine color. Patients are presented with two color chips and asked to choose which color is closer to their color – like getting an eye exam for glasses. If your urine is this color yellow or that color green, then he can home in on what’s going on with the kidneys. Since people are not so good at absolute judgement but better at paired comparison, showing people colors rather than asking them to recall a color helps him decide what’s going on with your body filtration. Very cool. We liked him. He’d make a good GP.

15 January 2018 – Another PET Scan.

On 15 January I went for my first Positive Emissions Tomography (PET) scan in the mobile PET scan facility that arrives every Monday morning at my hospital. A PET scan is an imaging test that allows a doctor to check for diseases in the body. The scan uses a special dye containing radioactive tracers injected into a vein in the back of my hand. I hate that. Lou and Jess run the lab. It’s in a mobile trailer that travels from hospital to hospital, but you don’t know it’s a trailer until they open the doors and the cold air rushes inside. I sat in the small waiting area for a few minutes while they finished up with the previous patient. Lou administers the tracer in the back of my wrist (which I hate!) and then it's into the 'tunnel of love' for the PET scan. The entire process took about an hour.

The results of the PET/CT scan: "No evidence by PET/CT scan evaluation for metastatic disease in this patient with known bladder cancer."

Hallelujah.

16 January 2018 – Dana Farber – Second Opinion

Now here's the kicker. My hospital pathology report stated no muscle invasion. But everyone we talked to recommended getting a 'second' and even a 'third' opinion. On 10 January 2018, I called Dana Farber Main Campus number, 617-632-3476, for a second opinion on cancer treatment as recommended by my oncologist.

I was referred to New Patient Coordinator at 877-442-3324. When I called that phone number the receptionist asked what type of cancer. I told her bladder cancer. I was referred to 'Kristen', Dana Farber New Patient Admission, Genitourinary Clinic, 617-632-2682. I told Kristin that I was referred to Dana Farber by my oncologist at My hospital in Wakefield, Rhode Island. I provided my Medicare Number and AARP United Healthcare Plan N identification to the admissions recorder and received a medical record number. You must write down all the phone numbers. Otherwise, it's like passing 'Go' without collecting $200 and you must start all over again.

During the phone call, I requested that my PCP and urologist be informed of the results of the second opinion. I explained the situation was small cell bladder cancer with neuroendocrine features and blue cells. This is regarded as an aggressive cancer although no one really has a valid definition of what 'aggressive' means. Does that mean it spreads in a week or a month or a year? Who knows?

I told my oncologist that we scheduled an appointment at Dana Farber and that they recommended sending them the pathologist report, slides and any imaging. The hospital health board recommended a PET scan, Monday, 15 January, 8:15AM at my hospital.

During the call to Dana Farber I explained that I had the operation to remove the kidney stone and bladder tumor on 10 November. I explained that the hospital cancer conference, on 2 January 2018, recommended 3 cycles of chemo therapy. Each cycle is 3 days. First day is Cisplatin. Next two days are Etoposide. At intervals of 3-4 weeks. Kristen recommended continuing with the prescribed treatment right away.

I made appointment at the Genitourinary Cancer Treatment Clinic with a Surgical Urologist, for Thursday, 23 January at 4 PM. We were instructed to arrive at 3:15 PM to check in. We followed the signs to Valet service on Jimmy Fund Way. The valet service takes your car and directs you to Concierge service to check in on 2nd Floor registration. Our appointed surgical urologist is on 9th floor.

Dana Farber is all business. They know how to process a lot of patients very quickly. All along the way there were people directing you to the next station. There was a CD drop off station. There was a new patient desk. Dana Farber is very efficient.

Our surgical urologist spent an exact total of 15 minutes with us. He explained that the radical cystectomy results in an increase of 30% in stroke probability, 6 -10 days in intensive care to recover, and that this type of surgery is second only to complications of open-heart surgery. Open-heart surgery is the most complicated surgery. Oh, and the readmission rate is something like 60%. That means that there will be distended bowels, bleeding, nerve damage, infections, etc., that require you to return to the hospital for additional surgery for up to 3 additional weeks. Then he got up and left the room.

Now this is where it gets a bit hairy. Brigham and Women's Hospital performed a pathological diagnosis. According to their records, the 10 November 2017 biopsy reported 'poorly differentiated neuroendocrine carcinoma (small cell) associated with high grade urothelial carcinoma with glandular differentiation'. 'Tumor invades the muscularis propria'. Now, after the TURBT procedure on 5 December 2017, the biopsy slides showed: "No invasion is identified. Negative for tumor. Marked acute and chronic inflammation." Thus, it appears that there was some muscle invasion of the cancer into the wall of the urinary bladder. But the TURBT procedure removed the invasive part.

17, 18, 19 January - Chemotherapy - Cycle 1

My oncologist worked out the following chemotherapy schedule. It called for six cycles; each cycle lasts for three days. In my case, each cycle starts on a Wednesday and finishes on Friday. Each daily session takes about five-to-six hours. Each session starts at 8 AM and ending sometime around 3 - 4 PM.

The oncology clinic gives you a nice 3-ring binder full of stuff about their wellness and rehab program, how to manage fatigue, local support groups, massage and Reiki therapy (right there in the clinic!), chemotherapy, financial advice, nervous system changes, urinary and bladder changes, and hair loss. Really, the least of my worries was hair loss. In retrospect, the biggest problems were anemia, fatigue, hearing loss, 'wobbly' walking, loss of balance, breathlessness, temporary blindness and vomiting. And feeling just wretched. Words cannot convene these side effects. The hair loss would be my 'red badge of courage'; I liked the idea of emulating Stephan Crane.

I had no idea what to expect with the first clinic visit. We bought a spiffy mail pouch I could bring stuff in like an iPad, phone, a book, some sanitary wipes, a couple of magazines, some tums and lozenges and tissues. Just odds and ends that I might need to pass the time. Each cubicle is furnished with a flat screen TV with remote control. The reclining chairs are very comfortable. To raise a blood vessel in your arm for infusion, they wrap your arms in several layers of warm towels. They make you very comfy. The chemo pump with IV drip is off to one side depending on which arm you chose. If I had to do it again (and I surely do not), I would choose a port instead of vein infusion. Basically, I didn’t like the idea of another hole in this old, tired body which could get infected which they can.

Each session is a cocktail of drugs. The first drug (as I remember) was Decadron which is an anti-inflammatory. I’d get Aloxi to prevent vomiting (always good). I’d get Emend to stop stomach upset and vomiting. And then I’d get a bag of Cisplatin which is an antineoplastic agent to treat the cancer. This bag was followed with two bags of Etoposide, also, an antineoplastic agent (topoisomerase inhibitor). Steven was my nurse. We got along well but after a while I didn’t feel the love; he couldn’t find a vein, so I’d ask for Kathleen who had ‘the touch’. Towards the end of the cycles, finding a vein got tougher and tougher. Cisplatin destroys the walls of veins and they don’t recover. So, I’m stuck with ‘soft’ vein walls for the rest of my life. They don’t tell you that in the handouts.

Julie sat with me through every single session unless she had some very critical errand to run. My friend, David, sat through a couple of sessions and treated me to a DeAngelo’s mushroom and steak sandwich which was much appreciated. Thank you, David! During one of the sessions, my hot medical oncologist stopped by. David said: “Your medical oncologist is very attractive.’ I said: ‘David, you’re not allowed to say those kinds of things anymore’. His reply: ‘I can if they don’t hear me’.

It was comforting to have someone there even if they’re on their smartphones or reading or whatever. Many patients had companions; some were alone. I felt sorry that they were there alone. Sometimes I’d be the last one out at 4 PM after starting at 8 AM. That’s a long day. But there’s always something to eat or drink for the asking. Mostly soft drinks and juice, no beer or wine which might liven things up.

7, 8, 9 February 2018 - Chemotherapy - Cycle 2

The second chemotherapy cycle started a short three weeks later. By the third day after treatment, I started to feel the hammer after the good drugs wore off. I started to feel run down; my oncologist offered a B12 shot but I declined. I didn't want to be punctured again and wanted my body to 'fend for itself' which sounds ridiculous since the chemotherapy is basically poisoning my body with lots of chemicals anyway.

During one of our meetings with my oncologist, we discussed bladder sparing and surgery. Again, like other surgeons, my oncologist said radical cystectomy is the gold standard, but I didn't care about the gold, silver or bronze standard. I told my oncologist that I wasn't going to be a bag man for the rest of my life. The oncologist replied: "Lots of people wear urostomy bags. Even prostitutes put glitter on their bags." I replied: "Do I look like a prostitute?" Re-certification for medical oncologists should include a session of sensitivity training and communication skill development.

16 February 2018 – First Radiation Oncologist Visit.

My hospital Radiation Center has a resident radiation oncologist who is their medical director. Julie and I interviewed him on 16 February; it was our first visit since I'd decided not to mutilate my body with a radical cystectomy. He was quite professional and polite. The staff including the reception office personnel and Nurse Patty were very respectful and understanding. The medical director explained how they do radiation therapy and we received their brochure that explains several types of radiation therapy available at their clinic. The clinic is clean and modern and well organized. There's an outside waiting area and then inner waiting rooms for privacy and then you're escorted into the radiation chamber.

We had several questions for him; like, is radiation effective against small cell endocrine featured cancer? He replied: "Yes, very effective." Very encouraging to hear that. One question a physician said I should ask the radiation oncologist was: "Am I crazy not to have radical cystectomy?" He thought that was an odd question. It's good to get a different perspective on treatment. It is still a mystery how they calculate dosage level, angles, beam width, intensity, duration, etc.

I emphatically told my medical oncologist, my urologist, and my nephrologist many, many times that I was not going to submit to radical cystectomy. Here's the catch; radiation therapy is supposed to include lower level of cisplatin chemotherapy every week for as long as you have radiation treatments. That is at least five weeks and maybe more. Since the five cycles of cisplatin chemotherapy (fifteen infusions) proved very destructive to my general well-being, I told my oncologist and radiation oncologist that I was not going to have additional cisplatin treatment. They'd have to do something else. I don't know what they planned but I trusted them.

24 February 2018 – A New Car.

In celebration of having cancer and suffering through two months of chemotherapy, I decided to get a new car. So, I traded in my 2007 Nissan Murano and purchased a new 2018 Nissan Murano. Since I already knew where all the controls were located on the dashboard, steering wheel, and any other location Nissan could hide a control, I thought 'why change now?'.

I was suffering from the effects of chemotherapy – extreme fatigue, nausea, dizziness, and generally feeling wretched. But the Nissan salesperson was very sympathetic and prevented me from suffering through a four-hour sales pitch for this feature and that warranty. I told him I could not be in a closed office since my immune system was so compromised. If I got a cold or flu, I'd probably die and not purchase the car. So, he did all the negotiations; all I had to do was sign on the dotted lines and it was a done deal.

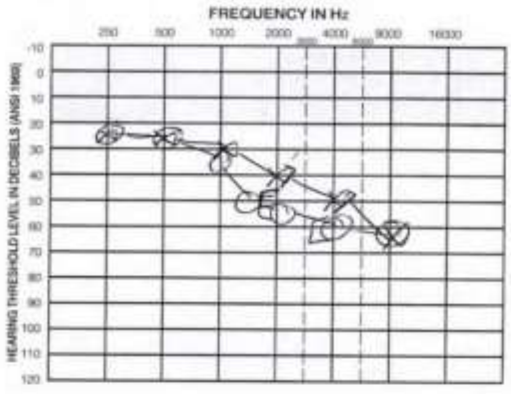
I filled out the post purchase questionnaire thanking Eric and Speedcraft for their compassion and understanding but nicked them on not acknowledging potential customers who sit in their waiting rooms for service or other appointments. Julie and I walked out of the show room one time since no one said 'Hello, can I help you?' or acknowledged our presence in over 20 minutes. I got the feeling we were invisible. I conveyed my invisible experience to the regional Nissan vice president in the post-purchase questionnaire. Now, whenever I take my new car in to be serviced, the Speed craft general manager says 'Hello, how are you doing?" while I'm sitting in the waiting area. A little honesty goes a long way.

28 February - 1, 2 March - Chemotherapy - Cycle 3.

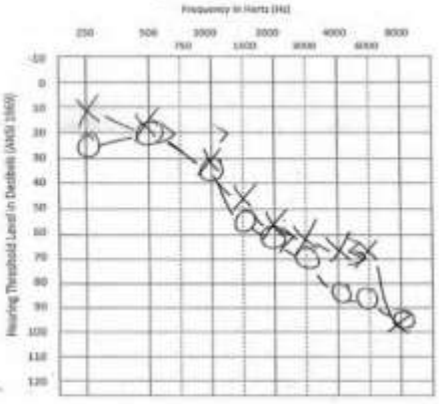
It was about this time that I realized I'd lost my hearing. During one of the in-hospital meetings with my oncologist, I mentioned that I thought my hearing was much worse because the cisplatin had destroyed my otoliths. Otoliths are tiny hair cells responsible for hearing and equilibrium. The oncologist replied: "You probably had poor hearing to begin with." The oncologist should have said: "Hey, let's by scientific about this and get an audiogram; then we can see what's going on with your hearing. I recommend the audiology department at our local university." A hearing exam (audiogram and articulation index) costs about $100 at the local university. Cheap. It would help if healthcare providers reached out more often to other resources and not jump to conclusions based on age, sex or whatever.

Fortunately, I had before and after audiograms of my hearing. You can see my hearing went from a moderate loss (without hearing aids) to a profound loss. I lost about 60 dBA of hearing at the higher frequencies (above 3,000 Hz.). I went to the local university Speech and Hearing Center for the post cisplatin test and audiogram. The audiology professor was extremely polite, understanding, efficient and cost conscious about my hearing assessment and advice. I spent $4,000 for a pair of Widex 'Evoke' Behind-The-Ear (BTE) hearing aids. Medicare and my supplemental do not cover hearing aids.

Pre Cisplatin December 2014



Post Cisplatin March 2018



21, 22, 23 March 2018 - Chemotherapy - Cycle 4

I really don't remember much about this cycle other than the first two days after treatment are great then the anti-nausea drugs dissipate and the hammer hits you. I would sleep 20 hours a day for 3 -4 days then be extremely tired and sick for at least a week. Then there'd be a week of feeling less-than-good, and then a marginally good week before the cycle repeats.

26 March 2018 - Emerson Hospital Appointment

A friend recommended going to see a urologic surgeon at Emerson Hospital outside of Boston for a third opinion. Even though I was in the middle of a 'chemotherapy fog' after my recent 21 – 23 March cycle 4 chemotherapy treatment we thought it best to get another expert opinion from a recommended source.

After some polite introductions, the doctor proceeded to describe the various types of surgeries: an illeal loop conduit, an orthotopic neobladder, and a continent catheterizable pouch. He depicted each type of surgery in big drawings on the pull-out wax paper you sit on in the examining office. He examined my lower abdomen and traced the incision from my belly button to the top of my sexual organs.

Rather than use robotics, he liked to get his hands inside my body and on the internal organs to see and feel the lymph nodes, bladder and prostate glands which would be removed. He didn't mention my 'seminal vesicles' but the literature says those are removed, too. He mentioned there's a hotel across the street where Julie and Mr. Darcy, our doggy, could stay if she wanted to be nearby; I'd be in Emerson Hospital for at least a week, maybe more.

We both liked him; he was quite polite and professional. Our interview took about 45 minutes. We left knowing a lot more about the intricacies of anatomy but not relieved about alternatives other than radical surgery.

11, 12, 13 April 2018 - Chemotherapy - Cycle 5.

It was about this time that I temporarily lost my vision. I remember the exact circumstances. I had put out a couple of empty firewood racks on the curb for ‘recycling’ when my neighbor, Gene, stopped by and asked if he could have them. I said sure! So, we got to chatting about this and that. Gene is a good talker; difficult to get a word in edgewise. We talked over the fence for a few minutes. Gradually, his body disappeared, and everything went white. All I could see was his face floating in front of me. I felt wretched. I said: “Gene, I don’t feel well; I’m going inside.” He said: “OK, I’ve got your back!” We were fraternity brothers 45 years ago; 45 years later he’s still looking out for me. So, I slowly trudged up the slope of lawn, got inside the solarium, sat down and vomited into my hands, the sink and finally the toilet. I had such a real sense of morbidity and death it was very disturbing. I said: “That’s it!” I decided to discontinue the chemotherapy. It was killing me.

The next day Julie took me to the cancer clinic for blood tests and a four-bag infusion of magnesium plus two units (bags) of blood. My magnesium level which caused my hallucinations was zero. I was severely anemic. That treatment took six hours. Did you know that receiving blood through a vein hurts like hell? It does.

The five cycles wrecked my body so badly that I told the oncologist and nurses that I was stopping treatment. After I told the oncologist what happened with losing my vision, vomiting, etc., the reply was: “You did the right thing.” I was flabbergasted. My rationale was that if five cycles hadn’t killed all those nasty little cancer cells, then one more cycle wouldn’t make any difference. I was wretched by this time – pale and gray, tired, suffering from vertigo, extreme fatigue, vomiting, hearing loss and weight loss. I had neuropathy in my fingers and toes and a continuous ‘chemo fog’ where you really can’t think very well and don’t feel like thinking that much because you don’t care. I was profoundly deaf; that’s the official audiological term since cisplatin is ‘ototoxic’. The veins in my arms and hands were collapsed and the blood vessel valves were blown.

My whole problem with these side effects is that healthcare providers know about them but don't take steps to mitigate them like prescribed metabolic supplements to promote magnesium absorption or vitamin B-12 supplements for iron deficiency. There's a supplement called 'Natural Calm' that you mix with water. The label says: 'balances your calcium intake and restores healthy magnesium levels'. Now why is it so difficult for a healthcare provider to recommend an inexpensive, over-the-counter supplement to replenish vitamin and mineral deficiencies caused by chemotherapy? Don't they teach that in med school?

Every visit to the medical oncologist involved a blood draw by a 'vampire' nurse. I'm not making that up – that's their official nickname. Can't healthcare providers predict what might happen in terms of blood chemistry and prescribe an inexpensive supplement or drug? Yes, chemotherapy included a dietician and wellness interview at every cycle but why not include a preemptive mitigation of the debilitating, soul-crushing, mind robbing side effects? Just tell people here's a prescription for such and such which will promote calcium uptake or iron retention or whatever.

21 May 2018 – An MRI Brain Scan.

I experienced severe nausea, dizziness, and vertigo during the chemotherapy; it's one of the know side effects of chemotherapy. During an oncologist visit, the oncologist discovered I might be suffering from positional nystagmus. This condition was detected by my rapid lateral eye movements. To rule out some other cause like a brain tumor, my medical oncologist recommended a cranial MRI. This is the loud 'whack, whack, whack' MRI exam but with the help of some good ear plugs it didn't bother me. Nothing serious found – no tumor or other serious issues.

15 June – 14 August 2018 - Radiation Therapy.

I started radiation therapy about eight weeks after the end of chemotherapy. In my case and because I chose the local Radiation Center, I received Intensity-modulated radiation therapy, or IMRT, which is a type of cancer treatment that uses advanced computer programs to calculate and deliver radiation directly to cancer cells from different angles. It allows people with cancer to receive higher, more effective doses of radiation while limiting damage to the healthy tissues and organs around it. This increases my chance for a cure and lessens the likelihood of side effects. Fantastic technology.

Thank goodness I choose radiation therapy instead of radical cystectomy. For me, it was painless compared to chemotherapy. My radiation oncologist told me there could be side effects, but I didn't suffer any. Radiation therapy was a cake walk. The treatment took place at my hospital's Radiation Center adjacent to the hospital. The radiation oncologist and nurse were excellent. The technicians and nurses and staff were excellent. After an interview with the radiation oncologist and nurse, you get a 'positioning' CT scan to determine the exact location of treatment, in my case the urinary bladder, right there in the center. Excellent.

The technicians mark your body with locators – first, with temporary stick-on markers and then with a ‘tattoo’. It’s just three small dots the size of a pinhead; one on my belly and the other two on either side of my hips. So, I got my first tattoo! I wanted a skull but that wasn’t one of the options.

To precisely target the tumor, my legs were fitted with a temporary cast based on the positioning CT scan. The cast positions my legs and torso in the exact same position over the seven weeks of treatments. My body cast was stored in the treatment room.

Each session took about 15 minutes. The intercom played Bob Seger music or other appropriate age-level music during the therapy. In my case, I’d get up on the table and lie on my back with the help of the technicians. Then, discretely, I’d lower my pants and underwear under a clean towel they provided to expose the treatment area which was my very lower abdomen down near my private parts. Everything they did ensured privacy and comfort. Then the technicians would align the treatment beam with the tattoos and leave the room, closing the foot-thick radiation proof door behind them. The music would start, and the treatment head would rotate 360 degrees around my abdomen stopping every 60 degrees or so. At each planned angle the treatment head would stop, I’d hear the whine of the energy, and see the lights dim ever so slightly. Creepy but very reassuring that the machine was working.

Radiation therapy the first five weeks was administered with an empty bladder; the last two weeks of seven were administered with a full bladder or as full as you can manage without peeing on the table. Depending on who I talked with about the beam width, intensity, etc., the first phase treated the abdominal area or the bladder itself. The second phase of two weeks treated either the bladder itself or the tumor. Since I opted out of additional cisplatin treatments during radiation therapy, my oncologist thought the extra two-week sessions were added insurance to eradicate any traces of cancer. I did experience occasional bloody diarrhea for three-to-four months but an infinitesimal price to endure for an otherwise painless, non-invasive, rather pleasant treatment. Often, I’d find myself drifting off to sleep while undergoing radiation treatment.

The following photos show the Varian Clinac 21EX that is used at my radiation center. It’s an amazing machine with big arms extend out and move all around you as you lie on the table.

In conclusion.

Follow-up meetings with my medical oncologist and urologist ended with ‘looks like the chemotherapy did its job’ which I interpreted to mean the cancer is gone or in remission or dead. You’re never sure but the last procedure confirmed that the bladder wall contained only ‘pre-carcinoma in situ’ which sounded pretty good. But who knows? The protocol in my case is ‘procedures’ (cystotomy) every three-to-six months.

Throughout this entire year, Julie and I received many, many cards, emails, books, and phone calls offering prayers, encouragement, advice, caring sentiments and an occasional bottle of vodka. When people heard about the diagnosis of cancer and treatments, they did not hesitate to offer help with yard work or stuff around the house. It was truly unexpected yet amazing how many people offered help. Whenever I’d walk Mr. Darcy around the neighborhood, people stopped and asked how I was doing and if they could do anything. We did have a fabulous ‘End of Treatment’ party to celebrate. Very festive with lots of wine, cards and vodka.

I was curious about how much all these procedures, treatments and visits cost, so I registered with Medicare.gov. It took only a few minutes to complete the online forms. I receive hard copies of both AARP and Medicare charges but liked the online records better. You can point and click easily to see detailed charges. What Medicare charged and what AARP said they charged agreed most of the time; the difference was only a few dollars or cents.

Only with one provider did I see a triple charge on the same day for the same amount; maybe it had to do with delivering anesthesia during a procedure. The same anesthesiologist name appeared on the Medicare bill although that person was not present with my urologist during the pre-op briefing. I received robo calls and text messages from the same anesthesiologist to rate that them which I found annoying. I included only one charge for that procedure in the consolidated table.

To make things a bit more difficult to understand, Medicare was billed for five chemotherapy cycles, but the charges for cycles three and four were joined across two monthly billings rather than by the discrete time period for each cycle which was three days. I was amazed at the cost of radiation therapy since I paid only $20 for the entire seven weeks of treatments. I wanted to pay $20 a visit but Maureen, the receptionist at the desk, said it wasn't necessary.

The following table consolidates the Medicare billing submitted by my various healthcare providers. The categorization is somewhat arbitrary but helped me organize the charges. They include: primary care provider, consulting physicians, labs, exams, pathologists, radiologists, oncologists, urologists, nephrologists, hospitals and clinics. In the left column is a terse description of the service and what Medicare was billed. The middle column shows what Medicare paid and then the right column shows the percentage paid by Medicare of the original billed amount.

Item	Medicare Billed	Medicare Paid	Percent
Exams, MRIs, etc.	$14,412.00	$3,587.94	25%
Radiation therapy	$104,461.54	$19,216.36	18%
Chemotherapy	$46,911.24	$10,641.26	23%
Oncologist visits, tests	$5,777.00	$1,214.78	21%
Specialist visits, tests	$4,864.51	$1,140.23	23%
Urologist visits, tests	$3,063.50	$909.35	30%
Procedure #1 (11/10/17)	$28,558.00	$7,773.20	27%
Procedure #2 (12/5/17)	$13,288.00	$4,088.82	31%
Procedure #3 (6/12/18)	$13,371.54	$2,237.18	17%
Procedure #4 (10/24/18)	$7,723.00	$1,728.60	22%
Total	**$239,147.33**	**$52,536.72**	**22%**

Healthcare providers who take Medicare patients are getting 25 cents on the dollar. That's like me giving the checkout clerk a dollar bill for a four-dollar loaf of bread. It doesn't make sense to me but that's the system. This table doesn't show what Medicare approved which is more than what Medicare paid. Why do we have such big differences between the amount Medicare is billed by the provider, what Medicare approved and what Medicare paid the provider? What is fair compensation for medical services? Should FICA payroll employee and employer contributions increase 400% to pay for Medicare? Can we make a FAX work 100% of the time? Can healthcare providers be honest with their adult patients? I guess these are some of the mysteries of life.

P.S. My fifth operation and biopsy showed absolutely no trace of cancer in my urinary bladder; not even pre-carcinoma in situ like the previous biopsy.