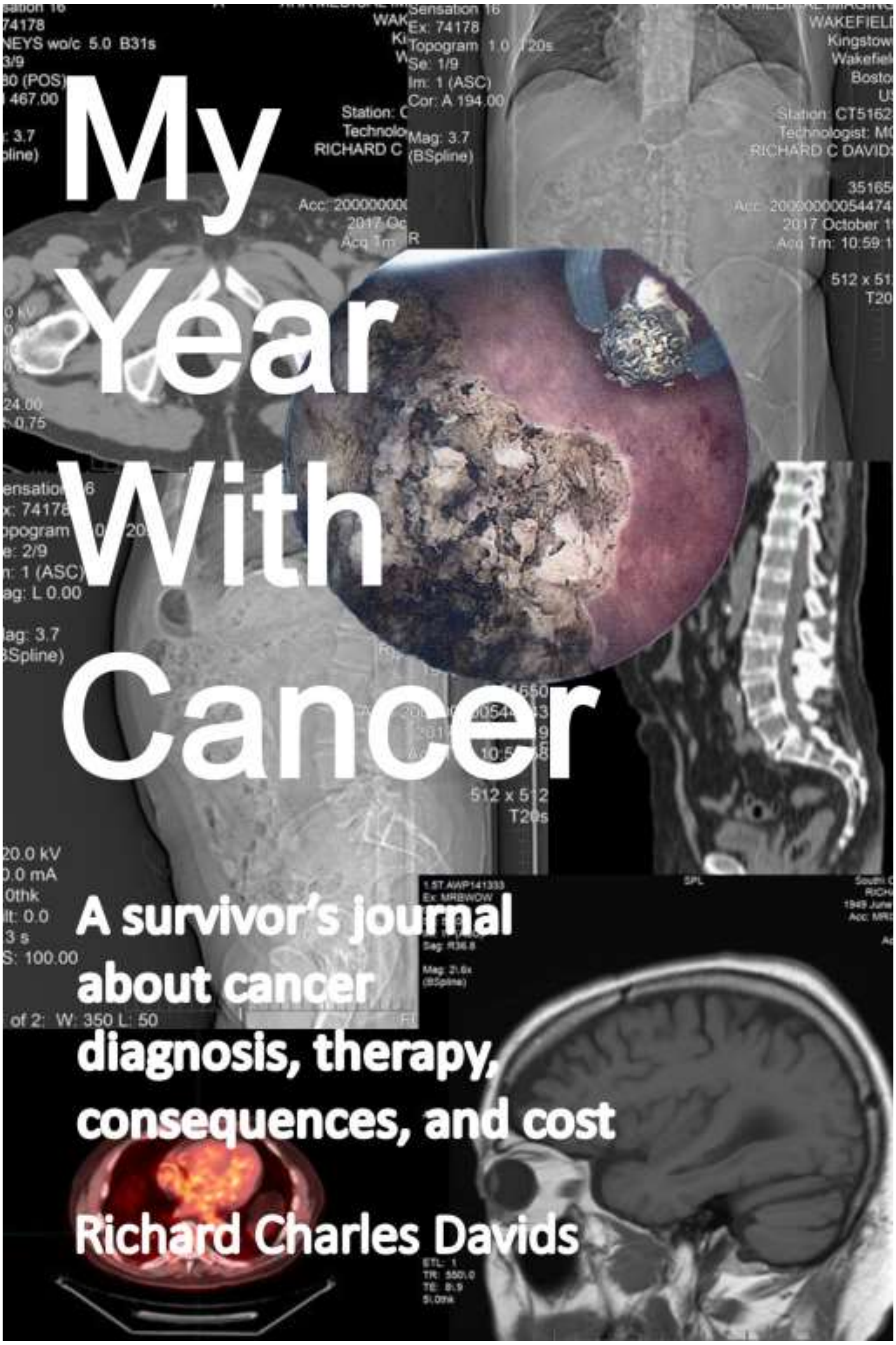

My Year With Cancer

A survivor's journal about cancer diagnosis, therapy, consequences, and cost

Richard Charles Davids

MY YEAR WITH CANCER

A survivor's journal about cancer diagnosis,
therapy, consequences, and cost.

Published by Richard Charles Davids at Smashwords

Cover design by Richard Charles Davids

Ebook formatting by Brenda Van Niekerk at Triomarketers

Cover design shows the artifacts of my diagnosis and treatment
through PET and CT scans, PET/CT fusion scans, and MRI imaging.

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Prologue

From 2017 through 2019, I had 6 surgeries, 120 hours of chemotherapy, and 7 weeks of radiation therapy to fight urinary bladder cancer. 2018 was my worst year. I made the treatment choices based on reading medical journal articles, listening to advice from healthcare providers, talking with friends, watching online videos, and reading testimonials of cancer survivors. What choices did I make and why? How much did all the healthcare cost? You are invited to find out.

Introduction

I was diagnosed with small cell aggressive urinary bladder cancer in late 2017. Julie and I interviewed medical oncologists, nurses, physicians, radiologists, and urologists at four major hospitals in New England to understand the type and extent of cancer and to get answers to our questions.

Getting answers was like putting a jigsaw puzzle together. No single physician had all the pieces of the puzzle. They might have one or two pieces on the board but there were a lot of empty spaces. It was up to us to find all the pieces, put them on the board and make sense of what the pathology reports, imaging analyses, and doctors' opinions meant.

I read technical medical journal articles about cancer, surgery, and survival rates. After consulting with friends, doctors, and wife, I decided on a treatment plan that was best for me. It's not that I did not trust what one physician recommended or what another practitioner would advise but I wanted to control my body myself. I needed to find out about options like surgery, chemotherapy, radiation therapy, side effects, and life-long consequences.

My journey is different than your journey. This journal contains my experience, not yours. You must find your answers to your questions. This journal is not a medical advisory and cannot be used as a recipe or formula to prescribe treatment. In no way does it supersede the advice of your physicians. Ask questions and get advice from as many people as your time allows.

This is my cancer journal. "My Year With Cancer". It's a patient's story. It's a journey I took with the help of many people. I hope it helps you on your journey.

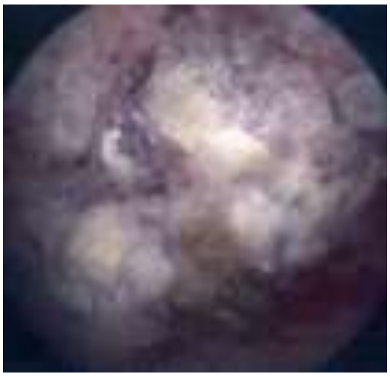
Ten percent (10%) of sales are donated to the American Cancer Society.

September 2017

First Sign of Trouble

I noticed a slightly ruddy color in my urine in late September 2017. I was pretty sure it was blood in my urine called hematuria but what caused it? I experienced no pain or discomfort. 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.

Images at the end of chapters are scans and photos taken as part of either diagnoses or during surgery. For instance, the following photo shows an ablated area inside my urinary bladder.



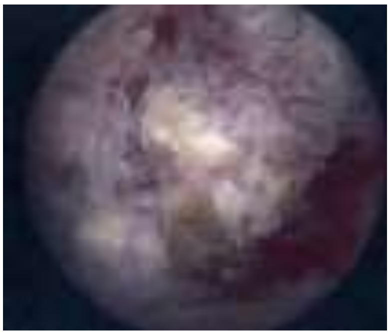
7 October 2017

Second Sign of Trouble

On 7 October 2017; I noticed the blood in my urine again, called gross hematuria (and it was gross), had returned. Of course, I searched the Internet for information. I suspected blood leaking out of some organ – a kidney, prostate, bladder, or somewhere else?

Sometimes a clot or clump of blood would pass through my urethra (a new word I learned) and appear in the toilet bowl. I had to look; not pretty. You could feel it passing through; it's very disconcerting when that happens. Where is that stuff coming from? I started to get worried. Julie, my wife, said:

"Welcome to my world". I thought the analogy was slightly misplaced, but I appreciated what she said and that she identified with my situation.



12 October 2017

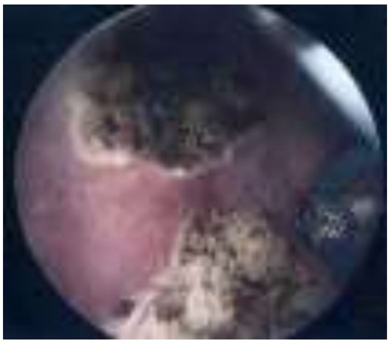
Primary Healthcare Provider Appointment

By 12 October, the blood in my urine was constant and very noticeable. Not a bright red color but more like a good Paso Robles California 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. It creeped me out.

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 general practitioner, or GP; he co-founded the clinic. They scheduled an appointment promptly for 17 October 2017.

The clinic took both a urine sample and a 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 computerized tomography (CT) scan. A CT scan shows detailed pictures of your organs and tissues.

After the exam, my GP directed me to the 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 is against rules. No playing favorites. I walked down the hall with my prescription in hand and downstairs to the CT office and made the appointment for the scan. The receptionist made the appointment for the CT scan on Friday, 19 October. Plus, I got two bottles of barium sulfate to drink. Chocolate favored. Not too bad.



19 October 2017

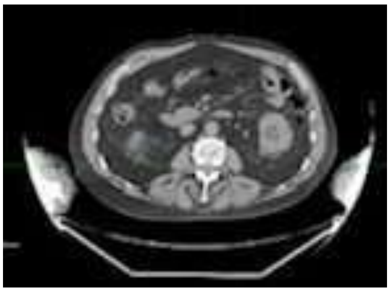
The First CT Scan

I returned to the clinic on Thursday, 19 October for the CT scan after drinking only one pint of barium sulfate. The receptionist gave me a pass on drinking only one pint instead of two. After I changed from street clothes into the ‘Johnnie’, the technician, Mary, administered an IV tracer in my right wrist (I hate that!) and set me up for the CT scan.

Mary was careful to make sure I was comfortable while she held the IV pack. It took about 15 minutes and 5 passes through the ‘tunnel of love’. That is the big, cream-colored, donut-shaped CT machine with all the electronics. It’s a quick way that uses X-Rays to detect cancer, heart disease, and other bad stuff in your body.

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 had 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. I was hoping she would say everything is good and you can go home with no worries. Wrong.

After exchanging my Johnnie for my street clothes, I asked for and received a CD of the CT scans. Pretty neat. 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 executable file that launched the program when you clicked on it. I couldn’t tell what I was looking at, but it looked interesting, I’m sure, to a urologist or pathologist. 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 smartphone and asked me to call the front desk at my internal medicine clinic where he worked. He said it was not urgent. Imagine, my 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 my GP 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 a 1 cm kidney stone in my left kidney and a polyp in my urinary bladder. Drinking plenty of water was the advice. Drinking plenty of water seemed a bit low-keyed; I expected something more powerful. He said to call the front desk and they would FAX the results to the urology office at 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 in the urology office 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. What could go wrong with sending a FAX; the clinic must do this a dozen times a day?

I called my clinic and told Mary that the urology office at the hospital did not receive the FAX. Mary replied, “A FAX takes time” and told Liz, her office mate, 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? I’m guessing it is.

I called Stephanie at the urology office in the hospital in the afternoon, 25 October, to make an appointment. Stephanie recommended I call their other urology office in another town since their 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 at my hospital on 26 October, 10:48 AM, and spoke to Linda, not Stephanie. 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 waitlist and you’ll get the next appointment. Please call me back in the morning.” I guess not. Maybe people in the same office space work in different time-space continuums. Linda said nothing about a cancellation, but I was thankful anyway. Persistence or stubbornness paid off this time.

I called my clinic again on 26 October and asked if they had a record of sending a FAX. 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 they had sent the same information twice before and the 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 paper report (I had the CD of the CT scan with me) and other transcripts and hand-deliver them to the urology office at my hospital 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 to the receptionist in the urology office.

I get a confirmation email message within 10 seconds from Amazon when I order a product; why can’t a clinic do the same for a FAX? My GP and other physicians admit interoperability is a serious problem. I explained the dropped FAX situation to my nephrologist later who said: “It happens all the time.”

Now I admit that Amazon is a lot bigger than the entire healthcare industry and a lot 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 guess it's one of the mysteries of life.

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 report 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 because it's your healthcare provider; make the call. Double-check. Your life depends on it. 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

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 the hospital and listened to him say, first, you have a cancer tumor in your bladder "Polyp's bleed, that's what they do", he said. Second, here are the options. He sat right down next to us and spoke to us face to face. I feared for the worst but kept my courage up.

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, prostate, 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 was not going to have my vital 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. I learned later that’s what you’ll do for the rest of your life after radical cystectomy. No one tells you that in the beginning.

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 neither pain in my back nor any indication of passing stones. But the CT scan found it. Amazing!

He said his office would make an appointment for the ‘procedure’. I guess surgery is an icky word. Whenever a physician invades your body with plastic and metal things and takes stuff out of your body, then it’s surgery, not a ‘procedure’. My urologist was Chief of Surgery at the hospital, not Chief of Procedures. Imagine someone asking you who did your surgery? “Oh, he’s Chief of Procedures.”

Now that’s reassuring. Walking down the hallways of the hospital, I saw signs that said ‘Cardiology’, ‘Cafeteria’, ‘Cancer Center’. I didn’t see any placard for ‘Procedures’.

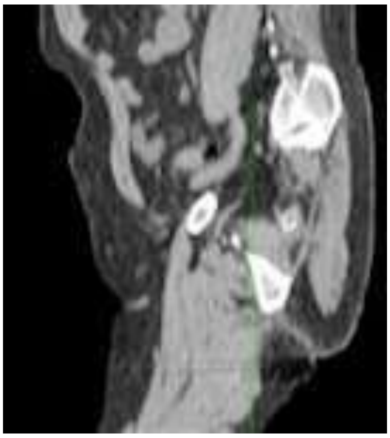
Julie and I left the office quite satisfied with his assessment, patient skills, interpretation of the CT scan, and his professional attitude. Our urologist made an appointment for the surgery (to remove the kidney stone and tumor) on 10 November 2017.

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 a thorough (deep) biopsy to determine the extent of cancer. The next step after a deep 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. Immunotherapy is typically useful in young patients; since I was over 65, immunotherapy was not a good alternative.

There is a healthcare principle known 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.

Deciding right away what course of action to take when you’re in shock at hearing you have cancer is difficult. But I trusted this urologist. At the time he was chief surgeon at the hospital, so others trusted him, too. Thinking back, it’s unreasonable to think one physician knows all the counterindications and outcomes of a procedure or course of therapy or the psychological impact.

A physician acquaintance told me that in 80% of the cases, the patient follows the course prescribed by the doctor. He said the 20% who don’t accept the doctor’s advice verbatim are usually engineers or doctors or scientists and they ask many questions and check the numbers. I was a human factors engineer for 34 years at a major aerospace company. I was not going to jump to conclusions or make quick decisions, and I made sure I was going to ask a lot of questions and read up on cancer prognosis, treatment, and outcomes. In my case, I decided to have the resection surgery, undergo chemotherapy, and then evaluate the results of 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 at my hospital for a Friday, 10 November 2017 procedure at 11:30 AM. 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 bedsheets, don’t sleep with the dog but you can sleep with your wife. Good advice. 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 (surgery).

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.

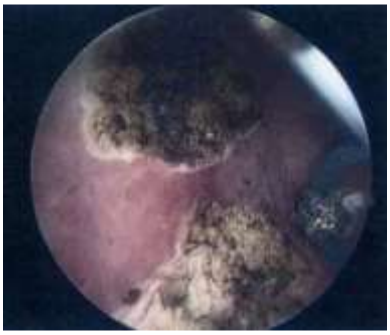
During the procedure, a scope with a cutting device mechanism is inserted through the natural channel (in my case penis) into the bladder and then the tumor is removed. The kidney stone is blasted with a laser and the bits are removed with a spring finger flex grabber (or something like that). But only the pathology reports can determine the extent of cancer. In other words, you may have a visible tumor, but it might be muscle-invasive which means it could be a Type II or higher type of cancer. The higher the type the more serious is the cancer.

I checked into the hospital accompanied by Julie. I was invited to a curtained cubicle and changed into the ‘Johnnie’. The gurney and covers were fairly comfortable. Since not much is covered up with the ‘Johnnie’ you have to leave your sense of decorum and privacy at the door. One way or the other they are going to see everything.

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, listen carefully to what they are saying, 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. I hate that.

We talked for about a minute and the next thing I remember is waking up in my hospital, room 313. My dick was taped to my left leg with a Foley catheter draining my body fluids into a bag I couldn't see somewhere off to the side of the bed. Blue surgical thread protruded from my penis and was taped to my 'meatus'. Meatus is a technical term. Guys know what a meatus is. I felt safe but despondent. Then everyone starts to visit – nurses, doctors, volunteers, wife.

Below is a photo of the urinary bladder where the tumor was ablated. It looks very ominous and evil. Nasty looking thing!



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 whiteboard 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 the hospital. Thanks to all the nurses, doctors, and assistants: Kate, Lindsey, John, Dante, Asahan, Alexandra, Julie (pre-op), Amy, Melissa (ultrasound tech), the anesthesiologist and Adam (anesthesiology), clean up people, my urologist, Steve (the 'stick' man), Mike (transportation), cafeteria staff, volunteers.

I did the 'pole dance' only once, too. That's where you get out of bed with the IV dangling from the IV pole, trundle off to the bathroom assisted by a nurse and then do a number two. If you're lucky.

The food was tasty and easy to eat. I didn't want to struggle with my food, knock over the tray, and disconnect the Foley. I had chicken stir fry and vegetable soup for dinner and scrambled eggs and oatmeal for breakfast. The bed was amazingly 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. For instance, how about a small (6 oz.) sample bottle of green tea since the water at this hospital tasted like bay water flushed over a hot cement sidewalk. Or lollipop throat lozenges to counteract the effects of intubation and sore throat. The lollipop style prevents swallowing and choking. I never heard back.

Hospitals use calf muscle stimulators to squeeze the lower leg muscles to stimulate blood flow. A good idea to prevent thrombosis but it’s a bit distracting especially when you try to sleep. It’s like a very firm massage but without nice hands and a happy ending.

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 annoying if you’re over 30.

It’s terribly boring and sometimes lonely lying nearly immobile in a hospital bed with a Foley catheter sticking out of your you-know-what. There’s not much to do.

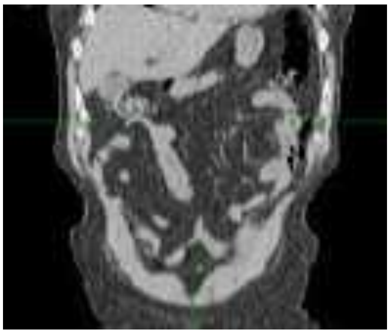
Why not have a hospital channel with tours of all the great things going on in the hospital? Take a video tour of the cancer center, the Da Vinci surgical system, the radiation center, diagnostic imaging, gift center, cafeteria, cancer support services, orthopedics center. Meet doctors and nurses and staff. Listen to senior leadership talk about what’s important to them at the hospital.

Such a video could be filmed and edited by the local university 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 at my local university is ‘Science, Environmental and Health Communication’. Sounds like universities and hospitals should collaborate more often.

Hospitals have a captive audience with patients lying in bed for hours, days, and weeks. Give patients something to do and take their minds off their pain. How about some fun stuff like learning how to play the 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. Take a patient’s mind off of the pain and discomfort.

Breathing is very important to prevent lung congestion; learning to play the harmonica in bed will help prevent congestion and fluid buildup. Give the patients some paper and a pencil and teach them how to make an impressive 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.



10 November 2017

Urologist Report

The following is an example of the ‘doctor speak’ language which I had to decipher. I learned some new words like ‘meatus’, ‘rollerball electrode’, ‘trigone’, and ‘hydroureteronephrosis’.

PROCEDURE: The patient was brought to the operating room and administered general anesthesia and IV antibiotics. The patient was placed in the dorsolithotomy position where all pressure points were padded carefully. The patient's genital area was prepped with Betadine solution and draped in a sterile fashion. Sounds were used to dilate the meatus.

A 22-French rigid cystoscope was passed per urethra into the bladder. Anterior urethra normal, prostatic urethra slightly converging.
Bladder mucosa was immediately notable for significant papillary tumor involving the posterior aspect of the bladder and continuing up the right lateral wall. The trigone was also involved. Ureteral orifices were identified.

Using a cold cup biopsy forceps, multiple biopsies of the tumor were taken and sent labeled "bladder biopsy".

A 26-French Iglesias resectoscope was then passed into the bladder. Tumor was then resected with care not to injure the ureteral orifices. The tumor fragments were then sent to pathology labeled "bladder tumor". The rollerball electrode was then used to cauterize all bleeding sites and to widely fulgurate this area. With no further visible tumor noted, the resectoscope was removed.

Our attention then turned to the left ureteral stone. The cystoscope was again replaced into the bladder. The left ureteral orifice was identified, and a cone tip ureteral catheter was used to perform a left retrograde pyelogram using half-strength contrast. This did show the stone in the distal left ureter. However, there was no significant hydroureteronephrosis. There were no filling defects consistent with tumor. A Glidewire was then passed into the left renal pelvis and over the Glidewire a balloon dilator was used to dilate the intramural portion of the ureter.

The semi-rigid ureteroscope was then passed into the distal left ureter. A large dark stone was encountered. Using the holmium laser with a 550-micron fiber and settings of 8/800, the stone was broken into multiple small fragments and a basket was used to remove these fragments. Stones were sent for analysis. Over the Glidewire, a 28 x 6 double-J ureteral stent was passed with the proximal end noted to curl in the renal pelvis and the distal end noted to curl in the bladder. The dangle position suture was brought out through the meatus and secured to the penis with a Tegaderm dressing. A 22-French 3-way Foley catheter was passed per urethra into the bladder, balloon inflated to 10 mL. Catheter irrigated freely and was placed to continuous normal saline irrigation. Of note, sorbitol was used during the TURBT and saline used during the ureteroscopy.

The patient tolerated the procedures well. There were no complications. Estimated blood loss minimal. The patient was brought to the postop recovery area in stable condition.

IMPRESSION:

1. *Papillary bladder tumor. This was broad-based, covering approximately 5 cm of area. Now status post TURBT. The patient and wife will return for pathology results.*

2. *Large left ureteral stone, now status post laser destruction and extraction. Will await stone analysis. The patient will return to the office for stent removal using the dangle suture.*

I'm glad 'the patient tolerated the procedure well". And how the heck do you use 'sounds' to dilate a meatus? Rock music? Symphonic melodies?

Another mystery of life.

12 November 2017

Constant Constipation

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 over-the-counter medicine. It took about 24 hours to finally get rid of the intestinal pain.

Maybe the hospital discharge paperwork could include some take-away stuff like a couple of packets of anti-constipation medicine. Or some explicit, easy-to-understand advice from the discharge 'goodbye' nurse like - "You're going to be so constipated that you'll want to rip out your intestines. Don't. Ask the doctor if you can take a stool softener and/or pain medication". Why is it so difficult?

14 November 2017

Removing the Stent

We met with my urologist on 14 November to remove the stent. A real stent is a soft, hollow tube that is placed temporarily into the ureter somewhere in the kidney and ends in the bladder. The stent is placed inside the channels to keep them open so the liquid drains. But my stent was different. It was a piece of blue surgical thread that was placed in my left kidney during the procedure, pulled through the bladder, then the urethra and out. The end bit outside my body was taped to my meatus. Creepy.

In his office, I was invited to discretely change into a ‘Johnnie’ in the office closet and then sit on the exam table. He placed a towel over my private parts. Not so private anymore when he stuck his head and hands under the towel.

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 entire stent thread pulled out of my wretched body. My urologist tells me to take a deep breath and he rips off the tape. That was a surprise. Then he tells me to huff and puff while he pulls out the stent. I screamed a tiny, tiny bit but was much relieved when it was over. Julie said I screamed quite loudly. The stent thread must have measured 6 feet long; at least it felt that long. It was probably only 2 feet but felt a lot longer coming out of where it was.

28 November 2017

Urologist Post Procedure Consultation

On November 28, 2017, Julie and I visited 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. Like something you'd find at Home Depot to pick up stuff on the floor but much smaller. Both the tumor and stone would be analyzed for content, cancer type, etc.

The most common type of bladder cancer is transitional or urothelial bladder cancer. Rarer types include squamous, adenocarcinoma, sarcoma, and small cell bladder cancer. Some of the risk factors for bladder cancer are exposure to chemicals like beryllium or smoking. I was not exposed to any of these risk factors.

The pathology report said 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.

Reading up on bladder cancer, I found out that there are five stages of bladder cancer and a total of nine categories within the four major stages of bladder cancer. From what I read there are three ways of describing staging based on (1) tumor (T) – size and location, (2) node (N) – lymph node involvement, and (3) metastasis (M) – spread of cancer.

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 and mutilate me.

The doctors we interviewed were great about describing the various operations complete with diagrams and drawings but not the life-changing impact. They don't talk to you about the downside. One nurse 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 YouTube 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, Cancer.net, 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 TURBT/chemo/radiation multimodal therapy was 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."

5 December 2017

Deep Biopsy Procedure

After the procedure to remove the tumor and stone, the next step in treatment required performing deep biopsies of sites in the bladder to assess the extent and depth of cancer. That means they punch holes in the wall of your bladder and remove stuff.

On 5 December 2017, at 2:30 PM, 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. This is when anyone who walked in with you must stay in the waiting area or leave for a call back. In the cubicle, you have a bag with your 'Johnnie' on the bed and are instructed to remove all clothing, put on the Johnnie, and lay down on the gurney bed.

The deep biopsy performed on 5 December required a 3-day (2 nights) stay at my hospital. The pathology report revealed "invasive high-grade urothelial carcinoma with neuroendocrine features. It did invade lamina propria, no definite muscularis propria noted.” That meant that the sample did not contain any muscle tissue. Not definitely, anyway. Nothing is really definite.

So, it’s off to the Internet to learn what is the muscularis propria. Apparently, “the bladder is lined with a layer of cells called the urothelium. This layer of cells is separated from the bladder wall muscles, called the muscularis propria, by a thin, fibrous band called the lamina propria.” But the biopsy did not include a muscle sample so a pathologist could not conclude if the muscle tissue was invaded. They didn’t go deep enough or couldn’t find it. I guess that’s what it means.

There was marked acute and chronic inflammation which was expected because my urologist scraped out parts of my bladder and then ablated the surface. 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.

The complication was caused by the proximity of the biopsies near the opening of the right kidney ureter into the urinary bladder. Each ureter enters the bladder on the posterior bladder aspect in the trigone. Wherever that is. I guess that the swelling partially blocked the ureter from draining fluid from the kidney into the bladder. Or there may have been a clot. My urologist did his best to avoid irritating the opening, but stuff happens. This is not good.

A blood analysis revealed that my creatine level was elevated, and I was close to renal failure. Not good. That was a shock because I felt no pain or discomfort, but the chemical blood analysis revealed the problem. So, my urologist requested the advice of both a consulting physician and a nephrologist. Good idea.

6 December 2017

Complications

A nephrologist was called into my room to assess the involvement of the kidneys both the one that contained the stone and the right kidney. Nice guy. But there was a complication.

Since I was near renal failure, the doctors considered puncturing the right kidney to allow it to drain until the swelling could be reduced.

His recommendation was: “if his numbers are not improving with an improvement in his edema, he may require transient percutaneous nephrostomy tubes.”

Great.

If my numbers do not improve, then I’d have to stay an additional day. I was not happy to hear that another operation and, in this case, a perforation of my wretched body might be required. Drinking plenty of water to raise the creatine levels was the doctors’ advice. There’s not much you can do so I was feeling rather despondent at this point. I just could not imagine another perforation with a drip hose sticking out of my body. Just thinking about it made me even more depressed.

Fortunately, Julie bought bottles of water so I could avoid the perforation and nasty hospital water. I downed a couple of bottles and avoided lancing my right kidney. The anti-inflammatory drugs administered by IV helped ease the discomfort, too.

7 December 2017

Leaving the Hospital

I was released on 7 December from the hospital. My ‘goodbye and farewell’ nurse removed the Foley catheter. I thought the Foley was just a simple tube from my bladder to the outside. But it’s not. It’s got this balloon thingy at the end that seals the tube inside the bladder. I’m glad I didn’t know about the balloon thingy before she withdrew the catheter. Somehow the nurse deflats the balloon thing first. Then she said: “Take a deep breath” and zip! Out it came. I was very happy.

One of the mandatory procedures is to confirm that you can pee after a bladder biopsy or surgery. Since my urologist stuck this springy grabby thing into my body, plus a flashlight, and an ablating hot thing up my peter it’s a good idea to make sure everything is working.

Once I felt stable, a nurse explained the procedure – take a pee in the bathroom and do not flush. They confirm the presence of pee with a spectrometer or smell meter or something. But you hesitate to pee because you know it’s going to hurt like hell because of the trauma to the urethra. So finally, I released whatever was still inside my bladder into the toilet and informed the goodbye nurse.

She packaged up all the lotions, sanitizers, and creams for me to take home, too. She said if you don’t take these, then we just throw them out, so I took them. Why waste good stuff? The goodbye nurse gave me a couple of plastic urinal bottles, too. I couldn't figure out why I would need them but thought what the heck.

The transportation guy brought in the wheelchair and wheeled me out to the reception area. Julie picked me up to go home but she had to stop at her clinic on the way home. We parked the car outside her clinic, and I stayed in the car. People were coming and going in and out of the parking lot. I started to feel an extraordinarily strong urge to pee. But I didn't have the strength and courage to walk into the clinic in my go-home jammies.

I'm getting desperate so I look around to make sure no one is close by. I didn't see anyone trolling the parking lot. I dug around in the ditty bag the goodbye nurse gave me with the 'take home' stuff. I found one of the urine bottles, pulled down my pajamas, and discretely peed into the plastic jug. Much relieved. I looked around again and didn't see anyone nearby. I didn't want visitors to think I was some kind of perv with my pants down around my knees with my dick in a bottle.

My advice is to take whatever the goodbye nurse gives you when you leave the hospital. You never know when you'll need that stuff.

19 December 2017

Another Urologist Visit

Another visit with my urologist in his office. One of many visits. We talked about the operation and details about the cancer tumor. He said the next step is a meeting of the cancer conference or 'tumor board' to discuss the results of the biopsy and recommend treatment.

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, my urologists’ comments, and other information, they recommended 3 cycles of chemotherapy. Each cycle is 3 days. The first day is cisplatin plus etoposide; the following two days are etoposide only.

Cisplatin is a platinum-based drug and one of the most powerful chemotherapeutic drugs for treating ovarian, bladder, and testicular cancer. Cisplatin damages the DNA inside the cancer cells and so prevents them from multiplying. Etoposide is used to treat small cell cancer, particularly lung cancer. Both have side effects including moderate neuropathy and hearing loss. How moderate is the loss is something unique to each individual. You find out later what they mean by moderate loss.

Chemotherapy can be administered either by a ‘port’ near the shoulder or by infusion through a vein in the arm. The port is inserted via an incision between the shoulder and neck using a local anesthetic. The vein infusion is through a large vein in either lower arm. Usually, the basilic vein.

I chose vein infusion since my oncologist initially said chemo would only be three cycles. That would be 9 sessions at my hospital in the cancer clinic. I chose infusion by needle rather than port. How bad could that be?

Big mistake. How many people do you know admit they made a mistake when they make a mistake?

9 January 2018

First Medical Oncologist Consultation

We met with my medical oncologist on 9 January 2018 in my hospital's Cancer Center. I do not 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. You get the luck of the door.

We had a good 45-minute visit. The oncologist explained emphatically that the only good course of treatment was radical cystectomy.

Somehow, I thought the oncologist was jumping to a solution without really talking about the up and downside of treatments. But since the cancer center was so close to home, I thought it would be convenient to get treatment there rather than travel to another state as some patients do.

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. 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 second floor of my hospital with a treatment area right off the main reception area. When you walk in a nurse greets you right away. It's a clean, well-lighted place. The infusion area is open with a central nursing area surrounded by twelve or so individual private booths for infusion. The oncologist ordered a Positron Emission Tomography (PET) scan, too. I felt things were moving along very nicely.

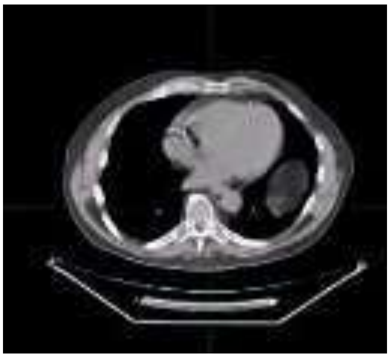
10 January 2018

First Nephrologist Consultation

On 10 January, we met with my nephrologist. They're known as the 'geeks' of medicine. 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, evaluated my reflexes with the 'thumper', and looked at my outstretched arms for wobbles. If your outstretched hands shake or wobble in a certain way, then it indicates something unusual is going on with your kidneys. I forget what but it was a neat way to infer a condition without sticking more needles in me.

He asked about my urine color. I told him it was sorta yellowish clear. I thought about that and then suggested using Sherwin-Williams paint color chips in a paired comparison test to evaluate a patient's urine color. He liked that idea.

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



15 January 2018

The PET Scan

On 15 January I went for my first Positive Emissions Tomography (PET) CT scan in the mobile PET van that arrives every Monday morning at my hospital. A PET scan is an imaging test that finds hot spots that can represent abnormal cell growth. The scan uses a special dye containing radioactive tracers injected into a vein in the back of my wrist. I hate that.

Lou and Jess ran the lab. It's in a trailer that travels from hospital to hospital in the county, 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 (did I say I hate that?) and then it's into the 'tunnel of love' for the PET scan. The entire process took about an hour. Here's the report.

PROCEDURE: PET/CT SCAN INDICATION: BLADDER CANCER

TECHNIQUE: 15.8mCi of F-18 fluorodeoxyglucose was administered intravenously via the vein.

PET/CT was performed from the skull base through mid-thighs. A non-contrast CT scan was performed for anatomic localization and photon attenuation correction.

COMPARISON: None. FINDINGS:

Head/Neck: There is activity at the glottis which is symmetric and probably related to vocalization.

Chest: There is no significant abnormal activity seen in the mediastinum or lung fields. There are no visible lung nodules on the CT portion of the exam. There are some basilar atelectatic changes noted bilaterally.

Abdomen/pelvis: There is no abnormal activity in the abdomen. There is prominent colonic diverticulosis.

Musculoskeletal: No significant abnormal activity.

IMPRESSION: No evidence by PET/CT evaluation for metastatic disease in this patient with known bladder cancer.

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

16 January 2018

Getting Second Opinions

Now here's the kicker. My hospital pathology report stated no muscle invasion which is good. But everyone we talked to recommended getting a 'second' and even a 'third' opinion for treatment.

Over 3 months, I contacted via FAX from my cancer clinic or phone call four New England hospitals. Two did not respond to my 'new patient request'. These were big-name hospitals in the Boston area. You try your best to get second opinions so you must send out 'new patient requests' to hospitals recommended by your GP, oncologist, or even a friend or neighbor. You don't know which horses come back to the barn.

When you have a cancer diagnosis, you start asking around. I asked neighbors and friends if they had any experience with cancer treatment. One neighbor preferred Johns Hopkins in Baltimore for prostate cancer. They purchased a condo to live near Johns Hopkins for a month at a time while the husband received treatment. He participated in the trial and conventional therapies for over ten years.

Another neighbor preferred a oncologist in Boston claiming, ‘he is the real deal.’ Good for him. That was his opinion. We’re all looking for the real deal. But the important thing is that you have confidence in your choice of physicians and treatment. You go with the best choices you have in the time you have to decide about treatment. Ask around. Don’t be shy. Your life depends on it.

On 10 January 2018, I called the main campus number of a well-known New England hospital for a second opinion on cancer treatment as recommended by my oncologist. I was referred to New Patient Coordinator. When I called that phone number the receptionist asked what type of cancer. I told her about bladder cancer. I was referred to ‘Kristen’, New Patient Admission, Genitourinary Clinic. I told Kristin that I was referred to this hospital by my medical oncologist at my hospital in Rhode Island. I provided my Medicare number and AARP United Healthcare Plan identification to the admissions recorder and received a medical record number. You must write down all the phone numbers. If you don’t keep track of things, then it’s like passing ‘Go’ without collecting $200 and you must start all over again.

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

I told my medical oncologist that we scheduled an appointment at this hospital and that they recommended sending them the pathologist report, slides, and any imaging.

During the call to this first hospital, 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 chemotherapy based on the hospital’s pathology report. Each cycle is 3 days using cisplatin and etoposide. At intervals of 3-4 weeks. Kristen recommended continuing with the prescribed treatment right away.

17, 18, 19 January 2018

Chemotherapy - Cycle 1

My oncologist worked out the chemotherapy schedule but this time it's for six cycles, not three as I was first told. And it's because of two different pathology reports from different labs. Pathology analyses of biopsies can be done by hospitals other than where you had your operation. That's a good thing. My medical oncologist sent out the slides, scans, and reports to another hospital, namely B and W Hospital, for a second look.

B and W Hospital performed a pathological analysis on my biopsy reports, slides, and scans, too. 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". However, after the procedure on 5 December 2017, the PET/CT scan showed: "No invasion is identified. Negative for tumor. Marked acute and chronic inflammation." This is why we get second and third interpretations of results.

Thus, it appears that there was some muscle invasion of cancer into the wall of the urinary bladder based on the biopsy but not for metastatic cancer based on the PET/CT scan. From what I've heard other cancer survivors say it's not unusual to get different opinions of the tumor and staging based on the slides, scans, and reports. Maybe that's why they're called opinions. Fortunately, the TURBT procedure removed the invasive part, but the therapy now required 6 chemo cycles instead of 3. A normal number of cycles is between 4 – 6 cycles. Oh, joy. But I'm glad they decided to go to the maximum recommended number of cycles. I wanted this stuff killed.

Each cycle would last for three days. In my case, each cycle started on a Wednesday and finished on Friday. Each daily session takes about seven to eight hours, starting at 8 AM and ending sometime around 3 - 4 PM. That's a long day.

The cancer clinic at my hospital 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. The least of my worries was the hair loss.

In retrospect, the biggest problems were anemia, fatigue, hearing loss, 'wobbly' walking, trying to stand still, loss of balance, dizziness, breathlessness, temporary blindness, and vomiting. And feeling just wretched. Words cannot convey these side effects. The hair loss would be my 'red badge of courage'; I liked the idea of emulating Stephan Crane. After I lost my hair (really it was a fuzzy top, not bald), my oncologist said I had a nicely shaped head.

Every visit to my hospital during treatment involved a blood draw by a 'vampire' nurse. I'm not making that up – that's their official nickname. I donated a basket full of squeegee balls to squeeze during the blood draw. My vampire nurse said everyone grabbed one; sometimes just to throw around the clinic.

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.

They make you very comfy. 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. 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 want to), I would choose a port instead of vein infusion. At the time, I didn't like the idea of another hole in this old, tired body that could get infected which they can.

Each session is a cocktail of drugs. The first drug per my Medicare report 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 cancer. This bag was followed by 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'. The difference was Steve used gloves and Kathleen found a vein using just bare fingertips.

Towards the end of the cycles, finding a vein got tougher and tougher. Cisplatin destroys the walls of veins, and they don't recover. Kidney dialysis has the same effect on blood vessels. 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 DeAngelo's mushroom and steak sandwiches which were much appreciated. Thank you, David!

During one of the sessions, my hot medical oncologist stopped by. Long black hair and a butt-hugging booty dress. 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".

My medical oncologist had a revealing sense of humor. Once after using the clinic bathroom, I mentioned to her that I didn't see one of those 'employees must wash their hands after using the bathroom' signs under the mirror. She asked if I had seen someone in the bathroom not washing their hands. I said: "No, I wasn't in the bathroom when the doctor came out." Her reply: "All men are pigs. I live with three of them!" It's good to have a sense of humor in a cancer clinic.

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 some 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.

A photo of my feet reclining in the infusion chair and Julie on her phone.

23 January 2018

The First Second Opinion

I made an 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 the Valet service. 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 the 9th floor.

This first other hospital 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. It 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.

7, 8, 9 February 2018

Chemotherapy - Cycle 2

The second chemotherapy cycle started a short three weeks later. My hair had fallen out. It’s disturbing to take a shower and see clumps of your hair between your fingers and sliding down the drain. You read about losing your hair; seeing and feeling it is quite different. But you realize that the chemotherapy is working.

By the third day after treatment, I started to feel the hammer after the good drugs wore off. It’s got a name – ‘chemo fog’ or ‘chemo brain’. 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 poisoning my body with lots of chemicals anyway.

Chemo-brain made me feel like a zombie – insensitive, unable to think straight or concentrate on anything someone was saying, clumsy, dull, depressed, weak, uncoordinated, tired. I lost the ability to make decisions. It’s like when you over-sleep and wake up thinking you’re still in a dream. You’re not sure where you are. You lose the sense of time and place. I cannot explain how you feel with chemo-brain. And it gets worse with each cycle.

During one of our meetings with my medical 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. Sometimes I think they don’t listen so well to what a patient says.

My medical 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 has a radiation center with a resident radiation oncologist who is the 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 were all sorts of treats to eat, too. Very considerate. There's an outside waiting area and then inner waiting rooms for privacy and to wait for your treatment. When the previous patient leaves then you're escorted into the radiation chamber. It's a foot thick shielded room with a very heavy door.

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, beamwidth, intensity, duration, etc., but I'm glad I had selected radiation treatment as an option.

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 a 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 and wretched body, I told my medical oncologist and radiation oncologist that I was not going to have additional cisplatin treatment. They'd have to do something else.

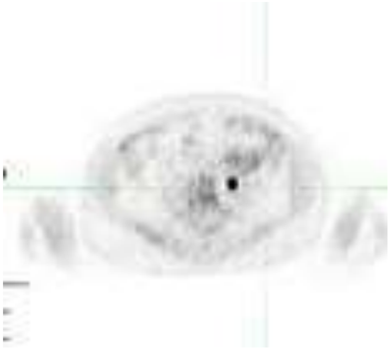
24 February 2018

A New Car

In celebration of having cancer and suffering through two months of chemotherapy and finding out I probably would not die young, 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?’

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 very 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 showroom 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. It happens sometimes and you wonder am I a ghost? I conveyed my invisibility 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 medical oncologist, I mentioned that I thought my hearing was much worse because the cisplatin had destroyed my otoliths. Cisplatin is ototoxic. Otoliths are tiny hair cells responsible for both hearing and equilibrium. The oncologist replied: “You probably had poor hearing, to begin with.” Now really?

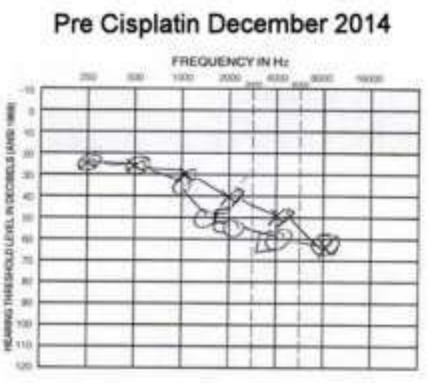
The oncologist should have said: “Hey, I respect your opinion. Let’s be scientific about this and get an audiogram; then we can see what’s going on with your hearing. I recommend the audiology department at your local university.” A hearing exam (audiogram and articulation index) costs about $100 at my local university. Cheap. It would help if healthcare providers reached out more often to other resources and did not jump to conclusions based on age, sex, or whatever bothered them that day.

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. My audiologist at the local university clinic said I was ‘profoundly deaf’. That’s a real diagnostic assessment. I lost about 60 dBA of hearing at the higher frequencies (above 3,000 Hz.). 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.

Fortunately, I had before and after audiograms of my hearing.

I had an audiogram done in December 2014 after I was diagnosed with a severe ear infection. When I learned the ototoxic effects of cisplatin, I had the audiogram done at my local university audiology center.

The results are below. You can see my hearing went from a moderate loss to a profound loss.


Pre Cisplatin December 2014


Post Cisplatin March 2018

21, 22, 23 March 2018

Chemotherapy - Cycle 4

I 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.

Mr. Darcy, our lovely Lhasa Apso poodle doggie often curled up with me while I slept.

26 March 2018

The Second Second Opinion

A friend recommended going to see a urologic surgeon at a hospital outside of Boston for another opinion about treatment. Even though I was in the middle of a ‘chemo fog’ after my recent 21 – 23 March cycle 4 chemotherapy treatment we thought it best to get another expert opinion from a recommended source. So, we drove up to Boston for the day.

After some polite introductions, the doctor proceeded to describe the various types of surgeries: an ileal loop conduit, an orthotopic neobladder, and a continent catheterize 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 where he’d make 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. After he described incisions and mucking around inside my body, I thought of inviting him to carve the turkey and make the mash potatoes at Thanksgiving.

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 at this 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 what radical surgery was involved in this ‘gold standard’ of treatment.

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 ‘regifting’ 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 like the Cheshire cat in Alice in Wonderland. 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 the lawn, got inside the solarium, sat down, and vomited into my hands, on the floor, in the sink, and finally the toilet. I said: “That’s it!” I decided to discontinue the chemotherapy. It was killing me.

I had such a real sense of morbidity and death. It’s very difficult to describe. It was a deep heavy feeling of doom; an oppressive feeling I could not shake. Words cannot convey the feeling. Something was dreadfully out of whack.

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. They told me my magnesium level was zero. I believe that the root cause of my hallucinations was some sort of chemical imbalance like missing the chemical element magnesium. I read later that it supports muscle and nerve function and energy. I certainly had lost a lot of energy with chemotherapy.

Besides a magnesium deficiency, I was severely anemic. The infusion of 2 units of blood and 4 units of magnesium 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., she said: “You did the right thing.” I was flabbergasted. After I stopped treatment, nurses said I looked like hell – gray skin, tired, worn out, depressed. I wish they hadn’t waited until I stopped treatment but told me earlier. Then I would have asked more questions.

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 lost about 10 pounds. Ten pounds I didn’t need but that’s a heck of a way to lose them.

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 probably know about them but don’t promote ways to mitigate them like recommending metabolic supplements to promote magnesium absorption or vitamin B-12 supplements for iron deficiency. 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?

Truth be told, my medical oncologist suggested a B12 shot but there must be other ways to mitigate the side effects of drastic chemotherapy. Yes, chemotherapy included a dietician and wellness interview at every cycle but why not include a preemptive mitigation course of supplements and nutritional aids for the debilitating, soul-crushing, mind-robbing side effects? Just tell people this vitamin supplement or mineral might promote calcium uptake or iron retention or whatever. Try it and see if it helps. I guess it’s one of those mysteries of life.

21 May 2018

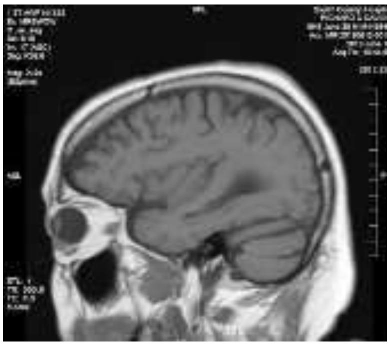
An MRI Brain Scan

I experienced severe nausea, dizziness, and vertigo during the chemotherapy; it’s one of the know side effects of chemotherapy.

During an oncologist visit, my oncologist conducted an eye test. She 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 magnetic resonance imaging (MRI) scan. It uses magnets to produce three dimensional images of your body. An MRI relies on aligning protons a certain way using radiofrequency (RF) current. Fancy sensors detect energy released by protons in your body when the RF current is turned off. The different magnetic properties of tissues are detected and displayed in the images. Pretty amazing stuff. Fortunately, it does not use X-Rays which can damage tissue; I’m not sure that would make a difference with my old brain.

The MRI machine produces the loud ‘whack, whack, whack’ experience but with the help of some good earplugs, the pounding noise didn’t bother me. Nothing serious found – no tumor or other serious issues. Good news finally! Medicare billed $4,024.00. Medicare-approved $4,024.00. Medicare paid $367.06. The bills are mounting up.



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 immediate side effects. Radiation therapy was a cakewalk compared to chemotherapy.

The treatment took place at my hospital’s radiation center adjacent to the hospital. The radiation oncologist and nurse were excellent. The technicians and assistants 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 technician marks your body with tattoos to align the radiation emitter– first, with temporary stick-on markers and then with a ‘tattoo’. I got three small dots the size of a pinhead: one on my belly and the other two on either side of my hips. I got my first tattoo! I wanted a skull and crossbones 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 same position over the seven weeks of treatments.

Each session took about 15 minutes. They 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, discreetly, 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 for 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 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 whole bladder or the specific tumor site.

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.

One positive thing about the radiation treatment is that when you complete the protocol you get a nice certificate to hang on your wall and show your friends.

South County Radiation Therapy

CERTIFICATE

of Completion

This certifies that

Richard Davids

has successfully completed radiation therapy treatments at 21st Century Oncology

Congratulations!

8-14-18
DATE

Dr. Shafman
PHYSICIAN

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

4 October 2018

Cancer Care Plan / Survivorship Plan

One of the excellent administrative products at my hospital is their Cancer Care Plan / Survivorship Plan. You receive it after you've completed your treatment plan which in my case was TURBT, chemotherapy, and radiation therapy. The Survivorship Plan contains a lot of good information about stuff not directly related to the cancer diagnosis.

The following is a list of the categories and items within the care plan. I deleted more sensitive information like practitioners names. While I did not fill in all the fields below, the plan is pretty comprehensive for summarizing treatment, dosage, schedule, and follow-up recommendations.

I received the care plan on 4 October 2018. It was the first time that I saw the results of the staging study based on an earlier PET scan. It was 9 months between the deep biopsy and pathology analyses and the staging study conclusions.

This Cancer Care Plan will facilitate cancer care following active treatment. It may include important contact information, a treatment summary, recommendations for follow-up care testing, a directory of support services and resources, and other information.

CARE PLAN
Prepared by: RN on 10/ 03/ 2018
at COUNTY HEALTH CANCER CENTER

GENERAL INFORMATION
Patient Name: Richard Charles Davids
Date of birth:
Age at diagnosis: Support contact:

CARE TEAM:

Hematologist/ oncologist:
Radiation oncologist:
Surgeon:
Primary care physician:
Nurse/ nurse practitioner:
Mental health/social worker:
Dana Farber Oncologist Urologist:

BACKGROUND INFORMATION:

Symptoms/ signs: Gross hematuria.
Family history / predisposing conditions: None.
Other health concerns: Hypertension.
Tobacco use-past: No. Tobacco use-current: No.
Cancer type/location: muscle-invasive bladder cancer w/neuroendocrine features.
Diagnosis date: 12/05/2017
New or recurrent cancer diagnosis: New.
Surgery: None-refused.
Surgical procedure & findings: TURBT 11/10/2017, Cystoscopy w/biopsy 12/05/2017.
Tumor type/histology/grade: small cell, high-grade invasive urothelial carcinoma.
Staging Study: PET. Date: 8/14/2018 Findings: Negative. Tumor - T2 / Stage II Node - N0
Cancer Staging Group - S II

TREATMENT PLAN AND SUMMARY

Patient's Height:
Patient's Weight:
Patient's BSA:
Patient's BMI:
ECOG performance status: Symptomatic but completely ambulatory. Comments: Pt refused chemo-sensitizing treatment with radiation.
Regimen: neoadjuvant cisplatin and etoposide and radiation. Treatment on clinical trial: No.
Chemotherapy agents: cisplatin, IV, 210 mg dose, D1 of each cycle, 5 cycles.
Chemotherapy agents: etoposide, IV 210 mg dose, D1, 2, 3 of each cycle.
Possible side effects of regimen: nausea, vomiting, neuropathy, low blood count, fatigue.
Reason for stopping treatment: Toxicity of treatment per patient's choice.

Treatment-related hospitalization: No
Serious toxicities during treatment: feeling bad, neuropathies, hearing loss.
Ongoing toxicities: Yes, grade 1 neuropathies. Radiation therapy: Administered to the bladder.

FOLLOW UP CARE

Medical oncology visits: every 3-6 months for 1-2 years; every 6-12 months for 3-5 years.
Imaging: abdomen-pelvic imaging only, as clinically indicated Cystoscopy: at 3 mon. and 12 mon., annually yrs. 3-5, then as clinically indicated.

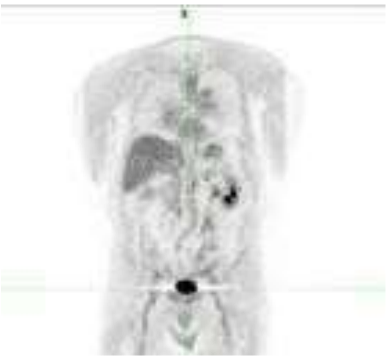
NEEDS AND CONCERNS REFERRALS PROVIDED

5 February 2019

Fifth Procedure

Now I’m getting a bit tired of all these procedures. I know the urologist needs to do them, but it wears you down. There’s the routine of getting to the hospital, getting undressed and onto the gurney, getting the IV stick, general anesthesia, waking up and afraid to pee because it'll hurt so much, and then going home.

My fifth operation (cystourethroscopy with biopsy procedure) showed absolutely no trace of cancer in my urinary bladder. Not even pre- carcinoma in situ like the previous biopsy.



14 April 2019

Another CAT Scan

Fortunately, getting a CAT scan is part of the diagnostic routine. Although not as decisive concerning the exact nature of cancer as a biopsy, the CAT scan reveals a bunch of other stuff which is pretty interesting.

For instance, after carefully reading the transcript (many times), I see that I have coronary artery calcification of 4 cm. Anything above 5 cm is considered aneurysmal dilatation and means I have atherosclerosis or ‘bad cholesterol’ (LDL). Fortunately, I’m being treated for it. I read this report at least a dozen times to search the internet for keywords in the report. Phrases like ‘pleural effusions’, ‘mild perirenal stranding’, and mediastinum. Who knew my ‘pelvic organs are unremarkable?’

PATIENT: DAVIDS, RICHARD CHARLES
LOCATION: CT
DOB:
ACCOUNT:
ORDERING PHYSICIAN:
0414-0018 CT/CT Chest/Abdomen/Pelvis C MR#: M000446848
SEX: M
REPORT #: 0414-0029 STATUS: REG CU EXAM DATE: 04/14/19 DI REPORT
PROCEDURE: CT Chest/Abdomen/Pelvis C INDICATION: F/U BLADDER CA
TECHNIQUE: A non-contrast CT scan of the chest, abdomen, and pelvis was performed. Automatic exposure control was used. Oral contrast was administered.
COMPARISON:
CT dated 5/21/2018. FINDINGS:
CHEST:
Mediastinum and heart: No significant mediastinal adenopathy. Mild dilatation of the ace ascending thoracic aorta measuring 4.0 cm.
There is coronary artery calcification.
Lungs and Pleura: Lungs are clear other than minor linear scarring at the left lung base. There are no pleural effusions.
ABDOMEN/PELVIS: The evaluation of the solid organs is limited due to the lack of IV contrast.
Liver/biliary: The liver is difficult to evaluate due to a lack of intravenous contrast. There are small foci of decreased attenuation in the liver which are difficult to evaluate due to their size. At least some were present on the PET CT although the comparison is difficult. These could represent tiny cysts or hemangiomas.
Pancreas: Normal.
Spleen: Normal.
Adrenal glands: Normal.
Kidneys/ureters/bladder: There is mild perirenal stranding unchanged. No hydronephrosis or hydroureter. There is some mild asymmetric wall thickening of the right side of the bladder although it is not well seen. The significance of this is uncertain especially since the bladder is nearly empty.
Gastrointestinal/mesentery: There is diverticulosis in the colon although no CT evidence of diverticulitis. No colonic distention or wall thickening.
Retroperitoneum/lymph nodes: No retroperitoneal adenopathy.
Pelvis: The pelvic organs are unremarkable.
Other: No free fluid or free air.
Musculatlive: Degenerative changes in the thoracic and lumbar spine. There is bilateral gynecomastia.
IMPRESSION:
No evidence of metastatic disease to the chest.
Tiny nonspecific foci of decreased attenuation in the liver which are too small to adequately evaluate. If there is clinical suspicion of hepatic metastases, an MRI of the liver may add additional information. Diverticulosis without diverticulitis.

Bladder not well distended. Mild asymmetric wall thickening on the right as compared with the left of uncertain etiology. Correlate with cystoscopy.
Dictated by:
Transcribed by: BS 04/14/19 1348

22 May 2019

Sixth Procedure

After getting settled on the gurney for pre-op, I strongly urged the first nurse to not start the IV stick in the back of the wrist. Chemotherapy treatments weaken blood vessels. That's a known fact. So does kidney dialysis. But she persisted and failed. Trying to insert a small needle in the back of my wrist felt like I was stabbed with a dull Number 2 pencil. I was getting impatient and a bit loud in my protestations about not sticking me in the back of the wrist.

Six nurses and 5 sticks were needed to find a 'good' vein in my basilic right arm vein. They kept saying it was for the convenience of the anesthesiologists. I looked at the two anesthesiologists who resembled NFL linebackers and thought they could just as easily lift my entire body as well as my hand during the operation setup.

I thought the patient comes first but maybe priorities need readjustment. I always sent my recommendations to improve patient care to VP Patient Care Services and Chief Nursing Officer who thanked me for the input. Whether things change – who knows?

My sixth operation (procedure) and biopsy showed absolutely no trace of cancer in my urinary bladder. Hallelujah! At this point, I decided to call it quits with the additional procedures every 6 months. After 2 clear biopsies, I just did not want to undergo the anticipation of going to the hospital again, more general anesthesia, needle sticks in my wrists and arms. The cisplatin weakened my blood veins to the point that any needle stick collapses the vein.

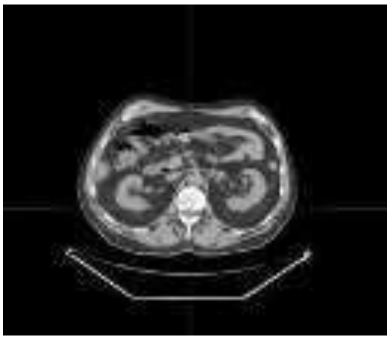
November 2019

Follow-up Urologist Meeting

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 are never sure, but the 6th procedure biopsy confirmed that the bladder wall was free and clear of any carcinoma in situ which sounded rather good.

But who knows? At my last meeting with my medical oncologist, she said that with this type of cancer and your treatment and staging, if it does not recur in one year then it usually does not return.

The protocol in my case is ‘procedures’ (cystotomy) every six months starting in November 2019. At the last meeting with my urologist, after six procedures, I declined any more procedures. I was getting very tired but had confidence in the multi-modal treatment I received. My urologist accepted this decision and said if I noticed any blood in my urine to call immediately. I left the meeting feeling great.



Family, Friends, and Neighbors

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 would 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.

Cancer Care Advisory Council

I emailed this journal to several senior leadership at the hospital. Staff on the Cancer Care Advisory Council (CCAC) read it and invited me to join the council. I accepted. We met every month on the third Thursday for an hour or so. Their objectives are:

Welcome input and feedback from patients and families about opportunities to improve the cancer care experience.

Formulate and recommend policies, programs, and services to improve the patient experience.

Suggest enhancements to the Cancer Center to promote a healing environment for patients and families.

Serve as community ambassadors for the outstanding quality of care provided at the SCH Cancer Center.

When I joined the CCAC had 17 active members. The CCAC was involved in the original planning of the cancer center which provides Reiki services for patients. They host speakers from hospital staff and Gloria Gemma Foundation, support Survivorship Celebrations, coordinate resource guides for cancer patients, Mindfulness Groups, Chair Yoga, and Massage. They produced four educational videos for cancer patients and a lot more.

I made some modest contributions. One idea accepted was to simplify the mission statement. Here is the new mission statement: “To advocate for the best possible patient experience across the continuum of cancer care”. This mission statement was modeled after St. Jude Children’s Hospital and the Red Cross.

Another suggestion was how to improve the cancer patient’s infusion experience. Many patients are alone. I thought why not make it more interesting. The infusion takes from 2 to 8 hours depending upon treatment and delivery mode. This idea was to ask patients during treatment sessions via a questionnaire if they would enjoy watching Osher Life Long Learning (OLLI) videos on their iPads or in-house video during infusion. OLLI “provides learning opportunities to enhance the enjoyment, meaning, and direction of adult lives as well as the health and well-being of adults. OLLI seeks to develop a community of older learners.”

Since patients undergo physical therapy in the hospital physical therapy center I donated one of my ‘Steampunk Mighty Canes’ to the cancer therapy center. These are dual-handled walking stick canes constructed from PVC pipes that engage both hands when sitting, walking, or standing. It was a model for a University of Connecticut senior design engineering project in 2019.

Another idea was to compile stories from cancer survivors and publish a ‘coffee table’ booklet for patients to read while waiting for infusion at the cancer center. Since most CCAC members are cancer survivors, each could write a one-page description of their experience. It would give patients more hope and less anxiety about cancer treatment. The working title of the booklet was ‘I Am A Survivor’. The purpose was to give patients hope and confidence that they are not alone.

The booklet ran into the usual bureaucratic obstacles like approval from all contributors living and passed on, all leadership, and all legal counsel until the end of time. Nothing became of it.

Some cancer clinics have a bell-ringing ritual to signal the end of treatment. After the patient completes all cycles of chemotherapy, they are allowed to ring a ships’ bell once. Since a complete set of 6 cycles would have killed me, I didn’t get a chance to ring a bell. So, I made another suggestion to use ‘successive approximation’ for bell ringing where the patient rings the bell once for completing the first cycle, twice for completing the second cycle and so forth. It would give patients a progrssive sense of accomplishment. No action taken on this suggestion. After all, it is an ‘advisory’ group and prone to ‘process’ rather than ‘product’ as I was told. Oh, well. I tried.

Here is a group photo; a couple of the members passed on. I am at the right end sitting down.

Medicare for All

Members of the CCAC met with the hospital president and CEO who explained the possible expansion of cancer center services while maintaining independence with other cancer centers. His plan includes a multi-million dollar investment in digital technology, especially robotic orthopedic joint replacement. The hospital employed about 1,500 people treating over 6,200 patients in 2019.

At the meeting, one of the attendees asked what ‘Medicare for All’ would have on a small independent hospital. The CEO replied: “It would be a catastrophe. We would lose 50 million dollars off the top. That means layoffs and cutting services across the board.” Why do politicians demand ‘Medicare for all’ without asking hospital CEOs what is the immediate impact? I guess it is another mystery of life.

Paying for Healthcare

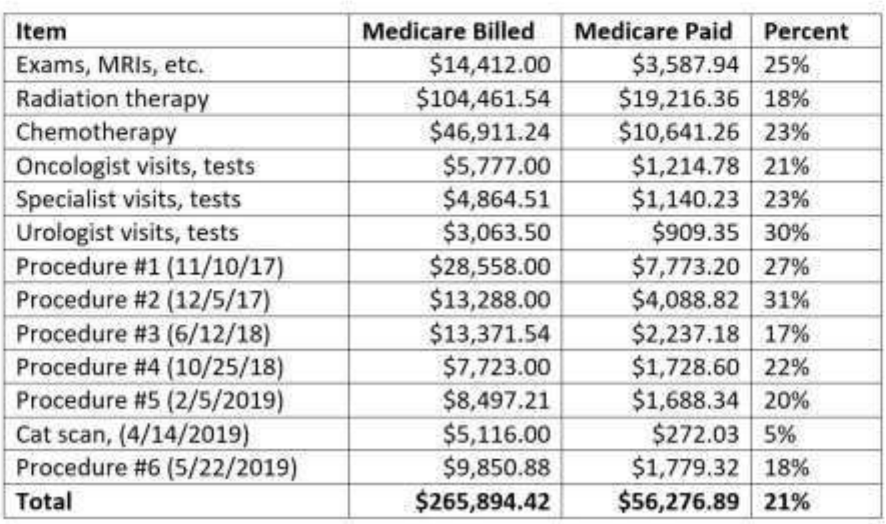
I was curious about how much all these procedures, treatments, and visits cost. I was over 65, so I registered with Medicare.gov. Medicare and Social Security are funded through FICA, the Federal Insurance Contribution Act. FICA is the federal law that requires employers to withhold three types of employment taxes from their employee’s paychecks. These taxes include 12.4 percent of compensation in Social Security taxes, 2.9 percent of salary in Medicare taxes, totaling 15.3 percent of each paycheck. Additionally, employers must withhold 0.9 percent of salary in a Medicare surtax for certain high-paid employees.

It took only a few minutes to complete the online forms to receive copies of my benefits. I received hard copies of both AARP and Medicare charges for healthcare services I received 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.

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 was not necessary. Imagine! Paying only $20 to listen to Bob Seger during treatment for 7 weeks? Since I was over 65, Medicare pays for the treatments thanks to my FICA contributions over 42 years of working and paying into my account.

How Much Did It Cost?

The following table consolidates the Medicare billing submitted by my various healthcare providers. The grouping of all the invoices into consolidated service titled ‘Item’ in the table helped me organize the charges. They include charges by my primary care provider, consulting physicians, labs, imaging service, exams, pathologists, radiologists, oncologists, urologists, nephrologists, hospitals, and clinics.



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 (10/25/18)	$7,723.00	$1,728.60	22%
Procedure #5 (2/5/2019)	$8,497.21	$1,688.34	20%
Cat scan, (4/14/2019)	$5,116.00	$272.03	5%
Procedure #6 (5/22/2019)	$9,850.88	$1,779.32	18%
Total	**$265,894.42**	**$56,276.89**	**21%**

The two left columns are a terse description of the service and what Medicare was billed. The next column shows what Medicare paid and then the right column shows the percentage paid by Medicare of the original billed amount.

Healthcare providers who take Medicare patients are getting 21 cents on the dollar. That’s like me giving the checkout clerk a dollar bill for a five-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 are there 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 so healthcare practitioners can get the right information in a timely way without wasting time? Can healthcare providers be completely honest with their adult patients? I guess these are some of the mysteries of life.

Author

Richard Charles Davids is a retired human factors engineer with 34 years at Lockheed Martin Space Systems Company, Sunnyvale, California. He grew up in River Edge, New Jersey. He was graduated from the University of Rhode Island with a Bachelor of Arts in Psychology in 1971 and from New Mexico State University in 1974 with a Master of Arts in Engineering Psychology.

Richard Charles Davids, Julie Yingling, and their doggie ‘Ziggy Stardust’ live in West Kingston, Rhode Island. He has sponsored and privately funded over a dozen senior design and capstone engineering projects at New England universities.

Projects study and propose solutions to issues in environmental safety, homelessness, refugee shelter, human waste recycling, driving and police safety, fall and injury prevention, healthcare, flood control, physical therapy, and snow plowing. A couple of projects won NMSU WERC Environmental Design awards.

Richard Charles Davids manages a website dedicated to exercise and Alzheimer’s Disease at www deepsloweasy dot com and a website proposing solutions for refugee shelter at www thehomeshelter dot org. Other interests include gardening, walking Ziggy, swimming, updating websites, reading, and thinking of new senior design engineering projects.