

A Guy's Guide to Throat Cancer

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not stop despite the chemo treatments. Betty had dozens of friends and colleagues who were concerned with her and always anxious for any updates. She eventually was settled into a nice nursing home in Parma in her school district, making access easier for her school buddies but was down at the main campus of University Hospitals in 4 5 Edmund A Rossman III A Guy's Guide to Throat Cancer

Backstory

This story begins with telling you about my sister Elizabeth,

aka Betty or B because our very young nieces had problems pronouncing her name, henceforth, calling her Aunt B, and me, Uncle E! You know how adorable little kids' mistakes can "B," and how they make their way into a family's history forever.

In the fall of 2017, Betty came down with an inoperable brain tumor. It was not discovered at once, but the nature of her symptoms required her to have 24-7 care. She was born with just one kidney and had complicated medical issues due to the tumor including a physical imbalance that made her dizzy and unable to go upstairs. Finally after stays in various hospitals and nursing homes, when we pressed to have a scan for a concussion injury, it was discovered that she had a brain tumor. She had chemotherapy treatments over the course of three months, going back and forth for overnight stays at the hospital and nursing home between August and December.

Betty had just started her twenty-fourth year as a teacher for the Parma School district. She was also busy as a volunteer at Our Lady of Angels Parish and had friends and family throughout the country concerned about her. She was never a big social media person, but she did use it for a short while in the first month. However, the tumor started acting on her cognitive and physical functions, and did

Cleveland several times. All in all, she was in three different nursing home and six different hospital rooms in the course of four months.

We as a family did our best relaying what was going on, which hospital she was at, where to send cards, and where and when she could have visitors. It was challenging to say the least, but we managed.

About half way through this, in early November, I was diagnosed with throat cancer. To be specific, oropharyngeal cancer. I could never pronounce it right, so I just call it throat cancer. The tumor in my neck was removed on November 30, and the biopsy a few days later confirmed it was stage 4B oropharyngeal cancer. I'd need a combination of chemo and radiation treatments. Stage 4C cancer would've been terminal, so I dodged the bullet there.

Betty ended up passing away on December 30, 2017, less than a year after we had suddenly lost our mother Eleanor on January 5, 2017. Our impromptu network was efficient at getting the sad news out, and over one hundred fifty friends and family were able to come to Betty's services, despite the cold Cleveland winter.

Due to the nature of our circumstances, my doctors, Dr. Shah and Mendpara, said I could postpone treatment a little while but had to get started by mid-January. I put in for an FMLA leave for twelve weeks starting then. When discussing with my co-workers the communication challenge we had with Betty, my supervisor, Cindy, asked if I'd ever heard of CaringBridge. CaringBridge is a social media closed platform, meaning I as a patient would control who could have access. People use it to send out an update once instead of five or six times like we did with Betty, hoping we didn't forget anyone. I checked it out and thought *Man, this would've been great to have with B!*

So I registered for it, invited my Facebook friends and others to subscribe and started sending out posts. In essence, journaling my battle with cancer. Many of my network had just gone through the trauma of losing my sister, just on the heels of losing my mother who had, at age eighty-six, been the last of her generation and the matriarch of our family. It was especially hard on my father, who I am named for, after losing his wife of sixty years to lose his eldest daughter and now faced with possibly of losing his eldest son. I didn't want to compound anyone's grief or worry, so I made most of the posts pretty upbeat. CaringBridge also allows for replies to my posts like Facebook, and once I figured out how that worked I really enjoyed their comments. When my battle was over and I'd won (for now), many people told me they were glad I was healthy, but they'd miss my posts! So for all my friends and family who supported me, I

say thanks, and this book is my way of paying back the love you showed.

The format is simple. First my raw CaringBridge entries, then the 'Extended version' (which for songs like Gimme Shelter if you google them, the extended versions are way cooler), my commentaries on the situation I would tell people about in person or on the phone and more descriptive of the various videos I used since the reader probably has not seen the same ones. My dad is not into computers that much so I would go into the CaringBridge descriptions with him, making him laugh and bolstering his spirits as much as he would do the same for me.

The Bible quotes are from a monthly religious magazine called *The Word*, which has the readings from every day's Roman Catholic mass. As I was a "shut-in" for almost three months straight, outside of going to treatments, I got into the routine of reading that day's Old Testament, Psalms, New Testament, and gospel readings. As you will see many times they applied to what was happening to me. Those coincidences were more than mere coincidences to me and showed me God was looking out for me, not letting my spirit grow weak, as I'm sure Mom and Betty were too.

I'm in remission now as I begin this in November of 2018. My only regret is I didn't post more, but I didn't realize God would have me use my passion for writing to get this story out despite having chemo-brain and some memory lapse. This story is not just for my friends and family but to all the guys and their caregivers, who are facing the same ordeal. Don't let pity or pride wall you off from your friends and family. Take it one day at a time, always looking for the good, the funny, the encouraging sounds and signs that point toward the joy of living.

"When cancer kicks you in the —, have it kick you forward!"⁷ A Guy's Guide to Throat Cancer⁶

My Story

January 20, 2018

W elcome to my CaringBridge website. I'm using it to keep family and friends updated in one place. I appreciate your support and words of hope and encouragement. My chemo and radiation treatments for throat cancer begin on Monday, January 22. Chemo drug is Cisplatin and takes about six hours to be applied, followed that day by a ten-minute blast of radiation. Chemo will also be done on February 12 and March 9. Radiation treatments will be everyday Mondays to Fridays until March 9. After that, the radiation resonates against the cancer without the beam for three to four weeks. I had a food tube placed in me on January 16, kind of reminds me of being a Borg from *Star Trek*. Also I had a medical port, which was placed inside my chest on January 17 so they don't keep pricking my veins for the chemo, blood draws, etc. The University Hospital team is very impressive. I also have a nutritionist and speech therapist that'll help me keep swallowing correctly. I got plaster casts of my teeth today, which are used to create "tooth trays." I'll use for fluoride treatments twice a day and plan to use them as paperweights! Stephen King would be proud, ha ha.

Extended version:

When I heard I might never taste anything again, naturally I was a bit PO'd. What would life be like without being able to taste a great beer, burger..., fill in the blank for your own appetite. So just to be sure, I scheduled a second opinion with the best doctor I could

find in the city treating this disease. Thanks to Google and the fact that I live in Cleveland—home of many fine hospital systems and all very competitive—I zeroed in on one and arranged for a review of my condition. My hospital sent all my diagnostic material, even slides of my biopsy, to this other doctor. He concurred on what my condition was and the treatment regimen. He did not agree on putting in a port or food tube unless I really required it.

He and I had a difference on balancing the "threshold of pain" and the risk of infection from the extra equipment. The port saved my arm from becoming a pincushion. As you'll see ahead, chemotherapy doesn't require only one injection of liquid plutonium (which basically is what it is) but several injections of various things. As if I didn't have enough problems, I didn't want to add "Nurses trying painfully hard to find a vein" to the pile of trouble I was facing.

He also would not recommend putting in a food tube unless it "really got bad" swallowing. It's all well and good trying to tough things out. Yes, it'd be really macho being independent of the tube and trying to swallow enough nutrition to stay healthy. But I'm a terrible cook, live independently, and couldn't see not taking the prophylactic precaution of having a source of nutrition inserted in my stomach prior to wasting away from hunger and having to go through that medical procedure halfway into my other treatments. I can't imagine having that procedure when my immune system was already down or getting up and down from the radiation table for a couple of weeks while the soreness went away, not to mention having my body to learn to sleep another way so I wouldn't roll on this new thing in my chest. It was definitely worth doing in advance while I was rested and relatively healthy.

One of my favorite books on working out is *Burn the Fat, Feed the Muscle* by Tom Venuto. He talks about progressive increments to build muscle. In the first week of training, doing easy sets of weights to get your body accustomed to the movements, then progressively increasing the weight load. These pretreatment precautionary measures were like that for me. They were some serious medical procedures—getting me acclimated to the hospital atmosphere, prepping 9
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my body for a more rigorous experience. The port and my food tube were weird, true that, but were also my aces in the hole down the line.

I mentioned Stephen King because as most of my family and friends know, I'm a huge fan. One of my plans for being off work was to catch up on all the movies and old books of his I hadn't done in a while. Little did I know how drained I was going to be. If I'd

have a buck
watching TV
Browns!

1. Tested and Ready

January 20, 2018

Yes, last week was all pretreatment tests and fittings, and next week the treatment begins.

Oh and yes, this site is ready too! Thank you to my beta-testers, Tom, Ann, and Kathy, who checked it out on various devices!

They said in one of the prep classes to keep a diary, it helps to prevent chemo-brain, so I'll be posting various things (won't get too graphic) that I go through or have found inspiring...tunes, quotes, etc.

Today's the feast day of Saint Fabian, a pope and martyr from around 250 A.D. A scripture reading from Wisdom 10:12 was used in the entrance antiphon that seemed appropriate to the moment "The Lord granted him a stern struggle that he might know that godliness is more powerful than anything else."

Comments:

Annie A.

Hey Ed, talked to Stark girls tonight and the Nuns at SJA Convent (St. Joseph's Academy-my sisters' high school) already have you on their prayer list. Lotsa Prayer Warriors out there for you!!! xoxo12 13 Edmund A Rossman III A Guy's Guide to Throat Cancer

Mary O'D.

Hello Eddie—We are praying for you and know you are STRONGER than your diagnosis and you are going full force to be cured of it. We would love to help you in any way that you need and are here for you. Go kick some ass!!!

John—your favorite cousin

Hey cousin, Thinking of you. Can they pour beer in the feeding tube?

Extended version:

I had two surgical treatments and one radiation “fitting” the week before treatments started.

On Tuesday, January 16, I had my “food tube” inserted. It was an all-day procedure that I had to fast for. They’re very thorough about asking questions about who you are and when you were born. Every doctor, nurse, and anesthesiologist did this, which was a little annoying, but better than making them mistake me for a colonoscopy patient. Leaving my brother, Tom, in the waiting area after getting prepped with a surgical gown, they prepped me for a few hours with drugs designed to get my body ready for the anesthesia and surgery, then they wheeled me through the corridors to the surgery room, which was fun after being in a curtained-off bed area for two hours. The crew had just come back from lunch, and I was glad they’d be more focused on me rather than their *Subways* (the hospital main food franchise, one of my favorites too) They BS’d with me for a few minutes, explained I’d be asleep shortly and before I could scoff at that, I was gently being woke up in the curtained bed area again, except this time with a large bandage just south of my solar plexus. Tom came in, and we hung out for a long couple of hours. When the time came for me to start moving, a special nurse came in to explain a girdle like wrap they wanted me to wear to help stabilize and protect the tube. This tube comes out about four to five inches from the body, and if left loose, it would hang over my stomach just below the belly button. I never left it loose because it would pull at the top and feel like it could slip out! I got rid of the girdle after the first few days and became an expert at taping it close to the body. Should’ve shaved first though; that would’ve kept me from some needless hair tugging!

Surprisingly the next day they scheduled for the port placement. This was in another part of the same hospital but did not require fasting or getting knocked out. It took about four hours, comprised of an hour of waiting, getting prepped, the procedure, then post-op waiting. Tom took me there too. I had the funniest trio of nurses. They could’ve been right out of a *Seinfeld* skit, making cracks about each other, their friends, and families almost nonstop! They also were playing a pop radio station and when they weren’t chatting, one would be singing. I only needed a local anesthetic, but the procedure required some ultrasound and other *Star Trek* type of targeting diagnostics. The port is about an inch wide or so, and I carry a card in my wallet that explains technically what it is in case I’m in an accident and emergency crews need to know what type of device it is, how it can be used, etc. The procedure is basically cutting me open, securing the port to my upper chest area, and feeding a tube into one of my major blood vessels to distribute whatever drugs or hydration I’m being given. It’s an easy target but requires some training and the right equipment to use. It is better than constantly pricking my arms, looking for veins. It is like using a soft-nosed dart and dartboard instead of the more traditional hard-steel darts and corkboard.

In the '90s I started one of the first websites in Cleveland as business manager of alternative radio station WENZ-FM *The End*. After Clear Channel bought us and I was laid off, I started teaching for Kent State’s Journalism School and working at Lakewood Library’s Technology Center. I worked on a lot of internet projects, so naturally knew the value of testing platforms before a big launch. I’m really glad my team gave CaringBridge a thumbs up!

And speaking of teams, I’m glad my sister Ann and girlfriend Kathy accompanied me to the chemo class! We went about two weeks before chemo started, and frankly I forgot a lot of the details. 14 15 Edmund A Rossman III A Guy’s Guideto Throat Cancer

It is not a bachelor-friendly lesson plan. There was a lot of talk about germs, using hand sanitizer, a soft toothbrush, baby shampoo, not exactly manly stuff. They also discussed moisturizers a lot. Almost everyone's head in the class (fifteen women, two guys including me) bounced like bobble heads when the instructress discussed products like Lubriderm, Aveeno, Vaseline Intensive Care, not to mention fun brands like imodium for diarrhea, milk of magnesia, and dulcolax for constipation. I was blissfully ignorant going into this talk, but as you'll see later on, I had major painful complications with some of these conditions. It's called learning the hard way. Avoid that if possible! During post-treatment, my workmates and friends did say I looked a lot better than they expected. Aquaphor was recommended for my neck region, where I had daily radiation treatments. It did start turning red like a severe sunburn, but thanks to my nurses nudging me and Kathy and Ann slathering the stuff on me, the damage never really got too painful and went away quickly. Thank, God, for women! "Whatever you do in life, surround yourself with smart people who'll argue with you" (John Wooden).

The prep class in hindsight was pretty useful. They got me to stock up on things like Gatorade and yogurt, hydration-oriented food with vitamins like citrus. I took it as advice from a lot of nutritional suggestions as if preparing for a marathon or an iron-man race, which in a way I was.

Chemo-brain was a term I'd heard and always just a joke I used when taking cold medicine. It's not a joke anymore. It's a form of what I call dementia—affecting memory, attention, discipline, verbal discourse, and the ability to learn. Thank goodness, the hospital had this great "chemo class" that taught me physical things like what metrics they use to watch your health and response to treatment. Things like white blood cell counts and platelets as well as the aforementioned hygiene and nutritional advice. And thank goodness, friends and family could join me in it because as I was being treated, much of the advice faded like background noise to me.

The Bible quote I used is also letting guys (and anyone) know that there will be a tough struggle ahead, and all the scientific prep in the world won't matter without faith and acting in a godly way—that is in observance of His laws and reverence for the role models that God and Jesus present to us. Jesus didn't indulge in pity on Calvary. He did have family and friends there to support him even if it was just bearing witness.¹⁷ A Guy's Guide to Throat Cancer¹⁶

2. EZ Does It

January 22, 2018

It was a long day, but I am glad to get the first chemo and radiation treatment out of the way. I was in an easy chair throughout the day, watching the news, reading, snacking, slipping blue Powerade, not a bad life, haha.

I was apprehensive though. In the morning I heard this rocking tune I had in my head all day, a motivating call to arms. It was *Walk on Water!* by Thirty Seconds to Mars.

Celebrated by having a Heath shake from Steak and Shake!

Comments:

Audrey J.

Smart man. Never underestimate the healing powers of a Steak & Shake milkshake!

Kimberly P.

I had no idea that Ed was dealing with this until recently. That's why I hadn't seen him at the library for some time. He's a sweet person who has a warm personality toward all of us at the library. I wish Ed a speedy recovery and stay strong, because all of us are standing in his corner. ED ROSSMAN STRONG!!!

Extended version:

“do you believe that you can walk on water? do you believe that you can win this fight tonight?” That was the chorus from this song. All

the shots in the video were filmed in one day on July 4, 2017, but I didn't know that as I was being driven to my first chemo treatment. I just loved the timing of hearing it and the attitude it expressed.

The day in chemo went from 8:45a.m. to 3:15 p.m. Kathy drove me and assembled a picnic-type bag with yogurt, Gatorade, nutri-bars, and some cut-up fruit. The staff also served lunch. I think I tried a turkey sandwich. Thanks for not remembering, chemo-brain!

Of course everyone's treatment will be different, but here's the timeline of how mine went. The biggest shocker to me was the variety of preparatory fluid injections there were and how only a little time the actual Cisplatin treatment was. We're dealing with liquid plutonium here; I guess that's for the best. It obviously had its impact! As you'll see from the variety of hoses they needed for the entire chemo treatment, I'm really glad I had the medical port. About ten were needed that they otherwise would've been sticking into my arm veins for...

8:45 a.m.—A saline solution containing potassium and magnesium for two hours

10:45 a.m.—A saline solution with lasix, a diuretic and two tabs of compazine, plus another bag of Aloxi for an hour

11:45 a.m.—Decadron, a steroid to fight anti-nausea, dexamethasone, about fifteen minutes between the two bags (sounds like a George Burns joke...I was in chemo, stuck between two bags)

12:00 p.m.—Emend, also to fight nausea, and mannitol, a kidney protector, also for about fifteen minutes

12:15 p.m.—Cisplatin, 225mg worth. The nurses were dressed in biological warfare outfits to administer this. They had all been wearing mouth masks anyway because it was January, the height of flu season, and obviously both the patients and pro's needed all the protection they could get. But the seriousness of seeing them don the 18 19 Edmund A Rossman III A Guy's Guideto Throat Cancer

Andromeda Strain-type outfits told me we were getting down to the serious nitty-gritty for an hour.

1:15 p.m.—A posttreatment hydration time, straight saline for two hours

3:15 p.m.—I was released!

The hospital made us as comfortable as possible. The chemo class had actually ended with a tour of the Infusion Center where the treatment would be. We were in a two-person cubicle with a really comfortable lounge chair, TV and remote for each side, curtain if we wanted privacy, and for the Cisplatin application, and chairs or benches for visitors. They even had an “oven” where they kept heated blankets! I didn’t indulge at first but would as the day went on...and on...and on...

I also learned how to disconnect the stand-up intravenous unit from the monitoring electronics power source (they also had backup batteries) and walk to the local men’s room. More on that walk later! I fought hard to contain the dragon and not make that walk, but then I realized in the last two hours that I needed the Cisplatin out of me, that’s why they give all the diuretics and saline hydration. So I gave in and sure enough, I started making the walk every twenty minutes or so.

Fresh air after being released tapped down the urge for a bit. My weight was about two hundred thirty, I could stand to lose a little water weight. However, afterward I did want to celebrate a little so we went to a drive-through restaurant that offered discount craft shakes until 4:00 p.m. I rarely was able to take advantage of it because of work. It tasted great and little did I know how soon it would be when I would not be able to enjoy it again!

I expected the chemo treatment to be more of a battle that initial time than it was. Overall it was a pleasant day, thanks to the

steroids! Even that night I was feeling good. However, I followed the doctor’s orders and did not go out to mix it up with friends at a bar to brag about my first treatment. Posing like Rocky when he was getting slugged by Clubber Lang and kept saying, “Aint so bad, Ain’t so bad,” after each punch. I stayed in and waited to see what they predicted would be an inevitable crash once the steroids wore off.

do you believe that you can walk on water? do you believe that you can win this fight tonight?

In Matthew 14:22–34, Jesus was seen walking on the water in a storm, toward the disciples in a boat. Peter (to confirm that Jesus was not a ghost) asked that he would come out to him if it is truly him. Jesus said yes, and miraculously Peter got out of the boat and walked on water himself. However, he’s distracted by the storm, lost focus on Jesus, and started slipping under the waves, crying for help. Jesus saved him and mildly chastised him, asking, “Why did you lose faith?”

Belief in the buoyancy of Christ can give anyone the power to persevere and create miracles themselves. Walking over the waves of chemicals being placed in the body, supported by the faith in God that there will be a good outcome of all this, can turn the tide of fear into one of optimism and as Nicholas Murray Butler said (in a quote a friend gave me in a plaque), “Optimism is the foundation of courage.” The power to overcome adversity (as my dad liked to say in closing conversations with his fellow police officers) comes to those who “keep the faith.” Jesus told Peter and the disciples in the boat, keep the faith, and you too can do miracles. You too can walk on water and win this fight!²¹ A Guy’s Guideto Throat Cancer²⁰

3. Rockin' Radiation

January 23, 2018

For my second day of radiation, I heard Journey already playing in the room...I don't know if they had it on for my sake or theirs, but I asked them to leave it on. Funny, I don't like the band that much, but I know all the words to their hits! And I knew I'd have that tight mask on for only about two songs, which did go by quick. I told them about my background in radio briefly and said, "We'll have to rock out again tomorrow!" Two other patients were in the waiting room. They were very chop-chop there, very efficient.

Don't stop believin', hold on to that feelin'
Journey—Don't Stop Believing

Comments:

Jim R.

Hi Eddie—Glad a Journey tune helped smooth the way. Saw Star Wars tonight in Brooklyn on the big screen. Thought of you! May the force be with you. Cousin Jim

Stephanie T.

Hi Ed, I miss you at Woods tonight. Our Simone brought delicious peanut cookies and potatoes chips, I will eat one for you. Stay joyful through your journey. You're in my thoughts and prayers. ☺ ♥♥

Extended version:

Going under the radiation gun typically causes apprehension in everyone, I'm sure. The radiology team I had were excellent. One had even remembered me from my church; we had a mutual friend whom I used to teach with and who worked the church fish fries as well as a reader at the Sunday masses! Hate to say it, there was a time when I attended more fish fries in a year than masses. Anyway, it was nice of her to recognize me, put a little normalcy into a surreal situation.

The hospital must've taken a survey and found that patients loved heated blankets! Here was another department who had an oven and

was glad to cover me up with one. For the neck radiation blast, I did have to take my upper body clothing off each time so these blankets were actually pretty practical because the room was kept a little chilly. I would hate to have the radiation gun overheat! No *Star Trek* phasers on overload needed here!

They had a mask that had been custom-made for me that I saw for the first time, and that couldn't be worn over clothing. It went from my shoulder region up over my head and made with a see-through mesh, so I wasn't blind. It looked like something medieval-jousting knights might wear, if it were made of metal. On it, they had marked specific places where they wanted to target the radiation beam, and when I was settled on a table, they would work on each side of me, aligning it just right. Then they asked if I could hear the music okay, and then skedaddled out of the room, closing a large vault-like door to the outside. Clang!

The treatment consisted of the Intensity Modulated Radiation Therapy (IMRT) technique. This is a computer-controlled approach that used precise targeting of the tumor based on a 3-D model created from my previous CT-Scan and MRI review. It "sculpted" around the tumor so that surrounding tissue would be less affected. While in the radiation chamber, I could hear the device rotating around me, shooting the radiation in at various strengths based on the target it was shooting at. Kind of like different calibers of bullets could be loaded into the same gun, based on what they had to go through, 22 23 Edmund A Rossman III A Guy's Guideto Throat Cancer

plastic, wood, car windshields, concrete, etc. No “Smart Gun” exists like this now; I’m sure it would be handy to prevent collateral damage. I remember someone advising to watch out for the caliber gun you bought for home defense. You wouldn’t necessarily want a shotgun if you lived in a crowded apartment complex for fear of the shot tearing through the walls into the apartments next to you! This computer-controlled radiation gun technique, IMRT, tried to avoid collateral damage as much as possible.

The treatment would last for about ten minutes long, fifteen to twenty minutes including doing a visual ID and dressing, etc. They let me bring in my own CDs and also had Pandora available if I just wanted to listen to any particular genre of music like alternative, Motown, or ’80s rock. They had a computer screen with my picture and vitals on it and every time they asked, “Is this you?” These people were fun but not playing around with misidentifying anyone.

I like rock in all its styles. I brought in CDs by Yes (lots of longer tunes), some faster paced tunes by Prince and Led Zeppelin, a Motown classics CD with a lot of energy, and a great Genesis greatest hits CD that the hospital owned that we played, although I was bummed that we couldn’t hear all of Suppers’ Ready (twenty-three minutes). We split that one over two days. I even brought some Aaron Copeland in once when feeling a bit patriotic to hear Henry Fonda do the narration for the Lincoln portrait for President’s Day. The staff were a little surprised, but I’d worked at a classical radio station in Denver and discovered the piece then. It fitted the treatment time perfectly and was inspiring to listen to. A guy can’t be too predictable!

The actual treatment was painless, although it was really doing a number inside me. The music I picked was a great distraction for me. I learned that distraction from thinking about a bad thing with thinking about a good thing was a Jedi mind trick I could play on myself to control my own attitude. I thought that by not thinking about the actual treatment going on, the less stressed I was, and the more effective the treatment would be. Just having the belief that it would work, lying back, and enjoying the tunes had a healing outcome...kind of like what happened in my golf game! When I was finally able to play again that summer, I was so grateful to be able to play again that nothing bothered me, and I had some of the best rounds of my life!