# CANCER: FROM DIAGNOSIS TO TRIUMPH

## **MY STORY**

A Comprehensive Guide for Overcoming Squamous Cell Head and Neck Cancer

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#### Cancer: From Diagnosis to Triumph - My Story

A Comprehensive Guide for Overcoming Squamous Cell Head and Neck Cancer

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#### For Cheryl, Heather and Austin

I would not have made it through this without all of your help, love and support. I love all of you.

#### For readers of this book

"You're braver than you believe, stronger than you seem and smarter than you think." - A. A. Milne

"Healing takes courage, and we all have courage, even if we have to dig a little to find it." - Tori Amos

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### Purpose of this book and overview

It's been a few years since I was diagnosed with squamous cell oropharyngeal cancer. As the years have gone by, I've continued to improve health-wise from the side effects of the treatments namely radiation and chemotherapy.

This book is about my journey and how I made it through the challenges I faced.

I'm not a doctor and I know there are physicians who write books about this type of cancer, but have never actually been through it personally. The perspective changes when you are the one being treated for the disease, dealing with the emotional feelings, the side effects and the worry about "will I be cured?"

I know there are those reading this who are either dealing with this type of cancer now, or know someone who is. My goal with this book is to not only tell you my story, but to give you necessary commentary as to the entire process - from diagnosis to recovery. I've tried to provide sound advice and information without a lot of technical medical mumbo jumbo. I wanted this book to be easy to read and understand. I also wanted to give you hope that you can beat this.

Just know you are not alone in dealing with this very common cancer. Let's begin with my story. LC

# Introduction

### My Story

I'll never forget the day. December 26, 2020. The phone rang, It was my doctor...

Let me back up. In September, I had gone in to my oral surgeon to have two impacted wisdom teeth pulled. Since I was in my 60's, it was a very difficult extraction. My lower right tooth in particular. The tooth had fused itself to my jawbone. After a long and uncomfortable (but successful) surgery, the doctor prescribed some pain medication and an antibiotic to prevent infection and to help with swelling along my jaw line.

At my follow-up a week or two later, my swelling had gone down everywhere except the lower right area of my neck. The doctor said I had a swollen lymph gland and he prescribed another antibiotic and I was told check back in with him in a week.

At the end of the week the swelling still had not gone down and it was recommended in no uncertain terms that needed to get a CT scan of that area. At this point I was not concerned at all about what was going on.

The scan came back and showed there was something unusual with that lymph node. This concerned my doctor and he immediately sent me to get a needle biopsy of the lymph gland. I was just a little bit anxious, but still thought this was no big deal.

The biopsy was done the week before Christmas and I waited for the results. After some time had passed, I began to wonder why no one had called with the results. My family had a nice Christmas and then on December 26th the call finally came (my doctor had waited on purpose to wait until after Christmas to phone me).

That's when I heard the words for the first time, "The test was positive. You have squamous cell head and neck cancer." It was graded at stage 3, but luckily had not spread to any other areas of my body. I credit the urgency my oral surgeon exuded in my still being here to tell you this story.

My life would never be the same.

I was still in a bit of disbelief with the diagnosis. My research showed that almost 80% of people who got this type of cancer were smokers. I've never smoked. Or possibly caused by the HPV virus. At the time, I didn't know what that meant.

My treatment protocol would consist of 35 daily radiation treatments, each lasting 20 minutes and 6 chemotherapy rounds.

My treatments were to begin in early January of 2021. I was fitted with a very uncomfortable wire mesh face mask that would then be placed over my face and bolted down to the radiation table to keep my head from moving. I would get radiation Monday through Friday and could not miss a day, as I was told it was the "cure" for the cancer.

More on the word "cure" later.

A difficulty with the radiation was that the cancer found in the lymph node was only an indicator that I had cancer. It did not mean that was the origination site of the disease. The doctors were never able to pinpoint where my cancer was. So, rather than having targeted radiation to a specific small area of my neck, I literally had my entire neck radiated, which caused some of the long term after effects I'll discuss later.

Another precursor to me beginning radiation was that all of my teeth had to be in good condition before treatment started, so they could withstand the radiation. I had three teeth that needed to be pulled.

Weekly chemo would be on one of the days I had radiation. Luckily, due to advances in chemotherapy drugs and the stage of my cancer, I didn't need a very strong dose of the drugs during my visits. The result was I had no nausea from treatments. But I did experience some side effects I wasn't made aware of ahead of time.

I continued to work my day job and during my lunch break, I'd go over to the cancer center for my radiation and chemo.

Radiation has a cumulative effect over time. For the first 3 or 4 weeks of treatments, I felt no different. But shortly thereafter, my throat began to get sore. Gradually, at first and then quickly it became difficult to swallow anything – even liquids. As the pain got worse, I began losing weight, as I could barely eat anything. I eventually lost 65 pounds. I don't recommend cancer as a weight loss program. 8-)

One day I went in for my chemo/radiation day combo. I went to the chemotherapy area first, had my temperature taken and got my chemo.

I then crossed the hallway to get radiation and they took my temperature again. It was 102 degrees. I tested positive for the original strain of Covid-19. Another kick to the gut.

Now I had to quarantine for a week. I was not allowed to leave the hospital as I would not have been allowed back in the building since I had covid. I was admitted to the hospital, put on an IV and administered remdesivir. Luckily I recovered quickly.

At the end of each business day during my quarantine, I was taken to the radiation area via a back door, as not to come in contact with others, for my treatment.

By this time, I was really having difficulty eating and food textures felt disgusting in my mouth. I also began to lose my sense of taste and smell.

After my stay in the hospital, I decided I could no longer work at my job, so I took a leave of absence. My wife and son began driving me to my daily appointments.

Ultimately I had to get a feeding tube inserted into my abdomen near my stomach. It was not a pleasant experience getting it put in.

The tube included a large plastic syringe. At the wide open end I would add liquid nutrition and then inject it into the tube. I still had the ability to eat and drink orally, but the pain was too great to do so. Hydrocodone became my best friend for a while.

I also developed sores in my mouth and a condition of abundant, never ending flow of mucus called thrush. I was given an oral rinse, which didn't help much.

It was a very surreal feeling going through these treatments. Being the person in the middle of the ordeal, my clouded mind thought everything was going fine. I never thought the cancer was going to kill me. But to my family taking care of me and seeing how my body was deteriorating from the chemo and radiation, they were fearful that I might die.

We were living in a two story house at the time and all of the bedrooms were upstairs. My wife was still working and she worried every day that I would get disoriented and fall down the stairs or mix up my medications while she was at work. It was a good thing my son was still living here at the time and could also keep an eye on me.

I do have to mention here that had it not been for my wife (and son) sorting out my meds, keeping nutrition in me, taking me to the cancer center every day, keeping me on track and my daughter calling me often for encouragement, I now truly believe I may not have made it through the treatments. I feel so blessed to have had support all around me. That is important to you as well, if you are being treated for this type of cancer.

Plus I had hundreds of friends on social media messaging, calling and texting me to help keep my spirits up.

My treatments lasted for a little over two months. But the ordeal was just getting started. I began noticing some side effects - many which are still with me today.

I had to keep the feeding tube in for a couple of more months as I still could not tolerate food in my mouth, nor could I swallow easily. My cancer doctor told me I had to keep the tube in until I could eat enough food through my mouth for two weeks and not lose any more weight. I do remember how happy I was when I reached that milestone and the tube came out.

Food still didn't taste good, so I found other soft foods that I could swallow. Cool things like high calorie protein shakes, pudding, apple sauce, ice cream, cottage cheese and sliced and chilled peaches. I was able to tolerate broth and chicken noodle soup.

To this day I still have very little sense of taste and smell. I've been told it could take years for it to return, it may come partially back, or never come back at all. (again - things they don't tell you before you start treatments).

Another side effect of chemo I had never heard of (nor was told about) was its potential effect on my short term memory. I noticed I was forgetting everyday things. When I had recovered enough to begin working part time again and was able to drive to work, I was forgetting where I was driving, or, on occasion I'd get lost and have to GPS my location.

Another side effect I was never told about was that certain chemo drugs (Cisplatin in particular) can cause severe hearing loss in about 50% of patients.

Three years after I finished my chemo, I noticed my hearing was not as good as it had been. I went in for a hearing test and my ENT told me I had severe loss and that the chemo could have been part of the cause.

I would tell you now, looking back, to be sure to ask your doctor about **ALL of the side effects you might experience**. Don't get caught by surprise like I did.

As time has passed, I have learned to enjoy eating again and I can taste some foods. I am hopeful that I'll get those senses back

I was extremely tired during my treatments and slept a lot. It took months for me to get some of my usual energy back. Even today, I probably sleep more than I used to.

The memory issues affected my job performance as well. I was having problems remembering job systems (I was in sales) and I kept forgetting how to use the computer software to enter customer information, forgetting customer names, the definitions of the products we carried and more.

Before my cancer, I was rocking it at this job. I was actually being considered for a management position.

Instead, I was eventually let go from my company.

That was not a good day. For the first time, I felt defeated from losing my job, my income and ability to help support my family.

I have been an entertainer nearly my whole life. I am a magician, ventriloquist, a singer and a guitar player. My memory shortcomings caused me to forget how to do some tricks, forget scripts and how to play songs on my guitar I had memorized for years. The radiation to my neck caused me to lose my normal speaking voice for a time, so I could not sing or do ventriloquism.

To help keep my spirits up, I would often order magic tricks to learn and to keep my mind distracted. I also started purchasing some old TV show comedy series I used to love as a kid and binge watch them. That helped my mood a lot. Give yourself small rewards as you move forward.

Another bummer (and I expected it), is I lost my hair. I have always been vain about my locks.

My hair had been thinning for a few years before I got cancer and I had gone to a hair loss clinic in Indiana - "PAI Medical - We Grow Hair Indy" for a transplant.

My transplanted hair looked phenomenal. but after chemo, I lost all of it. Thankfully, due in part to the procedure PAI used, my hair did indeed return. And transplanted hair is genetically programmed to never fall out. That was great news and a relief. Although my hair strands were thinner than before treatment.

Something I didn't expect was when I tried to grow a beard. It should have been white like my natural hair color. However, it came back as a mixture of white and jet black - not a good look. Just be aware that you may have changes to your hair quantity, texture and color after chemo.

Throughout all of my entire medical treatments and ups and downs, my family was very supportive.

A few weeks after my treatments ended I went to my doctor to get the results of my tests to see if the chemo and radiation had worked. I was pronounced cancer free in May of 2021. What a great thing to hear!

Earlier in the book I mentioned that my doctors said I had a 95% "cure" rate for my type and stage of cancer. So I was a bit surprised when I asked that day if I was cured. The answer was, "Well, we don't like to use the word 'cure.'" Just keep that in mind when you have your results follow-up.

So here we are nearly four years later. Let me give you an update as to how I'm doing at the time of this writing. I'm still cancer free.

First, let me say this book is not just to help you through your journey with squamous cell cancer with the facts of the illness, but to also give you confidence that you'll get through it.

This book and my story might sound like a downer, but let me be clear as I look back now.

I wanted to be as honest and transparent as I could as to what all I went through.

But get this:

**My life is great!** Even though I had the challenges of going through everything associated with cancer treatments, at the end of the day I grew closer to my friends and family, changed some of my diet and exercise protocols to make me better physically and worked on having a more positive attitude.

The 65 pounds I lost is weight I should have never packed on over the years. I'm now at the weight I was at when I was younger. I've kept it off. I still have bad days mood-wise, but I've gained a new and brighter outlook on life.

I still have very little taste or smell, but enough to enjoy eating again.

My short term memory has gotten a lot better to the degree that I can play my guitar again and remember scripts, song lyrics and chords. And I can drive like I used to without getting lost.

My voice is nearly back to normal and I can sing again (only without being able to sing as high as I could), I can perform ventriloquism and magic again.

My goal is to begin performing shows and taking my guitar to local venues to play and sing.

I eat a lot healthier and cleaner now. Organic fruits and vegetables, grass fed meats and hormone free foods.

I try to work out at least 3 days a week with weights. My wife and I recently purchased e-Bikes and I ride at least five miles a day on most days.

Just know that you can get past cancer. I did it and am appreciating life more.

Now let's dig into what this squamous cell cancer is all about. You will find similar repeated suggestions in different areas of the book. That's because many of these pieces of information cross over into different facets of this cancer.

You can beat this!

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