

A time for sharing

Valerie's story

After becoming a cancer survivor, Valerie started the San Diego Chapter of SPOHNC in 2000. From small beginnings, she now co-ordinates the only head and neck cancer support group in San Diego, sticking to the mantra of keeping everyone smiling and laughing at all times!

I must confess I promised SPOHNC I would write my ten-year survivor story. Only now it's fourteen years. Can you say procrastination? How time flies when you're having fun recovering from cancer. I'd better finish this before it becomes my fifteen-year survivor story.

My story starts during the Christmas season of 1998, whilst decking the halls, and hanging the balls, I felt an olive-sized lump in my neck. For the next three months, as I came down with various infections, four different ENT doctors misdiagnosed me. But the ever-present lump made me nervous, and I finally saw an ENT surgeon, specializing in Head and Neck diseases. After a biopsy he told me what I never expected to hear, "I'm sorry, but you have stage III, squamous cell carcinoma of the right tonsil." Whaaaaat! How could that be? I didn't smoke, or drink.

The novel writers cliché about going numb, actually exists. After the word cancer, I did not hear another word my surgeon said. He prescribed two surgeries, then radiation. Within a week I was admitted for my first surgery, which was a radical tonsillectomy, including half of my palette. Painful as it was, he wasn't finished with me. Ten days later, I was re-admitted for a neck dissection.

The admitting lady said, 'haven't I seen you before?" I said, "Yes, I was here for surgery ten days ago, and I liked it so much I came back for more!" Next, I had my radiation-field teeth extracted. After six weeks of recuperation, and feeling better, I started radiation. Fourteen years ago, the more sophisticated technology of today did not exist. They strapped me on a table, tattooed me, and radiated everything with a hundred miles around my head.

> **"Head & neck cancer radiation is daunting, and unlike other parts of your body, it severely affects your essential daily luxuries, like eating, breathing, sleeping etc."**

There's supposed to be about a two-week grace period before you feel the side effects from radiation. However, I'm such a petite, dainty flower that after the first few days, I started to feel some mild symptoms. And, it was downhill from there. My radiation schedule was interrupted twice. I became dehydrated because I couldn't even swallow water, and needed re-hydrating like a dried mushroom.

Later, I developed a blood clot in my leg, probably associated with inactivity and the steroids prescribed to address the inflammation. The cessation of treatment made me nervous, but my doctor assured me that it would not effect eradication of the tumour. I point these things out not to scare you, because everyone tolerates radiation differently, but to illustrate the need to be aware of what your body is telling you, and to be sure to inform your doctors of any problems.

Guided imagery helped me with relaxation, and every day, when the radiation beams were shooting into me. I imagined a Star Trek machine zapping the cancer cells until the exploded. I know that attitude, and humor is

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so important in life and recovery. Going through treatment I watched all the funny old sitcoms and movies I could find. I was too fatigued to laugh out loud, but I knew that laughing in my mind was just as therapeutic.

The popular phrase 'radiation is the gift that keeps on giving' is so true. As soon as they finish treatment, patients expect that they will bounce back to normal. Unfortunately, it's a slow recovery. For about three months after finishing treatment, I was down for the count with fatigue, burning tissues and eating problems. With a weight loss of 23 pounds, I was indeed a shadow of my former self. At that time, feeding tubes were not standard, and my doctor did not like the possible infections associated with them. He also knew that I was well informed about the importance of healthy nutrition.

It seems as though all of a sudden, from one week to the next, the fatigue lifted like a veil, and I gained back most of my old energy. I started exercising again, and although I grew stronger, that's what I lost the last six pounds because my throat still hurt and I wasn't eating enough calories to gain. I lived on my neighbours lovely organic eggs, any moist, pureed food I could get down, and my own recipe for nutrition dense milkshakes.

I think I continued to heal slowly for about four years. I still do not have the normal saliva I had before radiation, however there are prescriptions, and over the counter products that do help with that. Acupuncture for dry mouth helped me tremendously. Dental issues were not a problem until recently, when my teeth started to chip and break. Occasional neck stiffness bugs me, and I sometimes have trouble swallowing, but overall the 'new normal' makes for a happy life. I have become 'The Buffet Queen'. I eat anything that's not nailed down, with the exception of dry foods. I gained back ten pounds, and have the girlish figures I had in my twenties (except for gravity, but that another sad story!).

Going through treatment I vowed that if I lived through it, I would help those having to endure the same journey, so, in 2000, I started the San Diego Chapter of SPOHNC. My group started small, and sputtered along until my efforts at spreading the word started getting results. I ran ads in everything, exhibited at every cancer-related event I could get to, designed and brochures for the local chapter, and ran around San Diego distributing to anyone who would listen. We now meet every first Saturday at noon. The only oral, head and neck cancer support group in San Diego is now thriving.

I run an upbeat support group. I start every meeting with a clean joke. One time I forgot to tell a joke, and someone said, "Hey, you can't start yet. You haven't told one of your terrible jokes!"

"Laughter may not be the best medicine, but it sure comes close."

I tease new patients, "Geesh, you guys today have it easy. When I went through treatment, I had no mask, no feeding tube, no therapy, no support group." My regulars chime in and say, "Yeah, yeah, we know, and you had to walk ten miles each way in the San Diego snow to get treatment!" Even people who are anxious, and in pain laugh with us.

As well as educating patients, I book relevant speakers for the group. Most professionals I approach are generous in taking time from the busy schedules to come and talk to us. We have had nurses, ENT doctors, radiation/oncologists, cyber knife experts, social workers, patient advocates, therapists, psychologists, dieticians, nutritionists, life coaches, acupuncturists and more. I recently sent a translated version of SPOHNC newsletter to a prominent medical contact in Mexico.

I'm a volunteer for SPOHNC's National Survivor Volunteer Network, which matches survivors with anyone needing help or advice. It's rewarding to talk with someone who is nervous, anxious, or scared and to encourage them through the long, dark tunnel of treatment, and come out at the other end, hopefully smiling. I tell everyone the Big C stands not for cancer, but for COURAGE.

Of course, there are dark moments, when sadly we lose someone. That's very hard, and brings home the gift of being a survivor. Treatment modalities for oral, head and neck cancer have come a long way, and due to the rise in oral, head and neck cancer patients, more research is being done. The future holds the promise of hope for oral, head and neck cancer patients.

I wish you all well.

Valerie

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Support for People with Oral and Head and Neck Cancer
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