

# Accepting the Unexpected: One Couple's Journey

As shared by Marie R.

We sat together on the couch holding hands and looked around the room. We were sitting in a stark white examination room that seemed a little larger than others of its kind. The exam table was unique. Instead of being a flat surface with a pillow on one end, it looked more like a dentist chair. The wait for the doctor that would confirm what we thought was a terrifying diagnosis seemed like eternity. While waiting, we talked about what brought us to the office.

About ten years ago, my husband Gary noticed a red patch of dry skin forming on his leg. It looked like a rash. He didn't worry too much about it, but as time went on, more patches started forming and they became very rough. For the next few years, different doctors told him the same thing; the patches were eczema or psoriasis and they said to put cream on them. It was discouraging to keep trying different creams yet nothing seemed to work.

He finally went to a new doctor who suspected CTCL. Gary was told by the doctor that he would die with CTCL –not something you want to hear about your husband! Gary explained that the doctor meant that since CTCL has no cure, he would die still having the disease.

After a week of waiting, the doctor called with the results of the biopsy. CTCL was confirmed and Gary would be treated at cancer institute by a cutaneous lymphoma specialist. So here we sat, waiting for him to come in the room and tell us more.

The doctor entered the room with an air of confidence and friendship. He told Gary that he had a classic case of CTCL and went into details about the disease. He took lots of pictures and explained what the light treatment would entail. I frantically tried to take notes and absorb everything he was saying. The light treatment would cause Gary's skin to get red and become very itchy.

At this time I thought that we had one thing going for us. I had experienced a breast cancer scare seven years earlier and I was now cancer free. I had been through radiation with the daily scheduled treatments. We had gone through the stigma of telling people I had cancer. We thought we could do this together, however, it wasn't that easy.

One of the first problems that Gary encountered was the insurance. I had just gotten a new job and would carry the insurance. However, to include him in my policy would be very expensive and very little was paid out; it quickly used up our funds.

The physical aspects were also discouraging. Gary explained how getting the treatments were like being in a barbecue. It got hot and he could smell the lotion cooking on his skin. I would hear him trying not to itch at night since he couldn't sleep.

I think the hardest part of the first few months was accepting the fact that this was now our life. When the cancer goes into remission, it won't go away completely. He will always have it. At least I was told that I was cancer free. Gary has always given blood since we have been married. When he told them about the cancer, they explained that he could never give blood again. This was emotionally devastating for him. I believe at this time, depression was setting in and I wasn't sure what to do except try to be positive.

One of the positive aspects of going to the institute was that they had just started a support group with all the CTCL patients they were treating. I enjoyed going to these group sessions and finding out more about this disease. During the group sessions, Gary was able to talk with other patients that were experiencing the same feelings and discomforts. He realized that a prime reason he was struggling with this disease was because he has never really been sick before and had never been hospitalized for anything. It seemed that it was always me that was at the doctor's office or in the hospital.

Gary led the Cutaneous Lymphoma Foundation networking group at the cancer institute and I can see he really cares about those in the group. He works with wonderful doctors and one told a joke about Gary at a patient meeting that was really funny and showed genuine friendship between the two of them.



One of the special men in the group passed away and we attended the viewing. His wife told us how much her husband had enjoyed the patient group. I have also enjoyed this group and tried to support Gary as much as possible.

We also have great family support. Our children gave us inspirational quotes about having cancer and shared humorous videos. When a recurrence surfaced, one daughter paid for Gary to go to a tanning bed for treatment.

Each one of us deals with a loss sometime in our lives. It could be loss of health like Gary, a loss of your home through a natural disaster, or a death in the family. How you deal with this loss is up to you. Through the support of each other, our networking group and the Foundation, we have managed to remain positive. Your attitude makes all the difference.