

Vol. 1



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Real Life Stories:
from Survivors &
Caregivers

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Thank You to Barry Gates

Barry is the founder, host and gives oversight to the peer to peer Primary Central Nervous System Lymphoma (PCNSL) survivors and caregivers discussion (support) group. This e-book is dedicated to him.

Barry, we are all deeply grateful for your time, energy, commitment and love. As a four time 11 year survivor, deep peace to you, too.

Contributors to this CNSL E-Book

Information

The Primary Central Nervous System Lymphoma (PCNSL) Information Site that Barry created has information on PCNSL, how is it diagnosed, what causes PCNSL, and how is it treated, plus much more. He also has a page on information for caregivers, and the cognitive, emotional and financial challenges of the disease. Check out the web site at <http://www.pcnsi.info/>

To subscribe to CNSLymphoma (discussion and support group), go to: http://list.braintrust.org/mailman/listinfo/cnslymphoma_list.braintrust.org

Introduction to this E-Book

Enjoy the stories of both Central Nervous System Lymphoma (CNSL or PCNSL) survivors and caregivers. Each story is personal and powerful, and very little editing has been done to each story. Of course, each story is only a part of a very complex and intimate journey.

Please share this free e-book with others who would enjoy reading about the CNSL journey, its challenges and wonderful moments. In alphabetical order, the survivor stories are followed by caregiver stories.

Book Cover, by Alisann Smookler

When I was asked if I would like to create the cover for this book, I was terrified. Yes, fear crept in! I wanted it to be perfect, but I already knew, in my eyes, it would not be. I am unable to paint the same as I have all my life. But within just a few days an idea came to me. The design is primitive and imperfect just as the journey with CNSL is for us. The primary colors represent healing, energy and love. It begins with a blue broken heart and expresses the darkness we all feel during this journey as it meanders along the path to sunlight.

I have been painting since I was 10 years old, now 64. I had to stop painting during my treatments and still find it hard to do my dog portraits. But creating is my healing. My genres have been photo-realism (doors and windows) and pet portraits. I love dogs and always wanted to paint them. So I began painting them about 2 years ago. My first series was Rescue Dogs. I was very honored to be asked to do the cover of this book.

Editor

Richard T. Rossiter, D.Min. coordinated and edited this e-book of survivor and caregiver stories. Rich is a seven year survivor, living with his husband in Chicago, Illinois. Rich is available at rtrossiter@gmail.com.

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Alisann's Story

May 2013 I felt as though I had a sinus infection. Light-headed and just not feeling right. About a week later I also noticed when I looked at the digital clock I had vertical double vision. I went to my doctor and was told it was not a sinus infection, but a Schwannoma. I had a CAT Scan that day. It showed evidence of a Schwannoma. Because I had no insurance we were waiting to see how much the surgery would be.

Within a few weeks I was much worse. I was admitted to the ER on June 19, 2013. I could not eat; drink and I could barely walk. After an MRI, my Neurosurgeon said the scan showed 2 tumors and they were most likely cancer. My brain surgery was scheduled for June 21. My surgeon was able to remove one tumor but could not remove the second because of the location. I was given approximately two months to live. My options were Chemo and/or Radiation. After a lot of discussion with my doctors and husband I opted for 12 sessions full Brain Radiation. Those were completed in August 2013.

My last MRI (3/19/14) shows no tumors and the doctors are very encouraged. My journey is one of love, support and faith. I made an Affirmation Logo for myself when I was diagnosed. I wanted something tangible that I could see and keep reminding me of my courage and strength. It includes the word HOPE.

I assumed people I knew, and were close to, who had also been diagnosed with cancer would be my strongest supporters. I was mistaken. What I found is that there are those who run to you and those who run away from you. At first it really hurt. The ones I wanted to run towards me ran away. One even told me when I reported my first MRI after radiation was clear that I was looking for a NED ("no evidence of disease") I had not heard of that term. She told me she sees it in her cancer support groups all the time. So I looked it up and found out that she was saying I had far too high expectations and I should be more realistic. I was brought to my knees by her remark and then began to question myself. Too much time to sit and think. It was important for me to focus on healing and not negativity which was so easy to do.

There is nothing more realistic than waking up each morning and having to

wait a few minutes just to clear my head so I can take a step. Or hoping my eyes won't be too jumpy so I can walk a few blocks, or see my puppy dogs face, or even read an email from a friend. I am an artist. Before my surgery I was painting dog portraits and doors & windows in the style of photo-realism. I create baby ultrasound art. Being able to paint again is extremely hard as my ability to focus and hold my hand still while painting takes all the energy I can muster. I find that setting goals, even small ones like just making it to the end of the day so I can go to sleep helps me have a purpose. This is hard work and I have to be reminded that.

I have always been absolutely truthful to myself and my family about my diagnosis and my healing. I think that is what drives me to fight this battle. The love and support I have received from those who ran towards me has been beyond wonderful. People I do not know, from all over the world, have sent me prayers, gifts of faith, cards, their support and love. This from a group of artists who I only connect with on the internet.

My family has been truly wonderful. They say when you get cancer everybody gets it with you. My husband, who is the love of my life, does everything he can to love me through this. I found an Oncology Nurse who does nothing but answer questions. She is at the hospital and all I have to do is email her question and I have an answer within hours.

I also have Palliative care that comes once a month. This, for me, is very helpful. Many times I do not know the questions to ask, she informs me what I should be asking. I have found doctors, as wonderful as they are, only give you partial information. I am the type of person who wants to know the good, bad and ugly. I need to know what to expect, so give it to me!

I have never been one to sit and pray. But I have always been very strong in my faith and beliefs. When this all happened I found myself in prayer each morning at about 3am when I could not sleep. It is so comforting and my way of finding that quiet peace I so need in my healing. Now that I can get out and take short walks each day, that is when I pray. My meditation.

I recently found a Drumming group who meets twice a month. It is a healing group organized through a Cancer Support Foundation. We can talk, drum or just observe for 90 minutes. It is a healing experience for me each time. I still have a ways to go, but I am so grateful and blessed that I am here. Do I wish my head did not feel jumbled, that my hearing was 100%, that my eyes worked

better, that those side-effects from the radiation were not there, that I could taste food...absolutely! But the reality is they do not and each day I keep walking this journey knowing that each day I am still here, I am alive and feeling such love. Do I know what tomorrow brings? No, but it does not matter because I have today. And for that I am in gratitude. I have heard so many times “you don’t start living until you know you are dying.”

When I made a conscious decision to surrender this disease and not focus on every new ache and pain that is when I found my peace to live. There are good days and there are bad days. On the bad days my wonderful husband says “hey, just rest, cry if you need to and know I am here.” I watch him struggle as my caregiver and my heart is full of love for him. This journey is not easy for anyone and for me, coming to terms and surrendering is the only way I can get through each day. I am a perfectionist and needing to feel in control, I have learned nothing is perfect and the energy spent on trying to keep everything in control is exhausting. The inner strength and courage comes from not controlling my world and having too high expectations of people and situations. A very hard lesson for me to learn. So each day I meditate and I keep love, gratitude and creativity in my heart.

Alisann Smookler
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George's Story

For almost a year I felt myself getting weaker and less able to do simple chores. I could barely walk across the street and had to sit down because my ankles were weak and I couldn't feel the ground underfoot. Walking across the carpet at home felt like pins and needles stabbing into the soles of my feet.

One day in April my wife and I went out shopping. I pulled into the parking lot, and found that my legs and arms wouldn't work properly. After I struggled to get into the store, I couldn't verbalize my thoughts. I found my wife in the store and pulled on her shirt sleeve to get her attention. Feeling out of control, I just wanted to die because I thought I'd feel like this forever.

When we got back to the car my wife suggested that we stop for ice cream on the way home. By then I could talk but had limited ability to understand. Later, my wife said that a corner of my mouth drooped. Going back to the car again was a struggle to walk and maintain my balance. By the time we got home I was exhausted and felt like passing out.

When we told our family doctor about this episode, he said, "George, you have more problems than all my patients put together. I can't find anything wrong with you." At that point, my oldest daughter called from Tucson. When she heard what the doctor said, she told us to demand a blood test for thyroid disease which might explain my fatigue.

Thyroid medicine helped slightly, but I was still losing balance and falling down. The day I couldn't lift a bag of garden soil for my wife was the worst. I couldn't do anything I'd been used to doing. Spring was coming and we had always planted a garden. How would it get done if I can't lift a bag of garden soil? Why am I so weak?

My voice began to sound gravely. My wife said I sounded sexy, but I didn't think so. I thought I sounded like a frog. Then double vision and what seemed to be an eye infection sent me to our eye doctor. She spent most of the day testing me. Finally she told me that something was pressing on my optic nerve. I needed MRI soon. The specialist said that a scan wouldn't show anything because I was just a depressed old man. Prozac would be the answer but he ordered an MRI anyway. I had it on Friday. On Saturday the doctor called and told us to be in his office first thing Monday because "there is something there."

We learned that there were four golf ball-size tumors --- three in the center of my brain and one in the left frontal lobe. The oncologist was waiting to talk to us. What was an oncologist and what will he say? We soon found out. Dr. M. explained that the four tumors were most likely cancer.

We would need a good neuro surgeon soon. All my symptoms: aphasia, loss of balance, eye problems, partial paralysis, and weakness were all proof of the severity of the cancer. We needed a biopsy, fast.

We returned home in a state of shock. Where would we find a neuro surgeon? Then we thought of our friend who worked in the University Hospital. All of the neurologists were at a conference, she said. But the department head was there and she arranged for us to see him the next day and she would go with us. He looked at the scans and no one said anything. Then he said that it didn't look like a metzi. (Metastatic) I didn't know what he meant but he and our nurse friend looked relieved. The tumors appeared to be inside my brain but he would perform what he called a needle biopsy.

The day came for the biopsy. As my wife drove to the hospital, I saw the streets disappearing and the sidewalks taking over --- a scary feeling. Loss of control. I didn't know where things were. All reality was gone. At the hospital they gave me medication that kept me able to respond while they were drilling a hole in my head but kept me from being scared. Afterward, the doctor said that I had CNS Non-Hodgkin's Lymphoma.

Over and over, my doctors checked email from Sloan Kettering Cancer Research Center for survival statistics on patients 64 years old with CNS Lymphoma . None of the news was encouraging. Instead, Sloan Kettering sent a report warning not to give Whole Brain Radiation to one as old as me as it would only hasten death. By this time my wife had to feed me and help me dress. I drooled and could not think straight. But I prayed for help --- just to feel like a human being again. Our 45th wedding anniversary would be in four more months and doctors predicted I only had three months to live. My wife had just recovered from Guillain Barre and I felt she deserved some joy. It wasn't fair.

Anger at my doctors for not discovering the cause of all my problems kept me awake those first few nights after the biopsy. Why didn't they diagnose me sooner. Why did I have to become so deteriorated? Now my wife will be a widow and I will never see my grandchildren grow up. One night I had a vision. It was someone who had been killed in an accident. "Why are you spending energy being

angry when you can use the time you have left loving your family. Do you think I had time to say goodbye to my loved ones? No. It was so quick it was a shock to them. "From then on I knew I was going to be OK. I would live each day as it comes. And so I have.

I asked our pastor and all our friends and family to pray for me. The prayer chain grew and spread and peace came to me. I suspect hundreds were involved. There were two offers of a "laying on of hands" and I took advantage of both. Many angels on earth appeared in those days. The first one visited my hospital room, bringing us the gift of hope when he said that his cousin had recovered from CNS Lymphoma ten years previous. After that, we kept running into more friends, acquaintances, and neighbors who covered us with kindness and encouragement --- more angels offering gifts of hope and assurance.

When chemotherapy paralyzed my intestinal tract so that my stomach bloated and pain became unbearable I prayed that God would take me home or fix it. A nurse aid came to my room the next day, saying that she had once had that problem but fixed it with Colyte --- the medicine usually given to prepare for colonoscopy, something the doctors had not mentioned. They agreed to try it, however. The problem was fixed.

The possibility of death caused me to reflect on my life's accomplishments. I was pleased that my life had been fruitful and blessed with many answers to prayer. I believe that prayer helped make the chemotherapy less toxic and more effective in destroying cancer cells while protecting non cancer cells and organs.

This spring, 2014, marks the sixteenth anniversary of the day a biopsy revealed brain cancer, giving me twelve weeks to live. After I was pronounced in remission, I asked God to help get my memory back. In November 1998, I wrote three pages telling about my feelings and how grateful I was for surviving and regaining my memory. The following year I built a small backyard pond. My wife let me make my own mistakes as I still hadn't recovered the ability to follow directions and to predict what would be needed next. I struggled physically and mentally and it took almost a year, but we still have that pond, stocked with fish and a reminder of what I still can do even though I move and think slowly.

I love to tell this story of miracles and wonderful people who came into my life to offer support and encouragement to me and my wife. We celebrated our 45th anniversary with a big party, renewing our wedding vows up in the Colorado mountains. My legs are weak both from the damage done by the cancer and from

the chemotherapy, but I can think and function in a way that was not expected. I've lived to see my grandchildren grow up and have enjoyed many happy times, including my 80th birthday party.

George Brandt

Note: George's wife, Ann, also shares her caregiver story, beginning on page 36.

Jason's Story

10/04: left frontal biopsy showed primary CNS lymphoma
7/05: completed 9 courses of methotrexate-based blood-brain barrier disruption chemotherapy
9/05: Recurrence
4/06: completed Temozolomide x 6 cycles with isolated intra-ocular progression.
5/06: completed high dose ARA-C x 1 cycle, d/c by pt preference.
9/06: started on Chinese herbs
7/07: Completed 4 cycles of HDMTX
2/08: RT to orbits completed
4/09: Recurrence of cells OD; restarted Ivit MTX
11/09: Last Ivit MTX - vitreous has been clear since then

That is the break down from my Neurooncologist, Dr. Peereboom at the Cleveland Clinic.

My story begins in 1998 when I was hired as Police officer for Valley View Police, and was scooped up the first week on the job to play on the Ohio Lawmen softball team and went on to win a gold medal in the Police and Fire Olympics. I was, and still am the only officer from that department to participate and medal (Silver and 2 Gold) in these games. I was asked to play on this team by a neighboring Sergeant from Independence PD (IPD) Brad, as he has known me the better part of my life and knew I was a pretty good athlete.

I stayed with VVPD from 98-04 and decided to test at IPD. I was then hired on 8-11-04 and had to go through their entire field training program. I knew the job and all of the guys, as we were neighboring cities.

The FTO's (Field training officers) liked training a guy that was not right out of the academy, and I knew the job, I just needed to know their system.

I was with IPD about a month and a half when I was involved in a shooting on a major highway in Northeast Ohio (I-77 North bound) and after 3 days being off we came back to work and I asked the guys, "What we are doing today?" I was told that I was getting tested on the map of the city in the morning and I should study all the streets. This is roughly the last thing I remember as it all gets fuzzy.

The date is now Sept 28th 2004. IPD is on 12 hour shifts, so either 6am to 6 pm or 6:30 am to 6:30 pm. I was on nights due to low on rank, and I was the "late car" (6:30pm - 6:30 am). When the day shift guys started rolling in the guys were saying "Hi" to me and I was told that I was like a zombie and not responsive to anyone (not like me at all). Then it was about 6:10-6:15 and the day shift Sgt. Brad told the night shift guys that we could go home and they would handle any calls.

Most of the night shift guys left and I was still in the squad room. I will tell you the rest of this only because I was told these months later.

I was standing in front of the squad room door looking at the many post of Officer training schools and stolen vehicle reports along with BOLO's when I was asked by another patrolman, Jimmy Green, "How's it going Jay?" I did not respond, and he asked me again, with no response. He then said jokingly, "I get it ... you guys from the Valley are too good for us on the hill." Again, no response. I was then asked by another officer, "Will you answer Jimmy when he asks you a question?" Again, no response. "Jay! Will you at least look at me?"

I was told that I turned around one time, then kept on turning a 2nd time then a 3rd, then eventually 5 times! They thought I was joking around, until I stopped, looked at them and my eyes rolled back into my head and fell straight back to the floor and wacked my head on the terrazzo floor. I was having a full grand mal seizure.

They said I came to, and had a look on my face like I wanted to kill them (Jimmy and the other officer that came to me as I was on the floor). Jimmy said I was stronger than he thought was possible (adrenalin) and then I went into another seizure. I came out of it and had that same angry look on my face but they said I had zero strength.

I was rushed to a local Hospital (Marymount) and then Life flighted to the Cleveland clinic. I was not diagnosed right away with PCNSL but about a week later Dr. Vogelbaum made the decision that I did, in fact have this diagnosis.

I was out of it for about 2-3 months, almost as if I had Tourette's syndrome. I had no filter at all! I was swearing and telling everyone what I thought of them ... good or bad! I also had no concept of time.

I had 1 full round of BBBD (1 treatment in the left femoral artery and the 2nd in the right) under my belt along with the infusion of chemo into my Omayo Reservoir that was implanted in my head.

I was newly married and it was our 1 year wedding anniversary on 11-8-04. We could not go anywhere real fancy, as I was not of sound mind. We went to a local Steak House and I told my now ex-wife Jen, that I was going to use the men's room. I think I'm in there for maybe 30 seconds and Jen peeks her head in and asks if I'm ok. I tell her "Yes" and I'll be right out. What I think is another 30 seconds, and she walks in the men's room and says "Do you think it's odd that you have been in here over 30 minutes?" My reply was "Do you think it's odd that you are standing in a men's room of a public restaurant?"

She leaves, and the next thing I know, my Sgt. Brad shows up with my assistant Chief, asking me, "What are you doing?" I tell them "I'm shooting baskets, and want to play?" Brad tells me that Jen called him and shared I had been in there for over an hour. I told him, "I'll be right out." He comes back in what I think is another 30 seconds and says I've been in there far too long. He's a big guy, and he looked over the stall door at me, and asked "Have you gone to the bathroom yet?" I tell him, "No." He asks again, "Are you sure?" I tell him, "Yes I'm sure." He then tells me, "I hope you are right, because your pants are not even down."

He told me to come out and I said "Ok", but continued to just sit there. He then had to instruct me to "Stand up now!" "Grab the handle and turn it now!" He had to walk me through the simple steps of getting out of a bathroom stall.

I then go out to the dining area and the entire place is staring at me and the two officers and I began to yell and scream at the whole place. I was swearing and screaming like a mad man. Jen was crying and I was yelling at her, too.

That day she drove me to a church to see Dr. Issam Nemeh, a local "faith healer". I walked into this church with maybe 30-50 people were there. They were standing in a line to see this man, and his wife along with a little Irish nun. As I watched him lay hands on these people, some of them would fall down and be caught by others and some would just walk away. I noticed that each person took about 2-3 minutes and then he would move on to the next.

It is now my time to get up to the altar and I start with my swearing and yelling, "This is all BULLSHIT! YOUR'RE ALL A BUNCH OF ASHOLES," etc.

When I reach the 3 of them Dr. Nemeh was facing me and his wife was on his left (my right) and the nun was on his right (my left) and I'm being a complete disrespectful punk! His wife started to lose her balance and was saying "Something is going on with this guy!" "There is something happening here!" She

kept grabbing on to me and losing her balance ... I told Dr. Nemeh that he should work on this chick! "I'm fine compared to her!"

The wife grabs my face with one hand and tells me that I need to focus on the crucifix. I stopped swearing and carrying on, as Dr. Nemeh brought his hands up to my head. He said his prayers and after about 10 minutes, he opened his eye and said "You are going to be fine. Your brain tumor is gone." I smacked him on the shoulder and said "OK DOC!"

As I walked back to Jen I saw all of her family and some co-workers there. They were all asking me what he said, and how I felt. I yelled "HE SAID MY TUMOR IS GONE! SO LET'S GET THE F@&K OUT OF HERE!!" The Little nun came running up asking me why I was there and I started swearing at her (not myself), and told her "This was a bunch of BS and you're all snake oil salesmen." She asked Jen what was going on and Jen told her that I was just diagnosed with a rare form of brain cancer with a very bad prognosis. "We didn't know what else to do, so we thought we would come here."

The nun then asked her what is special about today. Jen told her that it was our 1 year wedding anniversary today. The nun said "I knew a miracle was going to happen today and I know it happened to your husband. Take this rosary and pleased let us know what the doctor says at your next appointment."

I went in for my next MRI and treatment and Dr. Peereboom came out with my MRI scans and he looked like he saw a ghost! He asked me how I was feeling and I yelled "Fine, GREAT!" (still very much out of it), and I then asked him how he felt. "You don't look so good doc!"

He said he has never seen this before or heard of this before with my disease. He showed me last month's MRI and it was all covered in tumor, and held it next to the one that was taken that morning and it was clear!! No signs of any lesion!

I continued with the treatments but after another month I woke up and told Jen, "I'm better." She asked, "What do you mean?" I said, "I know yesterday I was messed up, and today I'm not. Just like that, some switch went off in my brain and I was back to my normal self."

I had a very bad time waking up early from anesthesia resulting in me gagging and throwing up so many times, it actually led me to get aspirated pneumonia due to the vomit getting in my lungs. I chose to stop Chemo due to all of the issues and my MRIs were clear!

I then had vision issues from this disease and I went back to see Dr. Nemeah. When I walked in the room he looked at me, and after 3 years of seeing tens of thousands of people he said, "You're the cop. I thought we got rid of your brain tumor. Why are you back here?" I was floored!! I told him it was in my eyes now and it's like someone smeared Vaseline over my eyes. He had me sit down and he did his thing and I left.

Three days later I get a call from The VVPD cops to meet them for lunch. So, without even thinking, I jumped in the car and met up with the guys. When I got there they all asked me if I should be driving and as I was about to answer them my cell rang, cutting off my answer to the guys. It was the head of security for Dr. Nemeah and he said I just hung up with Dr. Nemeah. He said, "Call Jason Berger right this very second and ask him how his vision is doing? Call him right now." I told the guy on the phone that I just was about to tell the guys that I used to work with that my vision is clear as a bell!!

My vision unfortunately turned bad again and I did end up getting radiation to the eyes but they wanted to do WBR on me. I refused. If there is one thing that I am, it's being pretty witty. I never wanted to risk altering my personality for the sake of staying alive. If I'm going to live I want to live like me.

I then received a call just a few months ago from one for the dispatchers husbands (Joe) asking me if I knew anything about religious healing, so I told him my story and he was amazed. He asked if I still stay in touch with the faith healer and I have not. It's been over 6 years since I saw him and I had no idea if he was still practicing or even alive.

He calls me right back and said there is a healing service this Sunday in Cleveland and asked if I wanted to go. I said "Yes, of course," and we went.

I told Joe and Lucy that I would be shocked if this man remembers me after all these years and 100's of 1000's of people all over the world! I get up to him and he is being very polite, asking me how I'm doing, and then he looked at me in the eyes and said "HOW HAVE YOU BEEN?"

Lucy started crying and it was surreal that he remembered me! I then went out into the hall where his wife was (the falling down lady) and she too was very polite, and asked me how my service was. I said it was pretty good, and then she gets this look on her face of surprise ... "I CAN'T BELIEVE YOU ARE HERE!! I CAN'T BELIEVE THAT YOU ARE STILL ALIVE!!" She gave me a big hug and then took me over to this blind man that was there 9+ years ago at the first

healing service. She said to him "Take a guess who is standing in front of you?" I shook his hand and his face lit up! "Don't tell me ... we were just talking about you last night ... the cop ... the cop with a rare brain tumor ... Independence Police!"

I ended up doing an interview with him that is on some sort of web cast. I wish I could have stayed longer but I had to catch a flight to Chicago to see my Chinese doc Dr. Guo (healthriseing.com).

I feel great aside from the vision loss in my left eye and my memory is nowhere near what it used to be. I struggle with remembering things that I used to have recall on like no other. It's frustrating to not be able to do the things I've done in the past, but I'm still alive and doing well. I did end up taking a disability from the Police job and now I try to travel as much as I can.

Unfortunately I was just thrown yet another curve ball 3 weeks ago. I developed these small bumps on the back of my left tricep and my girlfriend was really on my case to get them checked out so I did. The dermatologist took a biopsy and it came back positive for lymphoma, so I had a cat scan and that came back clear. Great news, but they lost my pathology to confirm if it is in fact lymphoma on my arm or not. I'm not happy about this as it's been far too long to not have an answer!

Jason Berger

Marie's Story

These words were written on the last of day of my chemotherapy treatments for PCNSL. I received the cancer diagnosis in October of 2008 and finished my course of high-dose methotrexate therapy at the Dana Farber Cancer Institute in Boston 15 months later.

The Goal is Reached. December 10, 2009.

Today I drove myself to the hospital for the first time and came alone for my final chemo treatment. There is an odd joy and sadness to this day that I've awaited for so long. Now I will be untethered from my IV pole, and disconnected from the healing but toxic fluid cursing through my veins from a brown covered bag. I drew an X on the block marking my last infusion on the giant calendar I have hanging over my kitchen table. There are 11 other Xs preceding it – each painstakingly marked every month to show progress toward the goal of finishing my chemo.

It's almost Christmas and I have the spirit of the season, almost as never before. I have completed the medication regimen that rid my brain of its deadly lesions, which had caused double vision, hearing loss, numbness and burning on one side of my body and the inability to walk across the room without assistance. Whether or not I am cured, only time will tell. Many people with my illness relapse at some point, but young Dr. Andrew Norden thinks that I may be in that chosen number, that he and I and our huge dose of methotrexate may have beaten this formidable foe and won me a second chance at life.

I hope he's right, with all my heart. I know that last Christmas Eve, while my relatives enjoyed our annual family bash at my sister-in-law's big home, I was laying in my bed facedown, unable to muster the strength to change from my sweat suit into pajamas. A microwave-heated wrap was numbing the pain in my left arm so I could escape into the temporary respite of a merciful night's sleep.

This year, I'm humming Christmas Carols while hanging wreaths in my windows and stringing lights and holly on the mantle. Throughout the last 12 months I have felt the presence of God spurring me on, holding me up, copiloting my every decision and easing the fear of losing my life on a daily basis. I am not a religious person. I attend Mass only sporadically and I have always been a doubter. And yet, I have not been alone in this struggle: A nurse's aide in the early

weeks at the hospital comforted me with my mother's smile. I felt a hand in mine throughout the surgery that implanted my chemotherapy port, when no human hand was near. There's always the possibility that the young aide's resemblance to my deceased mother was coincidental, that the conscious sedation during the port procedure created the illusion of someone stroking my hand. But I don't believe either scenario. That's my choice and my solace.

Today my battle has ended, but not my war. I am cancer-free and they say I may resume a "normal" life. The life I will resume will never be normal, but I do not want it to be. Why should I go through the trials of tapping at death's door, crawling to my feet and witnessing the struggles of those around me in the chemo chairs and hospital beds if this were not to change me. I may return to my job and family but I will not pretend that the brain tumor never happened. It was the hardest-ever test of my endurance and my spirit, and yet, in many ways, the greatest gift.

Like late night TV host David Letterman's Top 10 List, here are the Top 15 Things I've learned from having cancer.

- 1) Love is most important. Having the love and support of friends and family is everything when you're fighting the fight.
- 2) It feels good to hug. Going from a hands-off, non-touch person to someone who is constantly hugging and being hugged is wonderful. I had no idea what I was missing.
- 3) Ask. Be aware of your own treatment, including medications. Don't assume the doctors and nurses always have it right. If someone gives you a yellow pill that's usually white, ask why. Mistakes are made and you are your own best advocate.
- 4) Never wear a Johnny unless you are so sick that you cannot dress yourself. Bring a sweat suit or some nice loungewear with you for overnight hospital stays. I found the better I looked, the better I got treated. Or maybe it just felt that way. Dress for success in the business world – dress for respect in the hospital world.
- 5) Write it down. Keep a journal of your cancer journey from start to finish. If you don't feel like writing when you're having a bad day, don't. It's not a required chore, but putting things in writing does make them seem more manageable and less scary.

6) Love your oncologist. He or she is your new best friend. This person is not infallible, but if you don't feel a huge sense of trust and admiration for your doctor, find another one.

7) Take your pills. As a person who wouldn't increase my high blood pressure medication when my family doctor asked me to, it was hard to carry around a suitcase of multi-colored pills for daily use. But I got used to it. You will too. Meds can help you physically and mentally. You may need both, at least for a while.

8) Find a cancer support group. Mine was the Wellness Community (now the Cancer Support Community -- MA South Shore). This is a place where you don't have to "put on a brave face." The people in your support group won't tire of your litany of symptoms or fears as your friends and family may. They are in the trenches with you. Find a group and go there every week, even if you have to ask someone to drive you. And give it time before you decide whether you like it or not.

9) Keep busy. No matter how bad I felt, I did things, even if it was just checking my email or getting my sister to haul me into her car and take me for a ride. Those early drives were a godsend, just to look out the windows at normal people doing normal things. I envied them because they were functioning so easily in a real world, but it sure felt good to look at them.

10) Pray. I prayed out loud and often --- sometimes for the strength to make it through another day, or to alleviate a symptom. I prayed hard before every chemo treatment and every MRI. I prayed to God, to Jesus and the Blessed Mother. You may have different beliefs, but faith in something higher than yourself can help get you through.

11) Set your goal on bedtime. One day near the beginning of my illness, a nurse named Sheila called to see how I was doing. I told her I was horribly weak and dizzy and could barely make it through the day. I told her that all I looked forward to was bedtime when I could escape it all. That's when Sheila said, "Then make that your goal. Don't think about next week, next month or even tomorrow. Just think about surviving until bedtime, and when you climb into your bed, you know you've achieved your goal again." It worked for me.

12) Stay off the Internet. It's fine to surf the Web or play Scrabble online, but don't Google your illness. The statistics may scare you more than the disease,

and most of them are out-of date. Trust me, your doctors know more than WebMd.

13) Remember it's temporary! On my second chemo treatment, I had an allergic reaction to the anti-nausea agent, Zofran. In the middle of the night, I went to the bathroom feeling like something was wrong. I looked in the mirror and saw what looked like the Stay Puff Marshmallow Man squinting back at me. My eyes were nearly swollen shut and I was shaking all over. I thought about the whole year of chemo treatments that lay ahead of me and I sat on the floor and cried.

A month later, on the night before my next hospital stay, my friend Joyce called to wish me luck. I told her there was no way I could go through it again. She said, "Listen to me, even if the worst happens and you get as sick as you did last time, it's only temporary. You will be back on your couch holding your dog again in three days. You can endure anything for three days. Don't panic, it's temporary." Out of all the advice that people and books gave me through the battle, I think this helped the most. And incredibly, I was never sick or nauseated again during another treatment.

14) Write the good stuff down. Since I am not the most "positive thinker" in the world, in fact I can be pretty negative, I would write down any promising statements from my doctor and read them back later when I would start to give in to fear. I wrote them on scraps of paper --- things like "My goal is to cure you." "Your tumor is no match for my methotrexate." "Your cancer is highly treatable." These few remarks from my oncologist were like lifelines in a sea of uncertainty. When your doctor gives you hope, write it down and reach for it when you need it.

15) Bring survival gear. If you have to stay overnight in the hospital, bring a laptop, cell phone, ear plugs, and an eye mask. You'll keep your mind active during the day and be able to sleep at night. If you have to spend an extended time as an inpatient, make your hospital room look a little like home. Bring your favorite quilt or comforter, your pillow and some family photos. When you wake in the night and see your things around you, you don't feel as much like a stranger in an alien land.

The end and the beginning.

So now this chapter of my story ends. I don't know if there will be a sequel. I hope not. I will need to make decisions about the next step in my journey to the "new normalcy" – whether I will go back to work full-time or help my daughter

raise my grandson. But I know that one aspect of my life will always be to reach out and take the hand of others who are frightened and alone.

I have been to the bottom of the well, have heard the laughter at the surface where real-world people were living real lives while I could only stretch out my hand to beg them to pull me up. And when the ladder was lowered to me, I climbed it, one rung at a time, slowly, sometimes slipping back a step or two, but always pushing forward, keeping my eye fixed on the light that knifed through the darkness leading the way out.

I had brain cancer, but my head is clear and my life is intact. The neuropathy on my left side is still there, my ears still echo and my left foot and knee still burn. But I guess there are worse things than being a red hot mama at 56 years old.

If you are facing a battle with cancer, you are already a survivor, and no matter how hopeless you may be feeling right now, remember, your life isn't over, you just have to fight for it.

Update 4/3/14 — I am now 5 years cancer free. I work three days a week as the head writer at Jack Conway Real Estate Company in the Boston area, and I take care of my two grandsons, Ben, 5, and Will, 3, on Mondays and Fridays.

I now have MRIs every six months, and the last one on 3/12/14 was blissfully all clear! I am enjoying my phenomenal second chance at life immensely and am happier than I have ever been as a wife, mother and grandmother of three beautiful little boys.

Marie

Nate's Story

I was diagnosed in August of 2007. I was 37 years old, employed as a business analyst by an investment bank in New York City while living and working from home in Pittsburgh. I made trips to NYC every month for some face time. I had been having headaches of increasing severity with increasing frequency for several months. But I put them down to any number of normal causes until one day when I was in NYC I came down with one so severe, that I found myself curled up under a colleague's desk in the dark moaning in pain. I flew home, and the next day went to the ER where they found a golf-ball sized tumor in my frontal lobe and "countless" smaller tumors spread throughout my brainstem. I was terrified. Initially, they thought it was stage 4 GMB. When the diagnosis came back as PCNSL, the surgeon said I was lucky; it was the "best of the bad options." Lucky? I guess it is all relative.

After wrestling with insurance who wouldn't cover Hillman, the top local Cancer Center as in-network, and consulting with many physicians, I started High Dose Methotrexate at 8g/m² (5 cycles) at Allegheny Memorial Hospital. A complication after my first round --- where they prescribed me Dilantin when they shouldn't have --- resulted in drug-induced hepatitis in my liver which prevented my continuing treatment for almost a month, and may have contributed to a disease I developed in the spring. But the delay in treatment changed my schedule such that I was able to go on a golfing trip between my 3rd and 4th cycles. (Always look for the silver lining!). After the 3rd cycle, my tumor showed significant reduction, and the tiny tumors throughout my brainstem were nearly gone. The golf outing became a celebration.

But after the 5th cycle in late November, my tumor had started growing again and the tiny tumors appeared to be returning.

I had a consult with MSKCC, and it was suggested that I try Temodar/Rituxan as a salvage treatment. It was in clinical trial at MSK, but I didn't want to relocate. However, after I collapsed at a bowling alley where celebrating my 38th birthday on December 15th (I lost the ball on my approach and fell and hit my head on the ball return), an MRI showed a massive resurgence--more cancer than the initial scan. I had to start immediately. I would stay in Pittsburgh under the care of my current doctors, supervised by Dr. Lauren Abrey,

then at MSK. I took my first round of Temodar leading up to Christmas and had my first Rituxan on Christmas Eve.

After one month (2 cycles of Temodar and the Rituxan), my tumor had shrunk by 80% and there was no evidence any longer of the smaller tumors. So we were going to go a second month and try for remission after which I would have stem cell replacement as consolidation treatment. But I began developing fevers for which they could never find a cause. In one case my fever reached 107. But because of the hepatitis --- and the fact that my liver had never fully recovered --- I was unable to take medication to manage them. So I was placed on an ice bed and wrapped in an ice blanket for that one. Perhaps the most painful experience of them all. Others reached 105 --- which were managed with ice packs (fortunately, not the bed/blanket wrap). During these fevers, my cell counts would plummet. I began requiring frequent transfusions, and platelet infusions. At one point in mid-march, they could not restore my blood counts, and wouldn't let me go home. I had a pic line inserted due to all the transfusions, but my blood wouldn't clot. So my arm just oozed blood constantly. I developed C-DIFF (turns out this was the most painful thing of all --- and it recurred several times during my various stays). I was moved to the cardiac unit so they could monitor me more intensely.

Finally, my doctor in Pittsburgh admitted that they had absolutely no idea what was going on and urged me to go to MSK. At MSK it was several weeks before they diagnosed me as having HLH, an extremely rare, mostly genetic blood disorder that very rarely can be acquired in which your immune system just eats itself. It was written up in the NY Times:

http://www.nytimes.com/2009/02/22/magazine/22wwln-diagnosis-t.html?pagewanted=all&_r=0

In those 2 weeks, my weight dropped to 127 lbs. (I am 6' tall and normally weight 170). My low platelet count resulted in some retinal hemorrhaging, which blinded me for almost 6 weeks (I still have flecks of the scarring in my vision today). But I also reached remission with the PCNSL. When they diagnosed me, I began an Etoposide chemo regimen which got me back on track. Once I was back on track, I had 13 cycles of low dose WBRT to consolidate before I had a bone marrow transplant in the fall. It is the only known cure for the HLH. But we thought it would serve as a good consolidation (in place of stem cell replacement) for the PCNSL, also.

The BMT was an ordeal in itself. For the first time, I had significant reaction to the chemo (can't recall the cocktail) used to wipe out my immune system. My mouth sores were so bad I was on intravenous feeding for 2 weeks. I couldn't eat or swallow. But on 9/26/28, it grafted. After that it was 3 months of follow up while I stayed at Hope Lodge in NYC with my father who took a leave of absence from work to be with me, and they let me go home to my wife and daughter (who had been in Pittsburgh the whole time with occasional visits to NYC).

Finally, though, I developed Epstein-Barr-Virus Lymphoma while on a victory vacation with my family to Florida and had to fly back to NYC after only a couple of days for a booster shot of bone marrow from my donor, two more weeks in the hospital and 30 more days at Hope Lodge. At last, in April of 2008, I was given a status of "disease free"! And returned home for good, and began the 18 month process of being re-vaccinated with all of my childhood vaccines which were wiped out by the BMT.

I returned to work part time that November and full time in January of 2009. I now have my same job, have even been promoted to vice president. My daughter who was 2 when this started is thriving at 7. I took up guitar and now regularly play open-mics in NYC when I'm there for work. Unfortunately, my wife and I are getting a divorce (one of the big changes that has come out of this--don't fret, it is the right decision and we're doing this amicably). Still it is hard. I learned a lot about myself during and after this experience. But I am a changed man because of it. I am a better person because of this. And while it is still a struggle sometimes, I am eagerly moving forward and getting on with my life!

Nate

Peter's Story

It is March again. Five years ago in March 2009, I accepted the PhD scholarship offer from UC Davis. I was happy, confident and looking forward to fulfilling my dream in United States. Five years later, I am still on track but what had happened in the last 5 years was far beyond my imagination, probably beyond most people's imagination.

At the beginning of my study in US, like most of the foreign students, I struggled to adapt to my new life. I registered for 24 units in the first quarter and did not even know that it means homework due every day from Monday to Friday. I did not set back but tried my best and even worked for over 100 hours per week. I had a strong body and used to work out regularly so I never worried too much about my health condition.

In July 2nd, 2011, after having muscular discomfort for a few months, I was sent to the emergency room right after an MRI check. The doctor told me that I had 7 tumors in my brain and the largest one was like a gulf ball. I was speechless, so shocked that I almost felt nothing. I told myself to hang on and keep focus on the immediate issues I needed to deal with. In the first week in the hospital, I prepared the documents for my parents' visa, dealt with the insurance company and hospital for my treatment and called my friends to help.

Unfortunately, my brain biopsy confirmed the worst. I was diagnosed with Primary Central Nerve System Lymphoma (PCNSL). The rare disease occurs only one out of 10 million populations and my oncologist at UC Davis had never treated this disease before. Quoting from one of the doctors, I had less than 1 percent chance to survive. Suddenly, I had to face death and there was no way I can prepare for it.

One patient helped me. It was in the preparation room for my infusion port implantation. A young guy came in and greeted my surgeon. He introduced himself as a liver cancer patient and he came to say goodbye. The surgery gave him 7 more years to live, and he had no regret in his last 7 years. I was impressed, not only by his words but the peaceful way he delivered it. It was at that moment I knew, if I was going to die, at least I could die peacefully without regret.

For me, the most effective treatment for PCNSL was high dose chemotherapy. Considering my age, I was given the highest dose. Luckily, I

transferred to an expert on PCNSL in UCSF and completed 9 rounds of chemo in 6 months. After finishing the entire treatment, my oncologist told me I had 50% chances of survival and if I could be in remission for another 2 years, I would be considered cured.

I was thrilled and grateful that I was able to finish the entire treatment after going through all kinds of serious and debilitating side effects. However, I had to face a new set of difficulties. At the end of the treatment, I owed the hospital over \$260,000 dollar and my school insurance was maxed out. As a foreign student, I was not qualified for most of the social assistance either. But I was not scared. I had learned that even in the importance of facing adversity with calm and courage. Things finally turned towards the good direction. UCSF medical center waived my debts. With the help of my friends, I managed to switch to another group health plan. At the end of 2012 summer, I was able to return to school and I decided to finish my PhD.

Lots of people asked me why I decided to continue my PhD. For me it is obvious. The most heartbreaking nightmare for cancer patients is not just simple death but the deprivation of their normal lives. I saw in the hematology department many patients decorated their rooms like home. One of my roommates insisted on wearing his own pajamas rather than hospital gown, and even went out for sushi in the middle of chemo infusion. Once I was able to go back to my normal life, continuing my studies is a natural choice.

I know my life can only be harder in the future. I am not worried though. Whatever you are, president of U.S. or African refugee, you will encounter your own obstacles. Luckily, I have learned that even in the worst case, I have the courage to fight for a better more meaningful life.

Peter

Rich's Story

Late in June of 2007, my husband Bill and I returned from vacation. Due to dizzy spells that kept me from participating in several events, the next step was for my general physician to order the MRI. He did so, and on June 27th my MRI was completed, and in less than an hour my general physician called me while I was traveling to my office, and told me a tumor has been found in the brain. I was emotionally frozen. I completed my drive to the office, and I'll never be sure how long I simply sat frozen in my office chair after arriving.

I eventually left my chair, walked to my Senior VPs office, sat down and lost it. She cared enough to let me cry for several minutes. I pulled myself together and shared with her what I had just learned. She asked me to go home, and told me she would contact my managers and the rest of the leadership team. From that moment on, I focused on myself and my family.

I was scared to call my husband and children, as I knew they too would be scared and have dozens of questions. Bill was out of town, and I can't imagine his trip back home. I also called a dear friend.

A golf ball sized tumor was removed on Tuesday, July 3, 2007 at Chicago Institute of Neurosurgery and Neuroresearch (now NorthShore Health System in Chicago). Pathology showed malignant CNS Lymphoma, left temporal lobe, B cell type. Today my MRI is every six months. Gamma Knife Radiation took place on July 13, 2007. I then completed the Insertion of a Power Port Implantable Port on July 25, 2007.

Methotrexate was the first chemotherapy he arranged, given at St. Joseph Hospital in Chicago. My white blood cell count dropped significantly, and my immune system crashed. I was removed from Methotrexate and remained in the hospital for a month.

I began Rituxan in the hospital. I was placed on Temodar from November 2007 through May 2008. Recovery was slow and challenging, but through it all remained support from my husband, good friend and family. To this day I deeply cherish each one of them.

Four months after the surgery, I returned to work part-time, while on Temodar. I slowly gained enough energy and desire to return to work full-time, back into my world of learning and development at a global finance company.

A couple years down the road, after leaving the city and purchasing a home in the suburbs, my husband and I found ourselves struggling like never before. Reactivity and anger was present. Dozens of times I found myself saying, “I don’t know what else to do.” Seemingly, our marriage was in trouble, yet I knew I loved the man very much. We continually challenged each other. He would tell me “you just said it” and I would say “those words never came out of my mouth”.

His anger, frustration and perceived lack of communication was frightening me. We entered couple’s therapy in March 22, 2011. Soon after beginning with our clinical psychologist, he requested I complete a neuro-psych exam. On July 7, 2011, Bill and I received the results of the neuro-psych exam. I knew I wouldn’t necessarily like the results, as the testing day was very trying and disturbing. I was NOT at all prepared to hear and later read the results.

The results explained why my husband and I were in such trouble. Bottom line is that I did not understand how much my language comprehension, behavior, writing, memory, hearing, and emotions had changed and were challenging me, both personally and professionally. Because I had not accepted the impact of the treatment, especially in the left temporal lobe, I was blaming and transferring way too much onto my husband. That was an eye-opening and very emotional week for me. It became clear that it was time to accept and more deeply understand myself.

We both then began individual work with separate therapists, seeing them weekly to this day. Therapy has reminded me that the birth of the human heart is an ongoing process ... and my husband has been alongside me every day. Since the craniotomy and removal of the tumor, there has been episodes of prolonged periods of fevers of unknown causes, mediastinal lymphadenopathy, Lymphadenitis, calcified granuloma of the lung, and a large cyst removed from my thyroid. During all these events I remain grateful that Lymphoma has not returned.

I remained with the global finance company until November 29, 2013. After careful consideration, I knew I needed to take care of myself. I’m a rather stubborn and independent 56 year old man who finally accepted that I couldn’t continue performing well without also giving up to much Self. My therapist was extremely helpful during these months. My manager and I talked last fall, and we agreed my disability would begin the day after Thanksgiving. I also began the SSDI process.

My cosmology has changed significantly throughout the years. Although I pastored in the 80’s and 90’s, today I don’t have a need to go to church, and am

quite comfortable with family time on Sunday morning. Do I worship? For me, worship is always a verb, and therefore is not something done to us or for us. Worship is something we do ... and I worship often outdoors. I also choose not to read or hear the language from many of today's spiritual sources.

Today I do coordinate and meet with a small multi-faith spiritual group on a monthly basis, where we learn about how science impacts our thoughts and beliefs, and also do rituals around gathering, letting go, creativity and personal transformation. Every once in a while we also enjoy walking a labyrinth or participating in a cosmic walk, reminding us of the unfolding of the Universe over the last 13.7 billion years.

I love walking outdoors, camping and marveling at the stars, listening to heartfelt music, gardening, and especially cooking. The Rossiter Cookie Castle (fictional company) had an early "closing" this spring, as my glucose was a little high!

My morning meditation is never the same, but I spend about an hour every morning stretching, sitting and giving thanks.

I stretch while watching 10-20 minutes of The Today Show, listening to morning headlines and weather for the day.

I sit upright, feet on the ground, often with my palms upright, take deep breaths and wish the world well. I often breathe quietly and deeply, listening to sounds around me. I allow myself to feel how good it is to be surrounded by hearts and love of family and friends.

I end meditation time by giving thanks for three things I'm grateful for today, followed by a deep cleansing breath, and then heading into the day.

I've also often enjoyed ending my day in our back yard hot tub. It's another place where I get comfortable with life's complexities and darkness, while also enjoying the light in the stars in the sky. I simply enjoy a good soak, and particularly if I am feeling fragmented or feeling grief. I then enjoy taking Jax (our family dog) for an evening walk before going to bed.

For me, CNSL has reminded me that the sacred and the mundane of life share the same space. Over the years I've slowly realized that for me there is no distinction between my spiritual and secular life. And in order to keep a sacred vision in my life before me, it takes study (I can only read about 30 minutes at a time), meditation and occasional conversations mostly with my husband (longer conversations are no longer possible as remaining focused is difficult) to maintain

a sacred way of seeing and living in the world. Over the years, my vision has deepened through deep initiations, painful illnesses such as CNSL and other surprises, and a willingness to take life on rather than avoiding it. I've learned so much from companions like Meister Eckhart, my husband Bill, my two adult children and my sister. Indeed, I can't imagine my journey of the last seven years without each of them, my mother, grandmother, other siblings, aunts and uncles and deep and abiding friendships. I am profoundly grateful for each of them.

I am also genuinely respectful and grateful for each of the medical and clinical professionals that have cared for me since day one. Their commitments to personal medical care has been astounding.

As summer approaches in 2014, brain fatigue and not having a driver's license are my greatest challenges. I remain very emotional when it comes to family issues. At a cognitive level, I can read for 30 minutes at a time, and then will need a rest. I can write for no more than a couple hours, and I struggle with my short-term memory. Afternoon naps are enjoyed.

Bill and I talk about moving back into the city of Chicago, as I need access to Chicago's excellent public transportation systems. Although we enjoy our home in the suburbs, I'm not comfortable relying on family and friends for transportation. We don't even have buses in our city. I want more of my independence back!

Jeff Foster writes a poem titled *You Will Lose Everything*. As a nearly seven year survivor of CNSL, the words are deeply meaningful, profound and truthful to me, so I thought I would end my story sharing it with you.

<http://www.lifewithoutacentre.com/essays-transcripts/you-will-lose-everything/>

You will lose everything. Your money, your power, your fame, your success, perhaps even your memories. Your looks will go. Loved ones will die. Your body will fall apart. Everything that seems permanent is impermanent and will be smashed. Experience will gradually, or not so gradually, strip away everything that it can strip away. Waking up means facing this reality with open eyes and no longer turning away.

But right now, we stand on sacred and holy ground, for that which will be lost has not yet been lost, and realizing this is the key to unspeakable joy. Whoever or whatever is in your life right now has not yet been taken away

from you. This may sound trivial, obvious, like nothing, but really it is the key to everything, the why and how and wherefore of existence.

Impermanence has already rendered everything and everyone around you so deeply holy and significant and worthy of your heartbreaking gratitude.

Loss has already transfigured your life into an altar.

Rich Rossiter

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Scott's Story

On January 24th, 2012, I heard the words “Mr. Baker, do you mind if we place an IV in so we can give you some contrast dye?” My experiences with two previous cancers taught me that there is only one reason for contrast dye after performing a “naked” scan. The imaging technician saw something fuzzy on the scan that he wanted to get a clearer picture of. At that very moment, I knew two things: I had a brain tumor and God had just answered my prayer to help me find my way. Not for one second did I consider dying, rather I began to develop a plan to get through what I knew was going to be a very tough battle. I had already survived systemic Non-Hodgkin’s Lymphoma on two occasions. In 1999, at the age of 29, I had a small bowel blockage due to advanced NHL, which had grown from my lymph nodes into my intestine. Upon inspection of several surrounding lymph nodes, my surgeon discovered that my Lymphoma had already spread to lymph nodes throughout my abdomen. He performed a bowel resection and, after a few weeks of recovery from the surgery, I began five months of chemotherapy. It was suggested that I could improve my chances of five-year survival from 60% to 85% if I agreed to 15 days of radiation to my abdomen. I agreed and the cost was 35% of my kidney volume. I had lost 75 pounds after surgery and before chemotherapy because I was unable to eat for about five weeks due to the pain caused by the smaller tumors growing after the main tumor was removed from my bowel. The good news was that everything changed after my first chemo treatment and I started eating immediately following that first treatment. I also went back to work and to the gym to try to rebuild all the muscle that I had lost. I achieved remission and returned to my life as it was. I truly believed that my diagnosis was a wake-up call, but I failed to make any real changes.

In 2006, just after Christmas, I was told that my cancer had returned. Again in my abdomen, but this time I had a golf ball size tumor resting on my kidney. Pain saved me yet again by alerting me that there was a problem. I had chemotherapy from January through March and had an Autologous Stem Cell Transplant (ASCT) in April of 2007. Again, I had achieved remission. We had two sons at the time. The youngest was still an infant and the oldest was only two years old. I realized how lucky I was to have survived this disease twice, but still only made minor changes in my life and the way I responded to the world,

particularly to my wife. I was aware that the most important thing to succeed at in life was to be the very best husband and father I could be, but I was coming up short. This became depressing so I turned to God to help me find my way.

In January 2012, I was having stroke-like symptoms such as slurring my speech, loss of balance, and the inability to construct an email. I went to the ER and it was determined that I had a brain tumor. The very second that I learned that I had a brain tumor I began to develop a plan to, not only fight the cancer, but to change my life completely. I didn't know how I was going to do that, but I was determined. I had brain surgery to get a sample to determine what kind of cells we were dealing with. I was diagnosed with Primary Central Nervous System Lymphoma (PCNSL), a very rare brain cancer with a dismal prognosis. Immediately when I returned home from the hospital, I began to research my disease. I searched the Internet for hours and was unable to find one encouraging article suggesting that I could be cured of this disease. I stopped researching for 48 hours because I found it impossible to stay positive with what I was reading. My oldest son, who had just turned 7, asked me a question that told me how important it was for me to find a way to survive. As soon as I put him and his brother to bed, I immediately opened Google and typed in "PCNSL Survivors". I found a 28-year survivor and a 10-year survivor within seconds. My whole mindset changed in an instant. I would learn that the 10-year survivor had started a website called the Braintrust a few years earlier and a support group that worked through email. I joined immediately and was so inspired by all of the members of the group, which consisted of survivors of PCNSL and other types of brain tumors that I had the most important tool to have in my arsenal --- I had hope. Hope led to an absolute belief that I would survive.

My research indicated that the best treatment for PCNSL was available at Sloan Kettering in NYC, which is only 2.5 hours south of home. I made the very unwise choice to seek treatment locally for a very difficult disease with the understanding that I would receive the same protocol as I would have received in NYC. I achieved remission for a brief time, but recurred almost immediately following treatment. By August 28th, 2012, I had almost lost my life, but my wife had arranged for me to be admitted to Sloan Kettering. I would receive an extremely aggressive treatment regimen from August until November and achieved remission yet again. This time I was offered an opportunity to have a second

ASCT if they were able to harvest enough viable cells. On Black Friday 2012, I learned that the apheresis was a success and I was going to have the transplant.

I entered the hospital on December 18th and was in isolation until January 14th when I was released and went to the Hope Lodge in Manhattan. There were moments during those 28 days where I really believed I was not going to make it, but with the support and expertise of an army of healthcare professionals, I survived and continue to recover from the effects of the treatment. I was able to coach youth baseball for both boys, participate in the Livestrong program at the YMCA, and I went back to work on October 10th.

I believe that my prayer was, in fact, answered. My life has changed completely. I view the world and respond to life's circumstances differently. I changed my thinking completely. My focus is on others rather than on myself. I am committed to helping others through support groups such as the Braintrust and WhatNext. Sharing experiences with other survivors is absolutely priceless. For the first time in my life I go to bed at night knowing that I am doing the very best that I can in every aspect of life. I have certain limitations, but I continue to improve. I am truly grateful for my life and all its blessings. I have been given the opportunity to continue raising our two boys, Jacob and Shane, with my wife, Suzette, which is the greatest blessing imaginable.

Scott

Ann's Story

People have asked me how I coped with George's battle with cancer. My answer: taking it one day at a time, not looking farther than the next day, and keeping busy. Also, even though it is not a river in Egypt, denial is a wonderful thing, used in moderation. I refused to accept the verdict handed down by the doctors, and only once did I allow myself to panic. Stubbornness and denial helped to get me through that Summer of George's Cancer.

There are, however, some things I would have done differently. The day that George lost cognitive ability --- aphasia --- in the store, for example. Why, I ask myself, didn't I take him to the Emergency Room? Why did I pretend that everything was going to be all right? My husband --- my rock --- whom I had depended on for forty-five years might die and I was pretending --- denying. My message to others on this subject: Denial can be a tool to keep you sane, but it can be overdone.

Early on, I learned a bit of what would be happening to George and how I would react. Later, I would write about it: George looked helpless and vulnerable, childlike in his anxiety and unable to express himself in words. While nurses installed the metal halo needed to keep his head still during the biopsy, I felt every turn of the screws going into his skull. Soon I felt a hand under my elbow and heard a voice ... a figure in a pink smock led me to a chair and placed a glass of water in my hand. Thank God for hospital volunteers.

Dr. Kindt wasted no time explaining his findings; still in his scrubs from OR, sitting beside me in the family waiting room he said that CNS Lymphoma would be confirmed by the pathologist, but no time would be wasted in getting treatment started. When George was settled in his room and I was allowed to see him, he was worse than ever --- drooling and mumbling. I swallowed my fear and tried not to show my horror. The doctors and nurses were gentle with me; they explained that the activity in his brain necessary to obtain a slide for the pathologist created some disturbance which would clear up gradually, which it did.

The treatment team began putting together the only protocol available for his advanced case. The attending physician would be a hematologist/oncologist. I would learn a lot about medical terms and hospital routines that summer.

The young doctor working closely with the lead physician searched the data base for other options, in the process learning that Whole Brain Radiation was not advised. When he shared the report with us, phrases such as senility, incontinence, early death. "I'll pray for you," said Dr. Schulz and he discretely left us alone to discuss and decide. We wanted no part of anything that would induce those things. WBR was not an option.

George's treatment plan called for him to be in the hospital more than he was home. Rituxin was just coming out of clinical trials as were most of today's cancer fighting tools. High dose methotrexate, vincristine, infused with a pump, then washed with saline, followed by Leucovorin took the whole summer. In between hospital inpatient visits we visited the outpatient clinic where George received chemotherapy through the port in his head (Ommaya Reservoir). He still has that port because he was expected to relapse within a year. Procarbazine, taken by mouth at home also came with a lengthy list of forbidden foods. I remember standing in front of our pantry in a panic that I might give him the wrong foods. The last couple of week's cytarabine was infused in the outpatient clinic. That was difficult because of the muscle aches.

My routine kept me sane: During the times George was receiving treatment in the hospital I would eat breakfast, walk the dog, pack a lunch and drive 21 miles to the hospital, hoping to catch the doctors in their rounds. The oncology unit had a comfortable family lounge with small kitchen and library. While George slept, I read and when he woke we would watch television or just chat --- that was after the chemotherapy was starting to work and his aphasia began to retreat. I would leave for home at the beginning of the rush hour, fry an egg or heat up a hot dog for supper.

Sometimes I would return home at the time of sunset, and marvel at the beauty of the changing colors. In the waning light of evening, I would putter in my flower garden, weeding, and plucking spent flowers, trying to stay busy. I didn't feel like talking to anyone but our grown children. One of them became the central communicator. They all took turns flying into town to stay with me, helping however they could. Toward the end of his treatment we learned of a brain tumor support group sponsored by the hospital and decided to look into it.

The annual picnic at a local park brought together a couple dozen patients with their spouses/caregivers. With a few exceptions the patients looked like ordinary people. However, months later, we learned that all of the old regulars

were shocked when they saw George and figured him as the first of the group that would die first. I was glad no one voiced that thought at the time.

The call came in September just after another MRI. The doctor's voice made my stomach tighten. "They're gone."

What's gone? What does that mean?

"The tumors are dead. There is nothing on the MRI."

If he were there in person, I would have hugged that doctor. We were like kids who had just been told we could have our birthday party after all. George was still weak and largely unaware of his surroundings, but he was alive and we were ready to celebrate. Our family reunion expanded to a party for friends and family. George ordered a new wedding ring for me --- the original one was worn thin --- and our pastor made a special trip up the mountain to preside over the ceremony of renewing our vows. Our son was the best man, the pastor's wife the matron of honor and the clicking of cameras from the gathering was heard the whole time. Afterward forty people joined in the feasting and celebrating.

Then we entered the world of survivors and never looked back. In this cancer journey we have met some amazing people and heard some terrible and wonderful stories. A few years later, I wanted to share George's story and the story of caregiving and brain cancer in general, to reassure others newly diagnosed. So, I wrote *A Caregiver's Story: Coping with a Loved One's Life-Threatening Illness*.

Ann

Note: Ann's husband, George, also shares his survivor story, beginning on page 8.

Ann Marie's Story

Time stood still. I didn't realize this until the first day back at my desk. The daily tear-off-page-per-day calendar stood at October 21. That had been weeks before. Was that the last time I had sat here?

It happens. Time stands still while it is lurching at warp speed in the direction of destruction. Nothing remains the same in the time-space continuum upon a PCNSL diagnosis. Does it depend on where you are? Will it revert to the last date on that calendar....the day, the hours prior to "knowing"?

When did this all happen? What did the doctors say those first few hours, days when the diagnosis was being groomed for our laps?

I should have written it all down. I should have written my sister's words. I should have videotaped her days in the hospital. They very well could have been her last. She was read the last rites, after all.

The "new normal" hit me like a cast iron skillet upside the head. Ahhhhh. Now I get it. There was life before PCNSL. And, there is life after PCNSL. And, they look nothing alike. This is the new normal. Get used to it.

And, so it went.

As the sister of a PCNSL survivor, I was part of a team of 2, her husband and myself. At least, it felt that way, so very often. We read, researched, "googled", drew on our personal connections in the herbal pharmacy field and called in non-existent "favors" of acquaintances from 20 years previous who were specialists in neuro-issues. We questioned the docs, asked questions of the docs, and looked at scans with the docs, talked to each other about what might happen. I remember the day the diagnosis went from an AVM to cancer. My brother in law took me aside in the hospital hallway and told me to start planning on a Christmas in the islands. He was going to take the entire family so that she, my sister, would have a great memory before she died. We didn't even know if she would make it that far.

But, we weren't a force of 2. We were as many as the number of people we shared her, our, story with. I must consider the contribution of his brother and family who let us stay with them at times when my sister was at the local Boston hospital. His brother even helped in the research. And, there was my cousin and his wife who offered to host Thanksgiving at their house for us, if we found we

were “stuck” there, as it were. I stayed with them on several occasions as well. There was my mother, who, week after week, drove to my sister’s house to take care of their 8 year old son. She made him meals, watched movies with him, waited at the end of the driveway for the school bus to arrive. And, let’s not forget all of the great family and friends who made the time to come and visit, or who sent cards and photos and those who prayed and prayed.

Once we got past the critical stage, past the ICU, last rites, being scared out of my wits, the idea of recovery became a reality. The frustration of her limitations was countered by her humor in the situation. Being reminded of the many times she hadn’t remembered where she was. She, knowing how little she was remembering, poking fun at herself and trying to focus on the benefits of short-term memory loss. For instance, she wouldn’t remember that she had just had an ice cream, one of her favorite foods. So, she reckoned, she could have one, even if one of us was there and reminded her.

My relief in that particular sense, was that she had no recollection of the terrible parts of the journey. She didn’t remember the diagnosis. She didn’t remember the ride to Boston, which, had she been well, would have driven her crazy. For there was the dropping off of my brother-in-law at the pharmacy to fill her prescription, probably for an anti-inflammatory and my driving to the gas station with her to fill the tank. She wanted a coffee, her other favorite food. I thought she would just get a cup at the convenience store inside, but when I looked around while pumping gas, I saw her walking to the coffee shop down the street. What should I do? Did she have money? Would she remember that I was there waiting for her? I couldn’t see the front of the coffee shop, so would have no way to know if she went in the other direction.

And, then, there was the key to the car, a Prius. I had driven it before, but never learned the specifics. I got in the car thinking I would drive to the coffee shop. Nothing happened. Did I break something? What was I doing wrong? I had no way to reach her husband. But, I was to pick him up after we finished. She was gone; the car wouldn’t start so I couldn’t move it. I couldn’t leave it at the station and he didn’t know we were stuck. It was a panicky moment.

After a bit, her husband showed up in the passenger seat of an electrician’s van. He had gotten the script and realized he had the key in his pocket, so he hitched a ride. And, she made it safely back from the coffee shop. I thought I might keel over with anxiety. But, the journey had barely begun.

We got on our way, and I was driving. A rarity in that dynamic...their car, a road trip, and I was driving. This must be bad.

Over the course of the next few months, what I learned was that the more we knew, the easier it was to speak with the doctors. Her medical team was incredibly supportive of our efforts and never made us feel as though our research, our questions, our concerns were unfounded or otherwise not worth addressing. I realized that being powerful in moments of deep challenge was a great antidote to feeling helpless.

But, the most important lesson I learned was that the absolute interdependence of our humanity is what saves us every time we are at risk. The more I talked about it or shared it...well, I wouldn't say, the better I felt. But, I will say, the less isolated and more hopeful I became. And, I wish I had written more as the experience was unfolding, because there is no way to fully recall with any level of accuracy, the hundreds of interactions, discussions, discoveries, feelings, suggestions, agreements, approaches during the experience. Much perspective can be achieved simply reflecting on our feelings at any one moment; especially in a moment of crisis. But, I do remember that in my deepest moments of despair, when a friend would say, "You're a great sister, she's lucky to have you working on her behalf." I would cry, be thankful and go right back to the business of getting her better.

Ann Marie

Lisa's Story

On December 18, 2013, our lives changed forever. With my 40 year old husband, Ben, receiving a MRI just a couple days before, the doctor discovered a small mass or lesion on his brain stem. The discussion of MS surfaced because of the lesion and other symptoms: double vision, balance issues, and partial hearing loss in his left ear. A next day spinal tap was ordered and results would take a few days, so we thought. Within an hour or so of coming home from getting the spinal tap in the hospital, a nurse called and we were ordered back with the understanding we would be there for a few days.

With only a financial will in place, we were highly encouraged to fill out Power of Attorney papers. Luckily, a year before we had had a conversation about our wishes if something should happen to one of us. A conversation, however, is much different than actually putting your words into legal-binding decisions. As two social workers signed off as witnesses to our choices, my heart ached and my eyes filled with tears.

Six days later which included a transfer to a state-of-the-art hospital, Ben was diagnosed with Large B Cell Lymphoma; specifically known as Primary Central Nervous System (CNS) Lymphoma. We were released on Christmas Eve facing the biggest battle of our lives: BEATING CANCER.

After asking the million "how's" and "why's", it was time for me to get into fight mode. This was a journey our family could not endure alone. Having two young children, Bryanna age 9 and Zakary age 6, I had to keep them protected yet be honest. My 11+ years as a full time special education teacher had prepared me to ask for help, look for resources, and never stop reflecting on what more I could do.

I was able to take partial FMLA to help Ben and enlisted the help of our parents to also assist with appointments and our children. Ben met with his employer and due to the nature of his job, went on short term and long term disability. I made sure on the home front our children's' schedules, routines, important phone numbers, deliveries, and anything else about our daily lives were posted in our kitchen. I created charts and taped them to our kitchen cabinets to make sure that in a moment's notice, I could leave and someone could take over. Our bathrooms also had signs on "how to wash your hands" and a list of medications Ben needed to take on a daily basis. Hand towels were removed from our home and replaced with paper toweling. Hand sanitizers, masks, and medical glove stations could be located in all parts of our home. All in the hopes to decrease the risk of spreading germs.

I took time to contact my insurance company and made connections with the appropriate people. I did research to find funding and support locally and around the country. I signed up for a grant through *The Leukemia & Lymphoma Society* to assist with co-pays. I joined an online support group for CNSL called braintrust.org started by Barry Gates. People from our church put us on the weekly prayer chain as well as other prayer chains all around the United States.

Not only did I take time to educate myself, but everyone in my children's school were informed of our circumstance. The staff made sure to watch out for the emotional well-being of our children. Our daughter met with the guidance counselor several times to discuss her questions and worries. I also had our children meet with a Child Life Specialist several times through the course of Ben's inpatient treatments. We made sure they were a part of the hospital visits, which gave comfort on both ends. While they had their time to talk and process, I read several books: *How to Help Children Through a Parent's Serious Illness*, *Healed of Cancer*, and *The Confident Woman: Devotional 365 Daily Inspirations*.

Having access to social media, spread our situation quickly. Friends and family members near and far blessed us with their generosity. I set up a page on Caring Bridge to inform everyone of Ben's journey. I was real, raw, and upfront with everything going on. Friends set up a web-based site for people to sign up to make dinners for our family, lunches for our children, and a carpool list. A PayPal account was also set up to allow people to donate money. Greeting cards filled with money, gas cards, food cards, and assortment of gift cards filled our mailbox almost daily. Gift packages showed up at work as well as our front door. Phone calls, texts, and emails showered us with love and prayer. Reminded us we were never alone.

With all the generosity and thoughtfulness coming from miles around, I never wanted to throw anything away. I decided to dedicate a wall in our dining room, which is centrally located in our house, to hang signs, cards, and pictures. A daily reminder that we have people in our corner. This helped us to stay strong and move forward even through the darkest of times.

About a third of the way into treatment our spirits were lifted when we learned Ben was considered to be in remission and the treatment was working. Another uplifting moment to remind us to keep the faith and press on. Still months left of appointments and grueling treatments, but a sign that brighter days were coming.

Being parents of young, involved children, I continued to make sure Bryanna and Zakary got to their activities. Keeping their schedules as normal as possible and involved in sports, school, and church activities, made the worrying less. My hope is our children will grow in a positive way from this traumatic event. That they comfort those in need and reach out beyond themselves.

As a couple, we tried not to get lost in all the treatment and medical jargon. It was extremely difficult at first and we both needed to find our new roles in our family. I probably started out way too protective, but through discussions and yes, sometimes frustration, we made things work. I had to learn to allow Ben to continue to live and continue on with his friendships by enjoying the outdoors and going out to dinner. We decided on reading a trilogy together, so that we both had something else to talk about rather than talking about our own lives. Date nights consisted of take out and an occasional movie.

The first chapter in Ben's journey ended with a benefit golf outing on May 24, 2014. This event brought family, friends, neighbors, and co-workers to celebrate Ben's victory and raise money to help off-set some of the medical costs and loss of wages. As I looked out among those who came, my heart melted and reminded me again, "We are never alone." We celebrated 12 years of wedded bliss a week prior, but this event will also hold a special place in our hearts. This was the day we said, "I do," all over again. Renewing our vows. Confirming our love and commitment to one another.

Ben is considered to have 'no sign of disease' and waiting for another crucial appointment in June to determine the next phase. An end to treatment, the start of the healing process, and an adventure into our 'new normal'.

The top 10 key factors that helped me as a caregiver, cope and push forward:

1. Reach out for help
2. Accept help
3. Prayers, prayers and more prayers: Keep the faith
4. Keep your children in the forefront
5. Research: Not just about the disease and treatment but about support groups and financial assistance
6. Ask questions. Nurses become your new best friends.
7. Continue to live life
8. Smile, not every day is bad
9. Allow yourself moments to be emotional, real, and raw
10. Remind yourself life is so worth living for and that you are NEVER alone

Ben's Journey Through Lisa's Eyes
Lisa Bellile (from Wisconsin)

