

“There is no medicine like hope, no tonic more powerful than belief that every trauma has a solution. The ability to hope allows us to face the trials of daily life.”

LEO BUSCAGLIA

Chapter 1

INTRODUCTION

“I am so happy and grateful that my daughter Celeste has had a miraculous recovery and her brain tumour has shrunk completely and has disappeared. I am so happy and grateful for family and friends all over the world who have prayed and fasted and visualized a full, complete, and speedy recovery for Celeste. I am so happy and grateful now that all the prayers and visualizations for Celeste have effectively restored her to complete health.”

*Written on a small notepad at midnight
Thursday, February 24, 2011*

Little did I know that night of the incredible journey our family was about to embark on and the impact it would have on thousands of lives. I will forever remember writing that note. I will forever remember that day. I will forever remember all the details of the events that occurred over the next two years.

At 4 o'clock in the afternoon on Thursday, February 24, 2011, my husband, Matt, and I had just picked up my 6-year-old son, Grayson, from school. Climbing back into our car, I scrambled to grab my ringing cell phone. It was Michelle, my children's step-mother. She hurriedly informed me that Celeste, my 12-year-old daughter, was in the emergency department of the Children's Hospital in London, Ontario.

Celeste had been having bad headaches, and we had a doctor's appointment coming, but when she started developing double vision that morning, Michelle, a neurology resident, took Celeste to see her doctor that day. He immediately sent Celeste over to the emergency department. They did a CAT scan and an MRI was scheduled.

Michelle announced, "Celeste has to have emergency neuro [brain] surgery tonight."

"We're on our way!" I said. I was in shock.

London is a two-hour drive from my home in Niagara. I began making calls to family and friends to let them know what was happening and to request their help arranging a priesthood blessing for Celeste before her surgery, a place to stay for Matt and Grayson while I stayed at the hospital with Celeste, and any other help we might need while staying in London.

Matt and I had been in the midst of a celebration getaway at a hotel in Niagara Falls, a gift from my parents to celebrate my fortieth birthday and our seventh wedding anniversary coming up that weekend. We raced back to the hotel, packed our bags, cancelled our dinner reservation, and informed the hotel we would have to check out a day early.

It was all so surreal.

When we arrived at the hospital, Celeste's father, David, himself a doctor of child psychiatry, met us and quickly explained that

the CAT scan and MRI had found a large mass (3 centimetres x 3 centimetres x 3 centimetres) near her pineal gland, close to the brain stem. It was blocking the flow of her brain fluid, which was building up, and that pressure was causing the headaches and double vision.

The surgery would relieve the pressure and the doctors hoped to get a biopsy of the tumour to assess if it was benign or cancerous. They had no way of knowing how long it had been growing. David then informed me that Celeste didn't know and that he didn't want to tell her until after we knew something concrete, until we had a firm diagnosis and treatment plan.

Armed with all this new information, I was taken to Celeste in her little children's room in the ER. How do you cope when you have just been told your daughter has a tumour and she doesn't know about it? How do you put on a calm face for your precious daughter?

You just do.

I was emotionally exhausted before I even stepped into her room, yet adrenaline and focusing on what needed to be done kept me marching on. We arranged for the bishop to give her a blessing before her scheduled surgery at 9:30 p.m. Celeste was tired, medicated to deal with the pain in her head, and she had a patch on her eye to help with the double vision.

Armed with her Pooh Bear, blanket, and Winnie the Pooh movie, Celeste waited for her surgery. Grayson climbed into bed with her and cuddled. When it was time to head to surgery, I went with Celeste to pre-op.

Celeste did so well, taking everything in stride. We joked with the nurses as they gave her meds to make her sleepy and off they wheeled her down the hallway. Now, looking back, I don't know how I was so strong to watch them take her away, my baby girl.

If I could have, I would have stayed holding her hand during the whole surgery.

It was a long, tiring wait in a cold, empty waiting room. Both Michelle and I tried to sleep on the tiny bench seating, to no avail. The surgery went well and, around midnight, we were ushered into post-op to wait for Celeste to wake and then finally have something to eat and drink. She hadn't eaten all day, poor thing.

The incision was about three inches long and she had a dozen stitches. They had very carefully shaved just that area of her head but it was all bandaged up now with a tube protruding from the incision to help drain the fluid. The tube was connected to a bag to monitor, measure, and collect the fluid. Every time she lay down or sat up, they had to adjust the bag to keep it level with her head.

When Celeste was finally in her own room in the children's ward, my adrenaline was gone. The pullout chair turned into a tiny single bed. As I settled down to sleep, I focused all my thoughts on visualizing Celeste well again. I started planning in my mind how to recruit all our family and friends all over the world to pray for her complete recovery.

My fervent prayer was for a miracle. I had just spent the previous year learning from Bob Proctor, personal growth and development expert, about how the mind works and how fear is generated by ignorance. I was determined to stay focused on the positive, arm myself with knowledge, and ground myself with faith and gratitude.

I felt calm. I fell asleep.



Five hundred miles away in the United States, in New Jersey, there was another 12-year-old girl and her family dealing with the

exact same situation. Hayley had been on a much longer journey to discovering the source of her symptoms. Over a period of six months, doctors told Hayley's mom, Laurie, that it was possibly everything from kidney issues or tumours on her adrenal to a thyroid problem or anxiety.

They had performed every blood and urine test imaginable, CT scans, MRI scans, MIBG scans, and ultrasounds, but it wasn't until Laurie finally took Hayley to another paediatrician that he recognized the double vision and her eye beginning to turn inward that he sent them directly to the emergency room. Within an hour, Hayley had been diagnosed with a tumour on her pineal gland, just at the top of the brain stem. She was then admitted to the ICU and scheduled the next day for neurosurgery to relieve the pressure of the hydrocephalus (fluid build-up in the brain).

Laurie and I, hundreds of miles of apart, shared a journey that no mother ever dreams of, and we had no idea then that we would share each other's journeys. We didn't learn of each other until three months later. This book chronicles our stories and how it is our wish that our story will help another mother when she gets the devastating news that her child has cancer.

One of our daughters survived. One did not.

During the days, weeks, and months following surgery, the learning curve, for both Laurie and me, was extremely steep. We stepped into a new world of hospitals, doctors, nurses, support staff, new terminology, new procedures and tests, and information and emotional overload as we tried to prepare ourselves for everything we needed to know and do to best help our little girls. There isn't a manual for being a parent when your bundle of joy is first placed in your arms, and there certainly isn't a manual on how to cope when you receive the heart-wrenching news that your beautiful child has cancerous cells growing in her body. You only hope

that all your life experiences thus far can help you deal with the difficulties that lie ahead.

As two mothers who have used every ounce of hope, strength, and courage necessary to help our daughters bravely face their treatments and adjust to life as cancer survivors, we wrote this book for you to share how we supported each other as one daughter learned her cancer had become terminal. We would like to share with you some of the things we did to cope during the long days and nights—through surgeries, diagnosis, treatments, and the aftermath.

We share the gift of the friendship that developed between me, Laura, the mother of Celeste, and my friend Laurie, the mother of Hayley. As the girls started their chemotherapy treatments, a rare and special friendship blossomed between us as we shared with each other the same journey of faith, hope, prayer, and desire to witness a miracle of healing for both girls. We strengthened and supported each other on low days and praised the miracles on good days.

We communicated by email nearly every day and when time allowed via Skype and phone. Our personal story is shared here through some of our email exchanges. You will bear witness to a friendship and love that blossomed during the long summer of 2011.

The following chapters include an introduction to Celeste, an introduction to Hayley, some of our emails, and what we have learned through it all.

Our main objective is to share how to find hope, strength, and courage. As we reflect on what it took to get through those long difficult months, we share tools, resources, and lessons we learned in order to help other parents and loved ones face the reality of caring for a child with cancer with hope, strength, and courage.

INTRODUCTION

In sharing the personal details of our stories, we wish to help you on your journey. Our experiences taught us what we convey to you: the importance of:

- Reaching out to the resources and family and friends around you for support
- Connecting with God/spirit, friends, and other parents going through the same thing
- Reflecting on the present situation through reading, prayer, meditation—arming yourself with knowledge to better learn how to help your child
- Expressing the torrent of emotions that will come up by journaling, talking it out, crying, and being creative
- Loving yourself, your family, God/spirit, and, most importantly, your child.

For you to get through your journey with hope, strength, and courage, it will be crucial for you reach out, connect, reflect, express, and love. That is what drove us to write this book.

It has not been easy to write this book and yet it has been healing.

All we can do is share what we have done and hope that it helps you.

