

## Brain Injury Survivor's Guide Chapter 1

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### Code Blue!!!

"Larry, you need to come to the hospital. There's been a Code Blue. We're in Medical ICU on the sixth floor." Beth's mother, Mary Jo, sounded frantic.

I glanced to my left as I stepped from the hospital elevator and saw Beth's parents and one of her friends sitting in the family room. My heart froze, and I seemed to move in slow motion toward them. My father had been a funeral director and I was very familiar with hospital family rooms. A doctor I'd never seen before stepped from the room and walked toward me.

"I don't expect her to survive the trauma."

"What happens in the next 24 hours is critical."

Thoughts careened and ricocheted through my brain faster than those little spheres in a pinball machine. Before I could form a sentence, another light would flash inside my head and another bell would ring. What in the world was happening?

Two hours earlier I had been sitting at Beth's bedside talking to her about things at home and the surgical recovery process. She was excited that one of her co-workers, Lisa, would arrive soon with frozen yogurt, one of her favorite treats.

Lisa sat in the family room clutching a soggy, brown paper sack. The look of concern on her face told me as much as the doctor whose words were not really registering.

"A R D S."

"One of the leading causes of death in Vietnam."

Shortly after I had left for home so I could be there when our 13-year old returned from his fishing trip with one of my co-workers, Beth was discovered near death by a nurse. She wasn't breathing. Emergency procedures were quickly initiated. The surgeon's office was called. He was on the golf course. Time passed. A pulmonary specialist was called.

Time passed. Too much time. The doctor who met me getting off the elevator was the pulmonary specialist. Beth's mother was there and overheard the specialist berating the staff for not contacting her earlier.

A day later I heard the same 24-hour message with a twist. Beth's kidneys had stopped functioning, and a nephrologist was called in for consultation. Beth was sedated with morphine in the hope that her body would heal itself.

During this time, loved ones were allowed to see Beth four times a day for fifteen minutes, and only two family members at a time were allowed into MICU. Between my five to eight minute sessions I tried to work and to provide comfort to our children.

"We may need to amputate her toes," was the message of the day. Oxygen being pumped into Beth was not circulating throughout her body. The team of doctors was growing.

For the past year Beth and I had taken dance lessons. Dancing had become our primary recreational activity. There had to be an alternative to amputation. A nurse explained how I should massage the toes and feet with a *miracle* ointment. She cautioned, "Be sure not to get it on your skin. It could cause severe headaches."

I'm quite sure my glare spoke more than I would verbally express at the time. Me having a headache or Beth having amputations? I know the nurse was trying to protect me; my heart thought she was ridiculous.

The subclavian allowed the staff to hook several IV bags to Beth. Her kidneys were not processing the liquid, and her body was blowing up like a balloon. She gained 25 pounds lying there. Each time I completed my short MICU visit by getting on the elevator, going into the parking lot, and crying almost uncontrollably.

There was another family living in the waiting room with whom we developed a relationship. Their loved one was also battling ARDS. The time between those short visits to see our loved ones were spent nourishing and encouraging one another. A twofold sadness enveloped our entire family when their loved one died.

Not only were we saddened by our new friends' loss, but we were saddened by the sobering fact that she had died fighting the same problem Beth was struggling to overcome. Her body fought those many complications for fourteen days and, almost miraculously, she began breathing on her own. The breathing tubes were removed.

Mary Jo stayed with Beth when she was moved to a private room for another week. She asked her mom what had happened. Beth had no memory of the month of August.

Months passed after she was released from the hospital before we discovered that Beth had suffered an anoxic stroke in the hospital that resulted in a brain injury.

**Her questions, however, provided guidance for Mary Jo. She discovered that Beth did not know she was married. She did not know she had two children. She did not know where she lived. More memory problems would surface.**

Beth had forgotten how to clean house or cook. She struggled for words when she spoke. She had no idea what three times three yielded. She had vision problems. She could not remember what happened two minutes previously. She did, however, remember Buffy our Cocker Spaniel!

Beth had determination. She wanted to cook for this family to whom she was beginning to adjust. I took three cans from the cabinet, three bowls, a can opener and showed her how to turn on the microwave. I walked out of the kitchen apprehensive but hopeful.

Sean, our youngest, and I watched TV while Beth busied herself cooking her first meal since returning home from the hospital. Within minutes she announced dinner was ready with a qualification.

"It doesn't look like very much."

I went to the kitchen. There was a bowl of warm green beans. There were also two unopened cans and two empty bowls. She had forgotten that I had placed three items for her to prepare.

Her concentration on preparing the beans caused her to focus both her brain and her eyesight on the beans. We would later learn that she had no peripheral vision; she could not see the other cans or bowls.

**Does any of this sound familiar to you?** We're sure you are experiencing very similar problems in your life. It's very possible that you, like Beth, have no outward signs of what is going on inside your head.

You look normal so people expect you to be normal. If you had a piece of shrapnel sticking out through your skin, people would be a little more understanding. But you don't, do you?

That's why we're writing this Survivor's Guide for you. The medical community can provide you with statistics. They can tell you "things" you should do if you are experiencing "such and such". They can tell you how the brain is supposed to operate and about left brain and right brain issues. However, if your medical professional or medical team has not personally had a brain injury, they don't really know what's going on inside your head and your life.

It is, after all, that same medical community who today defines what happened to Beth as a "mild" head injury. Their definition of a mild head injury is far different from yours and mine. A bump on the head is a mild head injury; loss of peripheral vision, loss of motor skills, loss of mental skills: does that sound mild to you?

When we began writing this book Beth insisted that the words, "**Knowledge is power to a brain injured person,**" be included. Those words were inspirational to her because she knew that learning how to live with her new limitations would lead to a more productive and enjoyable lifestyle.

Knowledge about brain injury and how it affects individuals differently makes it very difficult for medical professionals to completely understand its wide-ranging effects.

We were given a pamphlet written *exclusively* for people who had suffered a brain injury and who were experiencing the new world of cognitive difficulty. The pamphlet explained diffuse damage and how coup, contracoup, and centrifugal movement of the brain inside the skull caused that damage.

Tell us again who this was written for. Exclusively for a brain injured patient? Exclusively for a person who has cognitive difficulties? Exclusively for a person with a short attention span and who

has difficulty with words? Let us tell you a bit about a brain injured patient.

Beth's boss visited her shortly before she was discharged from the hospital. He commented about how many *Get Well* cards she had received. She responded, "Yes, but I can't read them." It was to this brain injured person that a pamphlet was written which explained the coup, contracoup and centrifugal movement of the brain that results in cognitive dysfunction!

Can you imagine what kinds of thoughts and concerns must have been going through the boss's mind? He and Beth had worked together for seven years in what began as a three-person office. Learning that she was unable to read the cards hit him as a caring person, and then it hit him as a boss.

So why has it taken us seventeen years to write this? Admittedly, we were finally prompted to action by the Traumatic Brain Injuries being suffered by our soldiers in Iraq and Afghanistan. We know firsthand the new life they and their families are entering. We know the best information about dealing with this new lifestyle comes from those who have been there. We know that knowledge is power to a brain injured patient.

But there is another reason it has taken seventeen years. Beth has problems today related to her experience and her brain injury. These memory problems are of a different kind. She does remember events in the hospital. She does remember the breathing tube, feeding tube, the four IVs and the catheter. She does remember being tied down with restraints.

When we pulled her medical records along with everything we had written and all communications we had received from so many sources to review for writing this book, Beth could not hold back the tears as she read them. All blame for the delay cannot be laid at Beth's feet. I began writing her story numerous times, each time becoming emotional and abandoning it.

We welcome you to our world even though you'd much rather be somewhere else. Who wouldn't? It's a world where virtually no one will understand what has happened to you, and that includes quite a large segment of the medical community.

It is a world in which family members and friends must provide knowledgeable support. It is a world that offers very little support for family members, the very people who are so important to the recovery, retraining and re-emergence of a brain injured person.

The purpose of this book is to address the needs of both patient and family. We have developed numerous strategies over the years that we will share with you and actually show you how to use them, when to use them and why you should use them.

A few of your brain functions are inside a cocoon; our goal is to guide you in helping those functions break through that shell and emerge as a beautiful butterfly.

Again, welcome to our world.

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Brain Injury Survivor's Guide is available at most online bookstores. Perhaps the easiest way to purchase a copy and get the fastest delivery is at Amazon.com. You can click this link to find [Brain Injury Survivor's Guide](#). Or, you can copy and paste the link in your browser:

<http://www.braininjuryguide.org/information/click.php?id=18>

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