

A CAREGIVER'S STORY: Part II

By Thomas Gallup

This is Part II of a story continued from issue publish on 6/19/2020. For Part I, scroll down to page 3 of this document.

Trigger Warning

This article contains content that some readers may find upsetting. Reader discretion is advised.

During the three months our son was in Shepherd Rehab Hospital, we were able to participate in a Support Group for Caregivers of Brain Injury Survivors. Those attending were all new to Brain Injury and all going through the same trauma we were. We found it to be a relief to hear that we weren't alone in the emotional turmoil that you go through as you first come to acknowledge your loved one may never be the same and that your life was about to change – perhaps forever.

When we got settled back in our home in Maryland, we were referred by the Brain Injury Association to a local Support Group that met one weekday evening per month. Although the meeting time was inconvenient for us, we attended a few of the gatherings. However, our son seemed to be so much worse off than the other survivors. Andrew has remained unable to speak or walk. He has periods of awareness most days but much of the time he is not very alert. He cannot move on his own. He needs round-the-clock care with special attention to turning when in bed and weight shifts when in his wheelchair. Honestly, we became a little discouraged when hearing that many TBI survivors from the group had less severe challenges.

At about four years post-injury, Stefani O'Dea and Catherine Mello were visiting our home and brainstorming some ideas. We all agreed that a Caregivers Support Group that met in Zoom would be ideal for those who couldn't get to inconvenient meetings or who didn't have a meeting reasonably close by. With the help of some other caregivers of severe TBI survivors we knew, my wife Suzanne and I had the first online meeting in January 2019. Since then, the meeting has attracted participants from all over the country – from New Hampshire to California. Attendance isn't overwhelming – we typically see 10 to 12 Caregivers coming in, but the benefits are remarkable.

Our meeting doesn't focus on our survivor's issues; we only focus on the caregiver. Each meeting has several focus questions to help participants share their thoughts and feelings. We try to keep our answers to 3-5 minutes so everyone can weigh in. Our questions try to get beyond superficial feelings and might include things like: What was your best win during the last two weeks? What energy boosting strategies

are you taking advantage of? Are you wrestling with guilt? If so, what kind? What do you say to the newcomer who is struggling with a survivor who isn't responding to therapy and who is ready to give up?

When I asked participants recently what they were getting out of the group, I had some interesting replies. Caregivers of individuals with severe brain injuries soon find that they are different from the rest of the world. Few outsiders can understand the pain, grief, aggravation, depression, burn-out and frustration we deal with on an almost daily basis. Sometimes we joke about being in a private "club" that we would never want to belong to, yet we do. Being able to share our feelings with others going through the same ordeal provides uplifting fellowship and empathy. Knowing that we are not alone gives us strength. We remind each other that we can either "be bitter" or we can "be better" by seeking fellowship with those going through the same trials. It is remarkably comforting to share raw, emotional heartache with someone else who understands and can say, "I feel the same way."

Our meetings aren't always serious and sad either. Those who've been coming around for awhile get to know each other and lighter moments get shared too. Like the time we laughed at how the family dog was caught licking up tube feed that came from a loose pump connection when we stepped out of the room. We celebrate each other's wins and support each other when there are setbacks.

We welcome anyone caring for a Brain Injury Survivor to come and check out our group. We meet the second and fourth Sunday of each month from 7:30 to 8:45pm (Eastern).

Tom Gallup lives in Olney, MD with his wife Suzanne. Together they care for their son Andrew in their home and moderate a nationwide Brain Injury Caregiver Support Group. For more information contact Tom and Suzanne Gallup at tpgallup@comcast.net or visit the group website: www.severebicaregivers.weebly.com.

PART ONE

On Sunday, April 19, 2015 my wife Suzanne and I were getting ready to go to church. Our pastor was to preach a sermon that morning entitled “New Life 101”. I didn’t realize at the time how prophetic that title would be. As I recall, the weather was nice that day and we were looking forward to a relaxing, leisurely morning with plans for lunch at a local restaurant after the service... But we never made it to church that morning.

We were feeling pretty comfortable up until that day. My small business was doing well, and the grand plan would soon include semi-retirement at age 58.

As we were getting dressed that morning, I turned my phone on and walked downstairs to my office. In a matter of seconds, our lives would change forever. There were five or six messages on my phone, which I thought was a little odd, since I don’t usually get overnight phone calls. As I started to listen to the first message, our home phone rang and I heard Suzanne pick it up. My brain was simultaneously trying to process the message I was hearing on my cell and the information that was likely being given to Suzanne. I ran up the stairs as fast as I could and grabbed the home phone from Suzanne’s hand. We were about to come face to face with every parent’s worst nightmare.

At about 11:00 pm the previous night, our son Andrew was taking his girlfriend home. He was driving a scooter that he had recently purchased while living in Del Ray Beach Florida and they were traveling north on a neighborhood street.

Andrew had a long and difficult journey after high school. It had taken him from Olney, Maryland to several distant parts of the country while he tried to get help with his fight against substance abuse. He struggled with many things and our heart broke for him often as we did our best to parent him through difficult times. But by April of 2015, we really thought he had pulled his life together. He had just finished training as a Behavior Technician at a Recovery Center near where he was living. He had six months sobriety. The next morning was scheduled to be his first day on the job.



Neither Andrew or his girlfriend were wearing a helmet that night. A young man driving toward him would turn into their path. Since both were probably going about 30 MPH, that meant Andrew impacted the windshield at approximately 60 MPH – head first. Andrew’s body acted as an airbag for his girlfriend. Within a split second, Andrew had suffered a severe Traumatic Brain Injury. He was on the ground, bleeding from multiple lacerations and not breathing. Blood was trickling from his ear. A person just arriving home heard the crash as he got out of his car, ran over and started CPR. Within minutes, Andrew was in a Level I Trauma Center being prepared for emergency surgery to save his life.

Within several hours, Suzanne and I were on a plane to Florida to get to his bedside. One of the things I remember is a friend of Andrew's calling from the hospital and telling me, "he is a fighter and he will survive." We had no idea what we would be in for when we arrived at the hospital.

Over the next few weeks, as the picture clarified, we started learning about Traumatic Brain Injury. Andrew's TBI was, and is, very severe. He would be in a coma for several weeks and when he finally opened his eyes, he emerged into a Minimally Conscious State (MCS). He is awake but only minimally responsive.

From the Del Ray Trauma Center, we transferred by air ambulance to a specialty brain rehab hospital in Atlanta, GA. Named after, and run by the Shepherd family, Shepherd Rehab took great care of Andrew and trained us well for the new life we would lead back in Olney when we brought him home. At Shepherd, Andrew was weaned off a ventilator and had his tracheotomy tube removed – both very scary events. But he remained in a minimally conscious state.

After 3 months, we were flown from Atlanta by air ambulance to Maryland. Driven to our home, we were deposited by the ambulance crew. As the door was shutting behind them, I thought to myself, "What now?" Here we were in our home, dining room converted with a hospital bed and a wheelchair and no nurses in sight. We were on our own to care for our – mostly – unconscious son who needed constant monitoring and 18 medications spaced out over 6 times a day. He needed to be turned in bed every two hours and vital signs taken. He has a stomach feeding tube, a colostomy port, a permanent in-dwelling urine catheter and an implanted pain and spasticity management pump. There isn't an extra inch of space available on this boy's abdomen.

The next months would prove to be a very difficult time for Suzanne and I. Our lives were consumed by Andrew's constant care and hospitalizations. Like many TBI patients, Andrew went through what is known as "Sympathetic Storming" whenever he was in pain. During Storming sessions, he would drench himself in sweat, become rigid as a board, his pulse and blood pressure race and his breathing rate goes off the chart. If we can't control these things with the drugs we were trained to use, we must call 911 – and we've called 911 a lot. Andrew would go on to have two surgeries during the next 10 months. Both would be life-threatening events.

Now I could go on for many pages about the hospitalizations, rehab admissions, stressful emergency surgeries and nerve-wracking procedures we have endured over the five years since his accident. But that is not what I want to write about. In Part Two of this series, I'll talk about the insights our family developed in the year's following his injury. I will discuss how we have found comfort and consolation in a very unique Brain Injury Support Group that meets online using zoom.

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