

A Caregiver's Perspective on Traumatic Brain Injury

Linda Herbert

My son, Jon, sustained a traumatic brain injury in June 2002 as a result of a car accident. He was 19 years old and had just completed his freshman year of college. Prior to his accident, Jon lived at home with my husband and me in northern Indiana; his older brother, Jason, was living away from home. Jon's accident changed his life forever and had a tremendous impact on our family.

Jon was in a coma for almost 4 months. His injuries were substantial. He spent almost a full year as an inpatient—first in the hospital and then in rehabilitation programs in Chicago, IL, and Gallatin, TN. Jon's accident occurred in June, and I was able to spend the first several months by his side. As a teacher, I returned to my job when school began in August. I then took every Friday off from school, for the entire school year, so that I could drive 8 hours to be with Jon over long weekends when he was in Tennessee. My husband spent as much time as he could with Jon, while also juggling work and tedious tasks such as dealing with insurance and applying for Social Security and disability for Jon. All of this could have been much worse if we did not have excellent insurance. The worst part for us was not knowing how far Jon would progress, how long he would stay at each facility, and what we would face as a family once Jon was discharged.

During this time, my husband and I made the decision to move from Indiana to North Carolina to be in a warmer climate and closer to family. I quit teaching, Jon was discharged, and we planned for him to live at home with us. Jon had made much progress with his recovery, but he continued to have major cognitive and memory deficits, as well as severe behavioral outbursts that we were not equipped to handle. He thus entered inpatient rehabilitation programs again, this time in Charlotte, NC, and then in Wauchula, FL. As much as I wanted to have my son at home with us, I realized that I was not equipped to be a full-time caregiver and to deal with Jon's deficits. My husband agreed, and we were fortunate to find a group home that cares for 3 men with TBI within 2 hours of where we live. Jon has lived there since 2004, and he is receiving excellent care.

Jon's traumatic brain injury affected my family greatly. It put much stress on the relationship between my hus-

band and me. It was difficult going through each stage of Jon's recovery not knowing what we would face, and we had difficulty finding the resources we needed. I was able to focus on Jon's recovery and accept the "new" Jon, but my husband had difficulty accepting that Jon would never be the young man he once had been. This was one of the reasons why my husband and I separated several years after Jon's accident. I also felt tremendous guilt when I realized that I could not handle being a full-time caregiver for Jon. I have come to peace with this now, as Jon is relatively happy in his home. We speak daily and I see him often. Jon's father died of a heart attack in 2012. Jon's older brother, Jason, became a firefighter, in part because firefighters were the first responders to find and treat Jon after his accident, and Jason aspired to help others as they had helped Jon.

As a family, what we faced was difficult, but many families face even more obstacles. As I said before, Jon had excellent health insurance, which allowed him to receive extensive inpatient therapy. We did not have to worry about personal finances, and since Jon's accident occurred before the age of 21 years, he was eligible to receive government assistance. Further, we did not have younger children to care for while going through this turmoil, and I was fortunate that my job allowed me to take time off to be with Jon throughout the school year.

Having a family member sustain a traumatic brain injury is life changing, not only for the individual but for the entire family. Every injury and recovery is different, and every family has a different story to tell. **NCMJ**

Linda Herbert former board member, Brain Injury Association of North Carolina, Raleigh, North Carolina; member, North Carolina Brain Injury Advisory Council.

Acknowledgments

Potential conflicts of interest. L.H. has no relevant conflicts of interest.

Electronically published April 1, 2015.

Address correspondence to Ms. Linda Herbert, 121 White Oak Mountain Rd, Columbus, NC 28722 (lberbert@windstream.net).

N C Med J. 2015;76(2):112. ©2015 by the North Carolina Institute of Medicine and The Duke Endowment. All rights reserved.
0029-2559/2015/76213