

The journey of an SLP~

In this life we all have our journey.....

Having had a beloved independent aunt without sight taught me that function was key for autonomy and optimizing skills despite personal challenges. This strong personal attachment reinforced my perception of the depth of patient input as a rich resource to guide successful return to life skills after a medical insult. As a speech language pathologist I have always felt that patient and family advocacy were a priority. I encouraged my patients and families to verbalize their needs to caregivers as well to each other as medical diagnoses shifted family roles, often times abruptly with catastrophic events. Such thinking led to my volunteer work as Director of Legislative Advocacy for our state association, OSLHA (Ohio Speech Language Hearing Association).

My clinical picture has always viewed the adult or child in my care as a family member. I saw my mother, my brother, my grandmother, my infant in the critical care bed or in the outpatient setting/chair.

Still.....

TBI, CVA -not a thought or diagnosis I had associated with my healthy, athletic, active 12 year old son. "Get here as fast as you can, but we can't promise he'll still be here when you get here." My heart stopped beating as I began to comprehend what I had just heard. "We cut off his orthodontics for imaging." "If he survives 72 hours, he will live." "We can't risk a craniotomy." I was told he must have hit his head as he fell when the 'spontaneous hemorrhage' occurred. As a clinician and a mother, I searched for the rationale behind my son's two cerebral hemorrhages that covered the entire left hemisphere leaving him in a coma, at risk for herniation at the brainstem and in a ventilator dependent state. My clinician's brain told me he would probably become non-verbal, have significant cognitive decline, and not have the future we as parents tend to foresee for our children as they approach adolescence. To the surprise of the medical team, he survived his catastrophic injury and it was deemed that he would survive placement of a G-tube and tracheostomy as he transitioned to his second intensive care. Nutrition was now on board and hyperoxygenation could be reduced.

Over months of recovery, his level of alertness increased and he became more interactive with his environment. I searched earnestly for signs of improvement. Our world was crushed with his facial hypotonia, flat affect and lack of bright spontaneous smile that we had come to love. Dysphagia was acutely obvious with lack of tongue and lip movement and lack of saliva management. Withdrawal from the strong medications that had saved his life tore at his body and left large dark circles under his eyes and a fragile shell of his former athletic body. His treating hospital shared that they did not see 'complicated patients' so recommended a nursing home for him.

After 4 weeks on a ventilator in intensive care, he could be transferred out of state to a Level 1 Trauma hospital that served a variety of patients on the rehab unit. We were blessed yet again as the paramedics that arrived at the scene urgently to take him for the initial hospital stay, volunteered to transport him to the out of state facility free of charge. God indeed had us in the palm of his hand. Fatigued yet full of faith we pressed on. Even after arrival at the new hospital, consideration of transfer to the acute setting was pondered for the first few days. As my son stayed awake longer, he was finally appropriate for initiation of therapy and a 'low level rehab stay.'



He received physical, occupational and speech therapies daily. We were blessed to have NDT trained clinicians working with him independently and in co-treatments. For those of you who know the work of Leslie Faye Davis (a well-known and dedicated NDT instructor): "To get to the lips" we indeed had to "go through the hips." Aggressive work was done to build

his core strength so he could better work off his trunk. It wasn't long before he could hold his head up and began to partake in and more daily interactions.



His inappropriate behaviors, related to his head injury, came and went and my heart was pierced as I had to watch him struggle. His vision finally seemed to focus and we learned that his vision was quite impaired. The hemorrhaging on the left side of the brain and edema on the right side of the brain had gotten the optic nerve. He received a formal diagnosis of homonymous hemianopsia which translated to him as "I see blurry to the left and what do you mean there is something on my right?" I can't tell you how many times I frustrated him by walking along and turning right without telling him first. (Talk about parting of the ways and teenage frustration).

A swallow study revealed functional phase of the swallow and confirmed severe oral dysphagia. He had learned to approximate his lips with his fingers to get bilabial speech sounds and yes, it's true, he ordered 'One of everything off the menu' from the hospital's Wendy's restaurant. I had to lower my head and chuckle as I respectfully declined the order. His vocal intensity was low with his reduced trunk support and I had concern for cough response should he need it. Despite the severity of the hemorrhages and cerebral edema we had much of my son back. He could communicate, tease the staff and enjoy some easy foods. 'Eagle eye mom' kept a close eye on his positioning and oral care. It was a happy day when I took a picture of his first empty tray as his endurance and volume of oral intake increased. The doctor's agreed to pull his G-tube, an uncomfortable occurrence I understand that my son says he will never forget.



We learned to refer to the site where his G-tube had been once placed as his 'second belly button', which of course he teased me about as I only have the one. I share these examples in the hopes of relaying the impact that using humor can have upon facing such odds. Over time my son went to outpatient therapies. Being the athlete who would motivate himself before the big game, he played the songs 'Another One Bites the Dust' and "We are the Champions" on his way to therapy sessions. He worked hard and was excited when he took second place in the state Special Olympics swim meet despite his "spastic gait" and tendency to "drop his left foot". I know, left hemiparesisreally with a severe left hemorrhaging? What??? It appears most of the damage to his young body was from the cerebral edema and not the massive bleeding that had covered the entire left hemisphere. God gave us such a miracle!

He was slowly transitioned back into the school system. First home schooling, then half a day at school, followed by half regular education classes with half special education classes for tutoring, compensatory strategies, and to learn self-advocacy. His participation with the Special Olympics one summer increased his overall endurance. Eventually, he returned to full day in regular education classes with supports for his vision. The love of reading he had had, as a youngster would take years to return due to limited visual fields and eyestrain. After many IEP meetings, joint efforts for socialization and hours of class time, he graduated from high school. President Bush awarded five letters of accommodation for educational achievement to the disabled students who graduated that year. With the tears brimming in my eyes, I could hardly see him limp his way across that stage.

Though reading was difficult, he found creative comfort in writing. I would like to share one of his poems with you. Upon first reading, it is awkward, slightly disjointedas his TBI journey was.....and then it coalesces into an emotionally charged ending.

LEARNING FROM YOU

C. HUGHART

Looking for a way
Never knowing what to say
Always looking for an answer
But receiving only questions
Attempting to find a path
But yet only feeling your wrath
I want to learn that is not a lie
I need your help so I can fly
I want to learn from you
But you leave me without a clue
As I look back into the past
It comes to no surprise that you were last
I remember how you always made me work
And the way you always smirked
I look back and finally saw
You helped me grow mentally without a flaw
I wanted to learn from you
But you have helped so much...
.....and I didn't have a clue.

Tomorrow is his 30th birthday. He still “snaps his left knee” and has dysarthric speech when tired. Nevertheless, his undaunting spirit has seen him through a college education, job search, marriage, divorce, and the birth of his son. A long road and a difficult journey, but one paved with love, faith and endurance. With God’s grace we have survived thus far and learned to appreciate each day, each love, each season.

I hope the sharing of our story:

- touches a reader

- that clinicians will take a second look at low-level patients and see hope
- that families will become stronger in times of crisis;
- that we can still see miracles in the eyes of our patients.



For C. and his son.....