

A Life Lived in Spite of Everything

Category: Making Assumptions

written by David Coulter | August 4, 2019

I was called to the NICU to see a baby who had just born with hydrocephalus. The CT scan showed he had Dandy-Walker syndrome. His teenage parents were told he would be severely handicapped, so they refused permission for a shunt and wanted him to die. The NICU staff was horrified and asked me (the neurologist), "They can't really do that, can they?" I said no they can't, and immediately called the hospital lawyer. She brought a judge into the NICU who agreed, obtained legal custody and assigned guardianship to a local advocacy agency. The new guardian authorized the shunt which worked well. The boy was discharged into foster care and eventually adopted. But then it got really interesting. Yes, he had Dandy-Walker syndrome and hydrocephalus, but he was developing normally!

When he was seven years old, he had normal intelligence and a normal neurological exam. He did have a big head. I asked him once what he liked to do, and he said he liked to play chess. He had a shunt malfunction at age twelve and almost herniated, but we treated him aggressively, and he recovered completely. He finished high school and received his diploma.

Unfortunately, he also developed an addiction, which he battled for several years and eventually recovered. The local newspaper published a human-interest story that featured this young man, whom I had met in the NICU so many years ago, and he was sensitive and articulate. He had become an advocate for other young people who were battling addiction. He explained how his own history had affected him, telling the reporter, "I never had any parents, so I had to grow up on my own."

I was startled. I had battled to save his life, arranged his guardianship, supported him in foster care and treated him after he was adopted. How could he feel unwanted? Did I do something wrong? He had defeated every assumption anyone had ever made about the value of his life. But maybe I had missed the most important assumption of all. A doctor's love can never replace what a parent provides.

He died at age twenty-three from a final shunt malfunction. He had lived courageously in spite of everything. And he taught us not to make assumptions about what a baby with Dandy-Walker syndrome might accomplish in life if we just give him a chance.

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