

Winner of the 2016 Living History Essay Contest

Ellen Dibler: A Life of Impossibilities

by Sandy Davis

In 1941, treatment and research for spina bifida took a back seat to polio and the prognosis for anyone born with spina bifida was grim. A congenital defect, spina bifida is the exposure of the spinal cord through a gap in the backbone. It can result in paralysis of the lower limbs, the accumulation of fluid on the brain (hydrocephalus), meningitis, and other complications including allergies, skin problems, urinary tract infections and depression.¹ As a child, Ellen Dibler did not let spina bifida dictate her life. At age 75, and one of the oldest people living with spina bifida, she continues to not let the disease define her. Ellen has her own plans.

Born April 4, 1941, in Cordell, Oklahoma, she was the firstborn child of Herbert and Minnie Nelson. They had to carry her on a pillow when she was first born. At two months old she had experimental surgery to treat the paralysis she that affected her from the waist down. Throughout her childhood, Ellen's parents would travel three hours one way from their farm to Oklahoma City to take Ellen to doctor's appointments and treatments. Sometimes she stayed. Ellen recalled "I was in the girls' ward with forty girls. Most of them had polio." Parents were not allowed to stay overnight. She further related "I remember being alone there. There was no air conditioning and I could hear the iron lungs."

Often, they would make the long drive starting at two in the morning so they could be on time for a 5:00 a.m. appointment, only to be kept waiting until three or four in the afternoon. Ellen once asked a doctor why they had to wait so long. Referring to the polio patients he responded, "Because we have to spend time on the ones who live." She was ten years old.

Ellen says it was there in the hospital that she learned to advocate for herself. In intense pain, she learned the medical lingo the doctors used so that they would listen to her when she talked. She had two or three surgeries a year, including muscle transplants and having her ankles fused. The week after her high school graduation she had bone taken from her leg and put in her vertebrae in an effort to prevent her scoliosis from crushing her internal organs. On three different occasions she was put in a body cast from her neck to her waist in order to control the scoliosis. It was a painful ordeal that lasted for weeks at a time. A few times Ellen felt like giving and "I almost prayed to die," she remembered.

Wearing two leg braces, Ellen always stood out from the crowd. She stated "When they asked what was wrong with me I told them it was like polio." She

¹ "Spina Bifida," *Mayo Clinic*, accessed March 31, 2016, <http://www.mayoclinic.org/diseases-conditions/spina-bifida/basics/complications/con-20035356>

described the first time she met another person with spina bifida. Ellen remembered “My parents had been asked to visit a family whose baby had spina bifida, to give them some hope.” After all, Ellen had lived to age five. According to Ellen “He had hydrocephalus. His head was enlarged and he was lying in a crib and that’s how I first saw him.” Ellen would be an adult before she received any social support as a person living with spina bifida.

Though not many women had a college education at the time, Ellen would once again defy the odds. She attended Southwestern Oklahoma State University as part of a vocational rehabilitation program. She earned a Bachelor of Science and did her internship at the University of Oklahoma School of Medicine, earning a degree in Laboratory Medicine.

It was in college that she met Larry Dibler. He was an athlete, which made Ellen nervous about the match given her disability. As the relationship grew serious, they met with a doctor who explained Ellen’s condition and the effect it would have on their married life, including intimacy. They married on September 24, 1964, and promptly moved to Naples, Italy where Larry was stationed with the U.S. Navy. She recalled “My parents watched me get on that plane without my doctors.” The doctors who had been keeping Ellen alive since birth.

The couple wanted to start a family. They travelled to Landstuhl, Germany, then home to the second-best OBGYN clinic in the world. The news was not good. She lamented “They told us I had a one in a million chance of getting pregnant and zero chance of carrying a baby to term.” After returning to the states, they found a doctor willing to oversee her extremely high-risk pregnancy, but there was a catch. Ellen had to sign a waiver stating that if the doctor thought her life was in danger he had her permission to perform an abortion. Ellen believed that if God allowed her to get pregnant he would see the baby to term. She signed the waiver. On December 13, 1968, Scott Dibler was born. Against all odds, Ellen had become a mother. Three years later Scott got a little brother named Alan. There were now two healthy sons born to the woman who had a zero chance of carrying a child to term. Ellen had learned to ignore the odds.

As her boys were growing up Ellen became involved with the Spina Bifida Association of Texas. She says that it was there that she found her voice. She spent ten years serving on the Board of Directors of the National Spina Bifida Association, traveling at her own expense to share her story and bring hope to people living with the disease. It cost upwards of \$20,000 a year for her travel expenses. At the time, her husband was working as a pharmacist and her boys were in middle and high school. The family took on the burden of the expense because they believed the work was important. Ellen could now be the encouragement for others that she never had for herself. On their 25th Anniversary, the National Spina Bifida Association named Ellen their Outstanding Person of the Year, an honor she is still not quite comfortable with.

In Washington, D.C. for a conference, Ellen was invited to attend the signing of the Americans with Disabilities Act in 1990. The ADA became paramount in Ellen's life six years later when she sued Corning Labs for wrongful termination after they fired her for not being able to carry equipment in and out of buildings. As long as the equipment was in place, Ellen was able to perform all other aspects of her job. She found a lawyer in Dallas who was familiar with the ADA and relied on a wheelchair himself. Together they fought Corning Labs and won. Today, the ADA not only guarantees equal access to employment, but it makes it easier for people with disabilities to attend college. Ellen had to walk up flights of stairs with fused ankles and leg braces. The law now requires equal access to facilities.

While the ADA was an important step, the most promising advancement in the treatment of spina bifida was the development of intrauterine surgery for pre-term infants diagnosed with it. First performed in 1997, the surgery allows for the decreased risk of death or need for shunt placement in the brain, as well as improved mental and motor function. Further, doctors now know that folic acid taken during pregnancy can help prevent the disease.²

At 75, Ellen shows no signs of slowing down. She and her husband spend time on cruises working with spina bifida patients, with Joni and Friends Family Retreats helping married couples who are affected by the disease, and with American veterans returning from Iraq, a population Ellen is sometimes able to reach because of her own disabilities. They do not have to hide their imperfections from her because she is vulnerable enough to share her own.

Ellen's life is a testament to both her tenacity and her faith. She became a Christian at age seven and says she has depended on God ever since. She credits God with her accomplishments, along with her unwillingness to feel sorry for herself. She remarked "I love parties, but don't invite me to your pity party. You have a choice." Which is the same thing she says if you ask her what motivated her. "I had a choice," she replies. She could give in to the disease and live a life void of what she wanted most, or she could learn to thrive despite her diagnosis. She chose the latter. In fact, she has found blessing in living with the disease and even believes "I would not be who I am today without spina bifida." After a lifetime of living with this disease and advocating for patients, what does this wife, mother, grandmother, and advocate want you to know? "Nothing is impossible," she says, "I love that God has given me another day."

² "Fetal Surgery for the Repair of Spina Bifida," *Monroe Carell Jr. Children's Hospital at Vanderbilt*, accessed March 31, 2016, <http://www.childrenshospital.vanderbilt.org/fetalsurgery>

