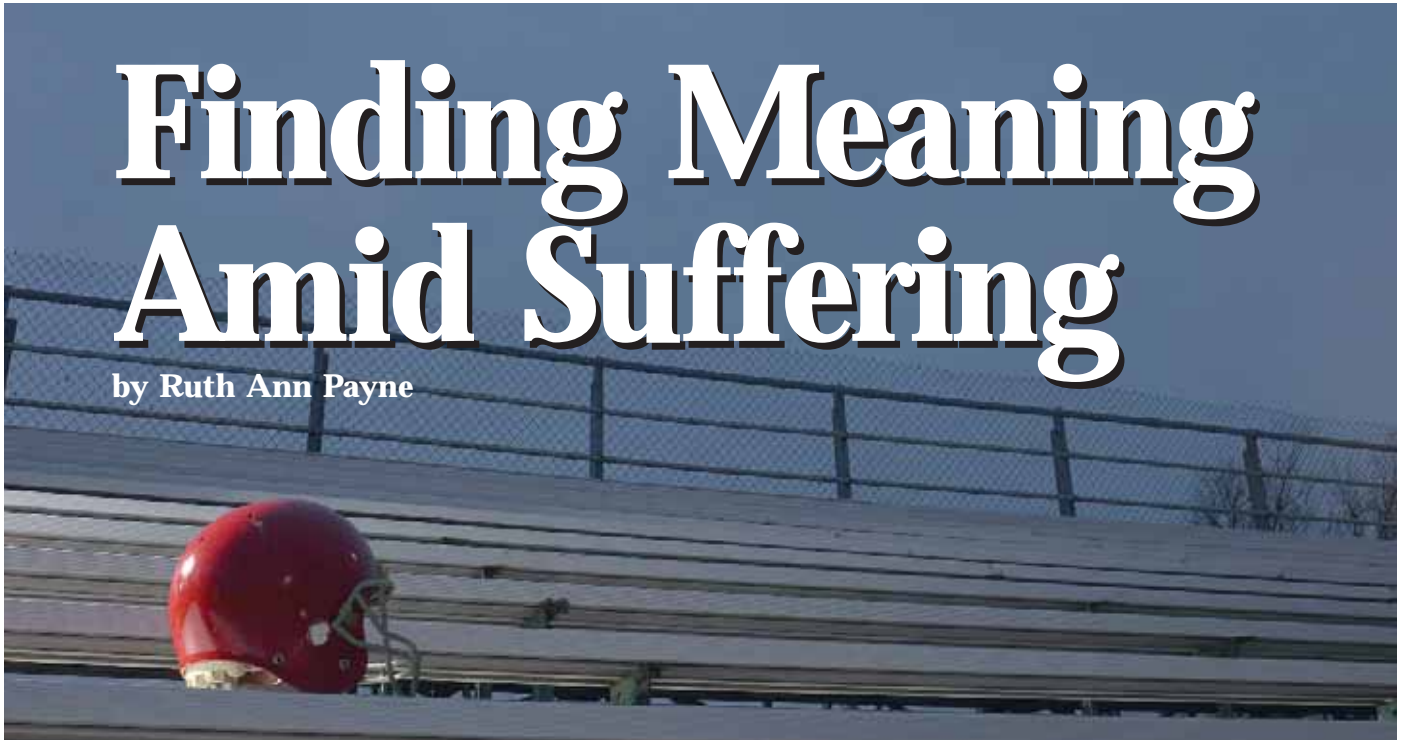


Finding Meaning Amid Suffering

by Ruth Ann Payne



What is life about? Is it finding true love, enjoying a happy marriage, having children and grandchildren or achieving professional success? Those may be the pursuits of some people. But for my husband, Jim, and me, in addition to those pursuits, life is about surviving each day as we fight against a terminal neuromuscular disease called amyotrophic lateral sclerosis, commonly known as ALS or Lou Gehrig's disease.

ALS affects the nerve cells that control movement of voluntary muscles in the body. These nerves gradually cease functioning and die, which results in progressive muscle weakness, atrophy, and eventually, total paralysis. The disease robs people of their physical abilities, yet usually leaves the mind unaffected.

Jim was diagnosed with the genetic form of

ALS more than 15 years ago and since that time I have been his primary caregiver. Being a partner to someone who is terminally ill can be overwhelming, scary and lonely.

Our story begins when Jim and I met during high school in 1958. Jim was athletic and participated in most high school sports while I was involved in music and various student organizations. Though we had different interests, we found lots of common ground and began going out.

**The Payne Family:
Ruth Ann, Kent, Jim,
Krista and Angie**



Shortly after we began to date, I met Jim's father who was then battling ALS. He was in a wheelchair, unable to move or speak. Even at that time I knew there was no cure for this disease, but didn't understand much about the condition itself. It was only a year later that Jim's father died from ALS. During that year, I had learned more about the disease but didn't give much thought to its potential impact on our lives. Jim was healthy and had just received a football scholarship to Carthage College in Carthage, Ill. We were in love and had many dreams we wanted to pursue together so we decided to marry in 1960 before Jim started college.

By the time Jim graduated, we had two children and I was pregnant with our third. Jim accepted a job as a teacher and coach and our lives seemed filled with happiness,

prosperity and good health. But that bliss came to an abrupt halt when Jim's brother was diagnosed with ALS. It had become apparent to me by this time that ALS was ravaging Jim's side of the family. Three of his uncles and his father had already died of ALS and now his brother had been given the dreaded diagnosis. This news caused me to start asking questions about what it might eventually mean for Jim.

Years passed, but the fear of ALS was never gone. During this time, Jim was a high school physical education teacher and a football and track coach. He was in great physical condition and highly respected by administrators and colleagues. The students and athletes considered him not only their teacher, but also their friend and mentor. Our three children were all well on their way to reaching their own personal and professional goals. I was managing a legislative office of a state representative. Everything was going so well for us.

But in November 1989, Jim started limping and it was difficult for him to pick up his right foot. I tried telling myself it was an old football injury that was haunting him. However, after extensive examinations, tests and review of his family medical history, a neurologist at the Lois Insolia ALS Center diagnosed Jim with familial ALS.

My first response was to fight. I was determined that this disease was never going to conquer our lives like it had Jim's family. I

started researching ALS to arm myself with the facts. But when the shock was over and the reality of it all sank in, I felt as though my life was ending. I was full of anxiety and fear. I kept thinking about how complicated life was going to become; how my roles as wife, mother and grandmother might change. Could I handle what was dealt to me? Would I ever be happy again?

For the next two years Jim was in and out of the hospital with pneumonia and was becoming noticeably weaker. He now needed to wear leg braces for added stability. It was during this period of time that he began using a scooter to move from place to place because the atrophy in his legs was worsening. We bought a van with a lift to transport him back and forth between home and school.

By 1992, it became clear that I could not handle the caregiving responsibilities by myself any longer, and our daughter Angie and her family moved in with us to

help. Months later, on a day when Angie was caring for her father, I received the dreaded call with news that Jim was being taken by ambulance to the nearest hospital because of his compromised breathing; a common but life-threatening complication with ALS. Now my partner in life was fighting for his life and the reality of it all hit hard. Over the next few hours, which seemed like an eternity, a tracheotomy was performed and a feeding tube was put into place.

Jim eventually was released from the hospital but was now on a ventilator. We chose to keep him home and turned our living room into Jim's new quarters. The Les Turner ALS Foundation conducted an in-service training with the workforce of nurses we employed around the clock. We encouraged teaching colleagues, former students and athletes to visit him often. We wanted to make our home as "normal" as possible given the circumstances.

That was about 11 years ago and we are still fighting this disease every day. Jim can't move or communicate and is totally dependent on a ventilator to live. He relies on someone to feed, bathe, shave, dress and even scratch his nose. So, what gives him the will to continue living amid all of this?

Jim is determined, despite his condition, to live each day to its fullest. He maintains a positive attitude for the sake of our children, grandchildren and me, more so than for himself. He wants to help find a cure for ALS and has



participated in the filming of a video about ventilation. He also writes letters on his specialized computer, enjoys his grandchildren by playing computerized bowling with them, listens to their stories, and watches them play ball in the front yard. He is an attentive listener and wise counselor to family and friends. His life has meaning and value even though his body is not cooperating.

Jim's spirit also gives us courage to be role models to other caregivers facing similar challenges. In fact, the entire Payne family is an inspiration for caregivers. To date, they have lost 15 family members to ALS and possibly more that they don't know about. Yet against such great odds the entire family remains hopeful and strives to live each day to its fullest.


The caregiving tasks associated with ALS are so overwhelming that I would never have made it this far if it weren't for the legion of family and friends who have



Ruth Ann and Jim Payne

labored, cried with and supported me through these years. The nurses who help with Jim's care have also become part of our family and are instrumental in our ability to cope day by day. We also seek support and guidance from those at the Les Turner ALS Foundation and other patients and families in the ALS community, as they understand our experiences and provide tremendous support. With this support, our determination and strength is renewed each day and we continue to survive.

We often find comfort through the words of those who have faced

similar life challenges. I'll end with a favorite quote from Helen Keller, herself no stranger to suffering, who has inspired us to push onward in our journey with ALS. She said, "Although the world is full of suffering, it is full also of the overcoming of it." 

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