

Inside the Diagnosis

The beginning was innocent. In July 1985 I received a shock from a hand-held electric drill. Within a week I'd recovered and felt fortunate to be alive.

But this minor accident heralded a permanent change in my life. I passed through the transparent curtain that separates physician from patient: I moved inside the diagnosis.

I have always enjoyed good health and was successful in competitive swimming and running. An ophthalmologist, I took pleasure in performing microsurgery. Approaching age 50 I feared any disability that would interfere with providing for my wife of 27 years and our five children. By the following November, however, progressive weakness of my left arm forced me to abandon performing any more surgery and prompted consultation at a university neurology department.

The differential diagnosis was broad; a major concern was a motor-neuron syndrome. I was relieved by the consultant's conclusion: the injury from the shock seemed isolated to my left arm, with some damage to the cord, causing long tract findings in my left leg. I was able to continue administration, education, and research.

During the summer my running times improved and I thought I was on the path to recovery.

Over Labor Day weekend I had a fever and headache. I tried to write a note to myself and found I couldn't use my right hand. The fever spontaneously broke and I felt normal the next day, but within the next few weeks I had the onset of fasciculations in the fine muscles of my right hand, which progressed to my right forearm and shoulder. I also noticed spontaneous fasciculations in my left thigh. My strength was ebbing.

With my rapid decline in the fall of 1986, more associates and coworkers expressed concern and offered help. I still traveled frequently, but found it more difficult to haul luggage laden with papers and reports. I was amazed by the automatic, solicitous assistance from strangers with whom I was traveling. As my clumsiness increased, I turned to aides for help.

My mood swung from despair to euphoria, hope to loneliness; I saw dreams lost. The reality of death slithered into my consciousness like a serpent and punctured and numbed my waking hours.

On March 30, 1987, a second consultant confirmed the serpent's bite with an unequivocal diagnosis of amyotrophic lateral sclerosis (Lou Gehrig's disease). Suddenly I was one of those "other people" to whom I thought these things always happen. The consultant wondered if the ALS might have been precipitated by the trauma of the electric shock. To me, it didn't matter; the reality and the consequences were the same. The death sentence had been declared and the prison of my body defined.

Noble Lou Gehrig's—it causes progressive loss of most voluntary movement over a two- to three-year period, eventually robbing its victim of speech, swallowing, and respira-

tion, but leaving his mind alert and all his senses intact. Unlike Alzheimer's disease, severe trauma, or cancer, ALS does not destroy the intellect or disfigure the body. Unlike AIDS, it does not endanger a spouse or family—like AIDS, it is a demanding test of their devotion.

When the diagnosis was made I felt transformed. Suddenly, the physician's desire to heal was transformed into a patient's desire for help, cure into caring, certainty into hope. Throughout my years of teaching, I had tried to impress students and residents with the importance of crawling inside the patient and trying to experience what the physician's words meant to him. I recalled the many, many patients referred to me with "hopeless" conditions. I remembered how so many were relieved when I chose words other than "disease," or "cancer," or "blindness." Above all, I stressed to my students the need to leave every patient with hope. Hope makes the horizon bright, the pain less, and each day worth living. I often tried to discern what patients wanted to hear, what they could accept, what was better told only to a loved one. I now found myself in that position, wanting to hear the truth, willing and able to accept anything, wanting to share the reality with the persons I loved as the kindest framework within which to cope.

"Are you sure?" "Could they be wrong?" "What can I do?" asked friends and colleagues. I listened to their accounts of pain and the torment of their (or their loved one's) own illnesses. Many wondered about the impact of my illness on them. And their emotions shone on their faces. I saw denial, anger, sorrow, disbelief, revulsion, recognition, sympathy, empathy, as each relived the secret terror of death and dying.

From here, from inside the diagnosis, I am impressed with the universal need that all people have to care and to give support in so many ways. Yet most leave room for the individual to assert his independence as best he can. Every day there is a new loss, every day a new insight, every day a new frontier. Every day I realize that joy comes not only from giving help, but from accepting help.

I draw strength from a lifetime filled with achievement, optimism, and curiosity. I see progressive handicap as a challenge and an opportunity to strive in a way that the able-bodied seldom experience. I use my ingenuity to discover new ways of accomplishing activities as my bodily functions deteriorate. I vow denial to the strength-sapping saprophytes of depression, despair, frustration, and fear.

As the patient, I find that the second-to-second hurt of living the diagnosis contrasts with the episodic pain of the physician's declaring a diagnosis, then walking away. As a physician, I have come full cycle: I live both sides of the diagnosis.

I realized an inner peace when my sentence had been declared, my time defined, my remaining tasks listed. To know the time of death and to be able to share with the people I love the emotions denied to those who depart so rapidly is a gift that compensates for the slow dissolution of movement. As physical ability is lost, there is no lessening of my will to bump against whatever obstacles I meet and to achieve whatever I can achieve.

David M. Worthen, MD
Potomac, Md

Reprint requests to 23 Stanmore Ct, Potomac, MD 20854 (Dr Worthen).

Edited by Roxanne K. Young, Associate Editor.