No question the word "irony" is overused. Somehow, though, it seems a fair representation of the fate that has befallen Richard Olney.

A neurologist, Olney had long been considered a leader in the fight against amyotrophic lateral sclerosis, better known as Lou Gehrig's disease. He founded the ALS Center at the University of California-San Francisco.

And though revered by colleagues for his science capabilities, he was cherished for the gentle empathy he displayed in treating people with ALS. The incurable neurological disorder starts with stiffness and muscular weakness and progresses to total paralysis while usually leaving mental faculties intact.

In May 2003, Olney, 57, noticed an odd symptom: weakness in one knee. Olney had three back surgeries to correct weakness that had spread to both legs. Each failed, and to his alarm he noticed a similar instability creeping up his right arm.

By June 2004, Olney learned that he himself had ALS. The scientist who was a master of one of the most baffling and devastating neurological diseases was now at the mercy of it.

Olney describes his gut reaction to the news as "stunned disbelief." He says that now the irony is not as stunning as it seemed given the incidence of the disease and number of caregivers in the field. ALS is not contagious.

But Olney says he has reached this strange juncture in his life with no regrets and strengthened spirituality.

"I've learned to focus on things I can influence and accept those I can't," he says.

Olney continued to treat patients as he had throughout his 25-year neurology career. It was not unusual for him to spend three hours with a newly diagnosed patient.

Life expectancy of ALS patients averages two to five years after diagnosis. In 20% of ALS patients, the disease accelerates at a slower pace, and life expectancy is five years or more.

But Olney appeared to have an especially aggressive form. Acutely aware that his mobility would soon deteriorate, he modified his home to accommodate a wheelchair, organized his estate and banked computerized recordings of his voice to compose sentences when his speech is no longer intelligible.

He also wrote to his patients to inform them of his diagnosis and his resignation. With characteristic grace, Olney apologized for "the disruption of your care" and thanked them for the honor of being their physician.
Seven months after diagnosis, he uses a wheelchair, his speech is slurred and he manages basic functions with the aid of his wife, Paula, a dialysis nurse, and two children, Nick, 27, and Amy, 24, who have moved back home. The man who once ran marathons now requires 20 minutes to get to the bathroom.

Paula, 52, met her husband when he was an intern and she was a newly minted registered nurse. She says she still struggles to accept the diagnosis.

"I'm not ready to be a widow. I'm mourning the fact that he won't ever know our grandchildren." But she says Rick holds her up: "He laughs, he smiles. ALS has only brought out all the good stuff in him."

The good stuff, former colleagues say, is his compassion and quiet, unassuming manner. "He never made his students feel they were saying anything foolish," says Cathy Lomen-Hoerth, Olney's former protégé, who now heads the ALS Center.

Among those wrenched by the news was Sean Scott, whose mother, Vanna Forrester of Watsonville, Calif., was treated by Olney until her death in 2003 at age 60. Olney, he says, is the patient's champion.

"He intended to help cure the disease," Scott says in an e-mail. "Rick is a man who never forgets that each patient is a person; they had dreams, now crushed. He was strong for them when they couldn't be. He was their voice when they lost it, their strength when it left them. He allowed them to die with a little power and a little dignity in a situation that usually strips you of both."

In a further irony, Olney will be a subject in a clinical trial that he designed, to see whether one of two existing drugs can extend life expectancy. He is cautiously optimistic that one of the two drugs could offer him more time -- if indeed he receives the drug and not the placebo -- but is realistic about his prognosis.

"One of the good things about this disease is that it gives you the chance to say goodbye," he says. The goodbyes are plentiful and frequently tearful. Neighbors stop by with prepared meals. Old friends from out of state are frequent house guests. Patients shower him with farewell letters.

Today, the Olneys savor every minute they have left. They go to movies, visit friends and take short walks. "There's no time to cry now," Paula says. "There's still a lot of living to do."