

Stronger Every Day

With an iron will and an unconventional new treatment, Charlie Smith is going toe-to-toe with ALS

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By BRYAN WOOLLEY / The Dalles Morning News

MULLIN, Texas - Charlie Smith is thinking about what he might do with the rest of his life.

"I don't want to go back to trucking," he says. "I want to be home every night to see my babies."

There are ranches for troubled boys in the Central Texas hills where Charlie lives. Maybe he could work at one of those, he says, or some place like them. Maybe he could be some kind of counselor.

"I'd like to tell those kids my story and what I've been through," he says. "Maybe I could help somebody who's wanting to give up."

Talking about the future is a strange new thing for Charlie. He wasn't supposed to have one.

In December 2002, doctors at the University of Texas Southwestern Medical Center at Dallas told him he might have amyotrophic lateral sclerosis (ALS), often called Lou Gehrig's disease. It weakens the body's muscles and then paralyzes them. It kills its victim, sometimes slowly, sometimes quickly, but always. In June 2003, the doctors reported that the diagnosis "has been confirmed."

ALS usually strikes people who are 50 or older. Charlie was only 25. The Dallas doctors said that he was the youngest ALS victim they had ever diagnosed and that young ALS victims usually die faster than older ones. The doctors predicted three to six months for Charlie, maybe a year.

"To tell somebody they have only so long to live, that really knocks a person's spirits down," Charlie says now.

Charlie first told his story to The Dallas Morning News in January 2004. He and his friends talked about what he used to be: the star of Mullin High School's six-man football team, its homecoming king, its Christmas prince, 6-foot-4 and handsome, strong-bodied and strong-willed, the leader among the little town's young men.

He and his wife, Rémy, had a 2-year-old daughter, Kyra, and 9-month-old Charlie Jr. Before his illness, Charlie drove a tractor-trailer rig, hauling stone from Mullin to home builders and landscapers in Dallas, San Antonio and Houston. He was on the road nearly all the time.

His calamity began one spring day in 2002 when he stepped out of his rig, lost his balance and fell on his back. His truck driver friends laughed, but the fall was the first symptom of his illness. It signaled the horrible change that was about to happen to Charlie.

At the time of the 2004 interview, Charlie had outlived the doctors' expectations, but he was sinking. His muscles were shrinking. His speech was slow and slurred. His fingers were stiff and curled. He had trouble breathing and swallowing.

Rémy dreaded driving the 30 miles to Comanche to buy groceries. She feared what she might face when she got home. "I was scared to death that I was going to be the one to ... you know ..."

To find Charlie dead.

Rémy thought of calling a hospice to help him through. Charlie was angry and defiant and stubborn, and sometimes depressed. He vowed that, despite the impossible odds and the doctors' expectations, he would recover.

Many Morning News readers were moved by Charlie's courage. Their interest led to the establishment of a medical fund for him, administered through a church in nearby Comanche. They contributed \$16,000.

A reader phoned the Smiths and told them of Dr. William T. Harvey in Houston, who was treating her husband and other patients for symptoms like Charlie's and seemed to be having some success.

Charlie and Rémy made an appointment and drove to Houston, three hours from Mullin, to meet the doctor.

Charlie says, "It was like a big weight was lifted off of us when Dr. Harvey said, 'Well, we can help you.' Before that, we had no chance. Before that, we were running down a one-way track."

The doctor

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Dr. Harvey is 67 years old, a graduate of the Air Force Academy and a retired NASA aerospace physician. During his 23-year career as an Air Force officer, he served as a biomedical engineer and a flight surgeon, and later in clinical aerospace medicine and in space medicine research at the U.S. Air Force School of Aerospace Medicine. After his retirement, he managed medical facilities for NASA and for a Department of Energy nuclear facility and for Lockheed.

His résumé says he's a clinician in general medicine, but all the nearly 900 patients he says he has treated in the past four or five years have had symptoms similar to Charlie's.

His board certifications are in aerospace medicine, not internal medicine or epidemiology. But in space medicine, he says, NASA physicians weren't able to depend on medical books, because the books they needed hadn't been written yet. Now he's working without books again, he says, because what he's doing is new.

His theory is outside the mainstream of standard diagnosis and treatment. Briefly and simplistically stated, it's this: Many patients who are diagnosed with ALS, multiple sclerosis, Parkinson's, chronic Lyme disease, fibromyalgia, chronic fatigue syndrome and other motor neuron diseases actually are victims of a bacteriological infection that can be cured or at least alleviated with massive doses of certain antibiotics.

The bacillus is *Borrelia burgdorferi*. Dr. Harvey says it's present in the blood of millions of people around the world, often from birth. It's relatively harmless, he says, until something triggers it to attack the nerves that activate the muscles.

Its presence in the blood can't be detected by the standard tests that most labs and hospitals use. According to Dr. Harvey, only two labs in the U.S. - one in Florida and one in California - are equipped to find and identify it.

He hasn't done clinical trials to test his theories, nor has he been published in peer-reviewed medical journals. Many doctors are skeptical that bacteria could be the cause of a motor neuron disease.

After the California lab discovered *Borrelia burgdorferi* in Charlie's blood, Dr. Harvey prescribed massive doses of antibiotics, some taken orally, some administered intravenously through a catheter in Charlie's chest.

Dr. Harvey has seen Charlie three times since his initial visit. He keeps in touch with the Smiths mostly by phone.

Charting progress

During the second office visit, last September, Dr. Harvey walked Charlie through all his symptoms, to determine whether any improvement had been made.

"I can get in and out of the bathtub," Charlie said. "I can take a shower by myself. My balance has come back. I can shampoo my hair without losing my balance."

Charlie's fingers were still curled, but he could straighten them a little more than before. He said he still had headaches. His ability to swallow had improved. "I eat steak every night," he said.

He had no pain in his legs, but some in his lower back. He no longer had difficulty breathing at night. He had regained the weight he had lost. His muscles, which had been shrinking, were coming back.

"Are you irritable?" Dr. Harvey asked.

"Sometimes I wake up in the morning and just want to get out of bed and run. And I get kind of angry."

"Are you depressed?"

"No."

"This is all good," Dr. Harvey said. "You're changing. I wish it were faster. It may be a longer journey than we thought it might be. We may be talking about a couple of years, or it could be that a sudden turn is just around the corner. We're getting somewhere with the disease. I think our course is the right one. You guys are fighters. I know you're going to gut it out."

Six months later, the slow improvement continues.

Charlie's chronic fatigue is gone. He can raise his arms above his head and lift his feet an inch or two off the floor. His shoulder muscles are filling out. He can rise from his wheelchair without help, and can stand erect, although sometimes a little wobbly. His speech is still slurred, but much clearer than it has been in years. His fingers are uncurling, slowly. He's beginning physical rehabilitation sessions in Comanche.

Still a struggle

While Charlie is improving, his illness has brought suffering to Rémy as well. She has lost weight. She's exhausted. Taking care of her husband and two rambunctious small children around the clock have worn her down.

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husband and two rambunctious small children around the clock have worn her down.

Charlie has been unable to earn a paycheck for almost three years. The Social Security disability check on which his family lives can't stretch through the month. Bill collectors harass her.

"Rémy has been through a lot of responsibilities that a lot of people wouldn't take on," Charlie says. "She has held her head up through it all. I've learned to appreciate the little things. The one good thing that has come out of all this is the time I've been at home with my kids."

Rémy, 24, laughs. "He wouldn't have ever known that Little Charlie has to have strawberry milk and Kyra loves chocolate milk," she says.

Kyra is 3 now. Little Charlie is a strapping 19-month-old. "They keep my spirits up," Charlie says. "I ain't got time to feel bad. If none of this had happened, I'd probably still be driving that truck, and I wouldn't have near the bond I have with these kids now. This is something to be proud of."

So when Charlie goes to work again, he wants to come home at night. His voice fills with energy and a kind of joy when he talks about that future day.

"At one time," he says, "I thought I was gone, that I was going away. But I'm not going nowhere no time."

Rémy's voice trembles. "The other day, I looked at him and I could see Charlie again."