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# Falmouth - Facing Debilitating Disease With Grace, Humor

By JULIA A. MORSE

Seth A. Carey cannot talk, but he can laugh.

Not yet three years after Mr. Carey was diagnosed with amyotrophic lateral sclerosis, or Lou Gehrig's Disease, the West Falmouth resident has lost several skills, but not his ability to smile, tease, joke, or laugh.

What Mr. Carey, 41, refers to as "the disease I'd never heard of," kills motor neurons and has killed almost all of his, but his spirit is very much alive.

Mr. Carey can no longer walk, talk, pet his cats, or roll over in bed, but he has not lost hope.

He calls himself "the drool master," poking fun at his inability to control saliva; and he equates mosquito season to "a form of torture."

Because there is no medicine that will alleviate his anguish, Mr. Carey sees laughter as his best medicine. He says that he uses jokes and denial to live in what he refers to as "a nightmare" for which there is no cure.

"Just so you don't get the wrong idea, I blink for 'yes'," Mr. Carey wrote on his computer screen Monday, explaining that his blank stare is not blank at all.

A computer program called Dasher, a free online device for anyone unable to type, allows Mr. Carey to express his thoughts in writing by applying pressure to a specially-designed computer mouse that is taped to his hand.

"This is where he spends his days," said Shannon L. Carey, Mr. Carey's wife of 2½ years, as she points to his two side-by-side computers. "Once I get him ready for the day, he's here."

Ms. Carey said that her husband's passion for fishing, making jewelry, and gardening has been replaced with writing stories, emailing friends, and researching new ALS treatments.

The disease has stripped Mr. Carey of his body and of his voice, but not of his mind. His wife says that he's the same person he was when they met: inspirational, giving, selfless, and incredible.

Mr. Carey was diagnosed with ALS on December 14, 2001. Four months later, the couple was married in a friend's back yard in Woods Hole.

Ms. Carey, 36, has since quit her job working at Jacobs Engineering on the Massachusetts Military Reservation, where the couple met almost six years ago, to take care of her husband full time.

“I feel fortunate to have been chosen to be his caregiver and I feel lucky to be his wife, but most of all, I feel honored to be his friend,” she said this week at their home on West Falmouth Highway—the same house Mr. Carey grew up in.

“We haven’t been married for that long, but Seth says it feels like it’s been 20 years,” Ms. Carey said Monday, smiling and stroking her husband’s arm, calling him “Sweetie,” making him laugh.

She is patient and calm, speaking softly as she gently adjusts her husband’s hand on the computer mouse after dabbing a white cloth on his chin.

“I don’t know how he keeps such a good outlook,” Ms. Carey said as her husband rolled his head to look into her eyes.

She added, “He’s an incredible guy,” as Mr. Carey looked away, starting to laugh.

“He gets mad when people say that kind of stuff about him,” she said, smiling. “But it’s true!”

Mr. Carey, a 1981 graduate of [Falmouth High School](#), went to college in San Francisco. He moved home to Falmouth to take care of his father, Francis G. Carey, a longtime biologist at Woods Hole Oceanographic Institution, who was sick with prostate cancer.

After his father died in 1994, Mr. Carey’s mother, Donia A. Carey of Falmouth, was diagnosed with leukemia. Not long after she was declared cancer-free following a long battle with the disease, Mr. Carey was diagnosed with ALS.

“Almost every single day, Seth made his mom dinner when she was sick,” Ms. Carey said. “And then, as soon as she got better, Seth got sick and we were thrust into the unknown of ALS.”

Mr. Carey has bulbar onset ALS, symptoms of which include uncontrollable outbursts of crying and laughing.

In his story “The House Across the Street,” Mr. Carey writes that, “I have always enjoyed a good laugh, but now was finding it hard to control. This was true for crying as well; I found I was crying over TV commercials and anything with a contrived ‘touching’ moment, which would normally nauseate me.”

Some of his first symptoms of ALS were the occasional slur of his words and post-nasal drip, which Mr. Carey calls “the perpetual river of snot in the back of my throat,” in “The House Across the Street.”

But the moment when Mr. Carey knew something was definitely wrong and that he didn’t just have allergies, as doctors had been telling him for months, came three years ago at The Lee-Side Bar and Grille in Woods Hole.

After Mr. Carey had finished only one beer, the bartender cut him off, assuming that he was drunk.

A few months later, in a neurologist's office at Brigham and Women's Hospital in Boston, Mr. Carey was diagnosed with ALS, but the doctor made it clear to him then that this was not just a diagnosis, but rather, a death sentence.

In his piece called "The Absolute Worst Thing," which was broadcast on WCAI 90.1 a few weeks ago, Mr. Carey wrote that, after his diagnosis, the doctors suggested they run another blood test, explaining that maybe he was lucky and would "only have AIDS."

The only definitive test to diagnose ALS can be done during an autopsy, which Mr. Carey has said he "would just as soon postpone." Doctors diagnose the disease by ruling out all other possibilities.

In the months that followed his diagnosis, he stocked up on all the things he knew he would miss doing the most, Mr. Carey said in "The Absolute Worst Thing."

"I knew I'd miss fishing," he wrote. "But how could I stock up on hugging Shannon?"

The Careys were married in March 2002. By the following Fourth of July, Ms. Carey said she had to begin helping her husband dress and bathe.

By their first anniversary, Mr. Carey was in a wheelchair. Six months ago, he spoke for the last time.

Aside from the 10 hours of care provided by hospice nurses each week, Ms. Carey is the sole care provider for her husband. She said that she wakes up at least every two hours during the night to change her husband's position.

"Seth doesn't sleep very well," Ms. Carey said, explaining that their strong support system is how they are able to make it from day to day.

They have a friend who does their grocery shopping, another who mows their lawn, and another who brings their trash to the curb on garbage day every week.

"Even just the littlest thing helps," Ms. Carey said.

She explained that, although their house used to be full of friends stopping by, visitors are not as common now that her husband's disease has progressed.

"I understand that it can be intimidating, but he's still the same person and he still has the same sense of humor," Ms. Carey said, looking into her husband's blue eyes. They both began to laugh.

"A lot of people talk really loudly to him, thinking he's deaf or something," she said. "They don't understand that only his exterior has changed."

In February 2003, friends helped organize fundraisers at Grumpy's Pub for Mr. Carey, including a silent auction and a raffle.

Ms. Carey said they were aiming to raise about \$25,000, but raised more than \$50,000 instead.

"Seth was amazed at first by how giving people are," she said. "It's just a reflection of the kind of person he is."

A few months before Mr. Carey was diagnosed with ALS, a new neighbor moved in across the street from the couple. It turned out to be a twist of fate that Mr. Carey calls “good fortune.”

That new neighbor was Ronald G. Hoffman, the founder and executive director of Compassionate Care Inc., a nonprofit that offers individualized support to ALS patients.

Mr. and Ms. Carey call him their “ALS counselor.”

Mr. Hoffman said that his move across the street from the Careys was “somewhat more than coincidence,” acknowledging that there was some sort of destiny involved.

Compassionate Care was born through Mr. Hoffman’s experience as caregiver for Gordon T. Heald, a longtime Falmouth resident who died from ALS in 1998. The organization was founded by Mr. Hoffman and Mr. Heald’s wife, Elizabeth.

The disease that “has no rhyme or reason,” Ms. Carey said, does not give her the ability to know what’s ahead, what’s the next phase, or what she and her husband can expect.

“Once I get used to one situation, everything changes all over again,” she said, explaining that Mr. Hoffman serves as a shoulder to cry on, an ear to listen, and a fountain of advice and perspective, Ms. Carey said.

“Shannon is doing this 24 hours a day, seven days a week,” Mr. Hoffman said. “They are living this together, 24 hours every day.”

Through Compassionate Care, Mr. Hoffman has provided the Careys with a wheelchair ramp outside their house, funded the remodeling of their bathroom to make it handicapped accessible, given them wheelchairs and a handicap van—all free of charge.

“I wasn’t born yesterday and I know nothing is for free,” Mr. Carey wrote in “The House Across the Street.”

“I kept waiting for him to lay his pitch on me. It never came,” he wrote.

But what’s most important to both Mr. and Ms. Carey is the support and guidance Mr. Hoffman has provided them.

“I shudder to think of how much more difficult it would have been without Ron’s help,” Mr. Carey wrote.

Although there is no cure for ALS, Ms. Carey said that her husband takes several medications and vitamins every day.

“We don’t know if any of them actually do anything to help, but he’s constantly trying new things,” Ms. Carey said Monday, as her husband began to write something on the computer.

She sat quietly, petting their calico cat named Cali, as he wrote out his thought.

“I try everything. Why not?” he wrote, and then smiled.

Ms. Carey said that the only medicine proven to have any effect for those suffering from ALS is called Rilutek.

“All it does is extend your life for three months,” she said.

Mr. Carey responded on his computer, “Anyone with ALS has two choices, which both end with the same result. They can give up or they can try.”

“I thought he was incredible before he became ill, but now, seeing him deal with this horrendous disease with such grace makes me feel completely awestruck,” Ms. Carey said. “He has taught me about appreciating life, and about friendship, love, patience, and strength.”