

## Losing to ALS: New mother, 29, is dying, can't hold her baby

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JOURNAL REPORTER

Tuesday, September 25, 2007



Copeland Still kisses the hand of his wife, Keri Brown Still, who has ALS. The disease has progressed quickly, affecting her arms, legs, torso and breathing.

(Journal Photo by Jennifer Rotenizer)

Keri Brown Still is used to persisting until she gets what she wants.

The right job.

The right man.

The baby who she had longed for all her life.

But, despite her tenacity and determination, Keri has run up against something that she can't overcome.

It has cost her the job.

It nearly cost her the man.

And it has robbed her of much of the joy of motherhood. Her baby, Kellyn, is just 6 months old, and Keri can no longer hold her in her arms.

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is killing Keri, and she can't stop it.

ALS is a neurological disease that attacks the nerve cells that operate voluntary muscles, muscles that control movement, including those that regulate breathing and swallowing. Intellect is not affected. The disease usually progresses quickly and is invariably fatal.

ALS can strike young adults, but it becomes increasingly prevalent as people age, said Dr. James Caress, the director of the ALS Center at Wake Forest University Baptist Medical Center. Keri's diagnosis most likely would have come sooner if she had been in her 60s rather than her 20s.

As many as 20,000 Americans have ALS, according to the National Institutes of Health, and about 5,000 cases are diagnosed each year.

Keri, 29, has been through one physical crisis after another, and each one has left her weaker. A few weeks ago, her breathing became more labored, and she had to gulp air to speak when she told her story.

"I'm very angry," she said. "I'm very sad and mad and hurt and abandoned by God or whoever."

A wedding portrait on the wall opposite her bed shows her glowing with happiness, her blond hair haloed by sunlight. On the day she married Copeland Still in 2005, she dreamed of a future with children and a happy family life.

She thought that within a few years, she would be swinging a baby through the air and introducing that child to the ocean. Now, she hopes that her mother, Joanie Brown, will live long enough to

teach Kellyn the things that she taught Keri. Brown has been facing her own mortality since she developed lung cancer in 2005. In April, the cancer returned, and she has been undergoing chemotherapy ever since. Knowing that her granddaughter needs her drives her to fight the cancer harder.

Keri, too, has fought fiercely against her disease. She consulted doctor after doctor, looking for hope. Most of them had no hope to offer.

A trip to Pennsylvania last week for a last-ditch effort, an experimental treatment, ended with Keri in intensive care in a Philadelphia hospital. She flew back home on a private jet, with a machine helping her breathe and medical personnel standing by. She had so much trouble breathing that she was unable to clear the carbon dioxide from her body. Doctors at the clinic that she had pinned her final hopes on said they couldn't perform the planned treatment unless her respiratory problems were resolved. That is not likely to happen.

Keri now uses a breathing apparatus called a BiPAP that delivers oxygen under pressure to her lungs through a mask. She sleeps with it and wears it some during the day. Doctors often prescribe BiPAP to stave off putting patients on ventilators.

Only one FDA-approved treatment is available for ALS, Caress said. The treatment costs about \$800 a month and extends a patient's life by about three months. The treatment doesn't make people feel better, he said. "All they're doing is getting worse slower. Most don't perceive it as having any benefits." Doctors who care for ALS patients treat symptoms and offer support services to help them deal with their most pressing issues, such as difficulty swallowing.

People with ALS usually die within three years, though some have survived much longer. Stephen Hawking, a famous British physicist, has lived with ALS for more than 40 years, although he is unable to move or speak. People with ALS can live longer with technological support, such as feeding tubes and ventilators, Caress said. But most people don't choose to live that way.

Last autumn, when Keri's disease began to progress more rapidly, her husband buckled under the stress. Copeland said that he became dependent on Xanax, an anti-anxiety drug, and he and Keri separated for a few months. When she started falling at work, Keri had to give up her marketing job at BB&T.

Keri is reaching the end of her battle. Doctors have told her that she will probably die in her sleep.

Those who love Keri have fought alongside her. Copeland eventually left his job at a concrete company, where he ran an excavating machine, to care for his wife full time. Her mother and her father, Harold Brown, spend hours each day with Keri, helping Copeland with Kellyn and looking after details that he is too overwhelmed to handle. Both Browns are retired. Phyllis Still, Copeland's mother, also helps out with the baby. His father and stepmother, Buddy and Cynthia Still, have come several times from their home in Virginia to help with the baby and clean the house.

Keri's friend Jennifer Lassiter started a Web site dedicated to keeping people notified about her condition and raising money to help with medical bills. Although Keri has insurance, co-payments are mounting. Other family members and friends pitch in when they can.

Keri's parents were married for 10 years before she was born. Harold Brown, bracing for the possible loss of both his wife and his only child, fights his emotions and tries to lose himself in his granddaughter's laughter.

The baby is a bright spot in the darkness that has engulfed the family.

Keri Brown Still grew up outgoing and independent. She became the friend that everyone leaned on, the person they would call when things went wrong and they needed someone to talk to. She was also a firecracker, said Lassiter, who met Keri when they were both freshmen at Appalachian State University.

"We were both loud and aggressive, both feisty," Lassiter said. "We have those kinds of personalities that don't play with others but play well together."

Keri graduated from Appalachian, then earned two master's degrees online, one in global economy and one in business and marketing, from American Intercontinental University School of Business. Keri talked to Lassiter about the kind of man she wanted to marry, a "good old boy" who worked hard and wouldn't sit around trying to find himself. The night after she met Copeland, she called Lassiter and said, "He's the one."

They met when Keri spilled a drink on him. He whirled around, annoyed.

"Hey!" Copeland said. Then his tone and attitude changed. "Oh," he said. "Wait a minute, cute little thing."

And that was that.

"I always drug her to everything I loved to do," Copeland said. The couple went to drag races, rode motorcycles, rode around in her Mustang convertible. She went tramping in the woods with him on his frequent hunting trips. He even bought her a bow so she could learn to shoot with him.

They married in August of 2005. They lived in the house on Leinbach Drive that Keri bought before they met, but they talked of building a house together. They talked about having a baby. Keri couldn't wait to become a mother.

Shortly after the wedding, Keri felt pain in her right hip. One day, as she walked at the mall, she noticed that she was dragging her right foot. When her problems persisted, she started going to doctors. A neurologist told her that her problem stemmed from nerve damage.

She demanded more information.

"Then what's doing it?" she asked. "Fix it!" She pushed for further testing. Another doctor diagnosed arthritis in her hip and prescribed prednisone.

When she became pregnant with Kellyn in 2006, the pain and numbness began to creep up her right leg, then moved into her left. ALS usually starts with weakness in one hand or one leg, then spreads to the other, Caress said. Keri went from crutches to a wheelchair within a few months. In December, doctors put Keri on bed rest and made a diagnosis: ALS.

Keri and Copeland, who had undergone counseling, repaired their marriage, and he moved back home.

"I wanted to make things right," he said. Now he cares for her night and day. When Keri felt well enough, he took her outside to enjoy the cool night air or the sight of the glowing moon.

The couple sold their two-story house at a loss when getting Keri up and down the stairs became too difficult. They moved into a one-story house in Pfafftown that was once owned by her grandmother, a house just through the woods from her parents' house. Copeland and Keri's parents patched up the worn house and decorated it to her specifications.

Kellyn was born March 10, weighing 5 pounds, 7 ounces. After Kellyn's birth, the ALS began to attack Keri's hands, arms and torso. At first, Keri could pick up the baby, breast-feed her and change her diapers. But Kellyn grew heavier, and Keri's arms grew weaker. By June, she could no longer wrap her arms around the baby.

Now, Keri lies inert in bed and smiles weakly while Copeland tosses Kellyn in the air, making her squeal with pleasure.

"No matter what you say, you can't make a mother feel good who can't hold her baby," Copeland said, his voice breaking. He wishes fervently that Keri could regain enough strength in her upper body to cradle Kellyn.

As their bills pile up, he longs to go back to work, but he knows he has to be there for Keri. The couple had no income from January until August, when disability benefits from Social Security kicked in. The Browns have paid many of their bills, and the Stills are still awaiting resolution of a disability policy that she bought at her last job.

Her mother and her best friend said that Keri's spark and fire have dimmed. They know that hope is all but lost. But knowing and accepting are two different things.

"Nothing prepares you for losing your child," Joanie Brown said. "It's like something's pulling your lungs out."

Lassiter said that the swift progress of ALS in her friend has been horrifying, "the most horrifying thing I've seen with my own eyes." Lassiter knows death is coming for Keri, but she said she isn't ready for it.

"At 29, I never thought I'd be helping my best friend die."

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■ Lassiter's Web site is [www.helpkeri.com](http://www.helpkeri.com). For more information on ALS, check the Web site [www.alsa.org](http://www.alsa.org) for the ALS Association or [www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail\\_amyotrophiclateralsclerosis.htm](http://www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail_amyotrophiclateralsclerosis.htm) for the National Institutes of Health.