

Stilley's Masterpiece: the Art of Enduring

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TELLING THE STORY OF TUCKER STILLEY IS NO EASY TASK, in part because your audience needs to accept a seemingly unbelievable premise: A completely paralyzed artist with a death-sentence disease continues to create acclaimed work, all from a hospital bed in the front room of a San Marino home.

Questions will follow: *What? How? And why?*

Those can be answered by describing how Stilley's amyotrophic lateral sclerosis forces him to operate a hybrid computer using his eyes — the only part of his body he can control.

But, like his high-concept artistic creations, Stilley is better experienced than explained.

A decade ago, doctors diagnosed the San Marino native with the incurable ALS, also known as Lou Gehrig's disease. The progressive neurodegenerative disease slowly stripped Stilley of his physical capabilities, then confined his atrophying 75-pound body to a hospital bed four years ago.

He cannot move, speak, eat or breathe on his own, nor will he ever again.

But as his body began to betray him limb by limb, Stilley's ingenuity and eyesight became his life-saving grace. With help from Stilley's brother, Phillip, the artist raced against ALS's clock to modify an eye-tracking system that allows him to operate a computer to type, speak and, most importantly, create high-concept imagery. Today, the high-tech computer exists in contrast to the homemade rig — made of old sailboat parts and using a softball as a de facto ball bearing — that keeps the screen in front of Stilley.

If a great piece of art demands close inspection, then this artist's story calls for an exhaustive explanation of how he's re-imagining the relationship between artist and technology. Or how he and his wife, Lindsay Mofford, have together raised a teenager wise beyond her years, a daughter he can no longer hug.

For those answers, it's best to enter his world by lying down beside him to watch how he works and lives. After a visit to Stilley's world, you begin to get the picture.

For better or worse, Stilley always has an audience in his room.

Typically, it's Mofford reading him the newspaper; their daughter, Juno Stilley, curled up in his bed watching an episode of "Monk"; or his brother Phillip bringing a print by for the artist's close inspection. Stilley's condition also necessitates around-the-clock in-home nursing care, meaning he is never, ever alone.

The parade of people can be found in an extra hospital bed adjacent to his own. As if the paralysis weren't enough, Stilley is hard of hearing, too. So to best communicate with him, a visitor must lie beside him and meet his gaze in an automotive rear-view mirror affixed to the top of the omnipresent computer monitor that faces Stilley. After Stilley reads the visitor's lips, he turns his eyes toward his beloved monitor, where an infrared camera below the screen tracks his eyes' movement and corresponds to the letters he selects.

Thankfully, ALS has not affected Stilley's cognitive abilities, which are on brilliant display throughout a wide-ranging email interview conducted prior to a visit to his bedside. But the process is maddeningly slow for Stilley's quick, creative mind: It took him 24 hours, he said, to type 2,300 words of responses to his interviewer's questions.

A conversation in person with Stilley is full of silence; as he types, only the whine of the ventilator breaks the quiet. And every 20 minutes or so, Stilley will need to break from the conversation to recalibrate the camera's tracking software, a frustrating inconvenience. To top it

off, he'll likely need saliva suctioned out of his lungs during a visit, a painful-looking process Mofford said even close friends find unsettling.

But through it all, Stilley's wit and wisdom are readily apparent, as he cracks a joke, offers a profound thought or demonstrates how he re-renders a criminal's mug shot into art.

"I'm always amazed by how alive he is," said renowned artist and close friend Sam Durant, whose sister-in-law was also diagnosed with ALS a few years ago. "Perhaps because of the physical incapacity, you're just aware of how incredibly alive he is. You realize what that life force is when you see Tucker. It's not in the body. It's in the spirit, it's in the mind, and I am always moved."

The motionless man is moving others with his art, too, as he has drawn praise from art critics and distinguished figures such as Durant, Randi Steinberger and Andrea Bowers.

"He's an incredible artist, and I think that he's highly under-recognized," said Bowers, an accomplished artist herself. "I think that's going to change. The work is too good."

Stilley works in a variety of media, though his computer-re-rendered imagery has garnered the most attention. According to Stilley, his work is "often served up on a bed of conceptual irony," and themes of a profound struggle of some type can be highlighted.

"I think he's created this character that is semi-autobiographic," said Bowers. "The narrative, what has happened to him, is part of the work. Through some of the imagery, you can tell some of Tucker's story."



After a diagnosis of ALS (Lou Gehrig's disease), artist Tucker Stilley has survived and continued to work thanks in large part to the support of his wife, Lindsay Mofford, and daughter, Juno Stilley.

The public's understanding of ALS has increased exponentially in the past eight months. The Ice Bucket Challenge, a social media craze, raised awareness and funds last summer, while Eddie Redmayne's recent

Academy Award-winning portrayal of physicist Stephen Hawking in "The Theory of Everything" brought even more attention to the disease, which afflicts an estimated 30,000 people.

But all the awareness in the world never fully paints the picture of how ALS affects a family.

Juno Stilley was only 5 when her father first experienced symptoms. Before Stilley permanently settled into the front room, the growing little girl watched her father use a cane, then a walker, then a motorized wheelchair. But Juno always made the best of it: As a Valentine Elementary School student, she and her friends hopped on Stilley's lap for after-school wheelchair rides in the parking lot.

"She is actually very cool with it ... disturbingly good," Stilley said. "We have an unspoken understanding that I couldn't even put into words."

As her spirit moved him, Juno's child-like innocence buoyed her mother. Seeking a miracle in the early stages, Mofford drove Stilley from one doctor to another and every alternative practitioner in between. She began to dread the emotional avalanche awaiting her at every red light as she stopped long enough to think.

"Every red light, I'd be crying," Mofford said. "And Juno would be in the backseat, saying, 'It's going to be OK.'"

Juno's poise carried over to her schoolwork, too. As a Huntington Middle School student, she penned a remarkable poem personifying ALS as an unwanted visitor. Mofford paraphrased her daughter's work from memory: *ALS came to the door. He was not invited, but he came to the door. He wasn't a friend. We told him not to come in, but he came in anyway.*

Despite the unwelcome guest, Stilley never wavered in his role as a parent. Family friend Florence Kelly, mother of Juno's best friend, Megan, said the San Marino High freshman never responds to invitations by saying, "Let me ask my mom."

"Tucker is very strong in that household," said Kelly, who has a Stilley creation hanging in her home. "He is her father, and he is the king of the house."

Kelly is one of the dozens who pack the Adair Street home for an annual Halloween party, which features a pumpkin carving contest judged by — who else? — the professional artist. Each submission is paraded in front of Stilley, and he renders a ruling on the winner.

Stilley's situation does not preclude him from a bit of fun. Mofford was asked what initially drew her to Stilley when they met at a New England prep school in 1978. As she began to describe his creative talents, Stilley's robotic computer voice interrupted: "My butt."

Mofford laughed, as she does often when near Stilley. "He had a *really* cute butt," Mofford admitted. "I just found him incredibly magical."

Stilley's technology and medical care have kept him alive, but he said all of the credit belongs with his wife's constant presence and undying support. And, in doses, the community has rallied around him, too. Kelly's husband, Chip, raised about \$15,000 in 2012 to help with Stilley's medical costs, which average about \$8,000 per month.

Despite the never-ending struggle, Stilley has managed to find value in the daily battle for survival.

"If I could show you how to die — or, more importantly, how to live in the face of death, to show you that you don't have to be afraid of anything, then I would not have to be disgusted to have lived," he said. "Then I could be proud. For some reason, that was important."



Tucker Stilley's rig and computer allow him to work as an artist, despite not being able to move anything other than his eyes.

The hardest part of telling Stilley's story is the already-written, tragic ending. As a promising new drug fights for FDA approval, Stilley is asked by a visitor if the drug gives him hope for his own future. The answer is immediate: "No." His nervous system is too fried, he explains.

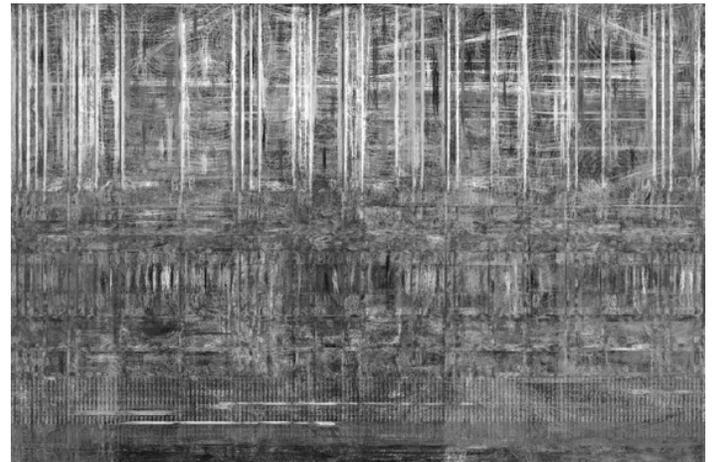
"I don't know if I could survive getting all better, however I would certainly try," Stilley typed. "I just can't think about it too much. That way lies madness."

And yet the hopeless man does not despair. There's no time for it, not with exciting developments coming down the road for him. A Stilley-written essay appears in the recently published "Artist Practice" book, and he'll be one of a dozen or so asked to test-drive a Google Glass-type product for ALS patients in its beta stage. There are upcoming exhibitions, too: in New York City on April 7 and at the Santa Monica Museum of Art's benefit on May 3.

As he carries on as only he can, Stilley's story serves to inspire, too. When exhibit-goers discover the piece they admire was made using only eyes and a computer, they often want the full backstory on Stilley.

"Every piece of artwork has a story, and sometimes it illuminates the work into a masterpiece instead of just another mediocre thingie," Stilley said. "I have been told I am an inspiration, but I do this to survive, not really to inspire — although I'm glad it worked out that way.

"So that's a good story."



Tucker Stilley's "Emergent Forest" is one of five creations a series. According to Stilley's website, "Emergence, an important concept in science and philosophy, is the process of small, simple elements in combining in some way to produce suddenly, wildly complicated and coherent forms, totally unpredictable from their simplest constituents."

For more information on Tucker Stilley, upcoming exhibits or to purchase artwork, visit TuckerStilley.com.