

Technologies Help Tucker Stilley Create

The multimedia artist hasn't let near total paralysis from ALS stop him from producing an array of artwork.

By James Klein, Editor

For over 30 years, Tucker Stilley has worked as an artist, sound designer and film editor on everything from Hollywood blockbusters like *Armageddon* to subversive documentaries like *Sir! No Sir!* to literally hundreds of music videos.

Diagnosed with Lou Gehrig's disease in 2004, Tucker has lost the use of his limbs and now relies on his computer to create works that range from meditative paint-washed canvasses to slide-show LCD screens. The pieces collected on his website, www.tuckerstilley.com, represent a broad range of media – video, music, photography, painting, collage, drawing, mixed media – there is even a graphic novel he wrote and illustrated about his struggles with ALS.

Stilley continues to work as a media editor, "In a limited sort of way. Against all odds I can still do everything that is required for the job. Of course I need an assistant, but that's not unusual for an able-bodied editor."

Though not a programmer, Tucker has developed innovative ways of combining existing computer systems and applications, which in turn have spawned ideas for new works.

"The further I got into it the more unexpected little relationships between various pieces of software popped up, things that would suggest new funny ways of working, which in turn suggest new funny little projects."

Not able to control a standard computer mouse, Stilley uses a special camera on his computer that tracks a small dot attached to his forehead, translating the movements of his head directly to the onscreen cursor. Buttons mounted on the arms of his wheelchair simulate the mouse's click buttons. Special software allows him to custom design a virtual onscreen keyboard, while another application tailors his keystrokes to the particular software he is using.

More information about the tech-

nologies he uses, and a video that demonstrates their uses, can be found in the online version of this article at www.alsala.org.

Stilley says of his computer systems, "I hope everything I've done becomes swiftly obsolete - then maybe we'll be getting somewhere. In the meanwhile if any of my techniques or attitudes inspires anyone I'll be a million times blessed."

He also looks forward to future medical and technical developments. "You can teach a computer program to translate brain states into desired output - words for instance or cursor control on a screen. Another trick is to route around the neural damage and convert nerve information directly into muscle stimulation. And then there's straight-up 'Borg' style trans-humanism..."

Stilley has several online projects, including another collection of his paintings, songs, videos and other expressions called *The Permanent Record of Newjack Rasputin*; and *All Hands on Board*, an ongoing blog, announcement board, and collective art space for his friends and family.

Tucker and his wife, Lindsay Mofford, a documentary filmmaker and a film and television editor, have a unique working relationship. "We have been together since our mid-teens. We have been professionally working together since our twenties," says Mofford. "Every project I have been involved in, Tucker has been there too...So for the past year, I've been only taking jobs I can do at home. This way Tucker can still be involved in my work. Also I can be here as a caregiver and artist's assistant."

As any family member of someone with ALS knows, the extra caregiving required can be difficult to manage. "Tucker's mother has been living with us for over two years," Mofford says. "We also have many friends and family and neighbors who have all really been sup-



Photograph by James Klein

Tucker Stilley at an October, 2008 benefit for him at the RedCat Theater in Disney Concert Hall

portive. But it still is too much. I don't get enough sleep and it's tough to always have to make sure someone is here with him."

She credits the Chapter with helping her family through the most difficult times. "When Tucker was first diagnosed, The ALS Association Greater Los Angeles Chapter was a useful place to go to get general information. Also, we go to the clinic at Cedars and love Dr. Abi [Dr. Abirami Muthukumaran, Director of the Center for ALS Care at Cedars-Sinai Medical Center].

"We love Jan [Janet Simms, R.N.] who runs our local Support Group, which we go to several times a year. Norma [Equipment Loan Pool Specialist Norma Segura] and the loan closet have been quite useful and terrific. The caretaker seminars are also pretty good."

What advice would she give to other families coping with ALS? "Try not to worry about the future and just take it one day at a time. Love him or her for what he/she can do today not what one used to be able to do or might not be able to do. Hold their hands, look them in the eyes and give them the strength to face the scary diagnosis. This action will also give you, the partner, the courage to get through it. Accept all the support that friends and family want to give...and take a break without feeling guilty."