

## **Technologies Help Tucker Stilley Keep Creating**

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

*By James Klein, Editor*

For over thirty 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](#) represent a broad range of media – video, music, photography, painting, collage, drawing, mixed media – there's even a graphic novel he wrote and illustrated that explores his struggles with ALS.

"I just kept accumulating interests as most people do, but I've been able to keep using them all, one way or the other," says Stilley. "I did spend an awful amount of time hanging around the [Studio for Interrelated Media at Mass Art](#). That may have cemented my permission to do work in whatever media I chose, but now it seems it all boils down to computers."

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.

"I looked at what there was out there and matched it up with what I wanted to do. I wanted to keep all the functionality I had. 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.

Though he is able to do everything most people can do on the computer, the interfaces available today cannot meet the intensive demands of a multimedia

artist.

“There are certainly a few things I can't do, mostly revolving around inputting multiple simultaneous streams of data. That sounds fancy, but you know, playing a MIDI keyboard with velocity and aftertouch, or using my beloved Wacom drawing tablet with its tilt and pressure sensitivity...”

Stilley continues to test new applications and improve the tools for translating his ideas into fixed forms of expression, pushing the technologies to better represent human consciousness. “That natural kind of complexity - I've had to take another approach to get that. I certainly always look for programs that can use chaotic random modulation - the ability to inject a calculated error into whatever you happen to be doing. I was always interested in so called ‘generative’ programs, that using an array of small simple rules can generate impressively complex results.”

More information on the technologies Tucker Stilley employs, and a video that demonstrates their uses, can be found on the [Assistive Media Ninja](#) page of his website.

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... :-|”

Lou Gehrig's disease has changed the way Stilley works in other ways. “Certainly I'm more decisive than I used to be. There is a subtle difference between wasting your time and waiting for the right moment. I'm trying not to let too much urgency creep into my work, but I have so far to go in such a short time. I will tolerate perfection but only as a by-product of process.”

Tucker explains the impetus behind his video *Gyre*, which is about the great pacific garbage patch, a giant accumulated island of trash that wind and water currents have pushed together in a remote part of the Pacific Ocean: “I figured out I was in mourning for the Ocean with whom I have a long personal relationship, so it was natural to dedicate the products of my weird little musical experiments to that wonder and sorrow...I was already using the garbage patch in the comic strip, but its voracious all-inclusive nature (self-organizing trash!) was resonating with my ‘trash-pirate’ working method. So then I got into the gyre for a while...in my mind that is. The closest I've been physically was when I spent a week on Kauai, just after my diagnosis. The Hawaiian Islands form the extreme

southern edge of the gyre...That's the last time I put on a mask and fins. That must be where it came from.”

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.

“At first I was skeptical that that many people would be interested,” Stilley says of the *All Hands on Board* networking site, “...but I didn't count on how much my friends needed a place to regroup after a couple of decades in exile. In fact, it's been so heart wrenching to see everyone signing up, making it their own, filling it with their video, audio, writing and pictures.

“Many of these people were deeply suspicious of the Web, *and they seem to trust our site more than say facebook*, so the site has turned out to be very gratifying, as well as practical. It's a really good way to let everyone know what's going on. I would definitely advise any PALS (or other extended families) to do it.

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. When I take jobs away from home, I miss and worry about him. I'm distracted and resent *that I* have to be away. So for the past year, I've been only taking jobs *that* 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 assistant.”

Lindsay Mofford is currently finishing a documentary film she directed and edited called *The Signature of All Things, A Centenary Celebration of the works of Kenneth Rexroth*, which will be premiering at [Beyond Baroque](#) in Venice on December 5, 2008.

Has she considered making a documentary about Tucker? “When Tucker was first diagnosed, we talked about it. It seemed natural because we are both involved in documentary film and we consider ourselves *archivists*. We love the film *Silverlake Life: The View From Here*, which documents a couple struggling with AIDS. However, we decided we couldn't formally make a film because we might be thinking about our audience instead of dealing with our own emotions. So instead, I bring out the video camera from time to time and Tucker created his website, which is a more beautiful way of expressing what he is going through.”

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 supportive. 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 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.

“I’ve been very lucky to have known and loved Tucker for thirty years,” Mofford continues. “Tucker has always been strong, courageous, a hero with great inner wisdom. It is much easier facing all of this with someone like him. Life and love *are* a gift and if one remembers that then this is just all part of the big adventure.”