

FUTURE OF YOU

Paralyzed ALS Patient Controls Home Through Eye Movements



Steve Saling in his specialized wheelchair with his son, Finn. (photo credit: Jen Yapp)

By Lesley McClurg

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Steve Saling controls his world in the blink of an eye.

Literally.

The assisted living facility Saling resides at is designed specifically for patients with amyotrophic lateral sclerosis (ALS). Saling is completely paralyzed, but when he blinks at a screen mounted to his wheelchair, he can open and close doors, propel himself forward, or, as STAT reports, call for the elevator.

"He'd summoned the elevator before he left his room, and indicated where he wanted to go. The secret is a small, white box on the wall above the elevator call buttons. After Saling's computer converts his blinks into radio frequency signals, the little box conveys them to a receiver in the basement. The signals are then sent as commands to the elevator's computerized operating system.

Saling recalled that there was skepticism about the elevator during the design process.

"The biggest challenge was convincing the elevator sub-consultant that we could automate his elevator," he says. "A few of the subs were reluctant to embrace change, but they all came around. It all came out beautifully."" ~ STAT

Saling was diagnosed with ALS, commonly called Lou Gehrig's disease, 10 years ago, at age 38. Over the last decade, the nerves in his body have atrophied and died, but his mind is fully intact. ALS doesn't interfere with sensory nerves, so he can still hear, smell, taste, feel and see normally.

'Our society treats prisoners with more dignity and respect than the chronically disabled, kept alive but with no life. I knew I had to work quickly to avoid their fate.'

~ Steve Saling, ALS patient

When he lost the ability to speak in 2009, he started communicating through a speech generating device, also controlled with eye movements. He narrates his story in a video below. (You can watch him make use of his automated residence starting around 9:21.)



When Saling started investigating long-term living solutions, he says, he became terrified by his future prospects. He visited men with ALS at nursing homes or hospital chronic care units and found them staring blankly at the ceiling from hospital beds, connected to ventilators.

"Our society treats prisoners with more dignity and respect than the chronically disabled, kept alive but with no life," says Saling on the video. "I knew I had to work quickly to avoid their fate."

Saling partnered with a man named Barry Berman, a nursing home operator and the CEO of the Chelsea Jewish Foundation, which offers senior care in Massachussets. The two envisioned a long-term care facility, which eventually became the Leonard Florence Center for Living — Saling's home today. A former landscape architect, Saling worked closely with the designers. The building is electrically wired so ALS patients can control doors, windows, beds, et cetera, through Wi-Fi devices mounted on their wheelchairs. The tablets or computers are touch screens that respond to eye movements or facial twitches.

"Technology levels the playing field," says Saling on the video. "There is no physical disability on the internet. If we met online, you would never know that I was paralyzed."

Although Saling will spend the rest of his life strapped to a chair, he hasn't lost hope. In fact, he says, he has an "extremely high quality of life," thanks to technology.

The technology, Promixis Environment Automation Controller (PEAC), which he credits for saving his life, is explained in the video below.



Until medicine proves otherwise," says Saling, "technology is the cure."

The statement is the motto for the fundraising and advocacy organization founded by Saling, the ALS Residence Initiative. The organization aims to construct other automated homes for the 30,000 Americans currently affected by ALS.