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## Fighting ALS, one gadget at a time

Kay Lazar, Globe Staff / Aug 14, 2010

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CHELSEA — Steve Saling talks about being lucky and as happy as he has ever been, which might seem odd, given that Saling cannot speak, walk, or move his hands.

His “voice” is the monotone of a computer, activated by an infrared beam he moves with almost imperceptible twitches of his head.

The 41-year-old former landscape architect has Lou Gehrig’s disease, also known as amyotrophic lateral sclerosis, a progressive nerve disorder that slowly paralyzes patients while leaving their mind intact. They eventually lose the ability to even breathe, often within five years.

Saling was diagnosed four years ago, a month after the birth of his son. Instead of despairing, he went into overdrive, determined to use technology to stay one step ahead of the relentless and usually lethal disease. Now he is blazing a path for many others.

Through a chance encounter shortly after his diagnosis, he teamed up with Barry Berman, chief executive of the Chelsea Jewish Foundation, and helped to design the nation’s first residence for ALS patients needing nursing care. Using customized infrared technology, patients have far more independence than in a typical nursing home.

Saling, who once specialized in making public parks accessible for disabled people, is its first resident.

The Leonard Florence Center for Living’s Steve Saling Residence officially opened yesterday in Chelsea. Tiny infrared transmitters in the ceilings connect to a master computer in the basement. This allows its residents to use small computers on their wheelchairs to summon an elevator, open and close doors, turn lights, televisions, and DVDs on and off, control the heat and air conditioning, even order meals from the cafe downstairs.

“My whole life has perfectly prepared me to be right where I am today,” Saling wrote in an introduction for the opening of the 10-bedroom residence. “I was a very good landscape architect and I am proud of my professional achievements, but my most important work will be done after I got ALS.”

With a mischievous smile, Saling recently demonstrated his masterpiece.

Using a teeny dot on his glasses that reflects an invisible infrared beam from a small sensor/transmitter on his wheelchair, he can control the “mouse” on his computer. He guides that mouse with subtle shakes of his head, and suddenly the shades come down in his bedroom, the lights go off, music comes on, and the door closes.

“I even have a remote-controlled bidet to wash and dry my bum, so that I maintain that independence,” he said, using the infrared beam to tap letters on the screen, telling his computer voice what to say.

Saling's designs were used for a second high-tech residence in the same complex for patients with multiple sclerosis. It didn't take long for residents in the ALS and MS homes, many in their 40s and 50s, to strike up fast friendships.

"We go out for a roll together, down to the marina at night," said Bonnie Berthiaume, a 58-year-old former computer software saleswoman who transferred from a nursing home into the MS residence.

They're also planning a skydiving outing, with Saling as the ringleader.

Surrounded by photos in his bedroom that capture his hardy, outdoors life before ALS, Saling, now a slight man with an ethereal glow, seems at peace.

His mother, Jean Saling, said that when he was diagnosed, he told his parents that the only thing that would make him sad is if they were unhappy about the news.

"He was always strong-willed," Jean Saling said. "But the ALS has given him a purpose in life."

Still, it has not been easy. She said that her son had always wanted to be a father. Steve Saling later said in an e-mail that he yearns to hold his 4-year-old son Finn, who visits often but lives about 20 minutes away with Saling's former girlfriend.

Finn "is a bitter-sweet reality," Saling wrote. "I'm right now watching my brother canoe to shore with Finn in his lap. I wish that could be me. I get to see him often, but it's not the father experience I hoped for."

While many ALS patients choose to forgo life-sustaining ventilation when the disease shuts down breathing, Saling intends to be fully mobile, living with a portable ventilator the size of a laptop computer, including batteries, that can hang off the back of his wheelchair.

The Chelsea project "will show everyone that a vented life can be a quality life," Saling said. "It is the honor of a lifetime to be involved with this paradigm-shifting venture."

And if ALS halts his ability to control his computer through eye or head movements, Saling is prepared.

"There is promising technology that will allow the computer to be controlled by thought alone," he said. "I am considering participating in a trial that hopes to make that a reality."

His indomitable drive is inspiring others. An estimated 30,000 people in the United States have ALS, and many end up in traditional nursing homes, spending long hours in bed because there has not been a place like the Leonard Florence Center, with specialized staffing and technology, advocates said.

With the Chelsea Jewish Foundation, Saling is developing 10 similar homes for ALS patients in at least four other states over the next five years. Yesterday, that goal got a boost when Chris Stevens, cofounder of Keurig, the Reading-based coffee company, donated \$100,000 of his own money and another \$100,000 from his parent company, Green Mountain Coffee.

Saling told the crowd of advocates who attended the opening that his son inspires him to keep going, hopefully for decades.

"Until medicine proves otherwise, technology is the cure," Saling said. "Thanks, and remember, life is good."

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