

At Home in the ALS House

BY MIRIAM DAVIDSON ON THU, 2011-09-01

The future is now for 10 people living with ALS at this state-of-the-art residence overlooking Boston harbor



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- The ALS residence is named for landscape architect Steve Saling, who has ALS and contributed to the design and construction of the building.

The future is now for 10 people living with ALS at this state-of-the-art residence overlooking Boston harbor

The lobby of the Leonard Florence Center for Living in Chelsea, Mass., is quiet and elegant, like the lobby of a fancy hotel. A fountain burbles in the background while comfortable chairs and sofas invite visitors to sit down and relax. In the sunny café, a gleaming glass case shows off fresh-baked pastries, macaroons and other treats, all free for the asking to the building's residents.

The elevator door opens and a long-haired man in a power chair emerges. It's Steve Saling, 43, a landscape architect who contributed so much to the design and construction of this building that the ALS residence on the second floor is named for him.

Saling, who received an **ALS (amyotrophic lateral sclerosis)** diagnosis in 2006, uses an eyegaze computer mounted on his power chair to speak, drive, call for assistance and perform many other tasks — including conducting frequent tours of the place he calls home.

After showing visitors around the ground floor of the Florence Center, which in addition to the bakery and café, contains a deli, chapel, day spa and beauty salon, Saling heads to the fully automated elevators. Looking at his computer, he calls the elevator and selects the second floor.

The Green House model

The Saling ALS Residence is one of 10 separate residences in this six-story, 95,000-square-foot skilled nursing facility that sits on a hill overlooking Boston harbor. Each residence consists of 10 private bedrooms and bathrooms centered around a common living room, kitchen and dining area. The ALS and MS (multiple sclerosis) residences share the second floor; the other eight residences in the building are occupied by elderly people and those undergoing short-term rehabilitation.



Opened in March 2010, the Leonard Florence Center is part of the Green House Project, a nationwide effort to build skilled nursing facilities with all the comforts of private homes. In contrast to the institutional nature of traditional nursing homes, Green House facilities feature small, group residences for six to 10 people, with care provided by teams of staffers who work together to manage the needs of each resident.

A resident entertains visitors in one of the Center's communal living rooms.

The Green House concept is part of a trend toward designing long-term care facilities to maximize the comfort and enjoyment of residents while still providing top-notch medical care and other services. Nearly 100 Green House homes operate on 43 campuses in 27 states.

Although the Leonard Florence Center residence is currently the only Green House in the nation with a residence designed specifically for people with ALS, Steve Saling and others hope it is the first of many.

The Steve Saling ALS Residence

"Welcome to my home," Saling says through his electronic voice, as he proudly opens the automated door to the Saling ALS Residence. The front door, like others in this building, is built to resemble the entrance to a house, with residential siding, doorbell, mailbox and lots of natural light.

"By looking, you would never know this is a nursing home," Saling continues. "I am sharing this house with nine other friends. My friend Patrick is even on a ventilator, which is rare to have outside of a hospital setting."



Steve Saling in his bedroom at the ALS Residence.

The living area is open and airy, with a fireplace and lots of room for people in power chairs to maneuver. Sliding glass doors open onto a patio where, on this beautiful summer day, residents are beginning to gather for lunch.

Prior to his ALS diagnosis, Saling was an architect who specialized in designing accessible outdoor spaces. This skill came in handy when it came time to design the patio of the residence; Saling made sure, for example, that the grass landing was reinforced so people could drive power chairs out onto it.

Saling also has a keen interest in technology and was given free rein to design the building's automation system. The system he created allows residents to personally control the environment from computers on their power chairs using voice, eye, hand or other commands. Signals are sent from the chair computers to a server in the basement, which then relays the signals to infrared transmitters in the ceiling that control the devices.

Saling says this unique automation system, called PEAC, already is being marketed to other health care facilities and may someday be available as a commercial product.

Lunch on the patio

Lunch today consists of a hamburger or hot dog grilled by a cook on an outdoor barbeque, pasta salad, green salad and brownies. There are plenty of staffers to help prepare the food and feed those who are unable to feed themselves. Residents also have complete access to the kitchen, and may plan their own menus and eat whenever they want.

Saling is joined by several friends from both the ALS house and the MS house across the hall. Everyone is eager to talk about how much they enjoy living at the residence, with people their own age (many are still in their 30s and 40s). The residents share stories about some of the outings they've taken, such as Red Sox baseball games, the beach, concerts and museums. They even have taken trips skiing and skydiving.

While having lunch, the residents are joined briefly by Barry Berman, CEO of the Chelsea Jewish Foundation, which built and operates the Leonard Florence Center for Living.

"Now that we've proven it can be done, we'd like to see ALS residences in cities around the country," Berman said. The main barrier to this goal is, of course, cost. Although Medicaid covers the residents' health care, construction and operational expenses necessitate both large, private donors and ongoing fundraising.



Like other residents of the ALS House, Steve Saling uses an eyegaze computer mounted on his power chair to speak, drive, play music, operate environmental controls and perform many more tasks.



Residents of the ALS and MS houses gather for a cookout lunch on the second-floor patio of the Leonard Florence Center for Living.

A remote-control room

After lunch, Saling retires to his room to show videos he produced of the skiing and skydiving outings. He plays blues and R&B music on his computer as he points out amenities in his room like the ceiling lift, which will transport him to the bathroom and back when he can no longer stand.

As in the rest of the house, Saling uses his eyegaze computer to control numerous features in his room. He can open and close the door, raise and lower the curtain, adjust the temperature, turn the TV on and off, and operate other devices.

The room is painted a warm, deep red, and the walls are decorated with paintings and photos created by Saling of places he's visited, including Italy, Germany and Belize. Pictures of Saling's five-year-old son Finn, who lives nearby and visits frequently, crowd the shelves.



ALS house staff prepares and serves meals from this kitchen, which is also fully available and accessible to residents.

A video of the skydiving expedition starts to play on the large-screen TV. Scenes of Saling's friends going up in an airplane and then jumping out (while strapped to an experienced parachutist) are accompanied by U2's "Mission Impossible" theme, Van Halen's "Jump" and other songs. When the scenes of Saling's own leap appear, the voice of Bob Marley is heard singing, "My life is perfect, because I accept it as it is."

That is exactly how Saling feels. As he wrote recently, "I am as happy as I have ever been and will contribute more than I ever would have if I'd remained healthy. Lou Gehrig may have said it first over 70 years ago, but I am the luckiest man on the face of the Earth."

Saling is indeed fortunate. Perhaps some day, ALS residences will exist across America, and many more people will be as fortunate as he.

For more information

To learn more, check out [videos of Steve Saling and friends from the ALS House](#) skiing and skydiving via Saling's Vimeo page.

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