

A New Concept in ALS Care Facilities

<http://alsn.mda.org/article/new-concept-als-care-facilities>



Architect's rendering of the Leonard Florence Center for Living in Chelsea, Mass. It will include the first dedicated ALS lodging and care facility of its type in the country.

A totally new type of care institution for people with ALS is being built in Massachusetts, and a man with ALS is helping design and raise funds for it.

"Before being diagnosed with ALS in October 2006, I had a great career, going on 13 years as a landscape architect," writes Steve Saling, 40, of Andover, Mass., in his MySpace blog.

"Ironically, one of my areas of expertise was in complying with the Americans with Disabilities Act (ADA) to make sure public places were fully accessible to disabled persons."

Now Saling is putting his expertise to work on the [Leonard Florence Center for Living \(LFCL\)](#) on Admiral's Hill in Chelsea, overlooking Boston Harbor. Groundbreaking on the center, which is being built under the auspices of Chelsea Jewish Nursing Home, took place in August. Estimated time for completion is 14 months.

The "Green House Project"

What's so unusual about the LFCL, apart from being the first dedicated ALS facility of its type, is that it will be a "Green House" residence (a trademarked term), one of 10 in a 90,000-square-foot urban mid-rise condo facility.

Green House homes (not to be confused with environmentally "green") are dramatically positive departures from stereotypical assisted living facilities and nursing homes. Scores of them, designed to accommodate the elderly, now exist across the country.

A 2001 study by the [Institute of Medicine](#) found that assisted living facilities often are characterized by problems with bedsores, malnutrition, infections, loss of activity in daily living functions, improper medication use, high levels of depression and poor quality of life. Judith Rabig, former executive director, of the national Green House Project, in 2005 told the White House Conference on Aging, "moving to a nursing home is a dreaded event."

By contrast, the Green House model was created to provide a home where people live in intentional communities with competent, consistent, well-trained caregivers, and are restored to lives "rich in autonomy, dignity and choice ... where priority is given to their quality of life," Rabig said.

"Eden Alternative" origins

The Green House concept is based on the [Eden Alternative](#), a nonprofit organization created in 1991 by William Thomas, a physician and geriatrician. Eden Alternative is "dedicated to eliminating the plagues of loneliness, helplessness and boredom that make life intolerable in most of today's longterm care facilities," says its Web site (www.edenalt.org).

Adapting this concept designed for the elderly, Saling and Barry Berman, executive director of Chelsea Jewish Nursing Home, teamed up and created plans for a facility uniquely suited to the needs of people with ALS.

"For me, this meant taking 31 years of experience with nursing homes and creating something dramatically different," Berman said. "It's been an incredible experience; we've all come to realize the time has come for a completely different model of care."

An array of aids, comforts

The ALS home in the LFCL will accommodate 10 people with ALS. They'll each have private, accessible bedrooms and bathrooms; dine family-style on home-cooked food they can order from the in-home kitchen as they wish; socialize in a central gathering room with a fireplace; and enjoy outside courtyards with lush vegetation.

The project is collaborating with the Assistive Technology Program at the University of Massachusetts in Lowell. Each ALS resident will have a technology package custom designed for his/her use by a senior engineering student, under the supervision of a professor.

Saling enumerated the assistive technology that will be available:

- Computer "command centers" on wheelchairs (usable by hand or eye controls, as appropriate) will regulate climate controls in rooms, open and close doors, call for the elevator, order a drink or snack from the kitchen or send a text message to attendants.
- Each bedroom/bath will have a ceiling track lift system.
- Oxygen will be available in each room.
- "Most importantly," Saling said, "When necessary to go on a vent, you won't get kicked out. All 10 rooms will have vent support."

Enter the "shahbazim"

Thomas, creator of Eden Alternative, coined the term "shahbaz" (plural "shahbazim") to describe caregivers. It comes from a Persian word that translates as "royal falcon." "Its quality of mystery is what makes it well chosen to define a new concept," he says in his blog (<http://shahbazim.blogspot.com>).

In the Green House concept of caregiving, shahbazim will be devoted to the arts of homemaking and lovingly prepared meals. They will operate in addition to a clinical support team that includes nurses, social workers, therapists, medical directors, nutritionists and pharmacists, who will visit the house regularly to provide services as needed.

Saling says the center's ALS facility is unique in this country, and possibly the world: "There are places that may accept an ALS patient, but you are just that, a patient. If unvented, a [person with ALS] might live in an assisted living facility, as I am now, or a nursing home. The problem there is that I'm 40 years old; the next youngest resident is twice my age. The thought of living the rest of my life [in a standard long-term care facility] is not very appealing."

Saling notes that some states only have one or two facilities that will accept a patient on a ventilator; some states have no such facilities at all.

Of the ALS Green House residence he says, "There really is no comparison to anything other than your own home, and then only if you happen to be a techno-geek."

Covering the costs

Vigorous fundraising is financing the basic structure of the LFCL and all ALS-specific equipment. Saling and Berman are highly optimistic they will meet their goal.

Berman said he expects that most, if not all of the people with ALS who move in to the facility will be enrolled in Medicaid, which will help defray some of their daily living costs.

Perhaps the largest problem right now is how to select the 10 residents for the new facility. Berman says he already has received hundreds of applications — including one from Saling — and some from other countries.

"It's a very emotional project for me. Our selection really needs to be geared to the ALS individual who wants to continue to lead an active life and take advantage of technology. The center can't be for someone who just wants to stay in bed."



From left, Steve Saling, landscape architect; Barry Berman, executive director; and Adam Berman, director of business development, at the LFCL construction site.

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Planning for more



When completed, the new-concept care facility will accommodate 10 residents with ALS.

Help could be on the way, thanks again to Steve Saling, accomplished architect in more ways than one. He, his family in Georgia and a coalition of elected officials, educators and health care industry experts are taking a different but complementary tack to building another ALS-specific care facility in that state.

“With the experience I gain in Massachusetts and Georgia, I would like to initiate similar projects in other states,” Saling said.

“It is my hope to make life on a vent look more attractive than death, and thereby increase the paltry five percent of us that choose to live when the necessity to vent arrives.”