

The road to recovery

Lexington facility offers hope for brain injury patients

Editor's note This is Part 1 of a two-part series on traumatic brain injury

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Curt Caldwell's room at Tewksbury Hospital has a sense of permanence about it. Decorated much like a college dorm room, posters hang alongside photos of family and friends. His space is in sharp contrast to the mostly bare walls in the rooms of other patients who will be able to move on far more quickly and conclusively.

Curt's current accommodations are the result of a traumatic brain injury (TBI) he suffered in a car accident in March 2008.

"When we got the call, they didn't think he was going to make it," said Curt's mother Deb, a Billerica resident.

He was initially treated at Boston Medical Central and eventually moved to Tewksbury Hospital a few months later — he has been there since. Deb has been a fixture by his side, spending most nights at

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the hospital after work.

Now 28, Curt is confined to a wheelchair and faces a long-term battle to regain much of the brain function he lost in the accident. He has trouble eating and cannot talk, although he is able to communicate through an apparatus that allows him to type messages on a large keyboard.

Deb believes her son will further improve, maybe not to where he was before the accident, but to a point where he could regain some speech and hold a job.

After nearly three years, Curt is nearing the end of his hospital stay. Deb has placed him on the waiting list at the Douglas House — a residence for survivors of moderate or severe brain injuries in Lexington — but it is unclear whether he will find a place there or be forced to move back home.

Long-term care is not universally available for



Derek Shibles of Goyette Construction works on the site of the future Wellness Center at the Douglas House in Lexington. STAFF PHOTO BY MATTHEW MODOONO

Levels of traumatic brain injuries

Mild

- Usually, the loss of consciousness is not prolonged, often lasting just a few minutes or seconds.
- About 75 to 85 of brain injuries are mild
- The vast majority of patients recover within two months
- Brain scans often appear normal
- An individual does not have to lose consciousness to have a mild TBI

Moderate

- Loss of consciousness lasts longer, often hours or minutes
- Persistent confusion for a couple of days or weeks
- Some behavioral, cognitive or physical impairment could be permanent or last for months
- Brain scans turn out positive for an injury

Severe

- Often the patient is in a coma for days to months
- Impact to brain function can often be permanent
- Possible permanent impairments to speech
- Emotional problems
- Loss of cognitive abilities
- Physical mobility issues
- Possible seizures

SOURCES: NEW YORK STATE OFFICE OF ALCOHOL AND SUBSTANCE ABUSE SERVICES, TRAUMATICBRAININJURY.COM

those with a moderate or severe acquired brain injury, but treatment and research at the Douglas House may improve the prognosis for people like Curt.

Douglas House

The Douglas House, which opened in 2008 on Oakland Street in Lexington Center, has much in common with most small apartment buildings. There is a common room, kitchen space, and 15 single-occupancy apartments. The biggest difference, however, is the residents.

Many of the residents have worked their way down a lengthy waiting list to be placed at the Douglas House, which is one of three homes run by Supportive Living Inc (SLI), a nonprofit organization that also operates the McLaughlin House in North Reading and the Warren House in Woburn.

According to SLI Executive Director Peter Noonan, the Douglas House receives affordable housing subsidies that reduce the costs to residents, who often contribute between \$400 and \$1,000 per month for their room and food. The Massachusetts Office of Health and Human Services provides financing to hire the nursing and support staff, who are directly employed by Advocates Inc., a third-party supplier.

Program Manager Huntley Skinner said the Douglas House staff tries to help residents learn life skills, build a sense of self-worth, find a job, and possibly gain enough independence to live on their own.

"We are sort of a like the Wizard of Oz who pulls the strings behind the scenes to help the individual," said Skinner.

During a typical weekday, there are five staff members on duty — a shift supervisor, nursing staff, and individuals who specialize in helping patients regain life

skills. They are taught to develop routines, including taking part in day programs in the Lexington community. They are provided with speech, physical and occupational therapies as needed and as funding allows.

Kathy Spenser, a nurse at the Douglas House, said she sees progress in residents, especially those who are able to find work, citing one resident who volunteers twice a week at nearby Cary Memorial Library.

Skinner said the key to recovery is doing things over and over again so residents can develop a sense of routine.

"Repetition, repetition, repetition — [that] is the big thing," she said.

Skinner said she often sees residents improve many years after their injury.

"More physical therapy, more occupational therapy, more speech, more social skill development ... if we continue to stimulate that person as a whole, there is room for more improvement in their lives than some say there is," said Skinner.

New hope for recovery

Current thinking is that recovery in TBI patients is limited to what can be achieved in the first year or two of treatment. But according to Dr. Laura Lorenz of the Heller School for Social Policy and Management at Brandeis University, brain injuries should be looked at outside of the normal medical model.

"As a long-term condition ... you don't expect people to recover [fully], but you can make their life better and help them deal with what they are going through," said Lorenz. "You can certainly help them become productive members of society."

A new idea has become more established in scientific circles: neuroplasticity. The term refers to an idea that neurons that have been lost because of some trauma can, to some extent, be redeveloped if the mind is

properly trained. This offers hope that TBI patients may be able to regain lost functions.

"The fact that plasticity is an accepted fact opens the door to the possibility of long-term rehab for [TBI] survivors," said Lorenz.

Lorenz is a partner in a new project at the Douglas House that will enable researchers to test the effectiveness of various rehabilitation techniques on the recovery of TBI patients.

A \$300,000 construction project is underway to add a Wellness Center in the Douglas House basement. Two research rooms are being constructed — a multimedia room with kitchen, which is expected to be completed by the end of March, and a fitness room scheduled for completion at the end of June.

"This is a pilot effort; we are envisioning developing a model of providing cost-effective community-based rehabilitation services," Lorenz said.

The Douglas House has written grants and hopes to

receive about \$300,000 in funding to begin their first research project, probably sometime in September of this year, according to Noonan.

According to a concept paper, an initial study will be focused on the importance of job training opportunities for brain injury survivors. "The hypothesis is that after 6 to 9 months of participation each [subject] will demonstrate improvement in skills related to memory and executive functions," the paper states. The study is estimated to take about two years.

Noonan said treatments like speech therapy could have multiple benefits for TBI patients — it can improve motor control and memory, and assist with decision-making skills. Criteria to evaluate progress include baseline and periodic measurements of skills, employability, emotional stability and quality of life, according to the paper.

This research is small in scale, Lorenz said, but could produce meaningful results. Lorenz said researchers hope to publish journal articles, make presentations at conferences, and contribute to advocacy for individuals living with a brain injury.

"[We hope to] improve the lives of individuals who participate as well as generate evidence for other programs in Massachusetts ... which then, in their adaptations and their research, builds momentum," said Lorenz.

Building momentum

Lorenz, like many of those who work at the Douglas House, has a personal connection to brain injury care. Her brother suffered multiple concussions as a youth hockey player in the 1960s and '70s — he later committed suicide. Studies have

'If we continue to stimulate that person as a whole, there is room for more improvement in their lives than some say there is.'

Huntley Skinner, Douglas House program manager

shown that depression can often follow a brain injury.

"Because of my brother and his experience and how that affected my family, that really motivates me," she said.

Lorenz said sports leagues, both on the youth and professional levels, have come a long way in their understanding of the impacts of concussions.

"If you got your bell rung, you would get back out there. The players themselves would have felt so negative about sitting out ... they don't want to be letting down their team," she said. "There was no protection or thought about high school athletes."

Lorenz praised the National Football League for changing rules to protect players by punishing dangerous hits to the head.

The issue has been further propelled into the national spotlight following the shooting of Congresswoman Gabrielle Giffords of Arizona, who is facing a lengthy recovery after being shot in the head in January.

Over the next couple years, Lorenz hopes to have more substantial data from the research.

"What's reasonable to accomplish is to have several groups of ... long-term brain injury survivors more than two years after their injury, or even 10-15 years after their injury, go through their program and perhaps have several waves of evidence for these individuals," she said.

Lorenz said the research being done at the Douglas House is a first step in developing interest and

establishing funding for major studies.

"In the future, we would hope to inspire the researchers to do other randomized control type trials. Many insurance companies — due to the medical model — are looking for big randomized control trails," said Lorenz. "We are hoping to convince larger studies to use this model ... and produce evidence that is considered."

Lorenz cautioned that expecting an increase in insurance coverage for long-term care of TBI patients is probably premature at this point.

Deb Caldwell hopes her son Curt can take advantage of any scientific advancement that could help him regain his cognitive abilities.

Deb said Curt has already progressed further than his doctors expected — the ability to communicate with the keyboard device was a major achievement.

"[The therapist] would work with him with the board ... at first, it wasn't understandable," she said. "The more she worked with him, he started to make sense."

Citing her faith, Deb said she is confident Curt will one day speak again.

Whatever happens, Deb wants for Curt what all parents want for their children: to live a meaningful life of their own.

"I just want him to be happy with himself," she said, "to be able to do something where he is making a difference."

Next week: Part 2, long-term care of traumatic brain injury