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 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

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; Traumatic Brain Injury.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 the most small apartment buildings. There is a common room, a kitchen, and a group of 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—shift supervisor, nursing staff, and individuals who specialize in helping patients regain life skills. These therapists 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 Spencer, 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 of the four rooms are being constructed—a multimedia room with a library, 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 Noo-
nan.

According to a concept
paper, an initial study will
be focused on the impor-
tance of job training oppor-
tunities for brain injury
survivors. "The hypothesis
is that after 6 to 9 months
of participation each [sub-
ject] will demonstrate im-
provement 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 im-
prove motor control and
memory, and assist with
decision-making skills. Crite-
rria to evaluate progress
include baseline and periodic
measurements of skills, em-
ployability, emotional sta-
bility and quality of life, ac-
cording to the paper.

This research is small in
scale, Lorenz said, but
could produce meaningful
results. Lorenz said re-
searchers hope to publish
journal articles, make pre-
sentations 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 con-
nection to brain injury care.
Her brother suffered mul-
tiple concussions as a youth
hockey player in the 1960s
and '70s — he later com-
mited suicide. Studies have
shown that depression can
often follow a brain injury.

"Because of my brother
and his experiences 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 them-
selves would have felt so
negative about sitting out ... they don’t want to be let-
ting down their team," she
said. "There was no protec-
tion or thought about high
school athletes."

Lorenz praised the Na-
tional Football League for
changing rules to protect
players by punishing dan-
gerous hits to the head.

The issue has been fur-
ther propelled into the na-
tional spotlight following
the shooting of Congress-
woman 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 indi-
viduals," she said.

Lorenz said the research
being done at the Douglas
House is a first step in de-
veloping interest and
establishing funding for
major studies.

"In the future, we would
hope to inspire the re-
searchers to do other ran-
domized control type trials.
Many insurance companies
due to the medical model
are looking for big ran-
domized control trials," said
Lorenz. "We are hoping to
convince larger studies to
use this model ... and pro-
duce evidence that is con-
sidered."

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

Deb Caldwell hopes her
son Curt can take advan-
tage of any scientific ad-
ancement 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 un-
derstandable," 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 par-
ents want for their chil-
dren: to live a meaningful
life of their own.

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