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Looking for coverage

Brain injury survivors struggle to find long-term care

Editor's note This is Part 2 of a two-part series on brain injury.

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At the age of 19, after completing his first semester of college, David Campagna developed a brain tumor. While the tumor did not take his life, it caused a brain injury impacting his short-term memory and his ability to eat.

Doctors recommended David, no longer able to live on his own, be placed in a state hospital for individuals with emotional difficulties. Not wanting to see her son in such a facility, David's mother, America Campagna, brought him home, where she cared for him for about 27 years.

But America is now almost 86 and she realized more help was needed to take care of David.

"About five years ago, we reached a stage that my husband was beginning with Alzheimer's [and] that left pretty much everything on my shoulders," said America, a Needham resident.

The family began looking into long-term residential care for David but grew discouraged by the lack of options, according to David's sister, Kathy Walsh. Some care facilities would have cost as much as \$9,000 per month.

"It was next to hopeless ... because of the availability of services," said Walsh, a nurse at Beth Israel Deaconess Hospital-Needham.

Eventually, the family found what they were looking: Support Living Inc., a nonprofit organization operating three residential facilities for brain injury survivors. After five years on a waiting list, David moved into a room at the Douglas House in Lexington on March 17, 2010.

At the Douglas House, David said he feels more independent — he has his own space and can interact with others. Staff provides some rehabilitation services and a new Wellness Center is being built downstairs to test various rehabilitation processes to gauge their effectiveness.

David's struggle to secure appropriate care is common for people living with the effects of a brain injury. Gaps in insurance coverage and state programs, as well as a lack of awareness of available services, can make it difficult to arrange care.

Insurance coverage

According to Carl L. Traina, president of Tonry Northwest Insurance

Agency in Lexington, there are typically three types of insurance for those with a brain injury: traditional health care, accident insurance, and long-term care (LTC) insurance.

If someone suffers a brain injury, LTC insurance would be the most beneficial policy to hold, according to Traina.

"[LTC] takes an individual and says at some place in your life, you may be in a hospital or nursing home," said Traina.

In Massachusetts, this type of insurance will usually pay between \$200 and \$400 per day for necessary care.

Traina said there are often one- or two-year limits on LTC policies, and while some can last a lifetime, they are more expensive. According to mass.gov, "Although prices vary, it is not unusual for a long-term care insurance policy to cost several thousand dollars per year."

According to Traina, most people who buy LTC policies are over 50. But those most at risk of suffering a long-term brain injury are between the ages of 15 and 34, according to the Massachusetts Emergency Department Discharge Database. These people almost never have long-term insurance, and once they need it, it is often too late.

For those with traditional health insurance plans, long-term rehabilitation is generally not covered, according to Peter Noonan, executive director of SLI, which operates the Douglas House.

"The policy might say 90 days worth of outpatient therapy for whatever type of injury it is," Noonan said. "Our argument is that in brain injury, that is not enough time."

As for accident insurance, this usually involves a one-time payout, often \$50,000, or one to two times the individual's annual salary, according to Traina.

"There is a gap," said Traina. "It can be very serious. Generally what happens is the facility that gives out the health care will look for other sources of funds. Does the family have it?"



Denis Hogle, who is living with a long-term disability as a result of a brain hemorrhage at age 36, moves down the pharmacy aisle at CVS in Lexington Center. STAFF PHOTO BY MATTHEW MODOONO

By the numbers

1.7 million people who sustain a traumatic brain injury (TBI) in the United States each year
3.15 million people living with long-term TBI-related disability in the U.S. in 2005
\$60 billion in estimated costs of TBI care in the U.S. each year
52,000 people die from TBI in the U.S. each year

SOURCE: BRAIN INJURY ASSOCIATION OF MASSACHUSETTS; JOURNAL OF HEAD TRAUMA REHABILITATION

EXCLUSIVE to this print edition.

"They either come up with funds [or] the facility gets some support from the state, or they don't get the service," he said.

Searching for care

State Sen. Harriette Chandler, D-Worcester, Senate vice-chairman of the Joint Committee on Public Health, said a resident called her seeking help for her son who needed long-term care after sustaining a brain injury.

"My constituent was housed in Lowell, services were in Newton. [They] had to go back and forth each day. That is ridiculous," said Chandler.

"She was thinking of quitting her job and taking care of him full time," said Chandler. "The mother would go on welfare ... now [we] have two adults the state would have to take care of. That is no solution to the problem."

Home care is often a less-than-ideal option for the patient and the caregiver. America Campagna never talks about caring for her son David as a burden, but the task does take time, energy and patience.

Nursing homes are another option, but are not always a good fit for brain-injury survivors, who are often much younger than typical nursing home residents.

"[They are] not the right age for it. They are going to stand out," Chandler said. "Some have behavioral problems that causes them to behave erratically, which may jeopardize people in a nursing home."

Nursing homes may also lack the

specialized care needed to administer long-term rehabilitation.

Other options

Massachusetts Health and Human Services does provide some long-term care for people with disabilities, but these services are geared primarily towards seniors and children. Information on the HHS website does cite some programs targeted towards those with a long-term brain injury. The caveat: "These services are available on a very limited basis due to funding."

Services include Community-Based Supports for Living, which provide assistance for individuals attempting to live independently at home. According to Noonan, the goal for many brain injury survivors is to equip them with the skills to allow them to live independently.

State services for those who would like to enter a residential facility like the Douglas House are also limited due to funding. HHS funds rehabilitation services for 13 of the 15 residents of the Douglas House.

According to Arlene Korab, executive director of the Brain Injury Association of Massachusetts, "If money isn't there, vendors won't come forward."

"It's a business," said Korab. "The big thing is we don't have the services either here or anywhere, and the services come with dollars. Right now, whenever the state is trying to cut the budget, the first place they look is human services and they are the most vulnerable populations."

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According to a 2007 study by the Massachusetts Traumatic Brain Injury Prevention Task Force, only 1,000 of 4,000 Massachusetts residents who are eligible for care through Massachusetts Statewide Head Injury Program are covered for these services "and many of these individuals are not receiving all of the services that they need." There are many more residents who need services but do not meet eligibility requirements.

The Brain Injury Association tries to help those who need assistance navigating the options for brain injury care. According to Korab, the advice her association provides depends on the needs of the individual.

"They call here for all kinds of things. Some people just call because they are looking for a support group to share problems and learn ... some are looking for job counseling," Korab said. "Sometimes the answer is there is nothing."

Closing the gap

In 2008, the case of Hutchison v. Patrick provided a victory for survivors of a long-term brain injury. According to the Brain Injury Association, which was involved in the lawsuit, a "landmark settlement was reached that will allow nearly 2,000 individuals with brain injuries" to move out of nursing facilities and other institutions.

The federal government will foot half of the bill for those approved to receive services; part of the agreement is it be cost neutral for the state.

"The agreement also requires the Commonwealth to create a new system of community services for persons with brain injuries, including new policies and procedures, a new treatment planning process, a new appeal process for individuals and families, and new quality standards for community services," according to the association's website.

The program is being implemented slowly. According to Pam Bush, director of communications at the association. "Thus far 51 people have been approved; eight have actually moved."

The state Legislature is also beginning to study ways to improve services for survivors. Recognizing there are significant gaps in care in Massachusetts, Chandler has established the Acquired Brain Injury and Traumatic Brain Injury Commission.

"If you are independently wealthy, you can have the best services," said Chandler. If not, "there are real limitations placed on you."

This commission will assess the availability, nature and adequacy of services, and hopes to file a report around September addressing gaps in care and funding.

According to HHS, about 97 percent of state residents have some kind of health insurance. Chandler said the state's high coverage rate is in sharp contrast to what it provides for residents living with the effects of a TBI.

"We think about ... in Massachusetts being first in health care and everything. We clearly find we are not first; we are not doing an adequate job at all," Chandler said. "We are missing people. We are missing a lot of people."



America Campagna of Needham, left, speaks with daughter Kathy Walsh and her husband Mark. Campagna, 85, cared for her son David at home for 27 years before he recently moved to the Douglas House in Lexington. STAFF PHOTOS BY MICHAEL PHILLIS



David Campagna, who suffered a brain injury as a result of a tumor at age 19, stands in his room at the Douglas House in Lexington, a residence for adult survivors of brain injury.

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Services provided by MassHealth

MassHealth has two home and community-based service waivers for individuals with acquired brain injuries, which have been operating for less than a year and currently serve 59 individuals:

■ 35 people were deemed eligible for a waiver to transition from a hospital or nursing home into a residential care facility.

■ 24 people were deemed eligible for a waiver to transition from a hospital or nursing home into their own personal environment.

MassHealth currently serves 100 people with traumatic brain injury through another waiver:

■ 63 people receive residential habilitation within a group home environment.

■ 37 people receive other types of care such as home- or community-based services, not including residential habilitation.

SOURCE: PAULETTE SONG, DEPUTY COMMUNICATIONS DIRECTOR FOR THE EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES