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For War's Gravely Injured, Challenge to Find Care

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When Staff Sgt. Jarod Behee was asked to select a paint color for the customized wheelchair that was going to be his future, his young wife seethed. The government, Marissa Behee believed, was giving up on her husband just five months after he took a sniper's bullet to the head during his second tour of duty in Iraq.

Ms. Behee, a sunny Californian who was just completing a degree in interior design, possessed a keen faith in her husband's potential to be rehabilitated from a severe brain injury. She refused to accept what she perceived to be the more limited expectations of the Veterans Affairs hospital in Palo Alto, Calif.

"The hospital continually told me that Jarod was not making adequate progress and that the next step was a nursing home," Ms. Behee said. "I just felt that it was unfair for them to throw in the towel on him. I said, 'We're out of here.' "

Because Ms. Behee had successfully resisted the Army's efforts to retire her husband into the V.A. health care system, his military insurance policy, it turned out, covered private care. So she moved him to a community rehabilitation center, Casa Colina, near her parents' home in Southern California in late 2005.

Three months later, Sergeant Behee was walking unassisted and abandoned his government-provided wheelchair. Now 28, he works as a volunteer in the center's outpatient gym, wiping down equipment and handing out towels. It is not the police job that he aspired to; his cognitive impairments are serious. But it is not a nursing home, either.

Like the spouses of many other soldiers with severe brain injury, Ms. Behee, also 28, transformed herself into a kind of warrior wife to get her husband the care she thought he deserved. By now, there is a veritable battery of brain-injured-soldiers' relatives who have quit their jobs and, for some extended time, moved away from their homes to advocate for and care for these very wounded soldiers during long hospitalizations.

In the eyes of five such relatives interviewed, the military health care system, which is so advanced in its treatment of lost limbs, has been scrambling to deal with an unanticipated volume of traumatic brain-injury cases that it was ill equipped to handle. Largely because of the improvised explosive devices used by insurgents in Iraq, traumatic brain injury has become a signature wound of this war, with 1,882 cases treated to date, according to the Defense and

Veterans Brain Injury Center.

In general, these caregivers said that their grievously wounded soldiers had either been written off prematurely or not given aggressive rehabilitation or options for care. From the beginning, they said, the government should have joined forces with civilian rehabilitation centers instead of trying to ramp up its limited brain-injury treatment program alone during a time of war. That way, soldiers would have had access to top-quality care at civilian institutions that were already operating at full throttle and might be closer to home.

In fact, many soldiers do have that access. But unlike Ms. Behee, many caregivers only belatedly come to understand how to negotiate the daunting military health care system.

Generally, after severely brain-injured soldiers are medically evacuated to the United States, they are treated first at Walter Reed Army Hospital or Bethesda Naval Hospital. Relatively quickly, the military, depending on the branch, initiates a medical retirement process that turns the soldiers' health care over to the V.A. If soldiers succeed in deferring retirement, they remain covered by a military insurance policy that, if pressed, pays for private care.

Still, the military hospitals tend to discharge seriously brain-injured soldiers to V.A. hospitals, regardless of their active or retired status. It is how the system works, and challenging it requires constant haggling, which often leaves the families of the severely wounded soldiers feeling abused, resentful and anxious for those soldiers without an advocate.

"We have been let down by a system that is so bungling and bureaucratic that it doesn't know what it can and cannot do and just says 'No' as a matter of course," said Debra Schulz of Friendswood, Tex., whose son, Lance Cpl. Steven Schulz of the Marines, 22, suffered a severe brain injury during his second tour in Iraq.

Offers of Help

Early on, at least two top-ranked nonprofit civilian centers, the Rehabilitation Institute of Chicago and the Kessler Institute for Rehabilitation in New Jersey, made overtures to the government. Since the Vietnam War, their leaders said, while the V.A. has focused primarily on the chronic care of aging veterans, the civilian acute rehabilitation system has been dealing daily with brain-injured patients, fine-tuning their care.

Dr. Bruce M. Gans, chief medical officer of the Kessler Institute, contacted senior military and V.A. physicians. "I said, 'Please let us help. Please let us be used as a resource,' " Dr. Gans said. "Especially in the early days, they had no capacity to take care of these kids. There was either no response or a negative response. We just didn't understand."

Last week, Dr. Joanne C. Smith, chief executive officer of the Rehabilitation Institute of Chicago, met in Washington with senior Pentagon officials and found far keener receptivity to the idea of extending civilian sector treatment to more soldiers, she said. After revelations by The

Washington Post of problems with outpatient care at Walter Reed and Bob Woodruff's reporting on ABC about traumatic brain injury, the tenor of the conversations was "action-oriented," Dr. Smith said.

"There was a high degree of acceptance that there is a gap in the military system's current ability to take care of particularly the profoundly injured," she said.

V.A. officials, however, do not believe there is a problem or any need for rescue by the private sector.

The V.A. has centralized the care for severe traumatic brain injury at four hospitals that specialized in brain injury before the war. Those four, converted into "polytrauma centers" by Congress in 2005, have been gradually beefed up and the level of care has improved since Sergeant Behee arrived at Palo Alto in the summer of 2005, advocates for veterans say. But they still have a total of only 48 beds.

Some 425 soldiers have been treated for moderate and severe traumatic brain injury at the polytrauma centers in the past four years, according to the Defense and Veterans Brain Injury Center.

"At the moment we are handling the numbers," said Dr. Barbara Sigford, the V.A.'s national director for physical medicine and rehabilitation. "The trauma centers are running close to capacity, but there are always beds available."

Harriet Zeiner, the lead clinical neuropsychologist at the V.A.'s polytrauma center in Palo Alto, said care at the polytrauma centers was "tremendous." She and Dr. Sigford said the great majority of soldiers and their families had been satisfied. A few disgruntled families, they said, grew frustrated with the slow recovery process and directed their anger at the V.A.; many went "through the system early on while we were still building the blocks," Dr. Sigford said.

Susan H. Connors, president of the Brain Injury Association of America, said she was more concerned about follow-up care once soldiers returned to their communities, a concern of all advocates for these soldiers. The polytrauma centers, Ms. Connors said, are "pretty good."

Dr. Sigford of the V.A. said, "We really are able to take care of a high-acuity group."

But Dr. Smith of the Rehabilitation Institute of Chicago disagreed in the strongest terms.

"The V.A. has not been doing this for the last 35 years, and there is no way, with the complexity of this injury, that the V.A. system is prepared to get to parity with the civilian acute rehabilitation system overnight," she said. "They're dabbling in brain injury, and you can't dabble in brain injury."

A Growing Group

The severely brain-injured are among the most catastrophically wounded soldiers, and recovery can be painfully slow or, in some cases, entirely elusive. “There is no prosthetic for the brain,” said Jeremy Chwat, vice president for program services at the Wounded Warrior Project, an advocacy organization.

The Wounded Warrior Project organized a meeting on traumatic brain injury in Washington attended by about three dozen caregivers last fall. One raised “a huge, sad ethical question,” Mr. Chwat said, related to the advances in military trauma care that have saved so many lives: “Are we doing these young men and women a service by bringing them home alive?”

Mr. Chwat said the severely brain-injured soldiers were a relatively small, but growing, subset of the wounded whose needs were particularly acute. “Their families need to know that they have options,” he said. “Our message to the V.A. is that the V.A. is still providing them care if they’re paying for a private facility. But that’s a cultural shift for the V.A., and, while their ears are now open, bureaucracies don’t change on a dime.”

That is a lesson Edgar Edmundson, 52, of New Bern, N. C., has been learning and relearning since his son, Sgt. Eric Edmundson, sustained serious blast injuries in northern Iraq in the fall of 2005.

Mr. Edmundson was aggressive, abandoning his job and home to care for his son, calling on his representatives in Washington for help, “saying no a lot.” But even he did not come to understand his son’s health care options quickly enough to ensure that his son was not “shortchanged” in the critical first year after his injury.

Two days before Sergeant Edmundson was wounded near the Syrian border, he visited with his father on the telephone. Mr. Edmundson urged his son, then 25 with a young wife and a baby daughter, to “stay safe.”

In an interview last week, Mr. Edmundson’s voice cracked as he recalled his son’s response: “He said, ‘Don’t worry, because if anything happens, the Army will take care of me.’ ”

While awaiting transport to Germany after initial surgery, Sergeant Edmundson suffered a heart attack. As doctors worked to revive him, he lost oxygen to his brain for half an hour, with devastating consequences.

A couple of weeks later, at Walter Reed in Washington, on the very day that Sergeant Edmundson was stabilized medically and transferred into the brain injury unit, military officials initiated the process of retiring him.

“That threw up the red flag for me,” Mr. Edmundson said. “If the Army was supposed to take care of him, why were they trying to discharge him from service the minute he gets out of intensive care?”

Mr. Edmundson fought the retirement on principle, winning a temporary reprieve. Still, he did

not understand that his son's military insurance policy covered private care. When Walter Reed transferred Sergeant Edmundson to the polytrauma center in Richmond, Mr. Edmundson believed that he was, more or less, following orders.

Mr. Edmundson was disappointed by what he considered an unfocused, inconsistent rehabilitation regimen at what he saw as an understaffed, overburdened V.A. hospital filled with geriatric patients. His son's morale plummeted and he refused to participate in therapy. "Eric gave up his will," he said. In March 2006, the V.A. hospital sought to transfer Sergeant Edmundson to a nursing home.

Mr. Edmundson chose instead to care for his son himself, quitting his job at a ConAgra plant. For almost eight months, Sergeant Edmundson, who was awake but unable to walk, talk or control his body, received nothing but a few hours of maintenance therapy weekly at a local hospital.

One day, by chance, Mr. Edmundson encountered a military case manager who asked him why his son was not at a civilian rehabilitation hospital. That is when Mr. Edmundson learned that his son had options. He did some research and set his sights on the Rehabilitation Institute of Chicago.

Sergeant Edmundson is now the only Iraq combat veteran being treated there.

The first step in his treatment in Chicago, Dr. Smith said, was to use drugs, technology and devices "to reverse the ill effects of not getting adequate care earlier, somewhere between Walter Reed and here."

For example, she said, Sergeant Edmundson's hips, knees and ankles are frozen "in the position of someone sitting in a hallway in a chair." They are working to straighten out his joints so that he can eventually stand, she said. They have taught him to express his basic needs using a communication board, and they hope to loosen his vocal cords so he can start speaking. He is also learning to chew and swallow.

"He has a profound cognitive disability," Dr. Smith said. "But he can communicate, albeit not verbally, and can express emotions, including humor and even sarcasm."

A couple of weeks ago, she said, when his family came to visit him, Dr. Smith asked Sergeant Edmundson if he was happy to see his daughter. He used his board to say yes. She asked him the same about his mother. He said yes. And then she asked him about his older sister, Anna Frese. He said no. She repeated the question twice more, wondering if he was pushing the wrong button, until, Dr. Smith said, "he looked up at me with a huge, wicked smile."

Searching for Options

In early 2006, Denise Mettie of Selah, Wash., signed away her son Evan's health care options without realizing it. She agreed to a medical retirement for her 23-year-old son only weeks after

he was initially declared “killed in action” only to be saved. That left him dependent on the veterans’ health care system, where, after a tumultuous journey through several hospitals, he now faces transfer from the “coma stimulation” program at Palo Alto to a nursing home.

“At the very beginning, there was a V.A. doctor who said, ‘You know, he’s not going to come any further, let’s put him in a nursing facility and let you get on with life,’ ” Ms. Mettie said. “I was not ready to give up on him then and I’m not now. If there is a private rehab that will take him, I’m going to get him there and finagle the finances by hook or by crook.”

Mr. Chwat of the Wounded Warrior Project said severely brain-injured soldiers should be offered a one-year moratorium on medical retirement so they can remain on active duty status with the insurance-covered privileges to seek private care if they want it. Dr. Smith and other civilian rehabilitation doctors suggest that the V.A., too, give the option of private care to soldiers who have been discharged or retired.

On the other hand, Dr. Alan H. Weintraub, medical director of the brain injury program at the private Craig Hospital in Denver, said wounded soldiers were probably better off in the military health care system, which he said offered open-ended care tailored to combat soldiers. Dr. Weintraub, a retired major in the Army Medical Corps, said private acute care was too expensive for the “funding stream” to cover.

Dr. Smith disagreed: “Are we accepting that these people are not going to amount to something anyway, so they’re not entitled to the best acute care that the United States has to give — at the front end of their potential life?”

Looking Ahead

“Jarod Behee was headed for a nursing home,” said Felice L. Loverso, the chief executive of Casa Colina in Pomona, Calif.

When Sergeant Behee arrived from the V.A. in Palo Alto, he was in severe condition, essentially nonresponsive, said Dr. Loverso, a speech pathologist. Casa Colina, which now has two other soldier patients and also provides their families housing, first worked to “wake him up,” weaning him from medications he no longer needed. He quickly started getting therapy bedside, making relatively steady progress and then quite rapid progress after a cranioplasty that repaired his skull.

“Potentially the same good things could have happened to Jarod at the Palo Alto V.A.,” said Dr. Loverso, a former V.A. employee himself. “I like to think it was due to our aggressive therapy.”

Because of his impairment, Ms. Behee said, her husband, who still has his old Superman tattoo on his calf, does not agonize over his situation. “He wakes up every morning with a smile on his face,” she said.

Lance Cpl. Steven Schulz, on the other hand, is just cognitively rehabilitated enough to experience anguish, his mother, Debra Schulz, said. Occasionally, Lance Corporal Schulz gets angry at his situation or feels guilty toward his mother, who describes herself as an “Old South yellow dog Democrat” who was not pleased when her son enlisted.

“He has told me that he needed to apologize to me for ever joining the Marines,” Ms. Schulz said. “I say, ‘Son, we can’t look back.’ ”