

MEGHAN SULLIVAN '08: ADVOCATING FOR HUNTINGTON'S

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Meghan Sullivan '08 and social worker Eric St. Onge at the Lowell Health Care Center.
(PHOTO BY JODIE ANDRUSKEVICH)

At age 19, Meghan Sullivan started noticing changes in her balance and caught herself twitching slightly. Though the symptoms were subtle, she and her family knew they probably signaled Huntington's disease. When Meghan was two and a half years old, her father was diagnosed with Huntington's, a progressive neurological disease with no known cure and a 50% chance of passing on to the next generation. Over the next 17 years, the disease changed John Sullivan's life—and his family's.

By the time Meghan was diagnosed, her father required constant care; he was hospitalized and could no longer communicate. Meghan knew Huntington's meant physical, emotional and mental deterioration. And she was angry about it. "I didn't know what my future would hold," she says. Diagnosed with just six weeks left in the semester, Meghan dropped out of school. Then she

remembered one of the things her father had said years earlier. “If you ever get this,” he told his daughters, “don’t lie down and die. Keep going as long as you can.”

Meghan talked to her academic advisor and discovered that if she changed her major, she could earn an associate degree with just four more courses. Student Development staff were willing to allow Meghan to stay in campus housing even though she could no longer study full-time. Within a week, she was back in school. “Riv was really supportive—we’re both so happy she chose here,” says Meghan’s mother, Cheryl.

Meghan also began advocating for Huntington’s research. “Advocacy helps me feel better,” she says. In fall 2007, she spoke at a dinner for doctors and Huntington’s researchers from around the world. She’s also spoken at the Massachusetts state house to support legislation helping the disabled and was the subject of a brief documentary for researchers at pharmaceutical company Novartis.

In May 2008, Meghan earned her associate in liberal arts. Since then, she has audited a course at Rivier each semester, and she and her mother have spoken in classes at various colleges, including Plymouth State, Franklin Pierce, Boston College, and Endicott. Meghan’s mother says people didn’t always understand why Meghan couldn’t work or take a full course load. “For a young person to think that Meghan’s 23 and could be in a wheel chair by 25—they have to deal with thoughts they don’t usually face until they’re much older,” she says.

Meghan’s father died in September 2008 without ever learning that he had passed Huntington’s on to his daughter. “My dad was in Tewksbury Hospital for eight years,” Meghan says. While many people in her shoes might choose to avoid similar settings, Meghan volunteers at the Lowell Health Care Center, a nursing home. “They have a whole unit of Huntington’s residents there, which is rare,” she says.

Meghan shadows the social worker at the health care center and provides companionship for the residents. “People think it would be sad for me, but it isn’t,” she says. She enjoys visiting with residents. She plays board games with them, brushes and braids hair, listens to them and holds hands to offer comfort and support.

Though Meghan doesn’t know what her future holds or how long she can continue her volunteer work, she’s driven to make a difference for as long as she possibly can. ■

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