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Charlton rallies around family hit by ALS

By Debbie LaPlaca

CHARLTON - Bonnie A. and Larry E. Gilligan once enjoyed the life of a typical suburban family - running to Little League games and volunteering at their children's schools. Today, the husband and wife of 11 years and their children, Daniel, 10, and Michael, 8, face the struggles of managing a debilitating disease and find comfort in the benevolence of a community.

Mrs. Gilligan, an Oxford Middle School teacher, and Mr. Gilligan, an assistant principal for four years at Gibbons Middle School in Westboro, bought their home in Charlton in 2002. The couple described life as busy yet rewarding before November 2004, when it changed dramatically. Mr. Gilligan was diagnosed with amyotrophic lateral sclerosis, known as ALS, and often called Lou Gehrig's disease after the famous New York Yankees player who died from it in 1941 at the age of 38.

Suddenly, the educators were forced to learn about the progressive and fatal neurological disease that attacks the nerve cells responsible for controlling voluntary muscles.

"From the time of diagnosis, the life expectancy of an ALS patient averages two to five years," Mrs. Gilligan said during a recent interview in the family's home.

ALS patients experience muscle weakness and atrophy throughout the body. As the disease progresses, the ability to control voluntary movement is lost. When it reaches muscles in the chest, patients lose their ability to breathe without support.

In August 2005, 10 months after diagnosis, Mr. Gilligan stopped working and now spends days at home with support from visiting personal aides.

According to the national ALS Association, the financial burden for patients in advanced stages of the disease can average $200,000 per year. It is a burden that the Gilligans' health insurance is not covering.

"He has a chronic disease, not an acute disease, so they cut us off," Mrs. Gilligan said.

Deb M. Whittredge, a friend and Charlton mother whose son plays sports with one of the Gilligan children, organized efforts to help. She and about a dozen people formed the Friends of the Gilligan Family committee.

"We've watched him slowly decline, losing mobility and sight," she said during a recent telephone interview.

"We decided to try to raise money for the medical equipment and things they are going to need for Larry," Ms. Whittredge said.

The committee's first fundraising event is a dinner set for March 24 at The Mill, 18 Mill St., Southbridge.

"When I was in education, I always taught that community is the foundation of education, and now it's coming true for me. The community is helping me," Mr. Gilligan, 38, said from a chair in the couple's living room.

Friends, committee members and staff of the Charlton school that the Gilligan children attend are working to help the family with immediate needs - a wheelchair that costs about $29,000 and a specially equipped van costing about $42,000.

"I'm speechless. I can't say enough," Mr. Gilligan said of their efforts.

In addition to the local support, the family is receiving assistance from Compassionate Care ALS of West Falmouth, a nonprofit organization dedicated to helping families hit by the disease.

"They are totally there to help patients and families," Mrs. Gilligan said.

Ronald G. Hoffman, founder and executive director of Compassionate Care, said the Gilligans spend nearly $200 a week on vitamins and prescriptions.

In a letter on the family's behalf, Mr. Hoffman said the Gilligans are in dire need of a wheelchair-accessible van and home-care assistance, which costs $12 to $15 an hour and must be paid out-of-pocket.

The Gilligans recently financed an addition to their home for a ground-level bedroom and bathroom. Compassionate Care is providing an $11,000 chairlift that allows Mr. Gilligan to move from the first-floor addition to the garage.

"The big thing is the gratitude that we have toward all these people," Mrs. Gilligan said.

"It's very humbling," Mr. Gilligan added.

According to the Massachusetts chapter of the ALS Association, the disease is not contagious and there is no cure. It strikes people between the ages of 40 and 70 and, in most cases, mental faculties are not diminished.

More than 5,000 Americans are diagnosed with ALS each year. About 30,000 people in this country have the disease at any given time. A gene mutation is the cause in 1 percent to 2 percent of the cases, and heredity accounts for 5 percent to 10 percent.

The cause for the rest of cases is unknown; it can strike anyone.

The March 24 dinner to benefit the Gilligans will begin at 6 p.m. with a cash bar, followed by a buffet dinner at 7 p.m. A disc jockey will provide music for the evening, which will include silent and live auctions.

To contribute to the Gilligan Family Fund, contact Compassionate Care at (508) 563-3677 or visit www.compassionatecareals.org. To join the Friends of the Gilligan Family committee or buy dinner tickets at $40 each, call Ms. Whittredge at (774) 230-3845.

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PHOTOG: T&G Staff/JIM COLLINS

CUTLINE: Bonnie A. and Larry E. Gilligan had a busy yet rewarding life, with their sons, Michael, 8, left, and Daniel, 10, center, but it changed dramatically when Mr. Gilligan was diagnosed with ALS.