Madeline Kennedy is a very busy woman. The 60-year-old Troy native (the former Madeline Ruether), is a volunteer, a golfer, a traveler, a bridge player and a mother of four. The title on her LinkedIn profile is Research Ambassador, a role that includes lobbying, personal counseling and community outreach. The word friends use to describe her is “remarkable.”

This is because Kennedy is also one of a group of people known as PALS - People with ALS. She was diagnosed with amyotrophic lateral sclerosis in May 2012, on her 36th anniversary with husband Brian, her high school sweetheart and now a Troy dentist.

“I have been on the straight and narrow my whole life,” she said. “I am a rule follower and did everything right. It feels like I was struck by lightning and I wasn’t even out in the rain.”

ALS, also known as Lou Gehrig’s disease, is a neurodegenerative illness with no known cause, no cure and no effective treatment.

“It’s an awful disease that robs people of their whole body and all of their dignity,” Kennedy said.

Her symptoms began, in early 2012, as a weakening of her leg muscles. She suspected the problem was neurological, but it would be months of testing, including six MRIs, three electromyograms and some spinal taps before she knew the truth. There is no test for ALS, simply the elimination of other conditions.

“And so it is not exactly a surprise when they finally say you have ALS,” she said. “But it is the worst news you can get. It is a death sentence.”

The average patient lives 3-to-5 years.

ALS is a relatively rare disease, striking 2 out of every 100,000 people. At any time, some 30,000 Americans may call themselves PALS.

About 5,600 people are diagnosed each year and as many die, according to the National Institutes of Health.

There is no precise count on the number of PALS in the Capital Region, but St. Peter’s ALS Regional Center in Albany, which serves 17 counties, sees about 150 patients a year, said Director Karen Spinelli.

“I can’t do nothing.”

Prior to her diagnosis, Kennedy was a psychiatric nurse at Four Winds in Saratoga Springs and a clinical instructor at Russell Sage College in Troy. After spending years as a caregiver and teacher, she found it “very, very hard” to change roles and accept help from others.

She has refused to take her illness, and its fatal prognosis, lying down.

“I can’t do nothing,” she said. “I just can’t. So I do what I can to try to have some control over an uncontrollable situation.”

One of the things that struck Kennedy when she began researching ALS was how little had changed since former Yankee great Lou Gehrig battled the disease nearly 75 years ago.

“I may have had a tough break, but I have an awful lot to live for.” - Lou Gehrig’s farewell speech on July 4, 1939

An awful lot to live for

One woman’s determination to fight ALS

By Barbara Pinckney
Photos by Dino Petricelli

“An awful lot to live for” - Lou Gehrig’s farewell speech on July 4, 1939

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ago. She believes one reason for this is the lack of advocates to keep ALS in the public mind. ALS attacks quickly, often impacting the person’s ability to speak and write. As it progresses, its victims become increasingly homebound. Many choose to remain private. Not Kennedy.

“People say ‘Oh you are so brave, you tell everybody,’” she said. “I don’t want this to be a secret. This is a disease, and we won’t progress unless we put a name to it and people understand.”

Kennedy is also more fortunate than many. The disease so far has been concentrated in her legs, giving her full use of her mouth and hands. She wears orthotic braces to keep from tripping over her own toes, and can not stand long enough to brush her teeth. But she can get around with the help of a walker or scooter, and she can drive a car.

Therefore, Kennedy has put her nursing and teaching skills to work as an advocate for the ALS community. The title Research Ambassador was bestowed upon her last October, after she underwent training during a conference sponsored by the Boston-based Northeast ALS Consortium.

She is part counselor, helping other PALS deal with the emotional and psychological aspects of the disease, educating them on dealing with the emotional and psychological aspects of the disease, educating them on the disease and encouraging them to take part in the registry and clinical trials.

Finally, Kennedy is part public relations person. She has made speeches, all of which are posted on YouTube, to raise awareness of ALS. When the regional center held a fundraising walk and fashion show, with about 1,200 participants, she took it upon herself to contact the local media. And when none of them showed up, she formed a committee to organize communication efforts.

“As is pretty remarkable,” Spinelli said. “She is a trailblazer and ALS needs that. She can speak where so many others can not, so she is the voice of many.”

Kennedy’s “get-it-done” attitude is evident in everything she does. For example, when she learned a Canadian group was handing out blue cornflowers, the international symbol of hope for ALS patients, she called a friend in Canada and demanded information about them, which she had written. These were given out at the fashion show. When more cornflowers were needed, Kennedy called the Canadian organization’s supplier. She was told it was a once a year purchase from a Chinese company that accepted minimum orders of 14,400 flowers for $5,000. Not to be dissuaded, she went straight to the man who does the purchasing for all of Canada, and he agreed to give her what she needed.

She is now trying to get the ALS Association in Washington D.C. to promote the wearing of blue cornflowers, hoping they will become as recognizable as the pink ribbons that represent breast cancer.

“I am not a do-nothing person,” she said.

Busy, busy, busy

This is just as true of her personal life.

“I am trying hard not to dwell on my future,” she said. “It’s not like you can ignore it, but I am very fortunate that I am only this far along. So I do what I can. I am busy all the time. Busy, busy, busy.”

Before she became ill, Kennedy was an avid golfer and tennis player. As her legs weakened, she took up bridge as a replacement for those games. Then, unexpectedly, golf came back into her life.

“At a charity event last summer, she met a disabled man who used a special cart to golf. He let her try it, and she was able to play five times over the summer. She hoped to continue while staying at her winter home in Florida.”

“I thought, if I can golf for one season, wouldn’t that be fun?” she said. “So again, not being a do-nothing person, I pursued it. I made some phone calls and somebody called somebody who called somebody else and in the end a man called the company that makes the carts and they were very moved. They didn’t talk to me, they didn’t meet me, they don’t even know if I’m real. But they said they would loan me one for as long as I need it.”

The cart was delivered to her Florida home in early December. All the manufacturer, Centennial, Colorado-based SolidRider, asked is that she send some pictures.

Traveling is another of Kennedy’s passions. When she was diagnosed, she and husband Brian had a trip to Paris planned. Since walking was already becoming difficult, she thought being a tourist was out of the question. Then a friend searched the Internet and found a scooter that weighs just 35 pounds, as compared to the usual 250. The Kennedys made their trip. A year later Madeline returned to France, this time on a pilgrimage to Lourdes.

She can travel locally by car, as long as there is someone to help her out of the car when she reaches her destination. On those rare occasions when she has not arranged for someone to meet her, she relies on the kindness of strangers.

“Sometimes if I really want to go somewhere, I’ll park and wait for someone to walk by and ask them to take my stuff out of the back and help me out of the car,” she said. “A total stranger. Isn’t that awful!”

One thing she has learned through her illness is just how kind people can be. But she would still rather give than receive. She has continued as a volunteer in the military courtesy room at the Albany International Airport, which provides members of the armed services with a place to rest between flights. Her son Jeffrey is in the Army and has been deployed three times.

“Enjoy doing that,” she said. “My friend told me that when I can no longer drive, she will come pick me up, because she doesn’t want me using that as an excuse to stop coming.”

Kennedy may be one of the area’s most visible and active PALS, but she wants to make it clear that she is just one of many. “I am not special,” she said.

2014 ALS Fundraising Awareness Events

April 26
WNYT and Taft Furniture - Collection Recycling Program Electronic and Air Conditioner Collection Drive 7am-1pm
Taft, 1860 Central Avenue, Albany.
Donations accepted and $15 fee for air conditioners.
www.wnyt.com for details.

April 27
5 Cherry Blossom Race and Walk for ALS – Niskayuna
Sponsored by Congregation Gates of Heaven Brotherhood
Walk 9am/ Run 10am (Sunday)
www.5kraceforals.com

June 7
13th Annual Paul Mullett Sr. Golf Classic Benefiting the St. Peter’s ALS equipment loan closet
Hinsdale, Massachusetts
8am Shotgun (Saturday)
Contact: Paul Mullett Jr. 413.445.6893

June 25
24th Annual ALS Memorial Golf Tournament Honoring John C. Daly and James W. Michaels
Van Patten’s Golf Course, Clifton Park
Contact: Scott Daly 377.2236 or Steve Michaels 857.1934

August 5
18th Annual ALS Pro-Am Invitational
The Country Club at Troy - Honoring Mohawk Golf Club
Contact: Paul Hickey 542.4014 or Kp Kirby 852.9749

October 25
13th Annual Walk to Strike Out ALS
Saratoga State Park - Orenda Pavilion
Parking at SPAC
Registration at 10am/Walk 11am
Contact: ALS Center at 525.1629

TBD
Fall into Fashion for ALS
The Country Club at Troy - Honoring Madeline Kennedy
Contact: Victoria Niles at 220.9090