

Another ALS story: 'You really don't appreciate something unless you lose it'

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They say you never know how strong you are until being strong is your only option.

While a terrible disease may be taking away Jackie Privitera's physical strength, those who know and love her say the diagnosis has only proven how resilient she truly is.

At the age of 52, she has been dealt an unexpected and life-changing hand in the form of amyotrophic lateral sclerosis, or ALS—a progressive neuromuscular disease in which nerve cells die and leave voluntary muscles paralyzed.

While ALS traditionally affects men, sometimes the disease doesn't discriminate by gender. For this mother and grandmother, it has translated into an attack on her limb muscles, gradually taking away her ability to walk.

"You really don't appreciate something unless you lose it," she said from her Georgetown home, surrounded by family and friends. "I could sit here and cry all day long about it if I wanted to, but what's the use? I just take one day at a time; that's all I can do. I have to keep on swimming."

Jackie is harnessing this determination and using it to help find a cure, along with hundreds of other local residents who are currently raising funds for the upcoming Walk for ALS on June 6.

She'll be touring the four-kilometre Georgetown walk route around Dominion Gardens in a wheelchair along with her teammates—her adult daughters, Holly and Jennica, and a group of friends who are former co-workers from Tim Hortons.

"My mom has a lot of people who love her," said Holly. "We do it (the walk) for her, and we do it for this disease. You don't realize the effects of certain things until it touches you or your family."

Holly was there on that cold November day two years ago when her mother's world changed forever. After months of thinking that something was wrong, and hiding it from her friends and family, Jackie finally sought medical attention for the deteriorating mobility of her leg. A neurologist broke the news that she may have the progressive disease that eventually affects the muscles required for all movement, speech, swallowing and breathing.

"She came bursting through door in a whirlwind of tears with a cloud hanging over her," Holly recalled. "She sputtered out, 'He thinks I have ALS.' I refused to believe it and started doing research of my own."

The feelings of disbelief and denial were shared by Jackie's husband Ralph, who had a heart attack earlier this year due to the



Georgetown resident Jackie Privitera's daily struggles living with ALS are made easier through the support she receives from those who love her, like best friend Janice Fennell (right).

Photo by Melanie Hennessey

stress of his wife's diagnosis.

"I knew it was there, but I didn't want to believe it. I thought we could beat it," he said. "We've been married for 32 years and gone through so many things, but this is a really big, big hill to climb."

Five months later, a specialist confirmed the diagnosis. As Jackie's emotions swirled, the realization that she won't be able to look after her young grandson hit home hard.

"I wanted to work until I had grandchildren, then I was going to quit my job and look after them," she said. "Now I can't even pick him (my grandson) up; I can't take him to the park."

The local woman is also overwhelmed by the feeling that she's letting others down.

"It's stressful because... mothers are supposed to be there to

take care of the family, but with ALS the kids and husband are going to end up taking care of you," she said through tears. "I didn't want this for us. It's a shitty hand to be dealt, but I also know I'm really lucky. My husband is great, I have two amazing daughters and friends I can rely on."

Besides her family, one of Jackie's biggest sources of strength is her best friends, Janice and Dave Fennell. Janice recalled the day she found out her dear friend and former co-worker has an incurable disease.

"She said to me, 'You have to promise you're not going to cry.' Little does she know I cried myself to sleep that night," Fennell said. "It's just not fair. I would do anything for her to get rid of all this. I'd walk on glass and through fire to make it all go away."

Fennell touches base with her best friend each morning via text or phone call to see how she's doing. She also heads over to Jackie's house often to offer support in person.

"It's hard to stay happy all the time. I have my moments and she (Fennell) has been my sounding board," she said.

Jackie has also found an ally in Dave, who was recently diagnosed with Parkinson's disease—another degenerative disorder that affects the nervous system.

The ALS Society has offered tremendous support and resources as well, said Jackie, including the recent installation of a chair lift in her house. The Walk for ALS helps fund this type of equipment and support services for those living with the disease, along with education and research.

As her condition slowly progresses, Jackie, her family and friends plan to keep doing whatever they can to help find a cure, from fundraising for the ALS Society to Jackie participating in studies conducted by renowned researcher Dr. John Turnbull at the ALS Clinic at McMaster University Medical Centre in Hamilton.

"We're all her biggest fans. We've just got to keep fighting for her," said Holly. "Your world comes crashing down, but then you have to pick yourself back up and help find a way to cure it or make it better."

Sign up or pledge now for the local Walk for ALS

The seventh-annual Walk for ALS kicks off at 10:45 a.m. on June 6 at Dominion Gardens. In addition to the walk, the event will also include a free barbecue, silent auction, photo booth and fun.

The Canada-wide fundraising goal for this year's round of walks

is \$4.3 million, with the local walk looking to raise \$200,000.

For more information on the Walk for ALS, to sign up or to sponsor Team Jackie or other local participants visit www.walkforals.ca/georgetownacton.

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