



### Turning her ALS diagnosis into a mission

Disclosing her illness helped Michele Stellato find support at work and a voice to advocate for herself and others.

By Kara Corridan

*A fully inclusive culture is vital to Prudential. As one way to cultivate this, the company asks employees to disclose whether they have a disability or whether they've served in the military and whether they identify as a member of the LGBTQ+ community, along with their gender identity. Knowing this information helps Prudential create inclusive programming and policies. This is the story of one employee with a disability who found it not only rewarding but critical to share her diagnosis.*

#### November 2019

At first it was the typos.

Michele Stellato noticed her right hand felt stiff. She couldn't move it normally. She was making lots of typos. She chalked it up to cold weather.

But during a game in her women's volleyball league, she couldn't serve the ball over the net.

This was a major red flag.

Stellato, who played volleyball during her four years at Ramapo College of New Jersey, had a serve so consistent she'd once scored 24 points in a row. But on this night, "I was serving it right in the net no matter what. My teammates were giving me tips — "Try lifting your elbow" — but I felt like I wasn't strong enough."



*Stellato's symptoms started within weeks of this photo, taken with her husband Kevin in Hawaii.*

#### January – March 2020

Both a nerve doctor and a neurologist suspected Stellato had carpal tunnel syndrome, but she felt there was more to it. Her first MRI, in January, came back clear. By March, her legs began twitching. This led to bloodwork, Xrays and six more MRIs of her brain and spine, all of which revealed nothing extraordinary. Doctors saw a completely healthy 32-year-old with normal test results.

"At that point," recalls Stellato, a director in Prudential Communications, "I could've backed off. I could've had carpal tunnel surgery. But I just didn't think that's what it was."

And then the pandemic descended.

Medical offices stopped taking in-person appointments. Doctors were fully focused on the unfolding health crisis. Stellato was faced with a choice: "Do I want to keep pursuing this, or do I wait? Not knowing was driving me nuts. So I kept pushing."

#### May 2020

Stellato's symptoms pointed to motor neuron disease. Motor neurons are cells that send messages to muscles throughout the body. Weakness in her hand signaled lower motor neuron disease; the twitching in her legs and muscle stiffness were signs of upper motor neuron disease. Having both forms meant doctors couldn't rule out ALS, amyotrophic lateral sclerosis, also known as Lou Gehrig's disease. There are roughly 30,000 people in the U.S. living with ALS. This neurodegenerative disease attacks motor neurons. According to the nonprofit Project ALS, as a person's motor neurons die, he or she loses the ability to walk, speak, swallow and breathe. It is usually fatal within two to five years of diagnosis.

Stellato felt her neurologist wasn't pushing hard enough for answers. She sought out other doctors. Her research led her to the Eleanor and Lou Gehrig ALS Center at Columbia University in New York City. Given COVID-19, a quick appointment wasn't an option. But she was seen on the Friday of Memorial Day weekend.

#### June 2020

Stellato was working from the home she'd recently bought with her husband of three years, Kevin. She was also interviewing for her current role at Prudential. And she was continuing to undergo testing at Columbia. Finally, on June 4, over Zoom, her neurologist diagnosed her with early-stage ALS.

She was stunned.

"It's a really hard thing to hear and to understand. But the call continued, and I met with a social worker, a physical therapist and an occupational therapist," Stellato recalls. They asked lots of questions: *Are you walking OK? Can you swallow?*

"I'm like, 'Yeah ... wait. Am I not going to be able to swallow?'"

In a way, getting such devastating news amid a lockdown was helpful.

"The world was so weird, and everything felt so fake already. I thought, 'Is this even reality?'" she says. "But the pandemic gave me more privacy. I chose not to take any time off. I could continue to work and take a minute to walk away and cry when I needed to. And my husband was there to support me."







*Her 2017 wedding to Kevin Stellato was held in the Outer Banks of North Carolina.*

**July and August 2020**

Stellato didn't wallow. Through Columbia, she met several other young women recently diagnosed. She learned what's most needed with ALS: funding for research and drug development. This is when her professional skill set came in handy.

"As a communicator, I felt I had a duty to help. I couldn't say, 'I have no idea what to do,'" she says. "I knew exactly what I could do."

So she told her story — to lawmakers, researchers, doctors and the media. "My role is to be the face of ALS, to make noise, to make people care. If I can get on the news, then politicians get more pressure from constituents."

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*Stellato in August 2020, filming a video for Fight ALS Now, the advocacy organization she founded.*

#### September 2020

Stellato's first day at Prudential was Sept. 8. She had not disclosed her diagnosis during her four-month interview process. But soon after she started, she needed to take a day off for a doctor's appointment.

"I didn't want to be the person who takes a day off three weeks into a new job. I decided, 'I'm going to tell them and let them support me.'"

After all, her diagnosis was part of why she wanted to work at Prudential: "I knew I wouldn't be the only employee with a disability. I wanted a larger employer that had resources and experience supporting employees with all kinds of unique needs. I knew there were good people here," she explains. "I had been at my previous job for seven years, where I was part of a small communications department, and decided it was time to get out of my comfort zone. At Prudential, I'd be joining a much larger team, which both excited and intimidated me. I knew my world was about to change regardless, so I chose to start a completely new chapter of my professional life, too."

She first told her then-manager, explaining that she had a health issue. She said, "Right now it's kind of minor, but it could be bigger. I have ALS. There's really nothing I need right now. I just wanted to let you know."

Her manager was caught off guard, but he thanked her for her honesty. "I'm even more glad we hired you," she remembers him saying.

Stellato then went to Human Resources. Their reaction: "How can we help you?" She assured them that at the moment, she didn't need anything.

#### February 2021

Throughout 2021, Stellato shared her news with more coworkers. She's found that an email explaining ALS and how it impacts her works best.

"I'll say, 'I talk slower at times and I type slower, but I don't want to be treated any differently. I'm very capable of doing my job but I'm letting you know so you can understand if I have a day off or if I'm late to a meeting.'"

Though she feels supported by her colleagues, the situation can be awkward.

"We're in a professional setting, but it's such a personal thing," she explains. "Some people have been very interested; others aren't ready for a full conversation."

#### April 2021

There are only three approved medications available to treat ALS, and as Stellato says, "they are not life-changing." None of them can stop or reverse the disease.

Potential treatments are stuck in long trials, "which doesn't make sense for people facing certain death," she points out. So when her doctor asked whether she'd consider participating in a study of an investigative treatment to slow the progression of ALS that showed promise, she readily agreed. "Right now it is the best option I have. I feel lucky to have the opportunity to try it."

While it is too soon to tell if the treatment is working, Stellato has experienced no negative effects, and the disease continues to progress slowly.

#### September 2021

As part of her advocacy, Stellato posts videos on Twitter illustrating the brutal realities of ALS. But in one, she broached the topic with humor, showing an "ALS obstacle course." As she explained, "These are simple tasks for anyone. But with my ALS, some of them are really hard, and some of them are impossible."

From there, she attempted twisting off the cap of a water bottle, cutting open a bag of frozen berries and walking with a cup of coffee. For that last one, she spilled the coffee as she got to her dining room table but cracked up laughing. "I'm trying to bring in my personality and positivity, because you get more bees with honey," she says of the videos.



*As part of her "ALS obstacle course," Stellato walks from the kitchen with a cup of coffee—and has to laugh when it spills.*

#### October 2021

Today, Stellato has trouble lifting her right foot as she walks. Even the smallest object can be a trip hazard. She now wears an ankle and foot orthotic that goes into her shoe like an insole and stops her foot from dragging.

She has minor accommodations in her home office, such as a standing desk and Microsoft Word's Dictate tool (now standard for all users). Since she needs both hands to operate her mouse and types mostly with her left hand, she's investigating alternate equipment.

"I joke that ALS is curing me of my many other flaws, like moving too fast, talking too fast and multitasking too much," she says with a smile. "Now I have no choice but to be deliberate with my time and conserve my energy. I'm a little slower than I used to be, but my natural speed was unnatural."

And yet, as a communicator, Stellato is extremely frustrated that her forms of communicating are impaired: "Talking and typing fast and presenting with a strong, animated voice were my professional trademarks."

She's had to adapt and reinvent herself, bringing new skills to the table.

"I'm more analytical. I'm letting others talk more and I'm listening better. I'm thinking things through before acting in a way I hadn't. I've gained more wisdom and more empathy."

As she closes in on two years since her symptoms surfaced, Stellato sees the big picture with a remarkable dose of gratitude.

"I'm still walking, I'm still talking, I'm still using my hands," she explains. "I'm still independent — and with this disease, some people are dead by now. It's grave to put it like that, but I'm doing really well for having a really horrible disease. The goal is to keep me where I am and hopefully one day we can cure it."

A natural storyteller, Stellato wants to help rewrite the next chapter of ALS: "I want to focus on what's coming on the horizon and how we're changing things — not the legacy of the sad story of this disease."

So she continues her advocacy work. She founded Fight ALS Now, and with her wide circle of supporters she has raised nearly \$100,000 for research. She's persistently pressing her Congressional representatives to pass legislation that will prompt development of new treatments and, ultimately, a cure.

"ALS is the worst thing that's happened to me, but I'm hoping to be the best thing to happen to ALS."

#### What it's like to disclose a disability

Michele Stellato can speak firsthand to the advantages of disclosing. She was in the uniquely difficult position of starting her new job at Prudential as she was getting used to — and going public with — her ALS diagnosis. But she initially held off on telling her manager and colleagues. "It's scary to be thought of differently," she admits. And her symptoms were so minor as to be unnoticeable.

But as her ALS progressed — especially when it started to impact her voice — and her work style had to change, she shared her diagnosis more frequently.

"By letting people know, it gives them a chance to understand why my voice may sound odd, or I remain quiet in a meeting or stop to catch my breath in the middle of a sentence. It helps explain why I may be brief in an email or slow to respond to Teams messages," Stellato explains.

When she discloses, it encourages a more empathic relationship between her and her colleagues. "I appreciate when my coworkers ask me how I'm doing and welcome updates about my ALS. We're all dealing with struggles in our personal lives. When we take time to recognize that, we bring more kindness and compassion to our interactions, and it instantly improves our partnership. And when you let people in and accept their support, it benefits everyone."

Her bottom-line advice: Be your true self at work. "You shouldn't feel like you're hiding something," she says. "If people didn't know about my ALS and they were constantly asking me to take notes, I'd be sweating. Now I just feel a sigh of relief. I don't feel like I'm bringing my team down. I'm just playing a different role. It's hard to come out and share, but what I get in return is well worth it."