Jamie-Lynn Sigler: 'Open, honest and real' about MS



'The Sopranos' actress explains why she waited to tell the world about her MS and what she's doing about it now.

by Stephanie Stephens

When actress Jamie-Lynn Sigler publicly disclosed her relapsing-remitting multiple sclerosis diagnosis last January, she really wasn't sure what to expect. "I woke up that day in tears, feeling vulnerable, exposed and scared," she says. "I knew this was going to be a whole new chapter of my life, but I didn't really know what that would mean."

In that sense, Sigler, who is probably best known for her role as Meadow Soprano on the mega-hit HBO series "The Sopranos" is just like everyone else who's been diagnosed with the disease.

Time to tell the truth

As 2016 began, she'd known for 15 years that she had MS, and had thought long and hard about whether to disclose it. "It took me 15 years to just accept that MS is part of my life. It's really difficult to comprehend that this is really a part of you and something you have to deal with," she says.

Then, when she tried to imagine telling people about it, she adds, "I only saw a negative—things being taken away. I thought people would judge me, limit me." So, for the

sake of her career, she'd chosen to stay mum about it.

"I used to think it was better to have people not know than to have people help me. Over the years, living like that took its toll, not just physically but emotionally."



Jamie-Lynn Sigler, with her husband, former Major League Baseball player Cutter Dykstra, and son, works to balance her professional and personal obligations. Photo courtesy of Jamie-Lynn Sigler

When word began to spread, Sigler became anxious. Would this mean the end of her career? Would people see her differently and, possibly, abandon her? Her husband, former Major League Baseball player Cutter Dykstra, was her rock that day, she says. Dykstra told her that he'd take care of their 3-year-old son, Beau Kyle, and that she could do whatever necessary to relax. Dykstra did eventually suggest that she pick up her phone messages and emails, and check her Twitter account, though.

"I think you might be surprised," he said optimistically.

In fact, Sigler was overwhelmed by the love and support from her fans as she sat mesmerized for nearly two hours reading their comments.

"By the end of the day, I felt empowered with a sense of responsibility I hadn't anticipated having," she says. "I suddenly realized I had a platform to use my voice to help those who felt isolated."

Now she's eager to talk about how she manages her condition, and about her marriage, her son and her career.

She's teamed up with Biogen as an ambassador and blogger for the "Reimagine MySelf"

(<u>reimaginemyself.com</u>) campaign to encourage others living with MS to make small but impactful changes in their lives. She writes about topics ranging from working while living with the disease to marriage and intimacy. "It's been a wonderful way to process emotions and feelings, to be as open, honest and real as possible, and just get to the nitty-gritty of it all," she says.

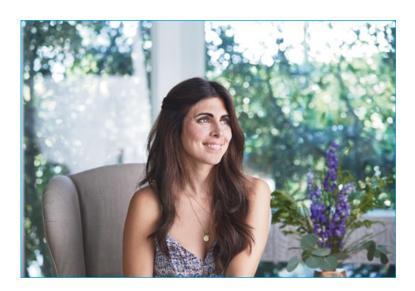


Photo courtesy of Jamie-Lynn Sigler

For Sigler, that means asking for help and support, staying active, and being faithful to treatment and medication plans.

Making choices that matter

It definitely took time for her to become so open, however. Sigler's symptoms began with bladder incontinence, and at that time, she managed it by wearing protection. "I'd request to have wardrobe fittings in separate rooms," she says. "I'm sure people thought that was a 'diva' move, but it was all embarrassing and weird, especially when I was 22 years old. It's what I had to do to do my job well, be independent and feel comfortable in case 'something happened.'"

Eventually, Sigler says, she got her bladder under control with medication. The rest of her symptoms, she says, primarily affect her legs. "I get some stiffness and spasticity, and I'm generally weaker on my right side than my left. I want to stay active, but I can't anymore, and I miss that sense of being so free in my body."

But, like many people with MS, Sigler has found ways to accommodate her symptoms while still doing things she loves.

Instead of running, she now hikes, making sure she doesn't get overheated. She also goes to spin class, where she sits in the back of the room, near a fan. "I may not be cycling at the intensity I used to, but I can still be resourceful and get my heart rate up," Sigler says.

Particularly when she's working, she's mindful of her energy, likening it to keeping her "gas tank" full. "I have to allocate it for the day," she says. "I wake up early and stretch, meditate and eat a really good breakfast. Between scenes I rest and put my feet up instead of chatting."

Even when it comes to what she calls "the vanity part of me," she's found workarounds. "High heels are hard for me and I miss them very much," she says. "I still have a pretty row in my closet that I stare at longingly. For my wedding, I found really amazing, comfortable wedges that made me look tall, like a princess. You still find ways to feel sexy."

The power of love

That's important to Sigler and her husband, who take special time for themselves, especially since he retired from baseball last June to pursue other business initiatives.

At one point, when they were planning a special weekend, "We looked at each other and I said, 'Let's not mention the MS words, and I'll just be your wife and you be my husband,'" Sigler recalls.

Stopping themselves from dwelling on her illness was a reminder, she says. "MS or any other chronic disease should never be the sole focus all the time, especially for the sanity and sanctity of a relationship."



Jamie-Lynn Sigler, shown with her son, Beau Kyle, has become more open about her MS since she disclosed it publicly last year.

Photo courtesy of Jamie-Lynn Sigler

That message carries over to the couple's sex life. "With having a busy career and being a parent, sometimes the last thing you want to do is have sex," she says. "It's such an important part of the relationship, though, and you can still figure out ways to celebrate and have control over that part of your lives in spite of symptoms."

Being 'Mommy'

Sigler cherishes precious one-on-one time with her son and is mindful of what she can and cannot do. "We might go to an indoor park if it's a hot day," she says. "I'll ask someone else, like a babysitter, to do things with him that I can't do. I do want to be his everything and it's hard for me to pull away."

Beau has already developed keen awareness, patience and sensitivity about his mother's MS, even though he doesn't know the name for her condition, Sigler says. "He'll say to people around us, 'Please wait, because my mommy needs to be careful.' And he knows if we play baseball that mommy is just pitcher or catcher, and if we play hockey, mommy is the goalie."

Next on her list

Sigler says she's carefully considering her next career move. "I'm trying to think of all aspects of me—other avenues that let me be home with my son," she explains. But she admits that her real passion is acting, and she's totally open to opportunities.

"I worked a ton last January with lots of great guest spots on TV," she says. "I shot a movie, and then got into focus on the Reimagine MySelf campaign and being with my family. Also, we have a new [entertainment] project in development that we hope will be exciting news to share this year."

She's excited and motivated to stay engaged with the MS community, too, she says. "The platform I have now as an MS advocate is that, while my MS is different than anyone else's, what we have in common is our emotional journey." She adds that with her blog, "There's lots of new content people can look forward to, and opportunities for me to have open conversations with the MS community. We want to keep getting the word out there on a grand scale."

Stephanie Stephens is a California-based multimedia journalist specializing in health and lifestyle topics.

For more about Sigler, visit Reimagine Myself.

Learn more about <u>deciding to disclose your MS</u>.