



Bride-to-be Caregiver Reframes Future with a Fiancé Living with ALS

Lynn Hogan became a caregiver early in her relationship her fiancé, Steve Ziegler.

“On our first date we went out and he was sitting next to me and he said, ‘You might notice — don’t get weirded out or anything — but you might notice some twitching, weird stuff going on with my arms. We don’t know what it is yet. But one of the things it could be is ALS,’” she recalled.

November is Family Caregivers Month, and data shows that caregivers, who spend an average of 11 hours per day providing care, also take on high levels of financial strain and emotional stress. The ALS Association provides resources to support caregivers.

Earlier this year, Lynn sat down with us to talk about her role as a caregiver.

Lynn met and got to know Steve Ziegler through work, where their connection developed and grew over time. She was at work when Steve let her know that his ALS diagnosis was confirmed – just a few months after that first date.

“As the day progressed, it kept sinking in and then at a certain point I just went to the bathroom and I just broke down. But even then, at that point you still don’t know how bad it’s going to be.”

Lynn told us about the average day providing care while also maintaining her career.

“It’s several hours of caregiving and basic wake Steve up, get him dressed, basic hygiene, get him his medication, get him breakfast, get him situated. And then on a normal day, I would go to work and his dad would come take care of him. I would work a full day and come home. His dad would go home and then I’d take over,” she said. After work, Lynn resumes her role as caretaker, prepping meals and helping prepare Steve for bed. Between all that, she said, they live pretty normal lives. “We both have jobs and we both go to his son’s baseball practices or hockey practices or watch whatever’s on TV that night. So, interweaved in all of the caregiving and the time that we have to put in to take care of the disease. We try to be a normal family,” she said.



Lynn reflected on the decision she made to continue building a life with Steve, who, she said, told her early in their relationship that he would understand if his diagnosis was too much for her.

“I could walk away and let him go through it alone and both of us would just be miserable,” she said. “We wouldn’t have each other, and he would be dealing with this end of life disease without anyone by his side. And I would be going through life normally knowing that he was alone.”

She added: “Another option is just to stay together, and I could just be next to him. I can’t cure him. I can’t heal him. I can’t make him better, but I can just be there with him. And that’s what I decided to do. I knew that it was the right decision because if ALS hadn’t been in the picture, we would no question be together.”

Lynn said that while juggling work and family and caregiving is a challenging, it’s not the hardest part.

“The hardest part about caring for someone with ALS is that one day I’m going to wake up. I’m not going to be a caregiver anymore. And he won’t be there,” she said. “If I could go through the rest of my life and be a caregiver, that’s all I want. But one day it won’t happen. And I’m going to wake up and he won’t be there. And that’s because of ALS.”

Lynn and Steve are getting married in January.

Please consider making a tax-deductible donation to The ALS Association Greater Sacramento Chapter and help give hope to people like Lynn and Steve. The key to a cure for ALS starts with you.