



**Jon Strum was in his 40s when his wife, Jeanne, was diagnosed with secondary progressive MS in 1997. Within five years, the very aggressive case of MS had left her quadriplegic. Today, more than 20 years after her diagnosis, she is nonverbal, receives her nutrition through a feeding tube, suffers from extremely compromised vision, requires assistance breathing, and has experienced significant cognitive decline. She lives in a subacute nursing facility, where Jon still sees her every day.**

Jon said one of the biggest challenges of caring for a partner is the way that it changes the relationship.

“If you’re a family caregiver, it requires a whole lot of special relationship training because your relationship is going to change,” he said. “When a caregiver and their care partner are married, for instance, as we are, it’s not a typical spousal relationship. It has different kinds of pressures and different kinds of situations that you have to face, and so I think dealing with relationship issues is important.”

By 2001, Jon chose to put his career on hold to become his wife’s full-time caregiver – a period of unemployment that lasted around 10 years. This, he says, had a profound impact on his life.

“I picked kind of a critical ten years to stop working,” he said. “I stopped working in my mid-40’s and I felt the need and the desire to go back to work in my mid-50’s. The challenge of trying to find employment in your mid-50’s is pretty overwhelming. I picked the wrong ten years to drop out of the workforce.”

This, too, devastated his finances, which he says is not uncommon with a family that is hit with a chronic illness.

Since Jeanne now lives in a facility where she receives more care than at a skilled nursing facility but less care than at a regular hospital, Jon now says that his role has transitioned from everyday caregiving responsibilities to more of an advocacy role. To help others and foster a dialogue about the challenges presented by MS and caregiving, he hosts the RealTalkMS Podcast, created for people living with MS – including patients, caregivers, family members, and friends.

