

Life With Pam



My wife, Pam, was diagnosed with MS in her mid-30s, after bouts of double-vision and “clumsiness.” For the first year or two, I sort of pretended like it wasn’t that big of a deal. However, she fairly quickly became dependent on a wheelchair and eventually lost all function except some use of her right hand. Now she needs round-the-clock care. Our three boys are grown up and moved out—one recently diagnosed with MS—and Pam and I both really want her to keep living at home. So far she is able to do so with in-home care and me: her husband and family caregiver.

For the past 15 years, our days have gone like this: I get up at 6:00 a.m. and help Pam out of bed with the lift. I take care of her restroom needs, then wash her and get her into her wheelchair. Then the certified nurse assistant (CNA) arrives so I can leave for work. Pam’s CNA feeds her breakfast, lunch and dinner, and manages her other needs including positioning to avoid pressure sores. Pam can be in her wheelchair for four hours at a time, and then she must be on the alternating-air mattress on her hospital bed (in our living room). After I get home from work we watch TV and talk; I scratch her nose for her or smooth her hair until bedtime. It may sound repetitive or leaden, and sometimes it is tough. But people get used to things—we’ve been doing this for a long time. Pam and I wouldn’t have it any other way.

My parents are now in their 90s and recently moved into a full-time care facility. They live a six-hour drive away from Pam and me. We’ve visited them occasionally over the years, but when I travel with Pam we have the Hoyer lift, shower chair, alternating air mattress, and much, much more. Working with the lift in hotel rooms has become impossible since hotel beds no longer have frames to slide the lift under. We have to get a suite in order to have

enough space... it's all very expensive. Plus, when we get there, I spend most of my time caring for Pam and not visiting with my parents.

I decided that if I was going to visit my parents again, I'd need to visit on my own. I researched Pam staying temporarily in a nursing home—I was told that nursing homes don't like temporary placements. We can't afford a CNA around the clock, and Medicaid will only pay for 16 hours per every 24. It felt impossible... until about a year ago, when through my volunteer work with the Society, I heard about a program that could fill the gaps in Pam's Medicaid-paid care for up to three full consecutive days. Pam could have the support she needs and I could visit my parents! We applied and were approved for the vouchers, and I traveled to see my parents this summer. It was wonderful to see them, and my siblings, too, and wouldn't have been possible without the Virginia Lifespan Respite Voucher Program.

After nearly 40 years of marriage, I really consider us to be “lucky”—if you have to face MS. Pam's unable to do anything physically, but has very little cognitive disability. I am proud to call myself a family caregiver. and I cherish every day I spend with Pam. People say to me, “I don't think I could do what you do.” I say, “Anybody can. You do what you have to do.”-Ray Heron

Editor's Note: Since 2009, Lifespan Respite grants have supported better coordination and delivery of services to family caregivers like Ray in 30 states and the District of Columbia. Vouchers to help family caregivers pay for respite are—or will soon be—available in a few other states, and the program needs ongoing funding. In honor of last month (November) being National Family Caregivers Month and as Congress wraps up its Fiscal Year 2014 budget, MS activists urge continued funding of the [Lifespan Respite Care Program](#). Our nation's more than 60 million family caregivers save our government \$450 billion annually and—more importantly—enable loved ones like Pam to stay at home surrounded by their support networks and connected to their communities.