



National  
Multiple Sclerosis  
Society

## Create a Virginia Caregiver Taskforce

**Position:** Support House Joint Resolution 680: Create a House and Senate subcommittee to study family caregiving and long-term care supports and services.

**HJ 680** Establishes a taskforce, or a joint subcommittee of legislators from the House and Senate; Advocacy Organizations and Family Caregivers.

### The taskforce will be authorized to :

- Identify and compile an inventory of policies, resources, and programs available to unpaid caregivers
- Identify challenges and barriers affecting unpaid caregivers
- Develop recommendations for the development of new innovative means of providing support and assistance to unpaid caregivers

### What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.

### Caregiving in Virginia

Nearly three-quarters of the older adults and individuals with disabilities residing in Virginia receive services and supports in their homes and communities and rely on an unpaid caregiver, often a spouse, partner, family member, friend, or neighbor, for assistance.

**1 million family caregivers provide over 956 million hours of unpaid care in Virginia each year. This can be valued at \$11.8 billion annually.**

There is not a complete inventory of services and supports for Virginia caregivers.

Respite (a short-term break from the stress of providing care) is the most frequently requested support service among family caregivers, yet a 2009 National Alliance for Caregiving -AARP report revealed that nearly 90% of Caregivers do not receive respite.

### MS and Long-term Services and Supports

- Up to 25% of people living with MS will require long-term care services at some point in their lifetime.
- A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that :
  - On average, caregivers spend 24 hours a week providing care.
  - 64% of caregivers were emotionally drained, 32% suffered from depression, 25% could not focus at work, and 22% have lost a job due to caregiving responsibilities.

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**Cheryl Rosser**  
Providence Forge, Virginia

My husband, William, was diagnosed with relapsing remitting MS in 1994 and our journey has been spent adjusting and readjusting our lives to accommodate the ever changing symptoms of MS. William and I both started out excited and confident that we would have successful careers and build a beautiful family together. We have three boys, ages 22, 17 and 13. We honor our wedding vows and have been committed to each other - "... in sickness and in health, until death do us part."

In 1999, William could no longer practice as a registered dental hygienist because MS affected the tactile senses in his fingers and he became a reluctant but willing stay-at-home dad. As the disease progressed, the roles in the household changed. William could no longer be the Cub Scout leader or

basketball coach. As I got more involved with the boys outside of the home, William started doing more inside such as cooking and laundry. Eventually, those responsibilities also became too much for him and I have had to take on more of our daily tasks.

Providing care for my husband is unique in that we never know what symptom will appear and what level of care he will need. *Faith, resilience, flexibility, patience and commitment* are the words I use to describe our ability to continue to run this race. The guilt and stress was weighing on me so much that 9 years ago, I had to leave my full time job as an accountant to be more available to care for William and our children. I go with William to every doctor appointment because his short term memory and cognitive skills have been compromised as a result of MS and he often forgets important information. As his MS progresses, more medical care appointments are necessary, especially physical therapy which is usually three days a week. William also needs assistance with getting dressed. I have to remain flexible in my schedule, so I am working a part time job to ensure I have health benefits for myself and the children. I also work as an independent contractor to supplement the income in our home. I am starting to evaluate whether I will be able to maintain my part time job, primarily because it is challenging for me to commit to a regular work schedule.

My husband and children look to me to care for them. Within the last few months my husband had an exacerbation and was in bed for two weeks. As a family, we had to consider how to once again readjust our other commitments. William suggested that he should move to an assisted living facility. My boys looked at me and said, "Mom, you need to quit your job to take care of dad." Yes, they are getting older and have a better understanding of the financial needs of maintaining a home and family, but from their perspective - taking care of their dad is my most important job.

It is hard to believe that we have been living with MS for over 20 years, but I can remember the day of diagnosis as if it was yesterday. It has affected our entire family. As a caregiver, I need better access to resources and supports so that I can continue caring for William at home, while also providing for myself and our children.



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