

**Table S1.** Survey Participant Demographics (N = 108)

**Gender**

- Female, 67.6%
- Male, 29.6%
- Variant/nonbinary, 1.9%
- Prefer not to say, 0.9%

**Race**

- White, 88%
- Black, 3.7%
- Hispanic or Latino, 1.9%
- Asian, 0.9%

**Relationship to individual with multiple sclerosis**

- Spouse/partner, 74.2%
- Parent/guardian, 7.6%
- Child, 5.3%
- Sibling, 3%
- Unrelated, 9.1%

**Knew individual when they were diagnosed, 87.5%**

**Length of time as care partner**

- More than 10 years, 35.7%
- 5 6 to 10 years, 25.2%
- 2 to 5 years, 20.9%
- 6 months to 2 years, 13.9%
- Less than 6 months, 4.3%

**Providing care to other family and friends, 41%**

**Geographic area**

- Suburban, 57.4%
- Urban, 26.9%
- Rural, 15.7%

**Appendix.** Description of Caregiver Protocol Resource List

The identified caregiver resources fall into 6 categories that were identified by the Caregiver Advisory Board and validated through the online caregiver survey. Within each category, the resources—including websites, publications, podcasts, and videos—will come primarily from multiple sclerosis (MS), health care, and caregiver advocacy organizations, as well as government agencies.

<b>LEARNING ABOUT MS</b>
<ul style="list-style-type: none"><li>• What it is</li><li>• How it’s treated</li><li>• MS disease courses</li><li>• Members of the MS care team</li></ul>
<b>NAVIGATING THE HEALTH CARE SYSTEM</b>
<ul style="list-style-type: none"><li>• Finding health care providers and resources</li><li>• Understanding comprehensive MS care: how to find a care team or create one on your own</li><li>• Making the most of medical visits</li><li>• Understanding MS medications</li><li>• Understanding the Affordable Care Act</li><li>• Understanding prescription drug plans</li><li>• Participating in shared decision-making</li><li>• Understanding alternative, complementary, and integrative treatment strategies</li></ul>
<b>SECURING YOUR FINANCIAL FUTURE</b>
<ul style="list-style-type: none"><li>• Financial planning for unpredictability</li><li>• Understanding the provisions of the Americans with Disabilities Act</li><li>• Navigating insurance needs: life, health, disability, and long-term care</li><li>• Managing prescription drug costs</li><li>• Understanding the Social Security disability application process</li><li>• Managing a career while providing care for a loved one</li></ul>
<b>CAREGIVER SUPPORT</b>

- How to take care of your own health and wellness (physical, emotional, spiritual, vocational) while caring for someone else
- Knowing where to find support

### **MAINTAINING HEALTHY, BALANCED RELATIONSHIPS**

- Understanding invisible MS symptoms
- Navigating a partner's physical, cognitive, emotional changes
- Understanding sexual dysfunction
- How to communicate openly and effectively

### **BUILDING SKILLS AND A TOOLCHEST TO MEET YOUR NEEDS**

- Learning the value of mobility devices and assistive technology for the entire family
- Understanding and managing disability progression
- Learning how to provide hands-on care safely and effectively
- Hiring help at home
- Becoming familiar with the components of long-term care