

**(S121) WHAT IS A CAREGIVER'S ROLE IN MULTIPLE SCLEROSIS?**

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Who is the caregiver for multiple sclerosis (MS) today? Is it a child, a teen, an adult child, a parent, a spouse, or a sibling of the individual with MS?

Whoever it may be, it creates a unique set of challenges, regardless of the level of care that is needed. Role changes within the family are a given. The amount of adjustment within the home varies, with involvement ranging from overseeing care to total caregiving. In a book, you may see the role of the caregiver as maintaining home safety, contributing to the quality of life, providing personal care, and maintaining personal dignity for the person with MS. However, the role does not end when the person has a personal provider, receives home health care, or moves to an assisted-living environment or a nursing home.

What, then, does the caregiver need to know, or what does the caregiver want to know, or what has the caregiver learned that would be helpful to others? By conducting surveys with actual caregivers, we asked them what their definition of caregiving would be, how many years of experience they had as caregivers, what they felt their primary needs or concerns were that could help others, and what we could do as an organization to provide these services to families. By gathering this information, we can develop an educational plan with priorities as seen through the caregiver's eyes and provide new caregivers with better education and support as they enter this phase of the disease.

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