Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, often times beginning in young adulthood. It presents in many different symptoms, at differing time frequencies and duration, requiring substantial caregiver assistance. One of the biggest challenges of living with multiple sclerosis is coping with the constantly changing state of the disease.

As a result, the physical, mental and financial burdens on family caregivers of people with MS are significantly greater than the general family caregiving population. This is the reality reported in *Multiple Sclerosis Caregivers 2012*, a survey conducted by the National Alliance for Caregiving with support from the National MS Society.

The study was designed to:
- Collect demographic, social/emotional, and attitudinal data about people engaged in caring at home for someone with MS
- Investigate how the changing symptoms relating to cognition, mood changes, and incontinence impact caregiving and caregivers.
- Explore the intersection of technology and care for someone with MS.
- Examine the triggering events for moving into a long-term care facility and better understand what resources or tools could help family caregivers keep their care recipient with MS in the home longer.
- Understand the role of men as the primary caregiver to MS care recipients.

**Methodology**

This report presents the findings of an online quantitative survey of 421 individuals who provide care to a friend or family member with MS. All respondents were members of a national online panel hosted by Research Now. In order to qualify for the survey, respondents must be currently caring for a friend or family member with MS and must help their care recipient with at least one Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL) other than just managing finances. Anyone who reported they provide paid professional care to someone with MS was disqualified from the survey.

After an initial review of existing research on the topic of MS Caregivers, a questionnaire was developed by the Boomer Project and the Southeastern Institute of Research, with substantial input from the National Alliance for Caregiving and the National MS Society. Responses were collected between June 2 and June 19, 2011. The survey lasted approximately 20 minutes. In total, 421 respondents completed the survey.

After the National Panel Survey was completed, the survey was also conducted within the MS Community. In total, 230 MS Community respondents completed the survey between July-October 2011.

**Findings**

Among the findings of this study:
- Half of MS patients experience "mental confusion" that negatively impacts caregivers in regards to their own mental health (43%) and overall financial situation (47%).
- In addition, 86% of family caregivers of people with MS indicated needing assistance in funding to pay for in-home care to help keep their loved one home and out of a long-term care facility.
- Half of MS caregivers see the day when long-term care facilities are required - and the top triggering event in the need for a long-term care facility is the need for 24 hour care.
- The survey also revealed that most caregivers of people with MS use the internet to search for information about the disease and how to care for someone (94%). Of those who use a given source for information, less than half found the information helpful.
- The long life cycle of the disease suggests the total number of years one serves as a caregiver will be significantly longer than caregivers in general. Already, MS Caregivers have been providing care for 9 years compared to less than 5 years for all other caregivers.

"The length of caring for someone with multiple sclerosis points to a real need for assistance for these individuals from family, friends, employers and social service programs. With more support for these family caregivers, more people living with this debilitating disease will be able to remain with their loved ones for a longer period of time."

– Gail Hunt, President & CEO of the National Alliance for Caregiving.

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