



## National Alliance for Caregiving

*Advancing Family Caregiving through Research, Awareness & Advocacy*

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### **75% of Family Caregivers of Someone with Multiple Sclerosis say Respite Care Would Significantly Help in Caring for their Loved One at Home**

Washington, DC- March 8, 2012: 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. It's not unusual to encounter periods of severe symptoms followed by remissions. 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 today in ***Multiple Sclerosis Caregivers 2012***, a survey conducted by the National Alliance for Caregiving with support from the National MS Society.

*Multiple Sclerosis Caregivers 2012*, which was funded by Sanofi US, is the result of a National Panel Survey along with a Survey of the MS Community conducted from June 2011- October 2011.

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.

**Click Here to View Entire Survey (available on Thursday, March 8 at 10 AM ET)**

[www.caregiving.org](http://www.caregiving.org)

The type of care provided by family caregivers of people with MS is assisting with a wide variety of Activities of Daily Living (ADLs)- personal care, including bathing, dressing, feeding, and toileting- and Instrumental Activities of Daily Living (IADLs), such as housekeeping, transporting to the doctor, cooking, and handling finances.

The most-commonly felt emotion upon their care recipient’s diagnosis with MS was compassion, followed closely by fear and anxiety. Half of caregivers of people with MS stated that their personal relationship with their loved one has improved and three out of four caregivers indicated that becoming a caregiver to their loved one has made them closer.

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 average age of all care recipients is 61, but the average age of MS care recipients is 50 and was diagnosed over 12 years ago. The mean duration of MS is 30 years, and it typically reduces life spans by 5-10 years.

“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.

## Methodology

This report presents the findings of an online quantitative survey of 421 individuals who provide care to a friend or family member living with multiple sclerosis (MS). The detailed methodology can be found in the full report: [www.caregiving.org](http://www.caregiving.org). For information on caregiving for someone with MS, go to [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

Profile of Caregivers	Total (n= 421)
<b>Household Income</b>	
Less than 15K	3%
15K to less than 30K	12
30K to less than 50K	15
50K to less than 75K	24
75K to less than 100K	18
100K to less than 125K	12
125K to less than 150K	6
150K to less than 175K	4
175K or more	5
<b>Current Employment Status</b>	
Employed full-time	58%
Retired	16
Employed part-time	12
Not currently employed	8
Stay at home parent	4
Student	2
Other	2
<b>Point when Providing Care Began</b>	
When he/she could no longer care for themselves	33%
When he/she began displaying symptoms of MS	30
Prior to diagnosis with MS	14
As soon as he/she was diagnosed with MS	12
When a previous caregiver could no longer provide care	6
Other	6

## **About Sanofi US**

Sanofi US is a diversified global healthcare leader that discovers, develops, and distributes therapeutic solutions to improve the lives of everyone. Sanofi US works to prevent and treat the diseases that we know of today, as well as those we may face tomorrow. With nearly 100,000 dedicated professionals in more than 100 countries, Sanofi US is devoted to advancing healthcare around the world. Sanofi US, with headquarters in Bridgewater, New Jersey, employs more than 11,400 professionals throughout the country. In 2010, Sanofi US donated over \$40 million dollars to non-profit 501(c)(3) organizations across the U.S. In addition, over \$500 million dollars in pharmaceutical product was donated to patients in the U.S. and in developing countries through our U.S. Patient Assistance Program and product and disaster relief programs. For more information, visit [www.sanofi.us](http://www.sanofi.us).

## **About the National Multiple Sclerosis Society**

The National MS Society addresses the challenges of each person affected by MS. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move forward with their lives. In 2011 alone, through its national office and 50-state network of chapters, the Society devoted \$164 million to programs and services that assisted more than one million people. To move us closer to a world free of MS, the Society also invested \$40 million to support more than 325 new and ongoing research projects around the world. The Society is dedicated to achieving a world free of MS.

Join the movement at [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

## **About National Alliance for Caregiving**

Established in 1996, National Alliance for Caregiving is a non-profit coalition of national organizations focusing on family caregiving research. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

Recognizing that family caregivers make essential social and financial contributions toward maintaining the well-being of those they care for, the Alliance is dedicated to being the foremost national resource on family caregiving research to improve the quality of life for families and care recipients. For more information, visit [www.caregiving.org](http://www.caregiving.org).

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