

MULTIPLE SCLEROSIS CAREGIVERS



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Conducted by



The National Alliance for Caregiving
National Multiple Sclerosis Society
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Supported by Sanofi US



The National Alliance for Caregiving

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the US caregiving community internationally. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

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.

The Alliance gratefully acknowledges the support and insight of the National Multiple Sclerosis Society in the development of this study.

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Multiple sclerosis (MS) is a chronic, unpredictable, often disabling disease that attacks the central nervous system. Symptoms can vary dramatically from person to person and can include loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness, and more. Depending on the specific person with MS, these problems may be permanent or may come and go. It is estimated that approximately 400,000 Americans have MS. The vast majority of people with MS live a normal lifespan, but the unpredictability of the disease can present many challenges, including the possibility of facing increasing limitations.¹

The unpredictability also presents many challenges for those providing care to a loved one with MS. In order to better understand the needs of family caregivers providing care for someone with MS, the National Alliance for Caregiving, with funding from Sanofi US, partnered with the Boomer Project of the South-

eastern Institute of Research to conduct an in-depth study of family caregivers caring for loved ones with MS. Specific objectives of this study include:

- Collect demographic, psychographic 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.

¹ National MS Society. "Multiple Sclerosis: Just the Facts." National MS Society, 2011.

This report presents the findings of an online quantitative survey of 421 individuals who provide care to a friend or family member suffering from Multiple Sclerosis (MS).

All respondents were members of a national online panel hosted by Research Now. Research Now is the world's leading marketing research panel provider and data collection services company. 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. Study results contain a margin of error of +/- 4.77 percentage points at the 95% confidence level.

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. Caregivers were alerted of the survey through the following sources: National MS Society Caregiver webpage, National MS Society self-help groups, National MS Society Relationship Matters program, National MS Society's Facebook page, National MS Caregiver website, Caregivingly Yours blog, personal blogs of MS caregivers. Specific numbers presented in this report reflect findings from the National Panel Study only. The data from the MS Community Survey closely resemble that of the National Panel with a few minor exceptions, including:

- Caregivers in the MS Community Survey report providing significantly more care each week than caregivers in the National Panel Survey (40 hours vs. 24 hours respectively).
- Caregivers in the MS Community Survey are slightly less likely than those in the National Panel Survey to indicate that their care recipient will need to go to a long-term care facility in the near-term.
- Caregivers in the MS Community Survey are slightly more likely than those in the National Panel Survey to report that they themselves would provide more care if their care recipient's condition worsens.
- Perhaps because they are providing more care, caregivers in the MS Community Survey report more negative impacts than those in the National Panel Survey in terms of financial situation, hobbies/activities, and mental health.

SUMMARY OF KEY FINDINGS

Here are some of the key findings from this research. Please see the “Detailed Findings” section of this report for more information on each of these findings.

Problematic Symptoms

- The most common symptoms of MS among respondents’ care recipients are problems with walking, balance, and coordination.
- In addition to being reported as the most *common* symptoms, these are also the symptoms that caregivers see as causing the most problems in care recipients’ day-to-day life.
- Many care recipients have other concurrent health conditions.

Care Provided by Family Caregivers

- On average, respondents spend 24 hours each week providing care to their care recipient with MS. The range is quite substantial, from just one hour per week up to 24 hours, 7 days a week.
- Respondents assist 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, handling finances.

External Help

- Only about a quarter of respondents report they are the *only* caregiver for their care recipient with MS. The rest share responsibilities with others. Those who share responsibility with others tend to be providing care for care recipients with more advanced states of MS.
- A quarter of respondents report there is paid in-home care for their care recipient. As with those who report multiple family caregivers, those with paid in-home care are generally providing care to those with more advanced MS.
- The number of hours spent providing care is similar between those who have paid in-home care and those who do not, implying that family caregivers are using paid in-home care as a *supplement* to their own care and not as a replacement.

Impacts on Caregiver

- The most-commonly felt emotion upon their care recipient’s diagnosis with MS was compassion, followed closely by fear and anxiety.
- The most common aspects of MS caregivers’ lives which are *negatively* impacted is their overall financial situation, ability to participate in hobbies and/or things they enjoy, and then mental health.

SUMMARY OF KEY FINDINGS

- One-third suffer from depression because of providing care.
- Half are physically exhausted, and nearly a third have received physical injuries as a result of caregiving (e.g., “injured myself lifting my care recipient”)
- Regarding work, 22% have lost a job due to caregiving, and 17% say that they are unable to hold down a job due to caregiving.
- The areas with the biggest *positive* impacts relate to relationships—those with the care recipient, the children of the caregiver, and other family members.

Choice in Providing Care

- Almost half of respondents feel they did *not* have a choice in taking on the responsibility for caring for their care recipient with MS. Past caregiving studies have shown that this can be a factor in caregiver stress.
- Those who feel they had a choice in whether or not they would provide care to their care recipient with MS generally feel less negative and more positive impacts than those who feel they did not have a choice.

Cognitive Impairment

- Almost three-quarters (71%) of care recipients display one or more emotional or cognitive symptoms, including emotional changes, depression, and mental confusion.

- Caregivers who provide care to someone with cognitive impairment are more likely than others to feel negative impacts from providing care.
- Those providing care to someone with cognitive impairment are more likely to say that they would find funding helpful to pay for in-home care, medical paid care at home, and respite care.

Information Sources and Technology

- The Internet is used frequently by caregivers as a source of information—both information regarding MS in general and information regarding providing care for someone with MS. Materials supplied by doctors are also frequently used.
- Almost half report participating in support groups—both online and in-person support groups.
- There may be an opportunity for improving upon these sources of information. Of those who use a given source of information, slightly less than half find them helpful. There is little difference in helpfulness ratings between different sources.
- Few respondents report they currently use caregiver training via the Internet, caregiving coordination systems, or medication support systems. Many, however, report they would be likely to do so in the future.

SUMMARY OF KEY FINDINGS

Gender

- Male respondents are more likely than female caregivers to be providing care to a spouse and to be the only or primary caregiver.
- Contrary to the initial hypothesis, there are many similarities between male caregivers and female caregivers. Men and women are equally as likely to feel they had a choice in providing care to their care recipient. Men and woman also experience similar negative and positive impacts from providing care to their MS care recipient.
- Men tend to use more information sources and use these information sources more frequently than women.

Long-Term Care Facilities

- Only three in ten respondents say their care recipient would go to a long-term care facility if their condition worsens and they need more care.
- Most respondents think it is unlikely their care recipient will ever have to go into a long-term care facility in the near future.
- Those who are caring for a spouse are much less likely to say their care recipient will ever have to go into a long-term care facility—both within the next year or within longer periods of time. Similarly, respondents who live with their care recipient report a lower likelihood

that their care recipient will have to go into a long-term care facility.

- The most promising opportunities for allowing care recipients to stay in their homes longer involve in-home care—both paid medical care and paid non-medical care.

Changing Symptoms of MS

- Those providing care to loved ones with frequently changing symptoms generally provide slightly *more* care in terms of number of hours.
- Among those caring for someone with frequently changing symptoms, many feel relief and appreciation when their care recipient's symptoms ease up, yet they are also constantly worried that their care recipient will take a turn for the worse and they wish their care recipient's symptoms were more consistent or stable.
- Those who are providing care for someone whose symptoms are frequently changing report more *positive* impacts from providing care, yet there are no substantial differences in the *negative* impacts.
- Those caring for care recipients with frequently changing symptoms may have a greater appetite for information on MS. They also see a slightly greater need for paid in-home care—both medical care and non-medical care.

CAREGIVER & CARE RECIPIENT PROFILES

The following describes the 421 MS caregivers who participated in this online panel research study. As noted in the methodology section, the results of the 230 respondents in the MS Community Survey were quite similar.

RESPONDENT PROFILE

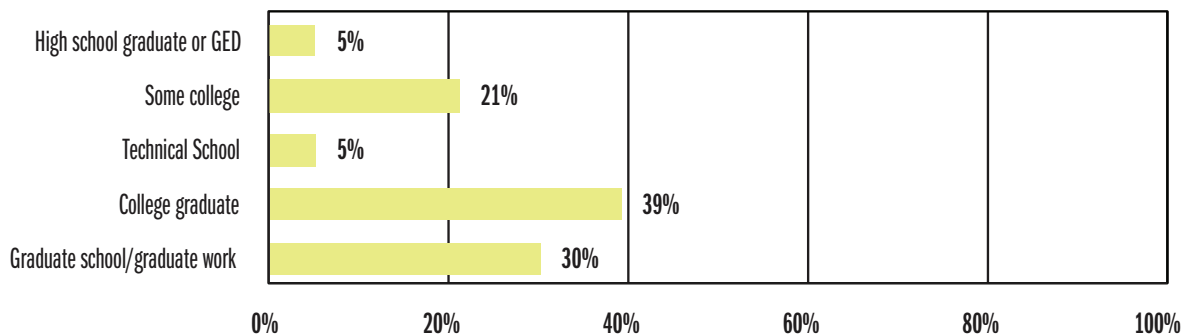
Respondents' ages range from 25 to 86, with the average age of respondent being 46. Respondents skew slightly more female, with 60% of the respondents being female and 40% being male.

The majority (72%) of respondents are married or living with a partner. The remainder are single/never married (17%), divorced (7%), widowed (3%), or separated (2%). Approximately four in ten respondents (38%) have children under the age of 18 living in their household.

Two-thirds of respondents have college or graduate degrees, making them somewhat better educated than average.

Figure 1: Respondent Education.

(QF-9. What is the last grade of school you completed?)

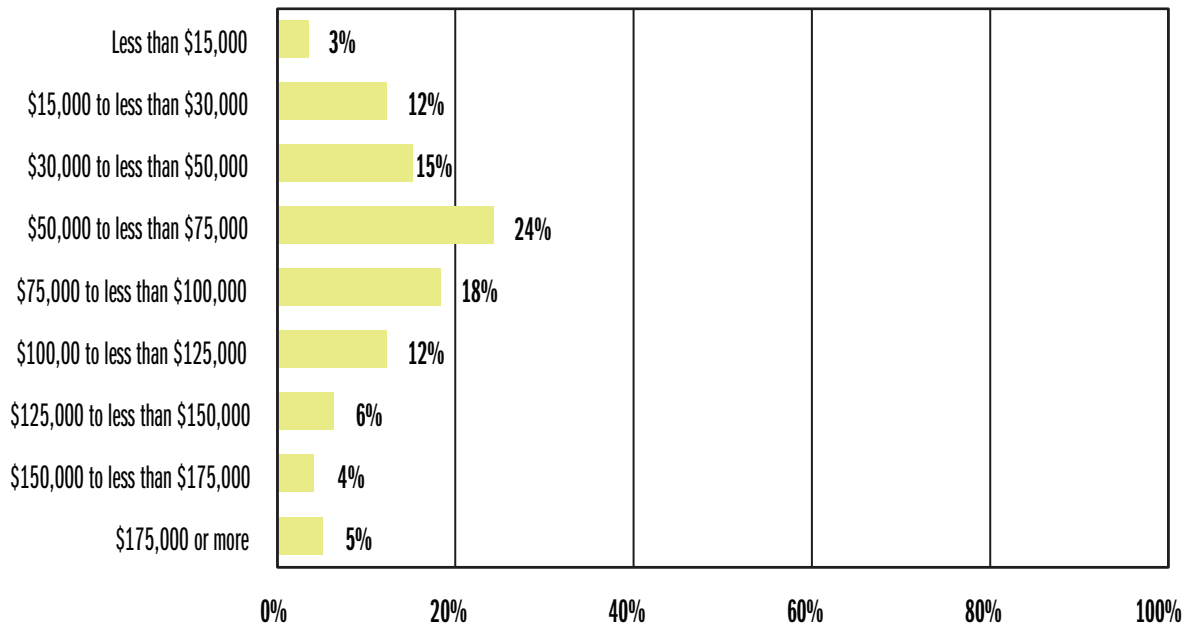


CAREGIVER & CARE RECIPIENT PROFILES

Respondents represent a range of incomes, with the median annual household income being \$79,000.

Figure 2: Respondent Income.

(QF-11. What is your total annual household income?)

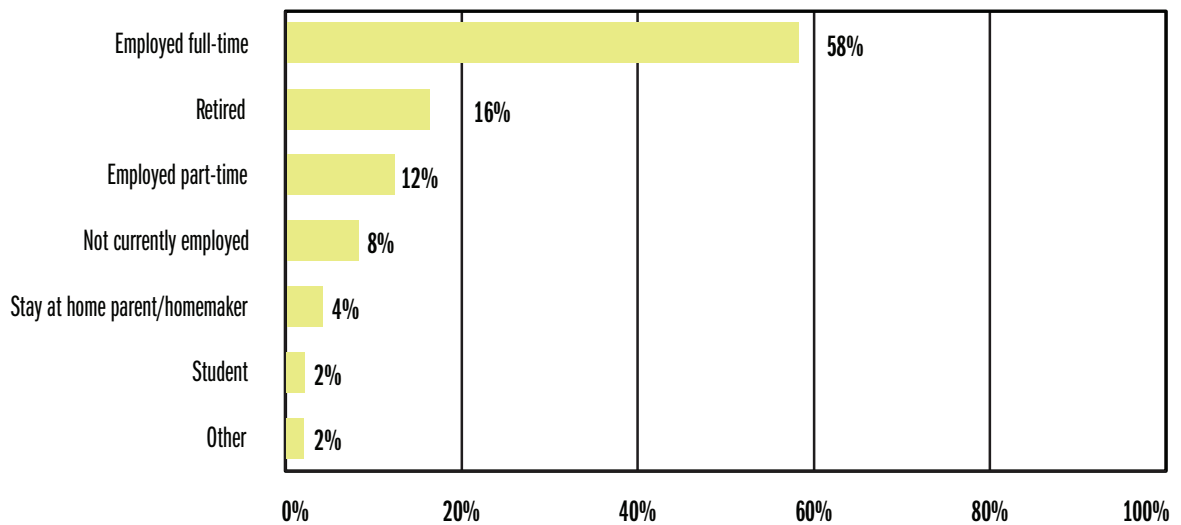


CAREGIVER & CARE RECIPIENT PROFILES

Almost six in ten of the caregivers are employed full-time, with most of the rest representing a mix of retirees, part-time employees, and those not currently employed.

Figure 3: Respondents' Employment.

(QF-10. Which of the following best describes your employment status?)



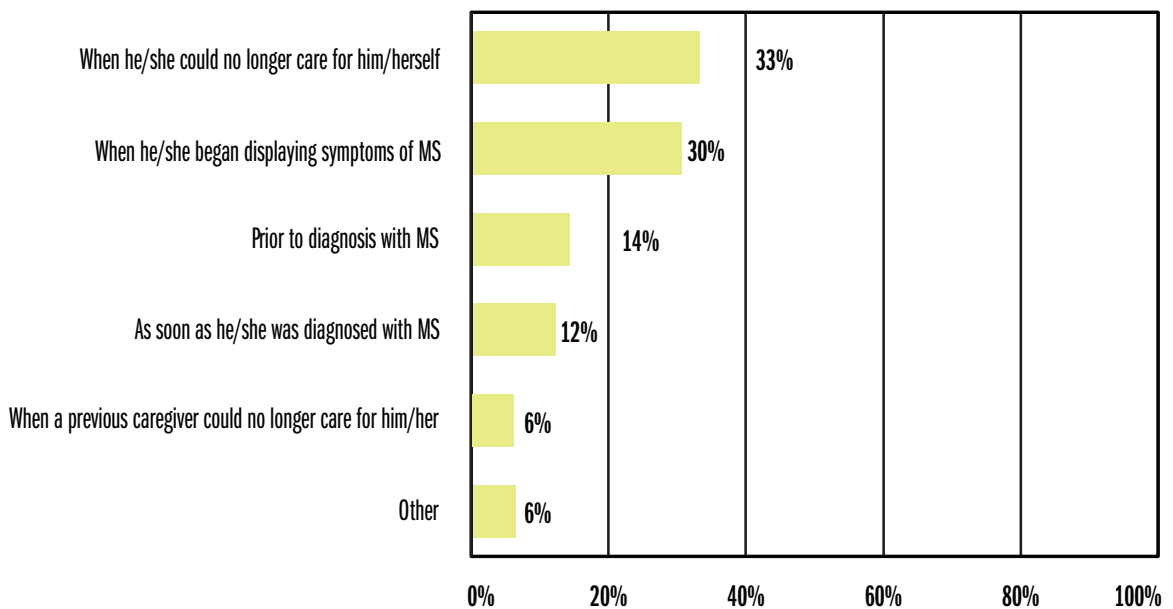
CAREGIVER & CARE RECIPIENT PROFILES

Half of respondents live in the same home as their care recipient. An additional 16% live in the same neighborhood but not in the same home, 11% live in the same town but not in the same neighborhood, 16% live in a nearby town, and 8% live in another town at least an hour away. That 8% would be considered long distance caregivers.

Respondents report beginning to provide care for their care recipient with MS at various stages of their illness. A third began providing care for his or her care recipient when he or she could no longer care for him or herself and another 30% began providing care when he or she began showing symptoms of MS.

Figure 4: Point at Which Respondent Began Providing Care.

(QB-7. At what point did you begin providing care for your care recipient?)



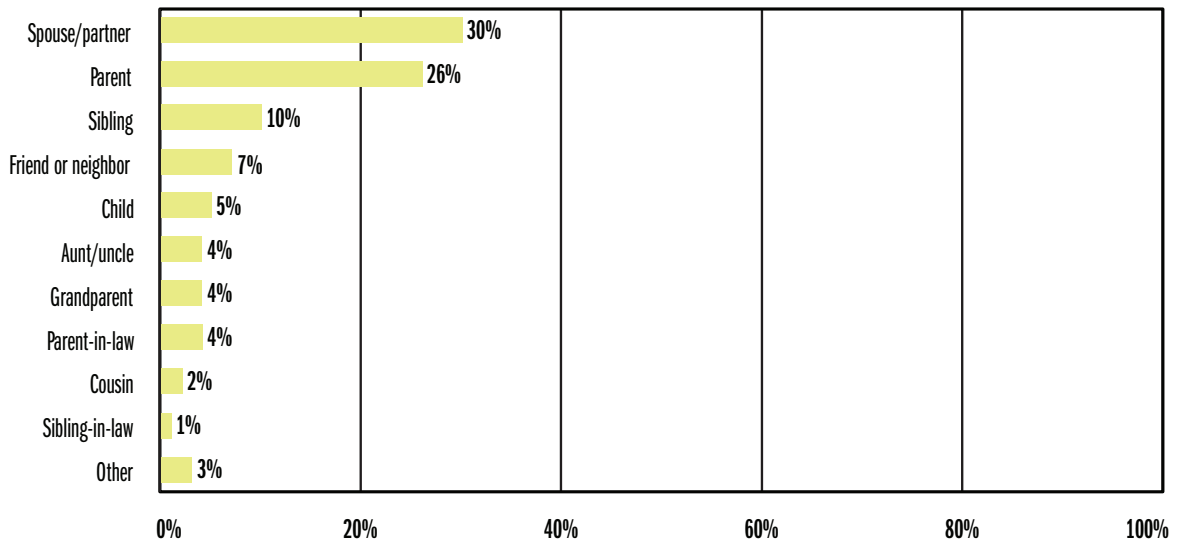
CAREGIVER & CARE RECIPIENT PROFILES

CARE RECIPIENT PROFILE

More than half of the MS caregivers who responded to this survey are providing care to a spouse/partner (30%) or parent (26%). Most of the rest are caring for some other family member and 7% are caring for a friend or neighbor.

Figure 5: Respondent Relationship to Care Recipient.

(QB-1. What is the relationship of your care recipient to you?)



CAREGIVER & CARE RECIPIENT PROFILES

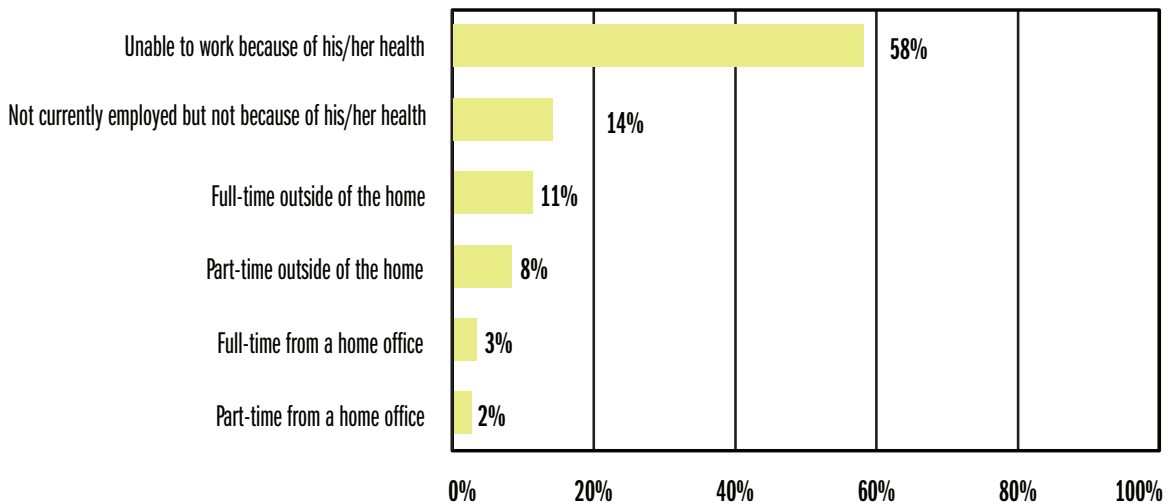
As with caregivers, care recipients skew female, with 68% being female and 32% being male.

The average age of care recipients is older than that of caregivers. Care recipients' ages range from 12 to 89, with the average age of respondent being 57.

Approximately six in ten (58%) of respondents report that their MS care recipient can no longer work because of his or her health. About one in ten (11%) reports that their MS care recipient works full-time outside of the home and an additional 8% work part-time outside of the home.

Figure 6: Care Recipients' Employment.

(QA-11. Which of the following best describes your care recipient's current employment?)



MULTIPLE SCLEROSIS PROBLEMATIC SYMPTOMS

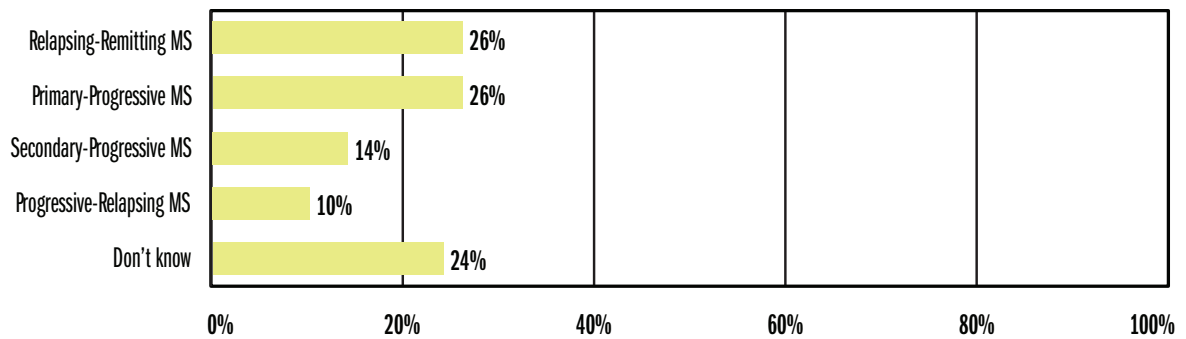
MS typically takes one of four courses, as described by the National MS Society²:

- **Relapsing-Remitting MS:** Those with this type of MS experience clearly defined attacks of worsening neurologic function followed by partial or complete recovery periods during which no disease progression occurs.
- **Primary-Progressive MS:** Unlike with Relapsing-Remitting MS, this disease course features slowly worsening neurologic function from the very beginning of the disease, with no distinct relapses and remissions. The rate of progression may vary over time, with occasional plateaus and temporary minor improvements.
- **Secondary-Progressive MS:** Following an initial period of relapsing-remitting MS, many people with MS develop a secondary-progressive disease course in which the disease worsens more steadily, with or without occasional flare-ups, minor recoveries (remissions), or plateaus.
- **Progressive-Relapsing MS:** Those with this relatively rare course of MS experience steadily worsening disease from the beginning of the disease, but also have clear attacks of worsening neurologic function. These attacks may or may not be followed by some minor recovery, but the disease continues to progress without actual remissions.

Care recipients of survey respondents to this survey represent a range of types of MS.

Figure 7: Types of MS

(QC-1. Which type of MS does your care recipient have?)



² National Multiple Sclerosis Society, “What is Multiple Sclerosis?” (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-is-ms/index.aspx>)

DETAILED FINDINGS

The Disease Steps Scale is a clinical rating scale that provides a straightforward assessment of functional disability in MS primarily based on how well a person with MS walks or moves from place to place.³ Disease Steps are measured on a scale of 0 to 6, with 0 being the least severe disability and 6 being the most severe. There is also an option for respondents to select if none of the options describe their care recipient's functional disability. The following describes each of the different Disease Steps:

- **0 – Normal:** He or she is functionally normal with no limitations on activity or lifestyle.
- **1 – Mild Disability:** He or she has mild but definite symptoms or signs, such as sensory abnormalities, mild bladder impairment, minor incoordination, weakness, or fatigue. There is no visible abnormality of gait.
- **2 – Moderate Disability:** He or she has a visibly abnormal gait, but does not require aids (such as canes or wheelchairs) to get around.
- **3 – Early Cane:** He or she uses a cane (or some other form of unilateral support including splint, brace, or crutch) for longer distances, but is able to walk at least 25 feet without it.
- **4 – Late Cane:** He or she is dependent on a cane or other form of unilateral support and cannot walk 25 feet without such support. He or she may use a scooter for greater distances (e.g., malls).
- **5 – Bilateral Support:** He or she requires bilateral support (e.g., two canes or two crutches or a walker) to walk 25 feet. He or she may use a scooter for greater distances (e.g., malls).
- **6 – Confined to Wheelchair:** He or she is essentially confined to a wheelchair or scooter. (He or she may be able to take a few steps but is unable to walk 25 feet, even with bilateral support.) He or she may also have worsening hand function and/or inability to transfer independently.
- **Unclassified:** None of the above describes his/her medical condition.

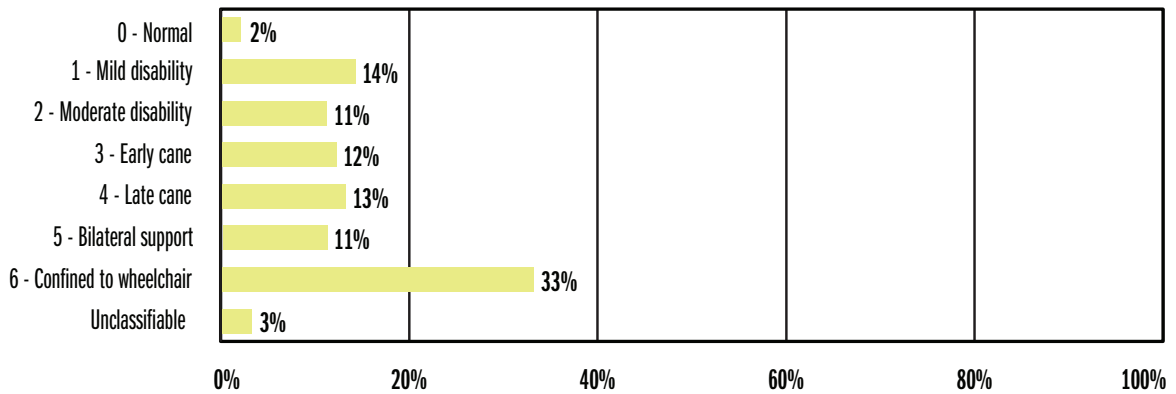
³ Hohol MJ, Orav EJ, Weiner HL. Disease steps in multiple sclerosis: a longitudinal study comparing disease steps and EDSS to evaluate disease progression. *Multiple Sclerosis*. 1999 Oct;5(5):349-54.

DETAILED FINDINGS

Care recipients of survey respondents represent a wide array of Disease Steps, with a third being confined to a wheelchair.

Figure 8: Disease Steps.

(QA-10. Which of the following most closely represents your care recipient's physical condition?)

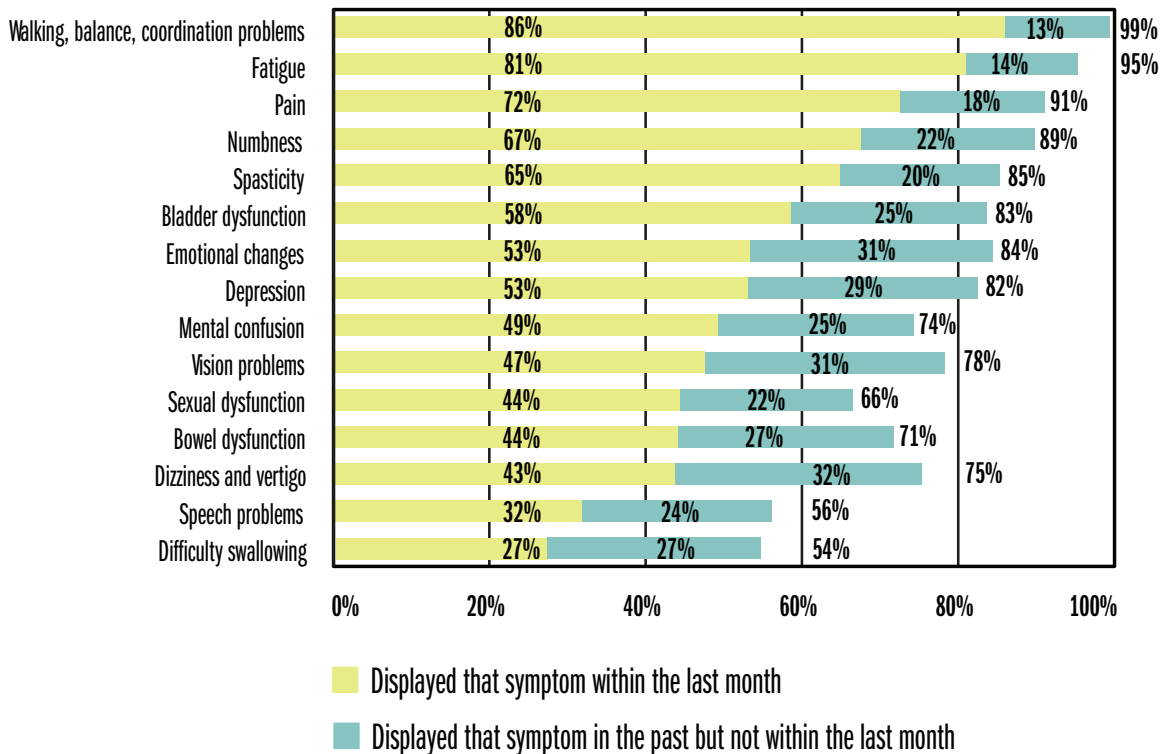


DETAILED FINDINGS

The most common set of symptoms of MS among respondents' care recipients is walking, balance, and coordination problems. In fact, virtually all (99%) of respondents report their MS care recipient has displayed this symptom set—and 86% report their MS care recipient has displayed this symptom set *within the past month*. Speech problems and difficulty swallowing are the least frequently displayed symptoms, with 32% and 27% respectively displaying those symptoms within the last month.

Figure 9: Symptoms of MS.⁴

(QA-8. For each of the following, please indicate if your care recipient has...)



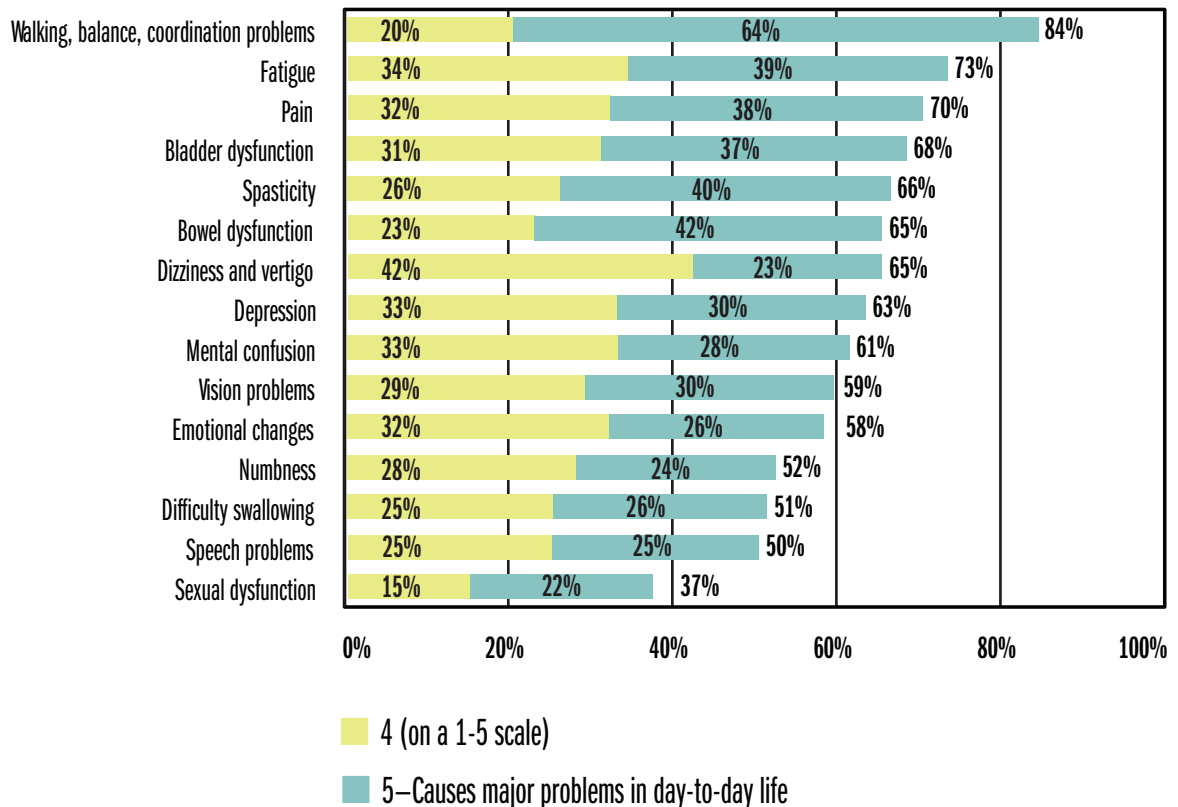
⁴ Spasticity was defined as “involuntary muscle spasms.” The rest of the symptoms were left undefined and were therefore left to respondents’ interpretation.

DETAILED FINDINGS

According to caregivers, in addition to being the most *common* symptom set, walking, balance and coordination problems are also the symptoms that cause the most problems in care recipients' day-to-day life.

Figure 10: Impact of Symptoms on Day-to-Day Life. (Only those who reported problems)

(QA-9. For each of the following, please indicate how much of an impact that symptom has on your care recipient's day-to-day life. Please use a scale from 1 to 5 where "1" means "does not cause a problem at all in day-to-day life" and "5" means "causes major problems in day-to-day life.")



DETAILED FINDINGS

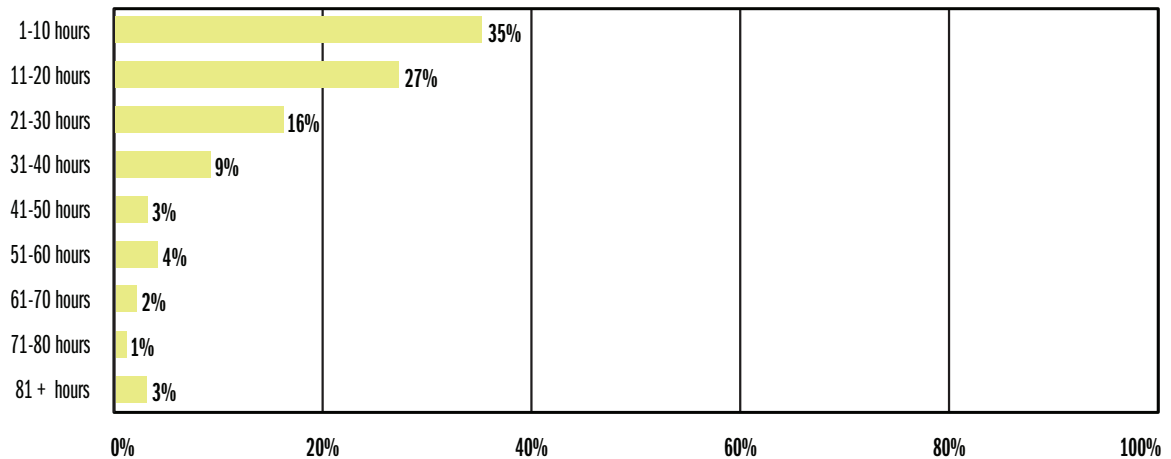
Caregiver respondents also report their care recipient has other health conditions in addition to their MS. Some of the conditions, such as mobility problems (experienced by 40% of the care recipients), cognitive decline (experienced by 20% of the care recipients), and frailty (experienced by 19% of the care recipients) are also symptoms of MS. Others, however, such as diabetes (experienced by 25% of the care recipients), cancer (experienced by 16% of the care recipients), and heart disease (experienced by 16% of the care recipients) appear to be completely independent of MS.

CARE PROVIDED BY FAMILY CAREGIVERS

On average, respondents spend 24 hours each week providing care to their care recipient with MS. Number of hours of care, however, ranges quite substantially, from just one hour per week up to 168 hours—i.e., 24 hours, 7 days a week. More than one in ten (13%) report spending 40 hours or more each week providing care to their care recipient. On average, family caregivers in general spend 19 hours per week providing care.

Figure 11: Hours Spent Providing Care Each Week.

(QB-9. Thinking about all the kinds of help you provide for your care recipient, how many hours do you spend in an average week providing care to him/her?)

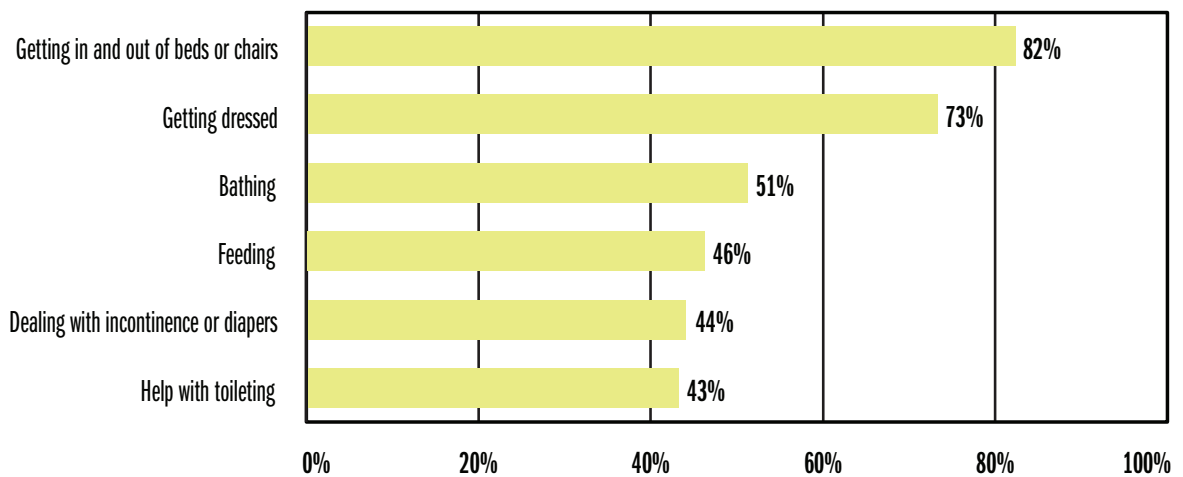


DETAILED FINDINGS

Respondents assist with a number of different Activities of Daily Living, with assistance getting in and out of beds and chairs and assistance getting dressed being the most common.

Figure 12: Activities of Daily Living.

(QA-6. Which of the following kinds of help, if any, have you provided within the last 12 months to the person for whom you care?)

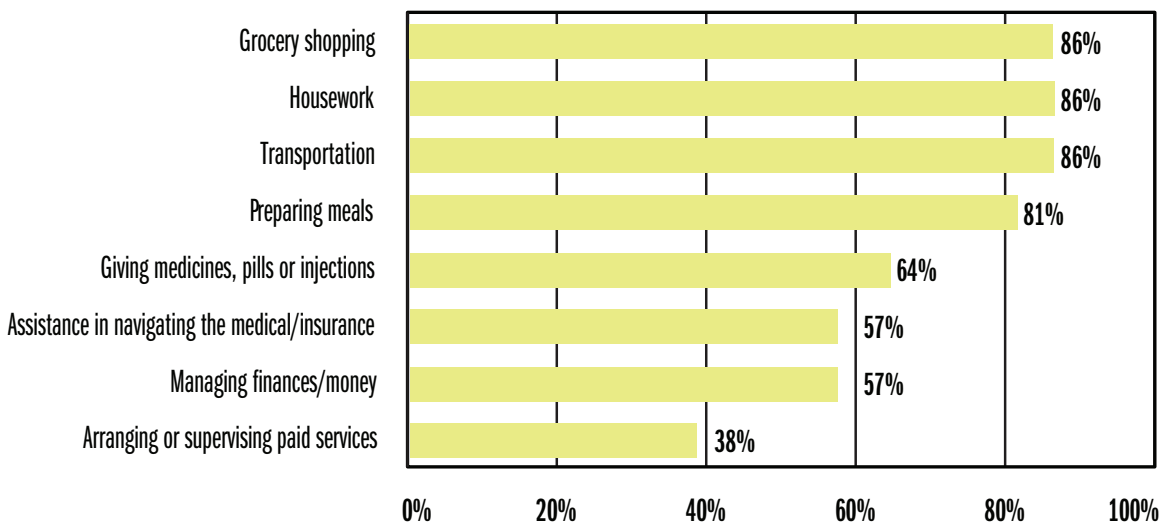


DETAILED FINDINGS

Likewise, respondents also provide assistance with Instrumental Activities of Daily Living. Grocery shopping, housework, transportation, and preparing meals are the most frequently performed IADLs.

Figure 13: Instrumental Activities of Daily Living.

(QA-7. Which of the following kinds of help, if any, have you provided within the last 12 months to the person for whom you care?)



EXTERNAL HELP

While some caregivers provide all of the care for their MS care recipient, many have help providing care—both from other friends and family members and from paid in-home care providers.

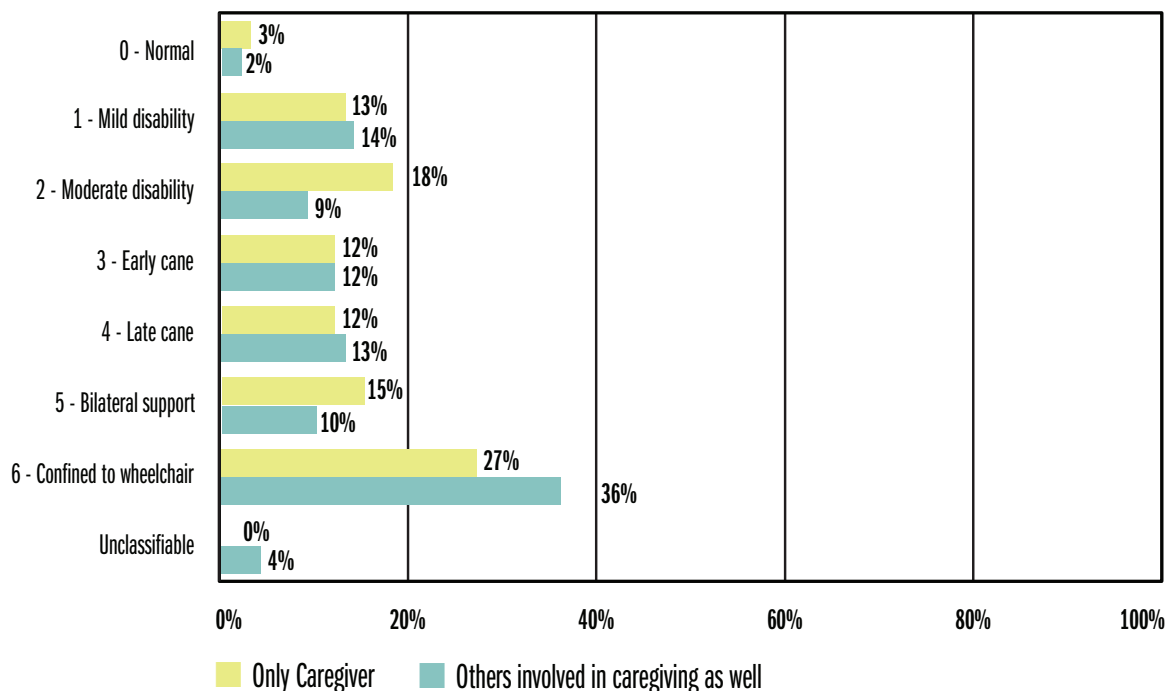
Number of Caregivers

Only about a quarter (27%) of respondents report they are the only caregiver for their care recipient with MS. The rest share responsibilities with others. Slightly more than a third (35%) report they are the primary caregiver, but others provide help as well, 19% report they share caregiving responsibilities equally with a family member or friend or with several others, and 19% report another family members or friend is the primary caregiver.

Those who share responsibility with others tend to be providing care for care recipients in more advanced states of MS. Specifically, 36% of those who share the responsibility of caregiving with others are providing care to someone confined to a wheelchair, whereas only 27% of sole caregivers are providing care to someone confined to a wheelchair.

Figure 14: Disease Steps by Number of Caregivers.

(QA-10. Which of the following most closely represents your care recipient’s physical condition?)



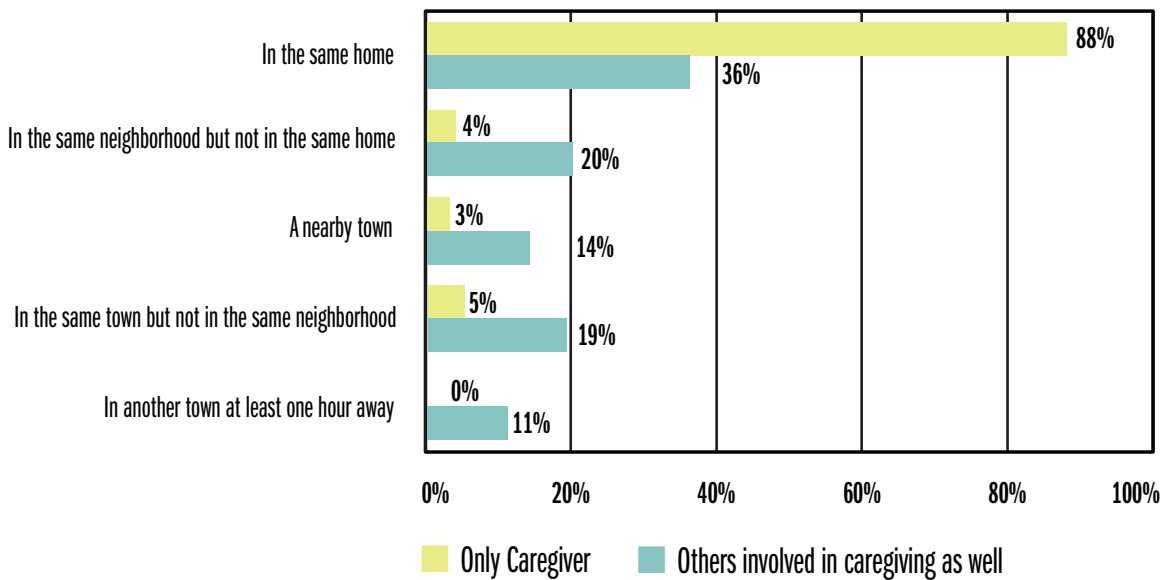
DETAILED FINDINGS

Sole caregivers are also substantially more likely than those sharing caregiving responsibilities to live in the same home as their MS care recipient.

Not surprisingly, those who are the only caregiver for their care recipient spend more hours per week providing care. The mean number of weekly hours of care provided by sole caregivers is 29 hours, whereas the mean number of hours per week of care provided by those who share caregiving responsibility is 22 hours—still a substantial number.

Figure 15: Location of Residence by Number of Caregivers.

(QB-2. Where do you live in relation to your care recipient?)



DETAILED FINDINGS

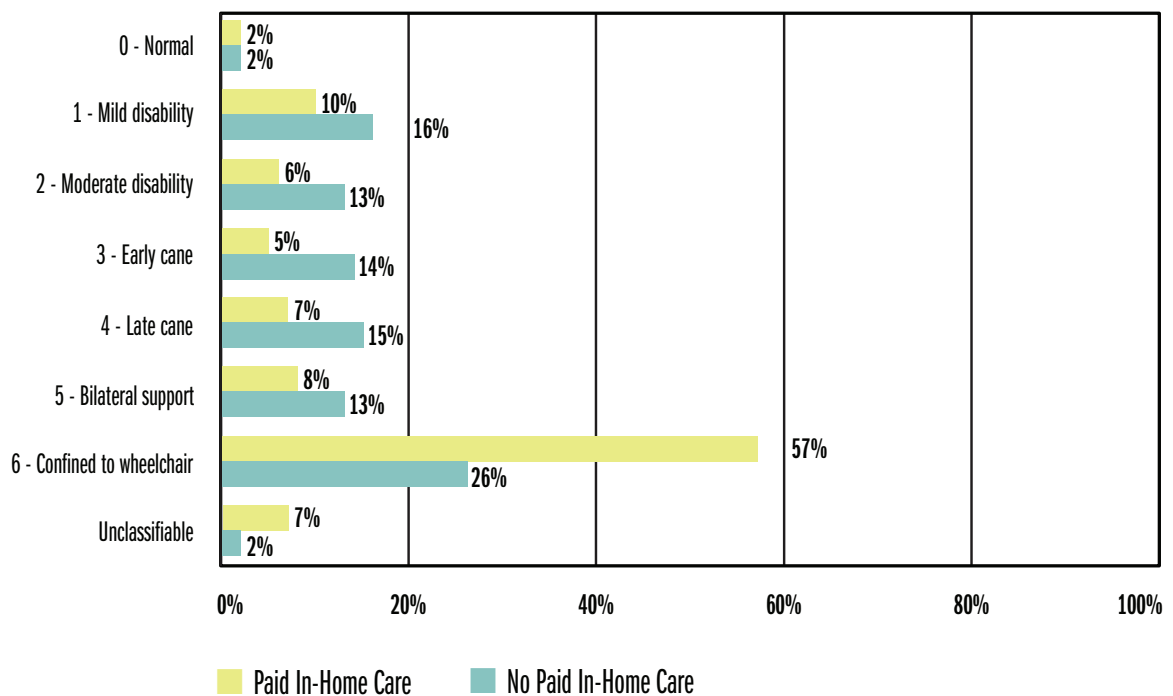
In-Home Paid Care

A quarter of respondents report there is paid in-home care for their care recipient. Those who have paid for in-home care report using different types of care providers—47% of those with paid in-home care use non-medical personnel, such as a housekeeper or companion, 37% used trained professionals, such as an LPN (Licensed Practical Nurse), an LVN (Licensed Vocational Nurse), an RN (Registered Nurse), a Physical Therapist or other registered therapist, and 27% are not sure how to classify their paid in-home care providers.

As with having multiple family caregivers, those with paid in-home care are generally providing care to those with more advanced MS.

Figure 16: Disease Steps by Paid In-Home Care.

(QA-10. Which of the following most closely represents your care recipient's physical condition?)

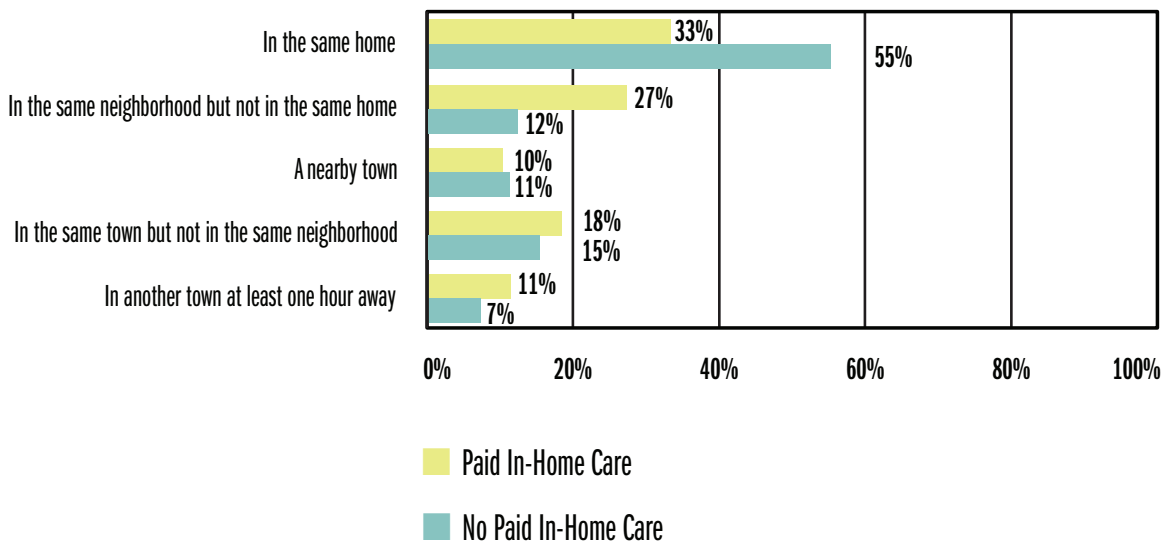


DETAILED FINDINGS

Those with paid in-home care are less likely to live in the same home as their care recipient.

Figure 17: Location of Residence by Paid In-Home Care.

(QB-2. *Where do you live in relation to your care recipient?*)



The number of hours spent providing care is similar between those who have paid in-home care and those who do not. This implies that family caregivers are using paid in-home care as a *supplement* to their own care and not as a replacement.

DETAILED FINDINGS

IMPACTS ON CAREGIVER

People living with MS are not the only ones impacted by the disease. Their friends and family, and, more specifically, their caregivers are also greatly impacted. These impacts include emotional impacts upon initial diagnosis with the disease and ongoing impacts on their day-to-day lives.

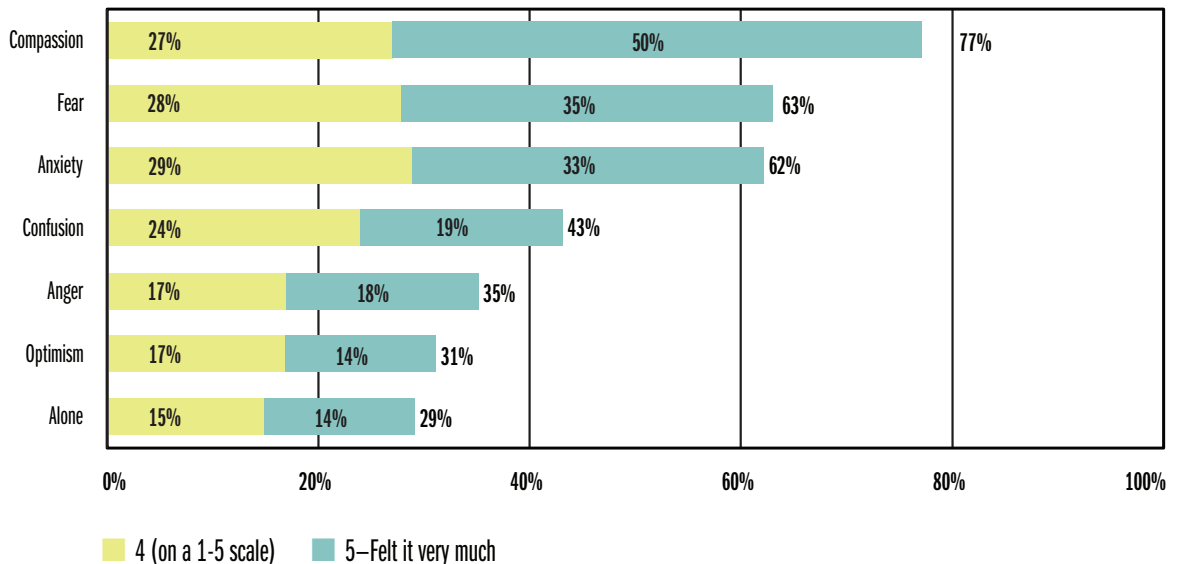
Emotional Impacts

Receiving a diagnosis of MS can have an enormous emotional impact on both the person with MS and his or her loved ones. MS caregivers report feeling a mixture of different emotions—both positive and negative—upon their care recipients’ initial diagnosis with MS.

The majority (77%) of respondents report they felt compassion when their care recipient was first diagnosed with MS. Many also felt fear and anxiety.

Figure 18: Caregiver Emotions Upon Care recipients’ Diagnosis with MS. (Only includes those who reported that they felt emotion)

(QB-5. Thinking back to when your care recipient was first diagnosed with MS, to what extent did you feel each of the following? Please use a scale of 1 to 5 where “1” means “did not feel it at all” and “5” means “feel it very much.”)



DETAILED FINDINGS

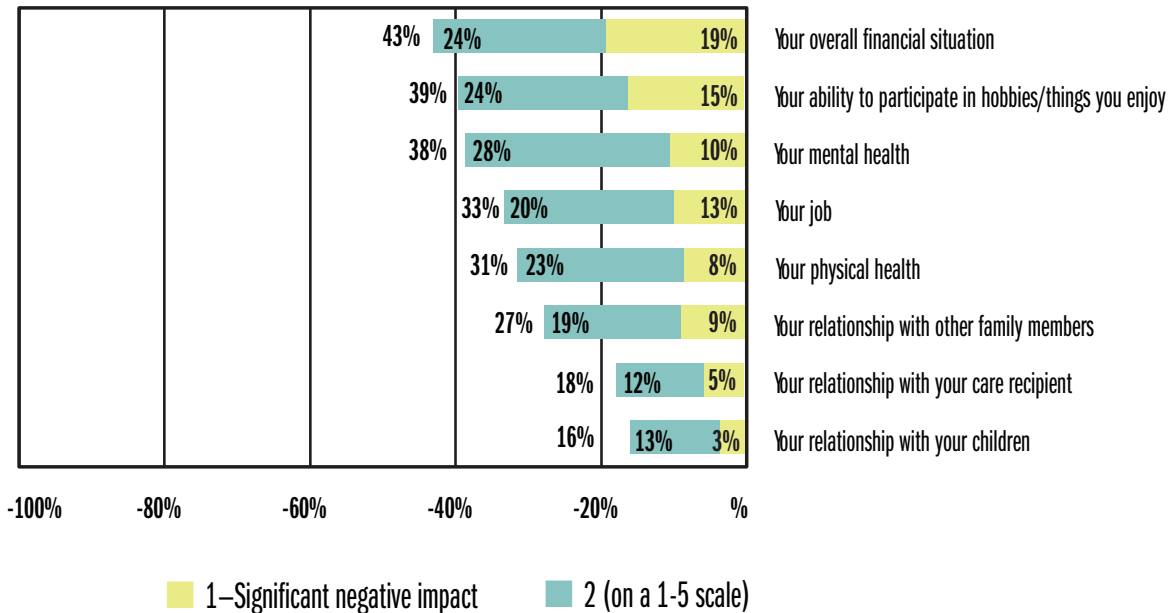
Impacts from Providing Care

Providing care to someone with MS has different impacts on the life of the caregiver. Some caregivers report mostly negative impacts, whereas others report positive impacts on their life.

Approximately four in ten respondents report that providing care to someone with MS has *negatively* impacted their financial situation (43%), ability to participate in hobbies/things they enjoy (39%), and their mental health (38%). Others also feel negative impacts on their job, physical health, relationships with other family members, relationship with their care recipient, and relationship with their children.

Figure 19: Negative Impacts on MS Caregivers. (Only includes those who reported negative impact)

(QC-4. To what extent has being a caregiver to someone living with MS impacted each of the following? Please use a scale of 1 to 5 where “1” means “had a significant negative impact” and “5” means “had a significant positive impact.”)



DETAILED FINDINGS

The specific impacts vary substantially by caregiver. Those who rated a “1” or a “5” on a scale of 1 to 5 where “1” means “significant negative impact” and “5” means “significant positive impact” were asked to give further details on what specifically was impacted. The following table shows the specific negative impacts as well as the percentage of respondents (among those who were asked each question) who report experiencing that impact.

Figure 20: Specific Caregiver Impacts.

OVERALL FINANCIAL SITUATION

I haven't been able to save as much money as I would have liked had I not been a caregiver	57%
Lost money because of negative impacts on my job	36%

HOBBIES AND THINGS HE/SHE LIKE TO DO

I no longer have time to do things I enjoy	57%
I no longer have enough money to do things I enjoy	36%

MENTAL HEALTH

I am often emotionally drained because of providing care	64%
I am extremely anxious because of providing care	34%
I suffer from depression because of providing care	32%

JOB

I make less money because of caregiving	38%
I can't dedicate as much time as I'd like to my job because of caregiving responsibilities	34%
Caregiving makes it hard to travel for my job	31%
I've been overlooked for promotions because of caregiving	25%
I can't focus on my job because of caregiving responsibilities	25%
I'm often late for work because of caregiving	23%
I have to miss a lot of days because of caregiving	23%
I've lost a job because of caregiving	22%
I'm unable to hold down a job because of caregiving responsibilities	17%

PHYSICAL HEALTH

I get physically exhausted from providing care	49%
I've received physical injuries as a direct result of providing care (e.g., injured myself lifting my care recipient, etc.)	31%
I get sick more frequently than before I provided care	19%

RELATIONSHIP WITH CARE RECIPIENT

I sometimes get frustrated with my care recipient	42%
My care recipient feels guilty that I have to provide his/her care	38%
We tend to argue a lot	14%

RELATIONSHIP WITH OTHER FAMILY MEMBERS

I don't have enough time to spend with other family members	27%
It causes tension over who will pay for care	22%
We argue about how best to provide care	20%
It causes tension over who will provide care	19%

RELATIONSHIP WITH CHILDREN

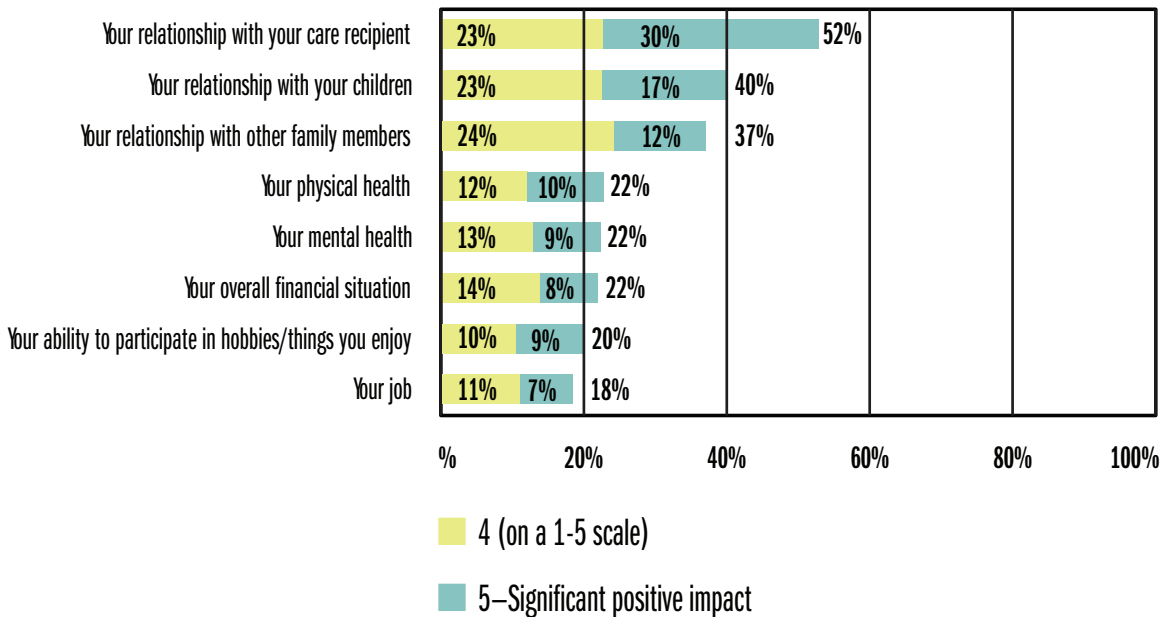
I can't spend enough time as I'd like with them	19%
They are resentful that I spend time providing care	14%
They are angry that I can't spend enough time with them	12%

DETAILED FINDINGS

Whereas many MS caregivers experience negative impacts from providing care to their care recipient with MS, many others experience positive impacts. The biggest positive impacts relate to relationships—with the care recipient (52%), the children of the caregiver (40%), and other family members (37%).

Figure 21: Positive Impacts on MS Caregivers. (Includes those reporting positive impacts)

(QC-4. To what extent has being a caregiver to someone living with MS impacted each of the following? Please use a scale of 1 to 5 where “1” means “had a significant negative impact” and “5” means “had a significant positive impact.”)



DETAILED FINDINGS

Becoming closer with the care recipient and other family members is the most frequently cited positive impact. Approximately three-quarters (74%) of those who say their relationship with their care recipient was significantly impacted say it made them closer with their care recipient, and 47% of those who say their relationship with other families was significantly impacted say it made them closer with those other family members. Slightly more than half (56%) of those who say their relationship with their children has been significantly impacted by providing care report that their children have learned responsibilities by helping them provide care and 47% report that their children have learned patience by helping them provide care.

In terms of health, 36% of those who say their physical health has been significantly impacted say they are in better shape now that they're a caregiver, 25% say that they find providing care very emotionally rewarding, and 22% say they now have a better outlook on life.

Approximately one in five (21%) of those respondents who report their overall financial situation has been impacted by being a caregiver say that they have actually been able to save more money than if they had not been a caregiver. Almost one in five (19%) of those who say their hobbies/ things they like to do have been impacted say that they have found new hobbies that they can enjoy with their care recipient, 15% now have more time to do the things they enjoy, and 8% now have more money to do the things they enjoy. Finally, almost half (45%) of those saying their job has been significantly impacted say that caregiving has taught them new skills (including things like patience) that they use on the job.

CHOICE IN PROVIDING CARE

Depending on the situation, caregivers may or may not feel they actually have a choice in providing care for their care recipient. In fact, almost half (48%) of respondents feel they did not have a choice in taking on the responsibility for caring for their care recipient with MS. Lack of choice has been shown to be a factor in caregiver stress.

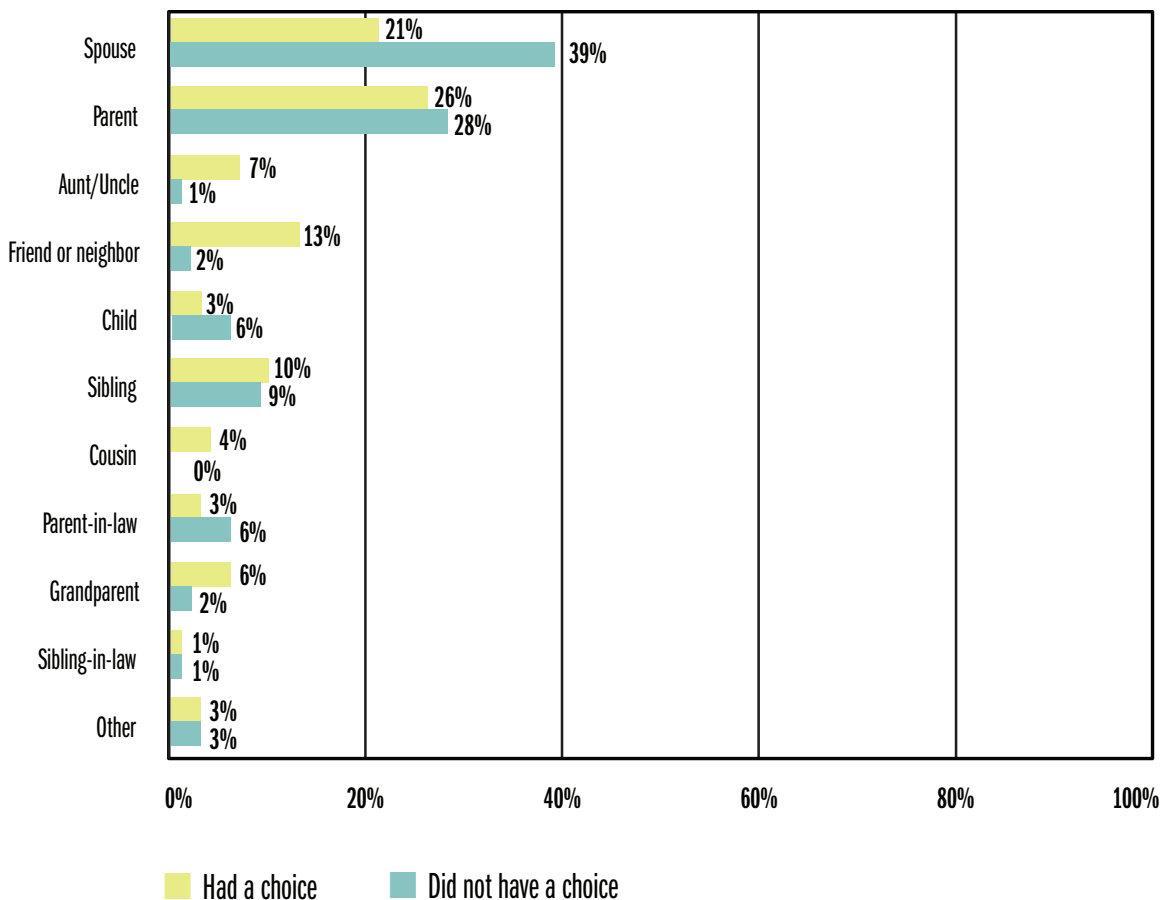
Care recipients of those who do not feel they have a choice in providing care generally have more severe disabilities. Four in ten of those who feel they do not have a choice in providing care are caring for someone who is confined to a wheelchair, as compared to only 27% of those who feel they have a choice in providing care.

DETAILED FINDINGS

Not surprisingly, those who feel they do not have a choice in providing care are more likely to be caring for a spouse than caring for someone of another relationship. Almost four in ten (39%) of those who feel they did not have a choice in providing care are caring for a spouse, as compared to only 21% of those who feel they have a choice in providing care. In contrast, those who feel they had a choice in whether or not they would be a caregiver are more likely than those who feel they did not have a choice to be caring for a friend or neighbor.

Figure 22: Relationship with Care Recipient by Choice in Providing Care.

(QB-1. What is the relationship of your care recipient to you?)



DETAILED FINDINGS

Those who feel they had a choice in whether or not they would provide care to their care recipient with MS generally feel less negative impacts and more positive impacts than those who feel they did not have a choice.

Figure 23: Caregiver Impacts by Choice in Providing Care.

(QC-4a. To what extent has being a caregiver to someone living with MS impacted each of the following.)

	PERCENTAGE FEELING NEGATIVE IMPACT		PERCENTAGE FEELING POSITIVE IMPACT	
	Among those who had a choice in providing care	Among those who did not have a choice in providing care	Among those who had a choice in providing care	Among those who did not have a choice in providing care
Your overall financial situation	32%*	54%*	27%	15%
Your ability to participate in hobbies/ things you enjoy	29%*	48%*	28%*	12%*
Your mental health	26%*	51%*	29%	14%
Your physical health	21%	41%	31%*	13%*
Your job	20%*	45%*	25%*	10%*
Your relationship with other family members	20%*	36%*	49%*	24%*
Your relationship with your children	15%	16%	47%	31%
Your relationship with your care recipient	13%	23%	65%*	39%*

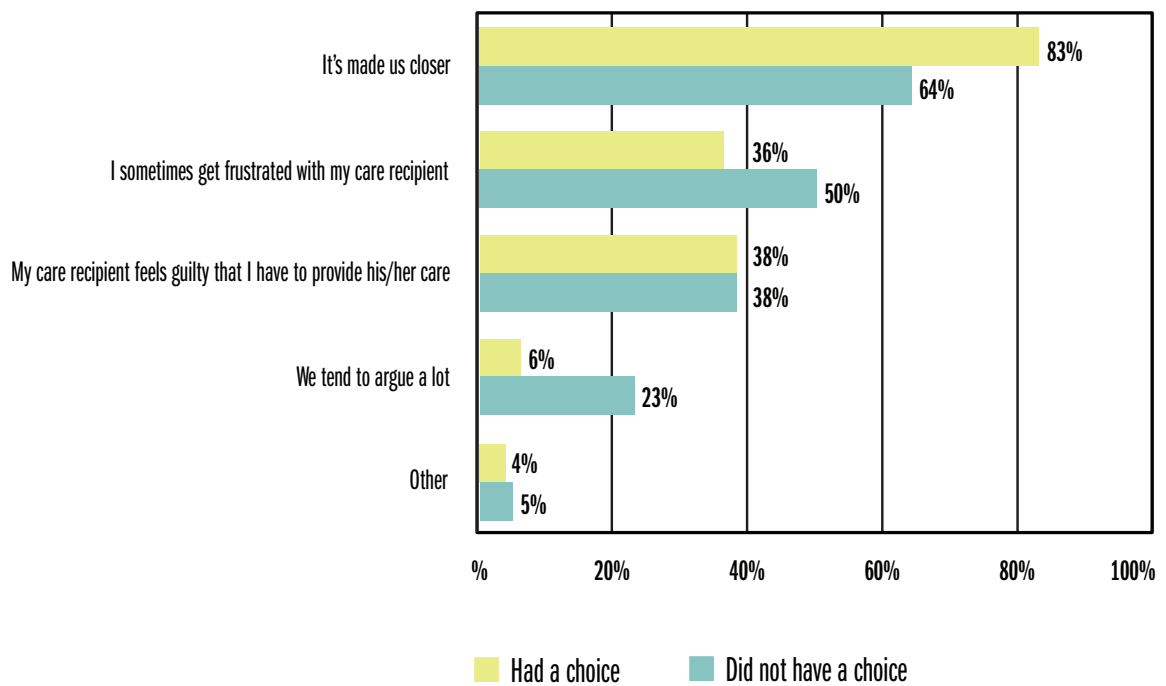
* Statistically significant at the 95% confidence interval.

DETAILED FINDINGS

There are also substantial differences on specific impacts within each of the categories. For example, those who feel they did not have a choice in providing care are much more likely than those with a choice to get frustrated and argue with their care recipient. They are also *less* likely to feel as though providing care has made them closer with their care recipient.

Figure 24: Specific Impacts on Relationship with Care Recipient by Choice in Providing Care.

(QC-5b. In what way has being a caregiver to someone with MS impacted your relationship with your care recipient?)

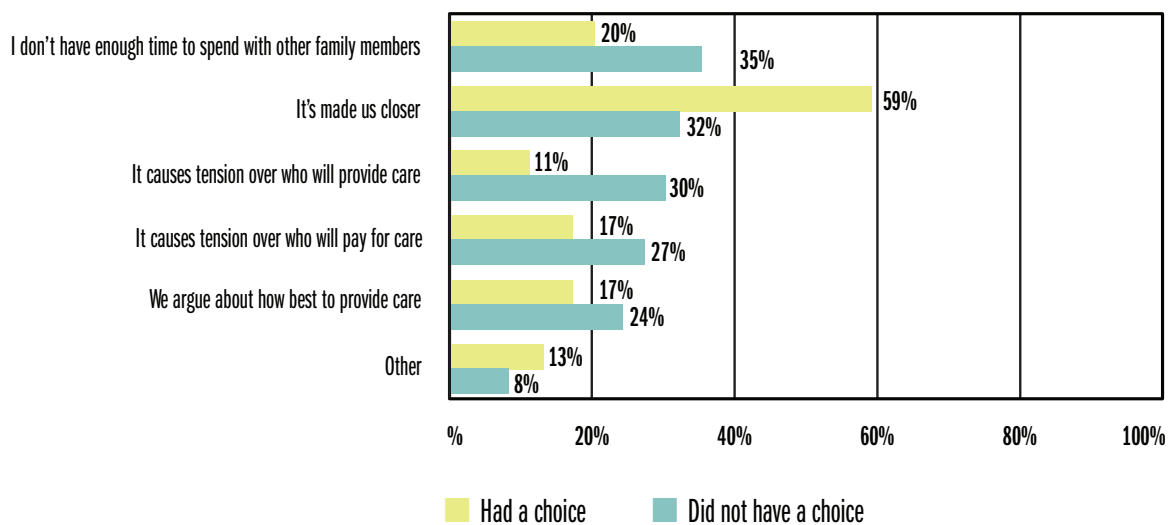


DETAILED FINDINGS

Likewise, those who believe they did not have a choice in providing care also see more negative effects and less positive effects in their relationships with other family members.

Figure 25: Specific Impacts on Relationship with Other Family Members by Choice in Providing Care.

(QC-5c. In what way has being a caregiver to someone with MS impacted your relationship with other family members?)



■ DETAILED FINDINGS

Those who did not have a choice in providing care are substantially more likely than those who did have a choice to say that they no longer have the time to do things they enjoy (73% vs. 37%). Those without a choice in providing care are also *less* likely to report positive impacts on their hobbies, such as finding new hobbies they can enjoy with their care recipient, having more time to do the things they enjoy, and having more money to do the things they enjoy.

Those who had a choice in providing care are also three times as likely as those who did not have a choice to report being able to save money because they're a caregiver (35% vs. 13%).

Finally, those who did not have a choice in providing care for their care recipient with MS are more likely to feel an emotional impact of providing care. Over three-quarters (78%) of those who did not have a choice in providing care report they often feel emotionally drained because of providing care, as compared to only 49% of those who did have a choice.

DETAILED FINDINGS

COGNITIVE IMPAIRMENT

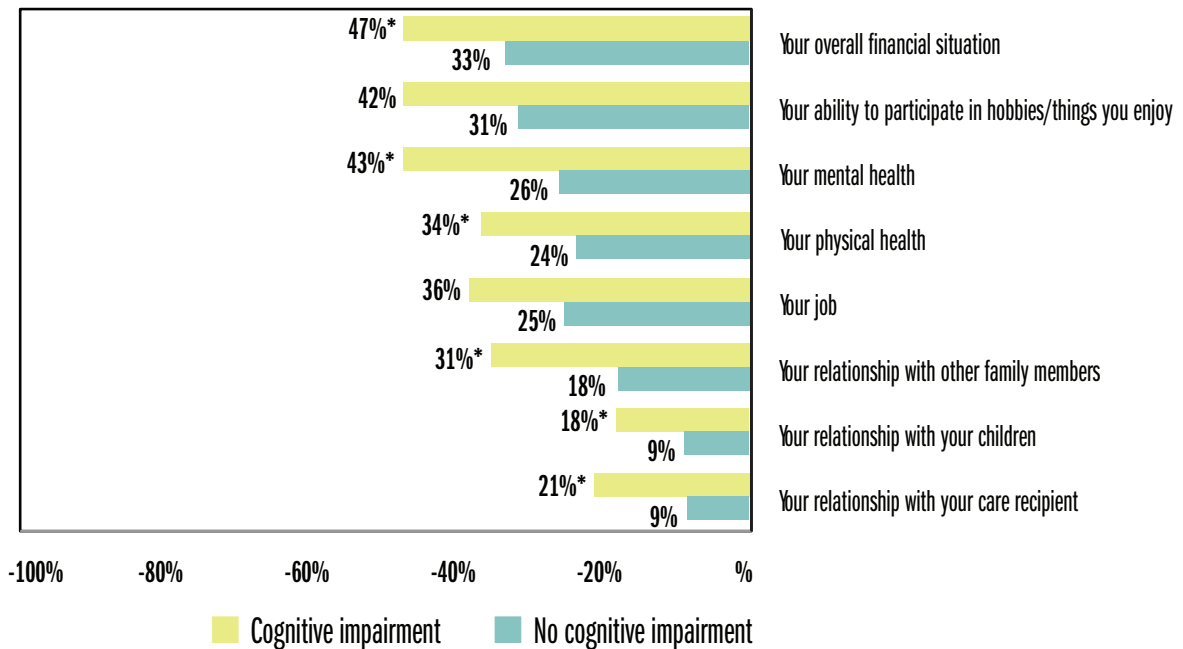
Apart from the physical manifestations of MS, there are frequently cognitive or emotional impacts to the person living with MS. As is indicated in Figure 9, 53% of care recipients displayed emotional changes within the past month, 53% displayed depression, and 49% displayed mental confusion. Together, almost three-quarters (71%) of care recipients displayed one of these three cognitive or emotional impacts. (The survey allowed respondents to define “mental confusion,” “emotional changes,” and “depression” as they perceived them. For purposes of analysis, care recipients who had one or more of these three symptoms were grouped into a “cognitive impairment” category.)

Survey results indicate that those care recipients caring for someone with cognitive impairment are significantly more likely to feel negative impacts as a result of their caregiving.

Figure 26: Negative Impacts by Cognitive Impairment.

(QC-4. To what extent has being a caregiver to someone living with MS impacted each of the following? Please use a scale of 1 to 5 where “1” means “had a significant negative impact” and “5” means “had a significant positive impact.”)

NOTE: Graph shows those rating the impact on that element a 1 or 2. *Indicates statistically significant differences.



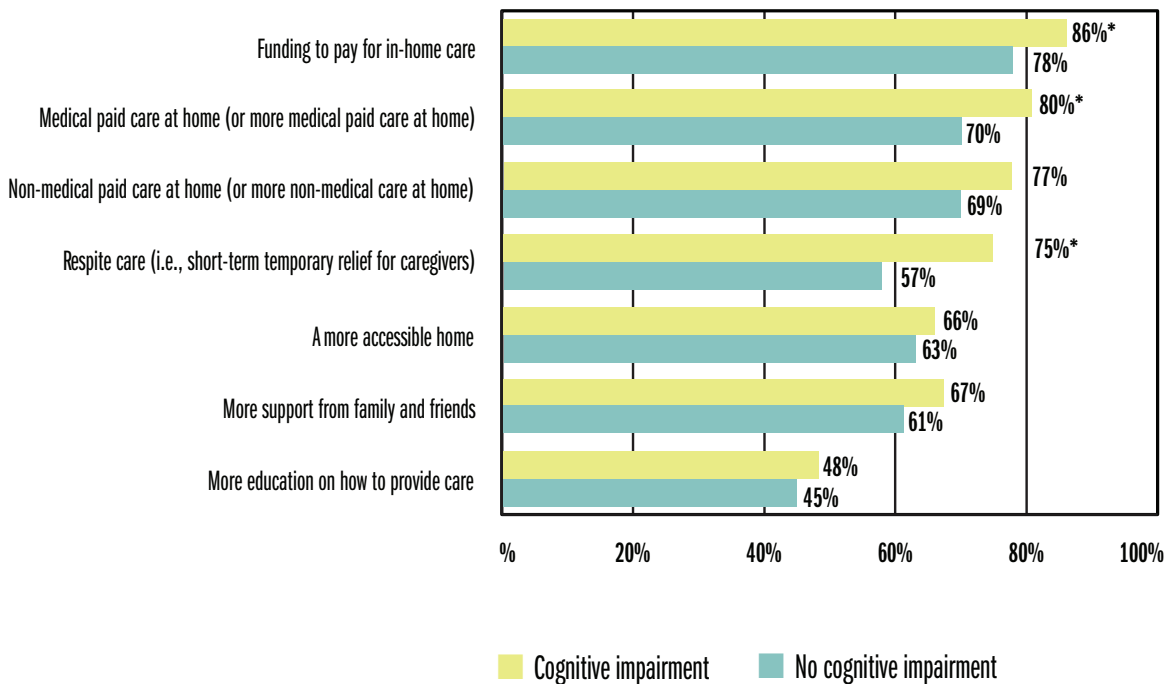
DETAILED FINDINGS

Furthermore, those caring for someone with cognitive impairment also need more help keeping their care recipient at home. For example, those caring for someone with cognitive impairment are more likely to say that they would find funding to pay for in-home care, medical paid care at home, and respite care helpful.

Figure 27: Help needed by cognitive impairment.

(QD-4. To what extent would each of the following help you take care of your care recipient in his/her own home so that he/she does not have to go to a long-term care facility? Please use a scale of 1 to 5 where “1” means “would not help me at all” and “5” means “would help me a lot.”)

NOTE: Graph shows those rating the helpfulness of that element a 4 or 5. *Indicates statistically significant differences.



INFORMATION SOURCES AND TECHNOLOGY

As indicated earlier, many caregivers felt fear, anxiety, and confusion upon their care recipient's diagnosis with MS. One way to alleviate such uncertainty is to seek more information on the topic. Many caregivers turn to technology as a way to get this information. Technology can be a tool for both educating caregivers regarding the disease of MS, as well as giving them specific tips and tools for providing care to someone with MS.

Results indicate that the Internet is frequently used by caregivers as a source of information—both information regarding MS in general and information regarding providing care for someone with MS.⁵ Almost all (95%) of respondents indicate they sometimes search online for information regarding MS in general and 85% indicate they sometimes search online for information regarding caring for someone with MS. Almost three-quarters (72%) read websites or blogs dedicated to MS caregiving. (Since this was an on-line survey, all respondents were on the Internet)

Respondents also report getting information from materials provided by the care recipient's doctor—82% read materials regarding MS in general that their care recipient's doctor supplied and 74% read materials regarding caring for someone with MS that their care recipient's doctor supplied.

Almost half report participating in support groups—46% report having participated in online support groups for those caring for someone with MS and 43% report having attended in-person support groups.

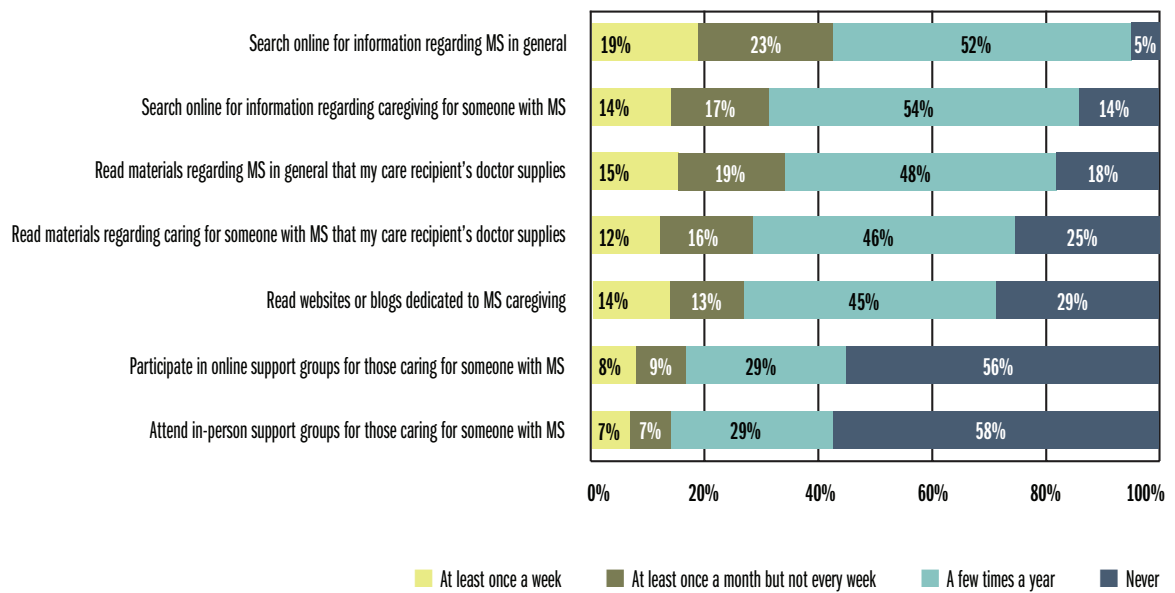
Frequency of use varies across different sources. Some respondents report using individual information sources very frequently (i.e., at least once a week), while others report using them much less frequently (i.e., a few times a year or less).

⁵ Since the survey was conducted online, it can be assumed that all respondents have internet access and know how to use a computer.

DETAILED FINDINGS

Figure 28: Usage of Internet and Support Systems.

(QE-1. How frequently do you currently do each of the following? Please indicate if you do it...)

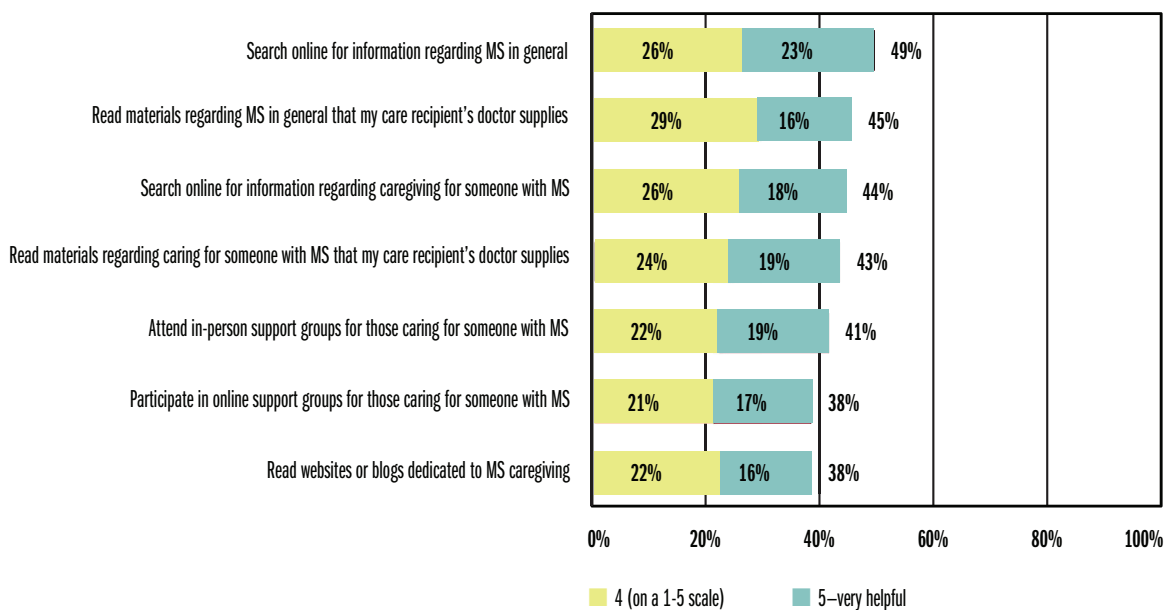


DETAILED FINDINGS

There may, however, be an opportunity for improving upon these sources of information. Of those who use a given source of information, slightly less than half find them helpful. There is little difference in helpfulness ratings between different sources.

Figure 29: Helpfulness of Information Sources. (Only includes those who reported sources as helpful)

(QE-2. How helpful have each of the following been to you as a caregiver for someone living with MS? Please use a scale of 1 to 5 where “1” means “not at all helpful” and “5” means “very helpful.”)



Those who are not currently using the information sources typically do not believe they would be very helpful. Only between 17% and 25% feel as though a given source would be helpful for them as a caregiver for someone living with MS.

With aging-in-place technology rapidly evolving and access to new tools and resources growing thanks to the Internet, the survey also tested three new potential caregiving technologies to gauge usage and interest in these technologies. Potential caregiving technologies tested include:

- **Caregiver training via the Internet** – Online training modules on topics that would help you care for your care recipient at home. Topics would include both physical and behavioral aspects of providing care.
- **Caregiving coordination system** – A shared electronic log for your care recipient’s doctor appointments and other caregiving needs, and the dates and times that each family member or friend is scheduled to help. You can use the system to request a volunteer for a certain time and family/friends can use it to sign up to help.
- **Medication support system** – A device that reminds the patient and dispenses pills when they should be taken. Electronic buttons can be pressed for directions on how to take each pill (e.g., on a full stomach, avoid certain types of foods) and possible side effects to watch out for. It also alerts the caregiver by phone or email if a dosage is not removed from the device within a certain time period.

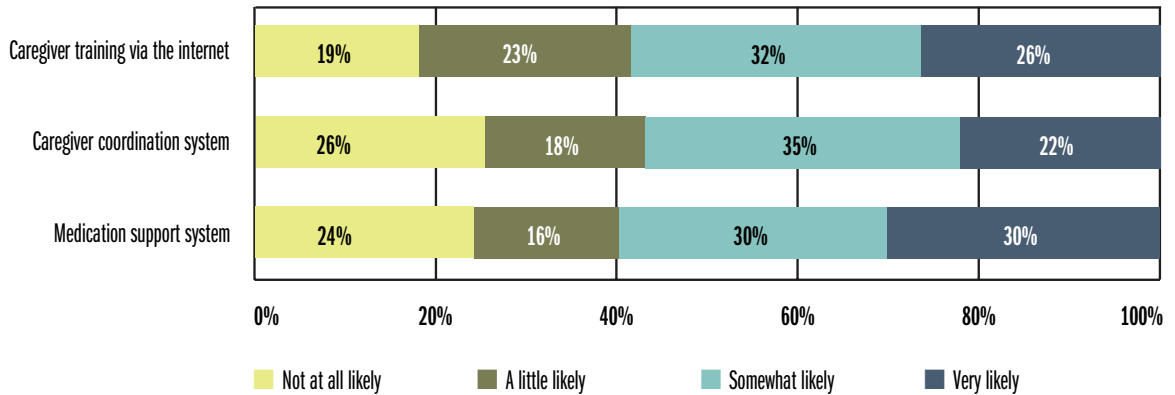
Few respondents report that they currently use these caregiving technologies. In fact, only 5% use medication support systems, 3% use caregiver training via the Internet, and 3% use caregiving coordination systems.

These technologies, however, do hold a great deal of promise. Assuming the technology were available to them for a nominal cost, about six in ten respondents report that they are at least “somewhat likely” to use each of the technologies. All three technologies received approximately equal likelihood of use ratings.

DETAILED FINDINGS

Figure 30: Likelihood of using new technologies.

(QE-4. Next, we will ask your opinion of three different technologies available to help caregivers. Please consider each one separately, and indicate your reaction to each. Thinking about the last few months that you have provided care, how likely would you be to use this caregiving technology if it were available for a nominal cost?)



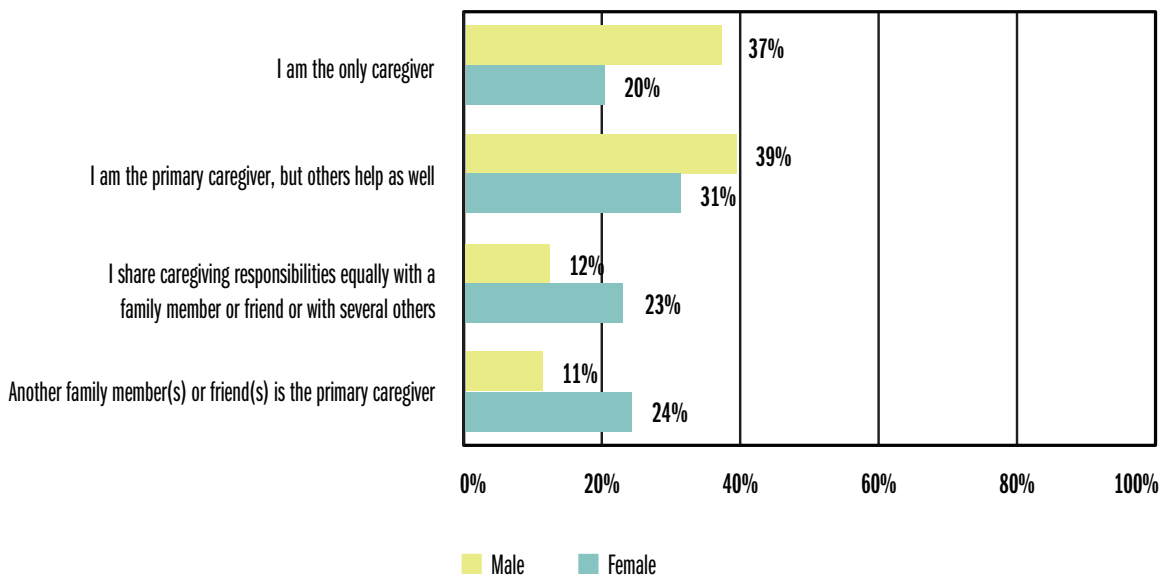
GENDER

As with many other autoimmune diseases, MS is two to three times more common among women than among men.⁶ Male spouses thus frequently find themselves in the role of primary caregiver, which is the reverse to the gender distribution of caregivers of many other ailments.

As expected, male respondents in this survey are more likely than female caregivers to be providing care to a spouse. In fact, almost half (47%) of male respondents report their care recipient is their wife or partner, whereas only 19% of female respondents report their care recipient is their husband or partner. Therefore not surprisingly, male caregivers are also more likely than female caregivers to live in the same home as their care recipient (60% vs. 43%). Male caregivers are also more likely to be the only or primary caregiver than are female caregivers, but are equally as likely as female caregivers to have paid in-home care.

Figure 31: Shared Caregiver Responsibilities by Gender.

(QB-10. Which one of the following best describes the distribution of responsibilities among you and other family members/friends?)



⁶ National Multiple Sclerosis Society, "Who Gets MS?" (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx>)

DETAILED FINDINGS

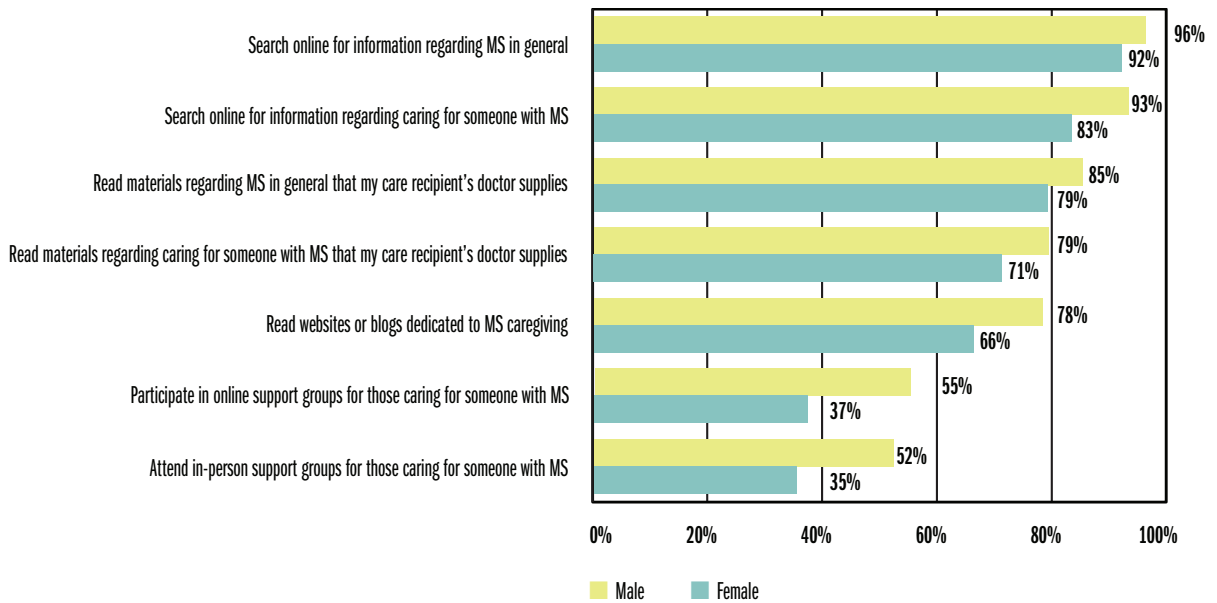
There are, however, many similarities between male caregivers and female caregivers. Men and women are equally as likely to feel they had a choice in providing care to their care recipient. Men and woman also experience similar negative impacts and similar positive impacts from providing care to their MS care recipient.

Men, however, tend to use a number of information sources more frequently than do women. For example, men are more likely to search online for information regarding caring for someone with MS, to read websites or blogs dedicated to MS caregiving, to participate in online support groups for those caring for someone with MS, and to attend in-person support groups for those caring for someone with MS. This last fact is especially interesting since male caregivers are generally less often participants in in-person support groups.

Figure 32: Information Sources Used by Gender.

(QE-1. How frequently do you currently do each of the following...?)

NOTE: Graph shows percentage *ever* using that information source.



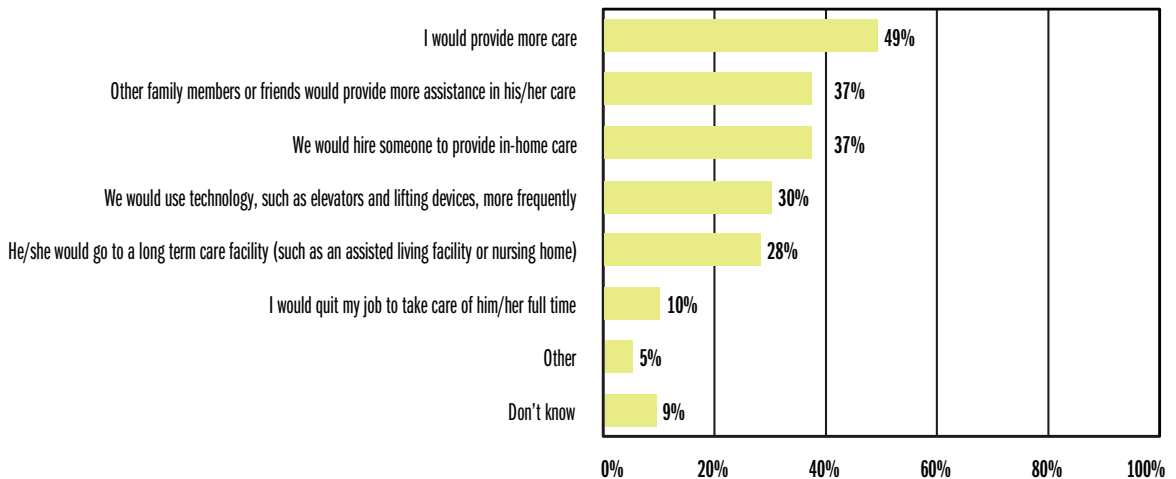
LONG-TERM CARE FACILITIES

Eventually, about a quarter of people with MS will need long term care.⁷ One of the key topics of interest of this survey was to examine the triggering events for moving into a long-term care facility and to better understand what resources or tools could help family caregivers keep their care recipient with MS in the home longer.

Whereas approximately half (49%) of respondents say that if their care recipient’s condition worsens and they need more care, they would provide him or her with more care. Over one quarter say that he or she would go to a long-term care facility (such as an assisted living facility or nursing home).

Figure 33: Potential Results if Care Recipient’s Condition Worsens.

(QD-1. What will happen if your care recipient’s condition gets worse and he/she needs more care?)



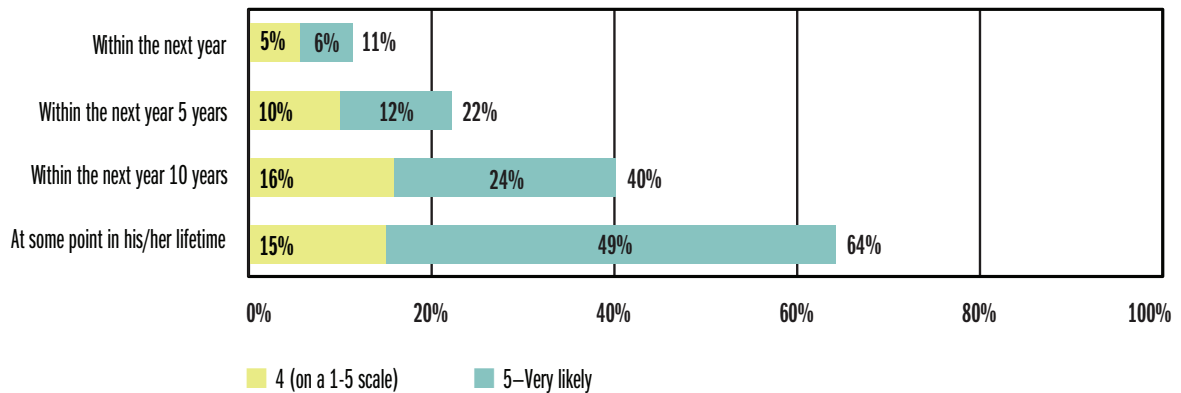
⁷ Buchanan RJ, Radin D, Huang G, Zhu, L. Caregiver perceptions associated with risk of nursing home admission for people with multiple sclerosis. Disability and Health Journal, 2010;3:117-124.

DETAILED FINDINGS

Most respondents, however, think that it is unlikely their care recipient will have to go into a long-term care facility in the near future. Only 11% foresee that happening within the next year, whereas almost two-thirds (64%) think it is imminent in their lifetime.

Figure 34: Likelihood of Going to Long-Term Care Facility.

(QD-2. For each of the following, please indicate the likelihood that your care recipient will have to go into a long-term care facility? Please use a scale of 1 to 5 where “1” means “very unlikely” and “5” means “very likely.”)



DETAILED FINDINGS

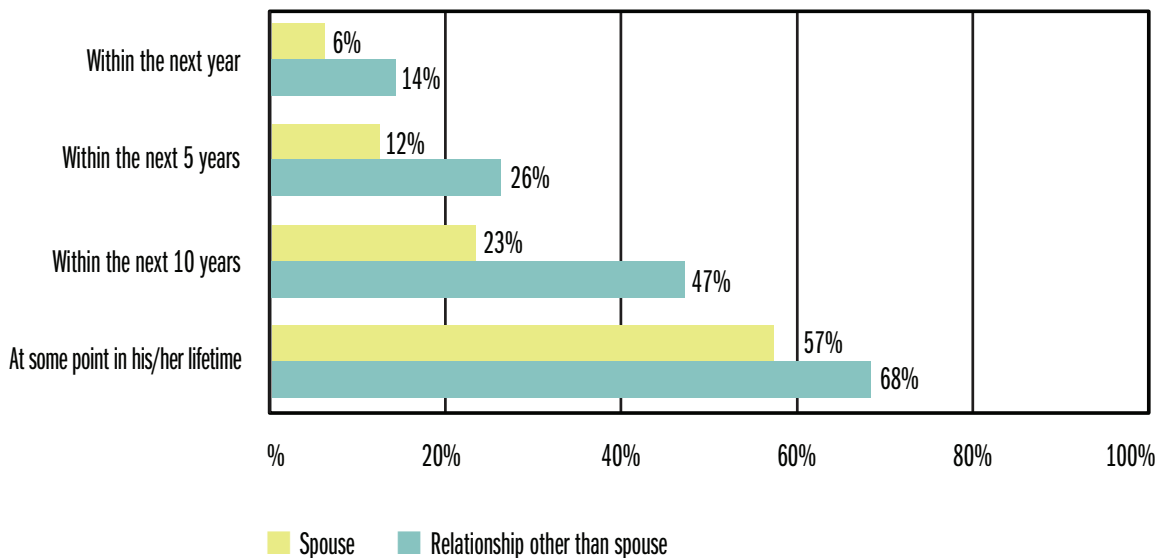
Not surprisingly, those caring for care recipients with more severe symptoms are more likely to predict their care recipient will go into a long-term care facility—both within the next year and within longer periods of time.

Those who are caring for a spouse report a much lower likelihood that their care recipient will have to go into a long-term care facility—both within the next year and within longer periods of time. Similarly, respondents who live with their care recipient report lower likelihood that their care recipient will have to go into a long-term care facility.

Figure 35: Likelihood of Going to a Long-Term Care Facility by Relationship to Care Recipient.

(QD-2. For each of the following, please indicate the likelihood that your care recipient will have to go into a long-term care facility? Please use a scale of 1 to 5 where “1” means “very unlikely” and “5” means “very likely.”)

NOTE: Graph shows those rating the likelihood a 4 or 5.



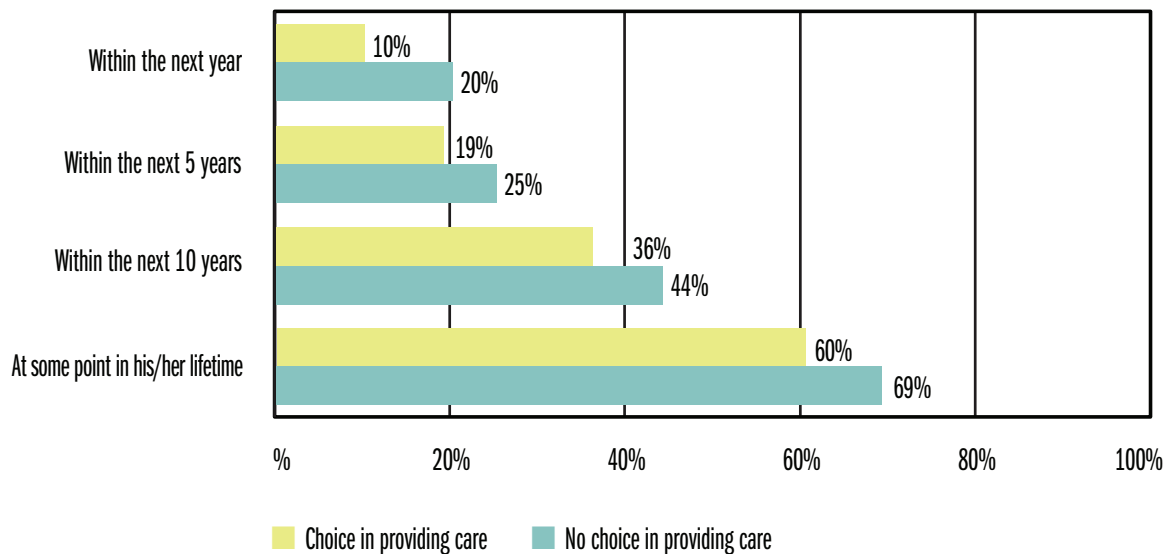
DETAILED FINDINGS

Interestingly, those who feel they have a choice in providing care report their care recipient is somewhat less likely than others to have to go to a long-term care facility, demonstrating that there is often an element of caregiver choice in this decision.

Figure 36: Likelihood of Going to a Long-Term Care Facility by Choice in Providing Care.

(QD-2. For each of the following, please indicate the likelihood that your care recipient will have to go into a long-term care facility? Please use a scale of 1 to 5 where “1” means “very unlikely” and “5” means “very likely.”)

NOTE: Graph shows those rating the likelihood a 4 or 5.

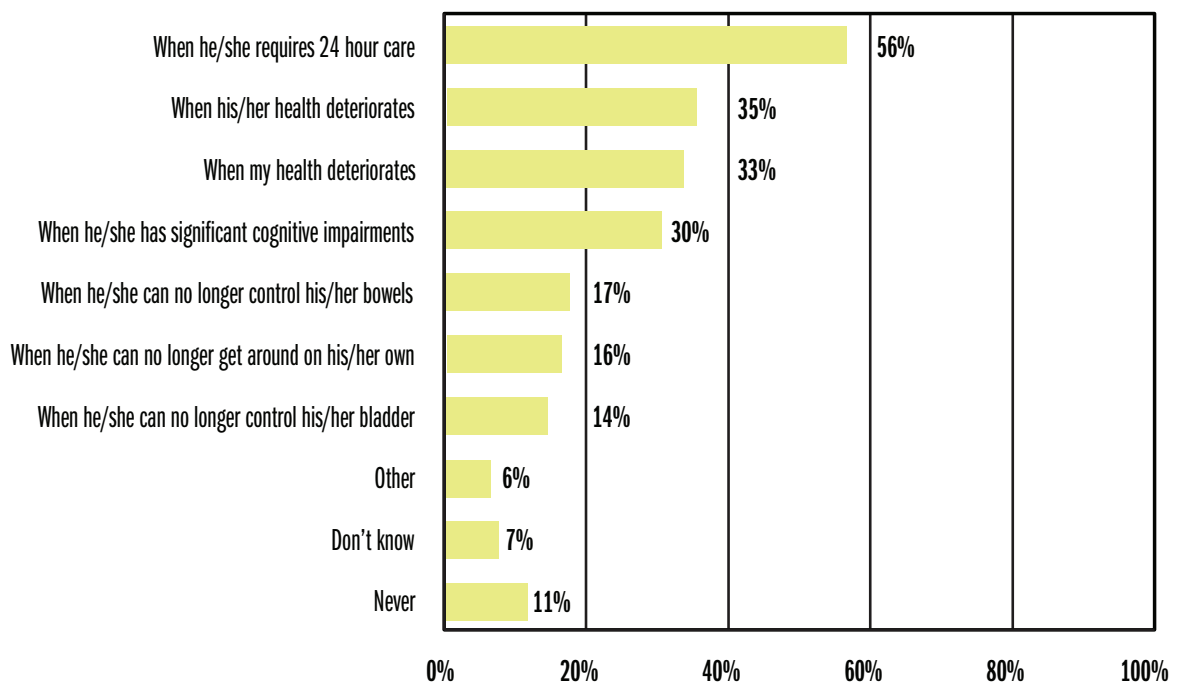


DETAILED FINDINGS

In terms of the specific incidents or tipping points that would trigger someone to go to a long-term care facility, slightly more than half (56%) say that that time will come when their care recipient needs 24 hour care.

Figure 37: Trigger Points for Going to a Long-Term Care Facility.

(QD-3. At what point would your care recipient go into a long-term care facility?)



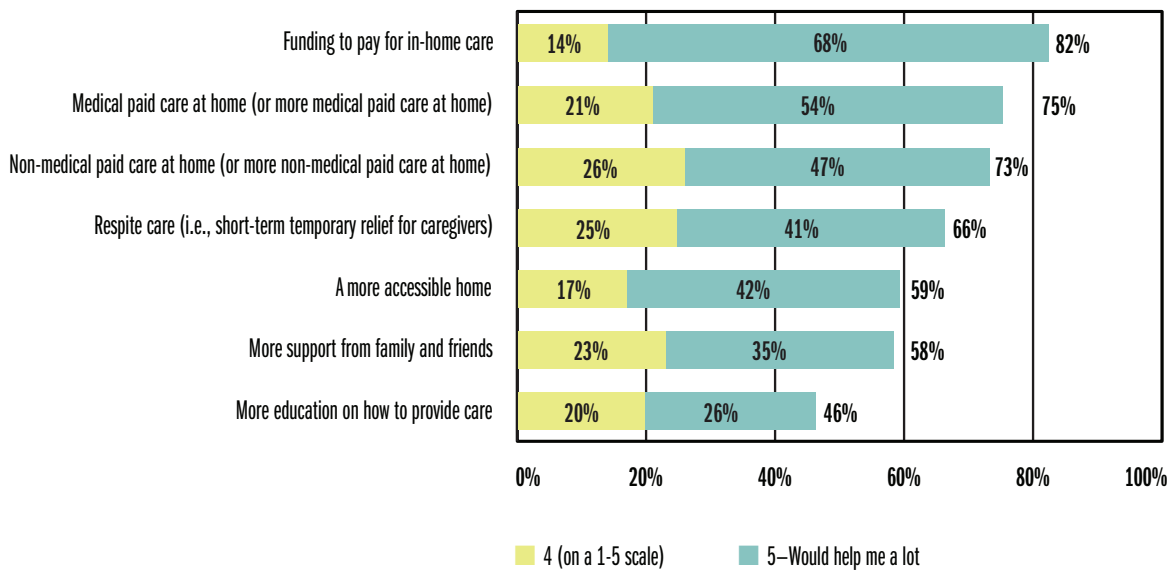
DETAILED FINDINGS

The survey also investigated what could enable care recipients to stay in their homes longer. The most promising opportunities involved in-home care. Approximately eight in ten (82%) respondents say funding to pay for in-home care would help them take care of their care recipients in the care recipients' home so that he/she does not have to go to a long-term facility. There is an opportunity for both paid medical care and paid non-medical care. Three-quarters say that paid medical care would help them, whereas 73% say paid non-medical care would help them.

Two-thirds would also benefit from respite care, whereas 59% would find a more accessible home helpful, 58% would find more support from family and friends helpful, and 46% would find more education on how to provide care helpful.

Figure 38: Opportunities for Keeping Care Recipients in Their Homes Longer. (Only includes those who thought opportunities would be helpful)

(QD-4. To what extent would each of the following help you take care of your care recipient in his/her own home so that he/she does not have to go to a long-term care facility? Please use a scale of 1 to 5 where "1" means "would not help me at all" and "5" means "would help me a lot.")

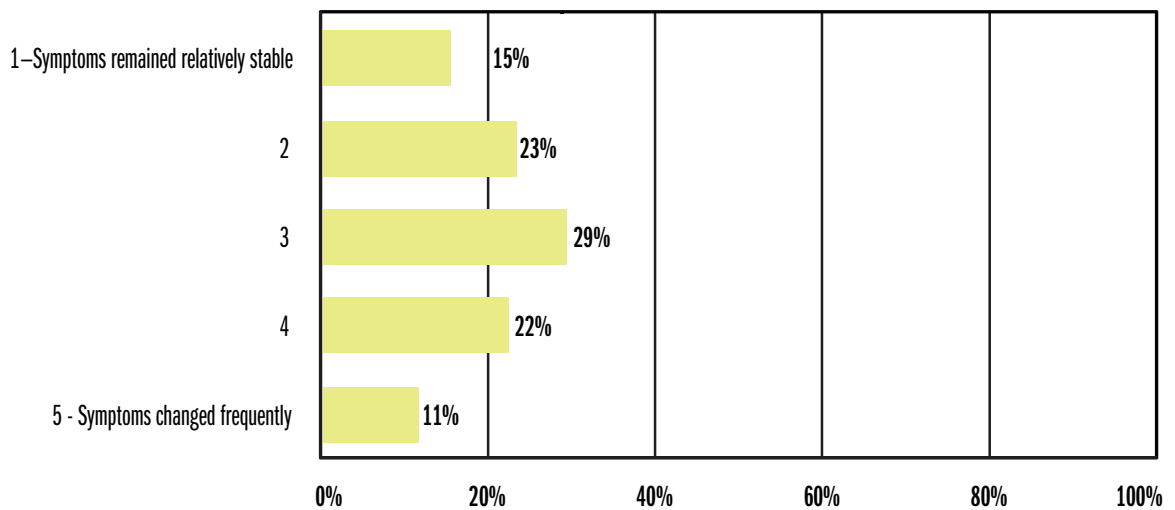


CHANGING SYMPTOMS OF MS

The symptoms of someone with MS go through different phases, from remitting to relapsing time and time again, to ultimately progressing steadily downward. The timing is not predictable and the caregiving roles vary over time. Some respondents report that their care recipient's symptoms are currently fairly stable, whereas others report that their care recipient's symptoms change frequently.

Figure 39: Stability of Symptoms.

(QC-2. How would you describe your care recipient's symptoms over the past year? Please use a scale of 1 to 5 where "1" means "symptoms remained relatively stable" and "5" means "symptoms changed frequently.")



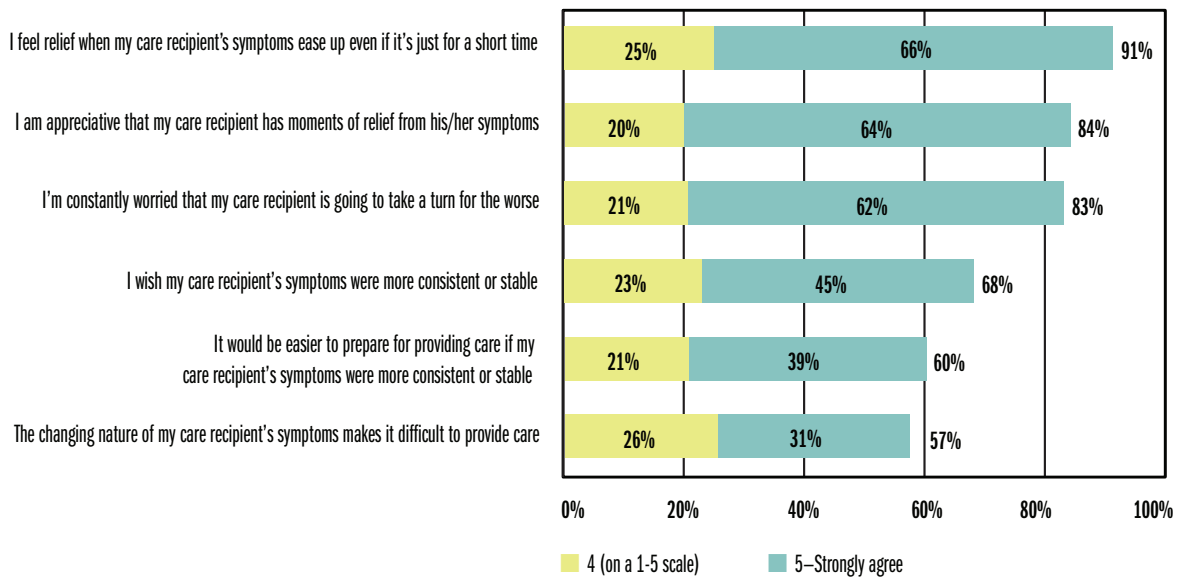
DETAILED FINDINGS

Those providing care to loved ones with frequently changing symptoms generally provide slightly more care in terms of number of hours. The average number of hours of care provided by respondents with care recipients who have symptoms that change frequently (as defined by those rating the stability a 4 or 5 on a scale of 1 to 5 where “1” means “symptoms remained relatively stable” and “5” means “symptoms changed frequently”) is 27 hours a week, whereas the average number of hours for those with more stable symptoms is 22 hours a week.

Among those respondents who provide care to someone with frequently changing symptoms, many feel relief and appreciation when their care recipient’s symptoms ease up. Yet, they are also constantly worried that their care recipient will take a turn for the worse. More than two-thirds (68%) of those caring for a care recipient with frequently changing symptoms say they wish their care recipient’s symptoms were more consistent or stable. Six in ten say that it would be easier to prepare for providing care if their care recipient’s symptoms were more consistent or stable, and 57% say the changing nature of their care recipient’s symptoms makes it difficult to provide care.

Figure 40: Caregiver Views Toward Frequently Changing Symptoms. (Only includes those who agree with statements)

(QC-3. How strongly do you agree or disagree with each of the following statements? Please use a scale of 1 to 5 where “1” means “strongly disagree” and “5” means “strongly agree.”)



DETAILED FINDINGS

Despite the desire for more stable symptoms, those who are providing care for someone whose symptoms are frequently changing actually report more *positive* impacts from providing care, indicating that temporary relief from symptoms may improve overall quality of life for the caregiver. Interestingly, there are no substantial differences in the *negative* impacts.

Figure 41: Caregiver Impacts by Stability of Symptoms.

(QC-4a. To what extent has being a caregiver to someone living with MS impacted each of the following.)

	PERCENTAGE FEELING NEGATIVE IMPACT		PERCENTAGE FEELING POSITIVE IMPACT	
	Among those caring for someone with frequently changing symptoms	Among those caring for someone with more stable symptoms	Among those caring for someone with frequently changing symptoms	Among those caring for someone with more stable symptoms
Your relationship with your care recipient	19%	17%	59%	49%
Your relationship with your children	18%	14%	46%	36%
Your relationship with other family members	30%	26%	41%	34%
Your mental health	41%	37%	29%	18%
Your overall financial situation	45%	42%	29%	18%
Your ability to participate in hobbies/ things you enjoy	37%	40%	28%	16%
Your physical health	29%	33%	26%	20%
Your job	35%	32%	23%	16%

DETAILED FINDINGS

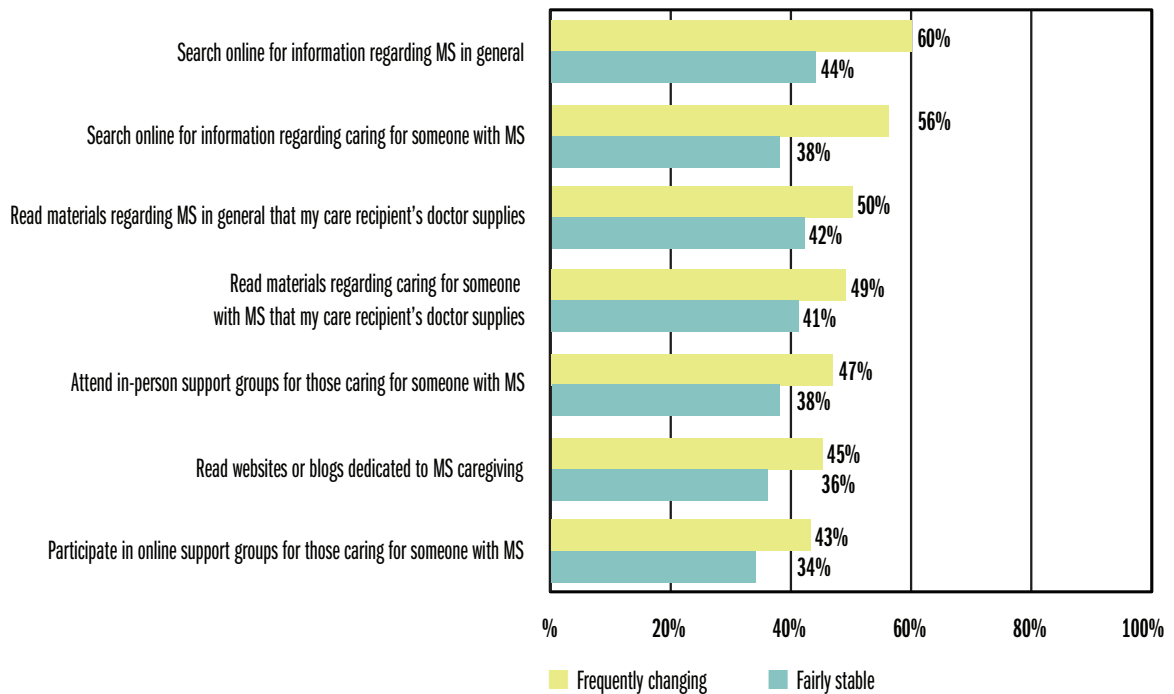
Respondents caring for someone with frequently changing symptoms predict a greater likelihood they will go into a long-term care facility—both in the near future and in the distant future.

Those caring for care recipients with frequently changing symptoms may have a greater appetite for information on MS. For example, those providing care to a care recipient with frequently changing symptoms find all information sources tested to be more helpful than do those caring for care recipients with more stable symptoms.

Figure 42: Helpfulness of Information Sources by Stability of Symptoms.

(QE-2. How helpful have each of the following been to you as a caregiver for someone living with MS? Please use a scale of 1 to 5 where “1” means “not at all helpful” and “5” means “very helpful.”)

NOTE: Graph shows those rating the helpfulness a 4 or 5.



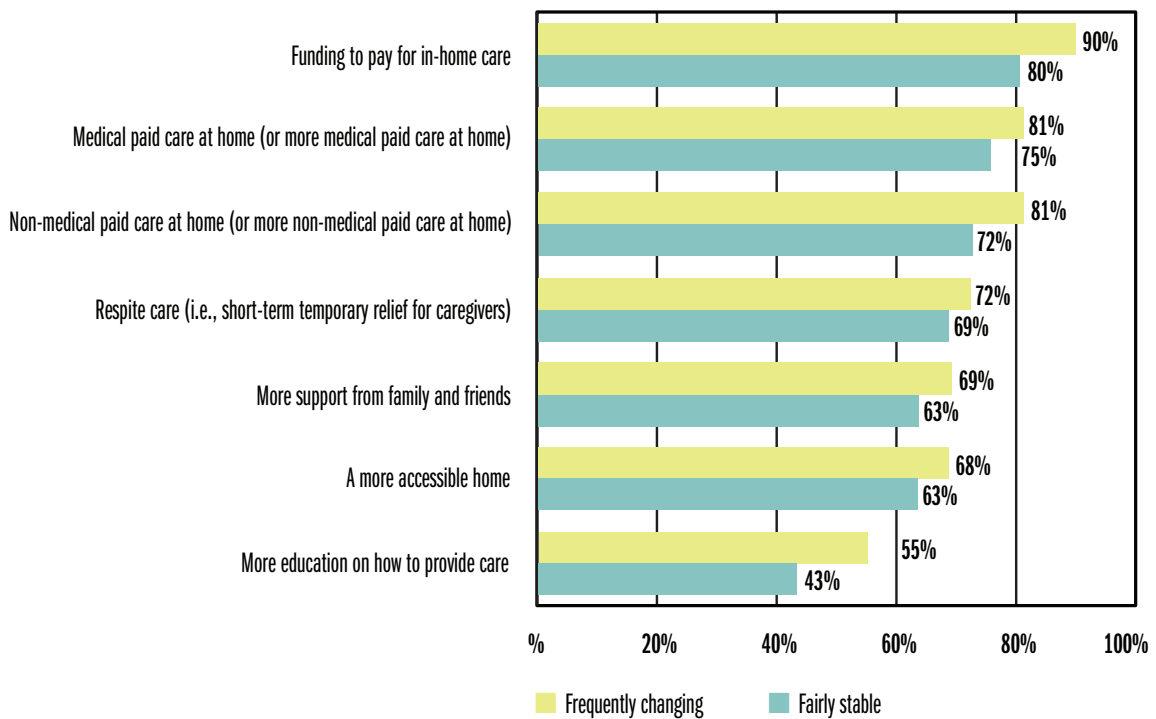
DETAILED FINDINGS

Similarly, caregivers providing care to someone with frequently changing symptoms are more likely than others to say that more education on how to provide care may allow them to take care of their care recipient in his or her own home so that he or she does not have to go to a long-term care facility. They also see a slightly greater need for paid in-home care—both medical and non-medical.

Figure 43: Opportunities for Keeping Care Recipient in Their Own Home by Stability of Symptoms.

(QD-4. To what extent would each of the following help you take care of your care recipient in his/her own home so that he/she does not have to go to a long-term care facility... Please use a scale of 1 to 5 where “1” means “would not help me at all” and “5” means “would help me a lot.”)

NOTE: Graph shows those rating the helpfulness a 4 or 5.



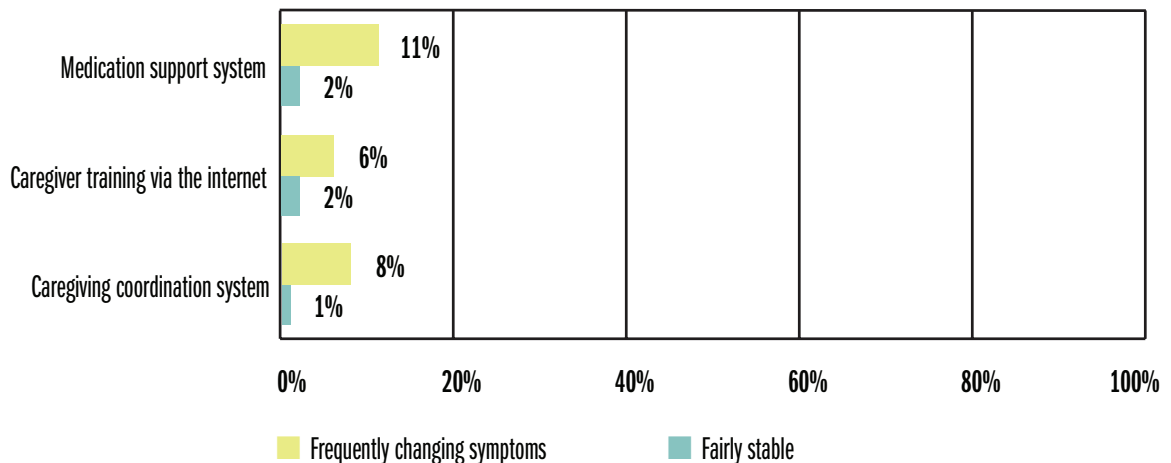
DETAILED FINDINGS

Those who provide care for someone with frequently changing symptoms are much more likely than others to have used caregiving technology tools, such as the three offered in the survey. That said, usage is still limited to approximately one in ten of those who are providing care to someone with frequently changing symptoms. Among those who have not used these tools, however, there are no differences in likelihood of using them in the future between those caring for persons with frequently changing symptoms versus those caring for persons with stable symptoms. These results would indicate that perhaps MS websites should have different approaches in offering information and education to caregivers dealing with frequently changing symptoms versus those whose disease is fairly stable.

Figure 44: Usage of Caregiving Technology Tools by Stability of Symptoms.

(QE-4. Next, we will ask your opinion of three different technologies available to help caregivers. Please consider each one separately, and indicate your reaction to each. Thinking about the last few months that you have provided care, how likely would you be to use this caregiving technology if it were available for a nominal cost?)

NOTE: Graph shows percentage currently using the tool.



This study sheds new light on several new aspects of family caregiving for someone with MS. In particular:

- The long life cycle of the disease suggests that the total number of years one serves as a caregiver will be much, much longer than caregivers in general: 9 years for these caregivers compared to less than 5 years for all caregivers. The average age of these people with MS was only 50 years; they can be expected to live to about 68-70.
- Caregiving for someone with MS has a substantial negative impact on the family's financial situation in 43% of the cases.
- For those caregivers who do continue to work, one-quarter say that they have trouble focusing on their job because of caregiving responsibilities.
- The likelihood of the care recipient going into a long-term care facility within the next ten years was estimated at 40%—with the triggering event being the need for 24-hour care. Given the likelihood of care recipients spending down and going on Medicaid, action to prevent nursing home placement would seem to be a good idea for the government financially.
- The role that mental confusion in people with MS has on family caregivers has not been studied as much as some of the more physical

challenges, yet it appears to affect the caregiver's financial situation as well as highlight the help needed to keep the care recipient out of a long-term care facility.

- For delaying institutionalization, 82% of caregivers say that assistance in paying for in-home care would help and two-thirds say that respite care would help.
- Of those who use a given source for information about MS—whether their doctor, the Internet or support groups—less than half found it useful.

Taken together, these issues create a rather compelling case for caregiver support at Federal, state, and local levels. According to the caregivers themselves, if they were to receive respite care along with help in paying for in-home care, they could perhaps delay placing their loved one in long-term care. The ten-year estimate of nursing home placement should be high enough to concern the Centers for Medicare and Medicaid Services (CMS), especially given that these caregivers had, on average, already been caring for 9 years.

Caregiver assessment to determine which family caregivers are most at risk of having to place their care recipients in long-term care would be a first step in helping them. Such assessments have been implemented in some states, such as New Jersey and California, and involve a healthcare professional, such as a nurse or

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social worker, determining the needs of the patient for care as well as the willingness and ability of the caregiver to provide them. The need for assistive technology in the home, both for safety as well as to aid the caregiver in carrying out necessary personal care tasks, should also be evaluated, along with the possibility of technological devices that might be useful, such as imbedded passive monitoring systems. The healthcare professional or the Aging and Disability Resource Centers should also be able to suggest local resource groups that might provide some financial relief to the family, such as Easter Seals, along with the necessary caregiver training. And, of course, respite care should be explored as a resource to prevent family caregivers from “burning out” and feel pressured to move to the long-term care solution.

As the most important MS resource, the National MS Society offers many programs for family caregivers of people with MS (www.nationalmssociety.org). Also, here are numerous sites for general caregiver support to be found on the web.

In summation, with the combination of the duration of care, the prevalence of mental confusion, and the high probability of long-term care placement, support to the family caregiver of someone with MS seems to rise to a critical level. We know who the care recipients are when they become disabled; identifying the family caregivers should be relatively easy. Proactively reaching out to them with support will help, not only the caregivers, but the care recipients, and ultimately the country, as well.

