

September 2022 Newsletter



September 2022 iConquerMS Spotlight

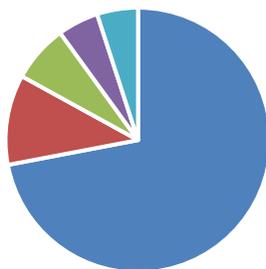
Caregiver Survey



MS caregivers are currently eligible to join iConquerMS. In an effort to better support their unique research needs and interests, we launched two surveys in April 2022, one for caregivers, and a second for researchers and healthcare providers. The viewpoint and experience of 116 respondents are summarized below.

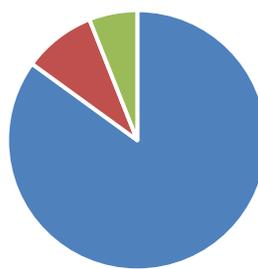
Characteristics of Caregiver Respondents

Caregiver relationships



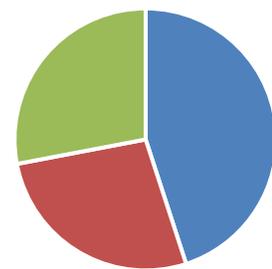
- Partner or spouse
- Parent or guardian
- Child
- Sibling
- Other

Caregiver Distance



- Lived with loved one
- Local
- Long distance

Caregiving Duration



- More than 10 years
- 5 to 10 years
- 5 years or less

1. The Caregiver Experience

When asked to describe their experiences as an MS caregiver in their own words, respondents presented a wide range of experiences and expressed emotions ranging from frustration and exhaustion to love and gratitude.

When asked to describe the physical, emotional, and/or cognitive MS symptoms that interfered with daily life for their loved one:

- 12% reported mild symptoms.
- 51% reported moderate symptoms
- 32% reported severe symptoms



2. iConquerMS

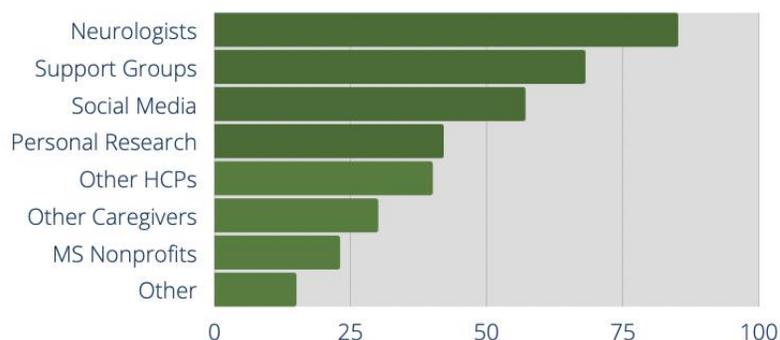
Nearly 70% of **caregivers** indicated an interest in signing up for iConquerMS. Respondents liked the idea of participating by answering surveys twice a year, engaging with other caregivers, taking part in research, and following the results of MS research.

Three-quarters of **caregivers** believe their loved ones would support their participation in iConquerMS to assist with research focused on caregiver health & well-being and to contribute to observer-focused research of MS patients.

In order to successfully engage MS caregivers in the initiative, iConquerMS will need to consider **caregiver** concerns about time constraints and the desire to be fairly compensated while performing a service of value.

3. Information Sources

The most common sources of information about MS for **caregivers** were:



4. Most Common Questions About MS

For loved ones, **caregivers** wanted to know:

- What does MS progression look like?
- Which wellness approaches are helpful?
- What is the right treatment for my loved one?
- How can we manage symptoms and cognitive changes?
- How can I improve my loved one's quality of life?



For themselves, **caregivers** wanted to know:

- How will caregiving impact my physical and mental health?
- Will caregiving affect my employment or cause financial concerns?
- How can my loved one and I manage our relationship?
- How do I parent a child with MS?
- How and where can I access caregiver resources?

5. Participation in Research

Nearly 75% of **caregivers** had not participated in past research focused on their health and well-being or insights as an observer of a person living with MS.



Of the 25% respondents who had taken part, half aided in caregiver-focused research and the rest assisted with observer-focused research.

68% of respondents indicated an interest to participate in caregiver-related research. 56% were interested in observer-focused research.

6. The Positives of Participating in Research for Caregivers

- Helping other families impacted by MS
- Having access to different medications, treatments, or interventions



7. Motivation

Respondents were motivated by the following:

- The idea of helping others
- Gaining access to information that may benefit themselves or their loved ones
- Sharing their experiences.



8. Healthcare Providers & Researchers

Healthcare Providers and Researchers felt the following caregiver topics were important for their work:

- Managing distress, sense of purpose, and life satisfaction
- Access to mental health treatment
- Care coordination to support caregiver respite
- Preparedness for researching MS medications and interventions to alleviate MS symptoms.

In their experience, **Healthcare Providers and Researchers** felt caregivers needed the following resources:

- Ways to address caregiver burnout
- Effective strategies and interventions for supporting partner and communication
- Solutions for handling the needs of the MS patient
- Guidelines related to appointments with loved ones and finding balance in knowing when to speak up and when to step away
- Local community support
- Resources for caregivers with low socioeconomic status or low health literacy.

