

# April 2021 Newsletter



## The Indispensable Role of Caregivers

It's vitally important to support caregivers and pay attention to their needs, as they are the backbone of many families living with chronic disease. Their perspective is valuable in many respects. As the closest and most constant observer of their loved one, a caregiver has first-hand knowledge of their challenges, symptoms, and the effectiveness of treatment. His or her knowledge of side effects, as well as physical or cognitive changes, and how these affect functioning and quality of life is relevant and crucial in both the healthcare and research settings.



In MS, the role of the caregiver is constantly changing. When a person with the disease is in remission, there may be less caregiving required, whereas if they are in the middle of a relapse or have advanced disease, caregiving may be a round-the-clock requirement. As MS caregivers are generally unable to anticipate the onset of a relapse, the progression of the disease, or even the functional ability of their loved one over the course of a day, the resulting ups and downs can be stressful and draining for everyone. Those providing support are often so focused on their partner's needs they may not have time to take care of their own. In this situation, over a

long period of time, it's conceivable that MS caregivers could become second victims to the disease. All of these things have dire consequences for administering care.



iConquerMS continues to expand its research collaborations to include caregivers to those living with MS, in hopes of easing their burdens and improving MS research in the process. In 2019, ACP partnered with [UsAgainstAlzheimer's](#) to apply for a grant from [Genentech](#) aimed at advancing health equity in patients with neurologically based diseases. With this support, the organizations developed two surveys to learn more about the challenges that caregivers face and their relationships with healthcare providers. Recognizing that there are features that are unique to providing care to someone with MS compared with Alzheimer's disease, questions focused on the common ground between the two conditions. These surveys were sent out to both communities, with very interesting results, which are summarized below.

Our data show the top three stressors experienced by caregivers are uncertainty about the future (54%), stress (46%) and not having time for oneself (42%). Other common challenges include not getting enough sleep (35%), the inability to leave home (33%), safety (32%) and financial concerns (28%). These percentages apply to those who indicated they experience these stressors "frequently or always." The remaining participants may have also experienced them, but less frequently. On the positive side, survey respondents also shared strategies they found helpful in managing these issues. Some said they benefit from physical activity or having a massage regularly. Others indicated they seek relaxation in music. Still others find it helps to take their loved one for a ride in the car or take a break and leave someone else in charge for a while.

According to the surveys, 77.5% of caregivers do not have sufficient access to the help and support that they need. Respondents were interested in using these services, with information and referrals, support groups, case management, and respite services at the top of the list. Our data suggest



information and referral resources were used most often, however participants were not aware of a variety of other valuable services, such as care management, transportation, and respite services. The vast majority of respondents (72%) had not received training or information to better prepare them for their role as caregiver. About half of those receiving training indicated

it was given at the right time, the rest responded training was too soon, too late, or only given during a crisis. Our data suggest that training was partially effective, as only 21% of survey respondents indicated it helped them address all situations (75% of participants said it helped them address some situations, and 5% said that training did not help them address the most key situations).



Regarding caregiver relationships with healthcare providers (HCPs), 6% of caregivers responding to the survey did not have their own physician. 22% of those seeing a doctor indicated that their doctor is not aware of their role as a care partner. 59% said their HCP is aware of these responsibilities, but the majority (79%) have not gotten help or advice from them about this role. Almost all respondents had accompanied their loved one to a doctor’s appointment. Results were revealing about many aspects of these visits. On the plus side, HCPs were respectful, made eye contact and gave clear information in understandable language. Most participants didn’t have a language barrier. However, more than half who needed language accommodations did not receive them. According to the survey, HCPs rarely asked caregivers how they were coping, and whether the cared-for person wanted them in the exam room. They didn’t always ask for the caregivers’ name or relationship to the cared-for person. HCPs were also less likely to discuss mood changes or treatment effects with caregivers and rarely provided information about research studies, despite the fact that all of these things were important to the vast majority of caregivers that responded. These data will be instrumental as ACP develops new materials to educate caregivers and HCPs about best practices, and resources for caregiving and self-care in the coming months.

ACP has a number of other ongoing activities aimed at relieving [caregiver burden](#) and increasing the voice of this important population in MS research. We very recently received an Engagement Award from the [Patient-Centered Outcomes Research Institute](#) (PCORI) to more intentionally expand iConquerMS enrollment to include care partners. This will be accomplished in a way that is similar to the pediatric expansion of the network, discussed in [last month’s newsletter](#). Through this effort, caregivers will be able to participate in iConquerMS in two dimensions – both as an observer and partner to the person living with MS, and as a



person with their own needs and priorities. We hope that all MS caregivers will consider [joining](#), there are some upcoming opportunities where your input will make a difference!

ACP's Care Partner Advisory Board (CPAB) is a dedicated group of 8 people working to identify the challenges faced by MS caregivers and develop a "Care Partner Protocol," which will be a living set of recommendations for them. This valuable resource will be provided by health care providers at the time of diagnosis and throughout the MS journey. It will also be available online. Members of the CPAB represent a wide variety of care partner roles including spouses to those living with MS, a parent with a young adult daughter who was diagnosed with MS in her teens, and a woman who has provided the primary caregiving for her mother since childhood. The group plans to survey the broader MS community through iConquerMS to obtain input from other caregivers for this important resource.



There's also a movement underway to include care partners in [patient-focused drug development](#) (PFDD) because they not only bring a different perspective than a person with MS, but they also play a significant role in participation in clinical trials and adherence to medication. In 2019, ACP received funding from [EMD Serono](#) to gather information from the MS community on this important subject, as well as in support of the CPAB and the development of the Care Partner Protocol. As part of this effort, we are surveying care partners to see if they know what PFDD is, whether or not they would be interested in participating in this type of activity as a care partner and what would be necessary for PFDD to be successful for caregivers. Please share your insights through this [10-minute survey](#)!

MS caregivers play an indispensable role in their loved ones' lives. They may also play a pivotal role in research. Are you interested in ACP's work to more fully understand and address the needs of MS care partners? Please take a moment to complete a [short survey](#). We will use the information you provide to keep you up to date on our activities. Want to be a part of the movement to put patients and their caregivers at the center of MS research? If you are a care partner to someone with MS and haven't already done so, please consider [joining](#) the iConquerMS community with your loved one today. By sharing your experience of the daily burden of disease, your interpretation of unmet needs, and the types of research questions most important to you, you can transform the research process from one directed by sponsors and investigators to one driven by the needs of patients and their caregivers. This change in impetus

