

# Accelerated Cure Project for MS

## February 2018



*Accelerating research towards a cure for multiple sclerosis*

### Care Partnerships - Living with MS as a Team

Living with MS requires a team effort by the caregiver and the person with MS, frequently referred to as care partners. While sounding very similar, the terms “care partners” and “caregiver” refer to different entities. In this article, the term “care partners” refers to both the person with MS and the person or people providing assistance and support, while “caregiver” refers only to the person giving support. There is a wide range of caregiving activities, just as there is a wide range of abilities and disabilities among people with MS. Someone giving care to a person who is newly diagnosed, or who has relatively few functional difficulties may be helping with injections of a disease-modifying medication or offering support in dealing with the medical team. Someone caring for a person with a more severe level of disability may be helping with daily activities like toileting, dressing, transferring, and feeding, as well as medical treatments. The personal and sometimes intimate nature of these activities requires mutual trust and respect between the person providing care and the person with MS.



Due to the unpredictable and progressive nature of MS, care partnerships must grow and evolve over time. Evaluating care needs must be an ongoing process, undertaken jointly by the person with MS, their medical team and their caregiver. Management of MS and its symptoms is easier if everyone involved learns as much about the disease as possible. The [National MS Society](#) is a good source of general information. For the best information about an individual, caregivers should rely on the person with MS and their medical team.

In general, healthy relationships are a two-way street in which both parties care for and support one another. The relationship between the caregiver and the person with MS is no exception to this rule. The person with MS needs a healthy caregiver, and an effective care partnership depends on the physical and emotional wellbeing of both partners. Often family members and friends willingly provide significant care and support over the course of many years after someone they care about is diagnosed with MS. This can be a positive and rewarding experience for some. However, caregiving can also be physically and emotionally exhausting, especially for the person who is the primary caregiver. Often caregivers tend to



neglect their own health while caring for the other person. It's important to pay attention to the caregiver's physical and emotional needs, and keep up on preventive health measures like exercise, diet, and regular medical examinations. It is also important for both the person with MS and the caregiver to stay involved in activities that they enjoy. Communication is vital in order to establish and maintain a balanced partnership.

According to [Forbes](#), one of the biggest mistakes caregivers make is trying to fulfill their role alone. When, in fact, the most successful care partners receive help from other people. There are many organizations that offer support and information to caregivers, several of which can be found on the National MS Society's list of [Carepartner Support Resources](#). The [caregiver section](#) of the National MS Society website contains links to helpful caregiver guides, support groups, and other valuable resources. Doctors may also refer to specific healthcare providers. The person with MS should always be part of the decision to solicit additional assistance and the selection of individuals or groups to provide that assistance.

All caregivers should consider taking a break, when necessary.

[Respite services](#) are available to allow caregivers downtime from their daily responsibilities. Some families use respite on a regular basis so caregivers can go out and do something for themselves (i.e. go out to lunch, or for a doctor's appointment). Others use it



periodically when caregivers must be away for several days (i.e. take a vacation, or attend a wedding). Respite services are provided both inside and outside the home. In-home respite includes help from family and friends, as well as the paid assistance of home care workers or companions. Out-of-home respite involves occasional, planned short stays in adult foster care homes, nursing homes or hospitals.

Survey results from a [recent study](#) show that only 45 percent of caregivers are in contact with their partner's health providers. Less than half of them said those providers involved them in health decisions or suggested ways they could help. About a third said providers were not willing to share information with them, perhaps missing opportunities for providers to hear about side effects and symptoms that caregivers noticed. This clearly demonstrates a need for healthcare teams to involve caregivers more in their partner's care, if the partner is willing. The



federal health privacy law, called HIPAA, allows patients to designate individuals allowed to receive information about their condition and care. Once a person with MS has given permission for the healthcare team to talk with his or her caregiver, healthcare teams can provide training and support to help caregivers have the most positive impact on their partner. It's important for care partners to talk about the side effects of medications, pain or bothersome symptoms and communicate this information to the healthcare team. If the person with MS is unable, caregivers can convey this information during their partner's health appointments, by email, or speak to health care provider on the phone.

As mentioned in the [August 2017 newsletter](#), Can Do MS is a lifestyle empowerment program for people with MS and their caregivers. In-person programs and online resources, provided by a multidisciplinary team of MS professionals, help people with MS and their caregivers develop a true care partnership. These programs offer information about MS, as well as opportunities to share experiences with others living with MS. They are designed to help care partners figure out how to communicate and problem-solve more effectively with one another, and live full and healthy lives in spite of MS.

