

Accelerated Cure Project for MS

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*Accelerating research towards a
cure for multiple sclerosis*

Caregiver burden – What counts is how you carry it

MS is a chronic, unpredictable, often disabling disease that attacks the central nervous system. Symptoms can vary dramatically from person to person. The majority of people with MS are initially diagnosed with [relapsing remitting MS](#) (RRMS), which means their symptoms flare up at times and then return to baseline. Most people who are diagnosed with RRMS eventually transition to a [secondary progressive](#) course in which there is a progressive worsening of symptoms over time. As symptoms progress, or flare, the person with MS may be unable to perform their usual activities. At this point, responsibility for completion of these activities must shift to someone else, a caregiver.

The role of the caregiver for someone living with MS may change as symptoms progress. Early on, they may have to provide support for temporary flares and then enjoy periods of time symptom free. As MS progresses, it becomes increasingly disabling and the symptoms that once faded (or remitted) after a flare may become more permanent. When a person with MS is in remission, there may be less caregiving required, whereas when someone is in the middle of a relapse, caregiving may be a round-the-clock requirement. The unpredictability of MS affects the caregiver in a way unlike other chronic diseases. Caregivers are often unable to predict the onset of a relapse, the progression of the disease, or even the functional ability of the patient over the course of a day.

Multiple Sclerosis is
like looking both ways
before you cross the
street then getting hit
by an airplane

In some cases, MS caregiving is physical work as the disease can affect vision and mobility. For example, a person with MS may need help standing up, walking, getting out of bed, taking a shower, dressing, or getting

on and off the toilet. MS can also affect cognition and memory, leading to more widespread effects including a loss of intimacy or losing the ability to work and communicate effectively. Recognizing that every situation is unique, people are generally forced into different roles in their lives when chronic illness or disability strikes. The individual providing assistance typically takes on added responsibilities, while the recipient loses independence. Providing care to a loved one can bring individuals closer. However, it can also put a strain on relationships, especially if changes aren't welcome and affect future plans. Adjusting to new roles is challenging, but adjusting to unwanted ones is even more so.



Caregiver burden is defined as “the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member.” It is a response to the physical, psychological, social, and financial stressors associated with the caregiving experience. Caregiver burden can be both [objective and subjective](#). Objective

burden refers to the tasks required to provide care. Subjective burden is the extent to which the caregiver “minds” performing them. No matter how it is categorized, increased caregiver burden can have a profound impact on the care provider and recipient. Without proper training (for example, lifting or transfer techniques), the physical aspect of providing care to an individual with more advanced disease can potentially lead to injury. The cognitive effects of MS (problems with memory, attention or information processing) are far reaching. Both the physical and cognitive effects of MS add to caregiver burden and have a rippling effect on the lives of those involved.

A 2011 [study](#) revealed some interesting facts about caregiver burden. Researchers contacted MS participants in the [NARCOMS Registry](#) requesting their assistance in identifying and recruiting their “informal caregiver” for the study (the person who provides the majority of unpaid care to help cope with the effects of MS on daily life). Data was collected via telephone interview from 530 caregivers to people living with MS. Results of the study revealed a direct relationship between caregiver burden and recipient’s overall health (burden levels were higher if the person with MS wasn’t feeling well, and vice versa). In addition, caregiver burden was directly related to the frequency of bladder dysfunction in the person receiving assistance, the number of hours per week spent providing assistance, and the extent to which caregiving responsibilities restricted the caregiver's ability to participate in activities that were important to them. Researchers also concluded that caregiver burden was significantly greater among men than among women, and that caregivers of either gender assisting males with MS experienced significantly greater burden.

Another [study](#) concludes that psychiatric symptoms and cognitive impairment in MS have a greater influence on caregiver distress (and reduced quality of life) than physical disability. Results show depression in a person with MS (the most common psychiatric symptom) directly impacts depression in their caregiver. Further [research](#) proves the reverse is also true. Depression in an MS caregiver is associated with the physical and emotional health of the person with MS receiving care. Investigators in the first study demonstrated this reciprocal relationship for other psychiatric manifestations of MS, such as irritability, aggression, delusions and dis-inhibition. These conditions are often difficult to



manage and may lead to social isolation for both partners, straining their relationship and possibly leading to worsening symptoms. In this light, it's not surprising that data showed these were the most disturbing psychiatric symptoms for caregivers.

The [National Alliance for Caregiving \(NAC\)](#) is a non-profit coalition of organizations focused on advancing family caregiving through research, innovation and advocacy. In 2012, they conducted a [survey](#) of 421 individuals who provided care to a friend or family member with MS. Results indicate caregivers spend an average of 24 hours per week taking care of their loved one and the impact on their lives is mixed. The positive effects are mostly related to relationships between the care recipient and other family members. For example, just over half of the respondents said that caregiving brought them closer to their children. According to the survey, the most common negative impacts of providing care are on finances (22% of respondents had lost a job and 17% reported being unable to hold down a job due to caregiving), the ability to participate in hobbies, and issues with mental health. Almost half of respondents felt they did not have a choice in taking on the caregiving responsibilities.



Those indicating they had a choice generally felt fewer negative and more positive impacts than those indicating they didn't have a choice. Half of respondents to the NAC survey reported being physically exhausted and nearly one-third were physically injured as a result of providing care. According to the NAC survey, almost three quarters of the people living with MS receiving care have emotional or cognitive symptoms. Caregivers providing care to those with cognitive impairment were more likely to feel negative impacts from their role. Finally, those providing care to loved ones with frequently changing symptoms generally provided slightly more care in terms of number of hours. Many reported feeling relief and appreciation when their care recipient's symptoms eased up, yet were also constantly worried that their care recipient would take a turn for the worse and they wished their care recipient's symptoms were more consistent or stable.

[Caregiver burnout](#) is “a state of physical, emotional, and mental exhaustion and distress that may be accompanied by a change in attitude – from positive and caring to negative and unconcerned.” It is the unfortunate result of high levels of burden over an extended period of time. Understandably, this has dire consequences for administering care. Recognizing the signs of caregiver stress is important. Physical signs may include fatigue, exhaustion, trouble sleeping, decreased strength and endurance. One should also watch for

psychological or emotional symptoms, such as irritability, anger, depression, inability to concentrate, memory problems, social withdrawal, and feelings of isolation. This level of exhaustion is preventable by knowing the signs, proactively asking for help and having ways in place to reduce stress. It is important for a caregiver to know their strengths, where they may need help, and the resources available to them.



Helpful tips to avoid caregiver burnout

There are many ways to manage care provider's load and avoid burning out. Providing assistance can be isolating so make sure you have a support system of people you trust to help you through the difficult and lonely times. Whether it is other caregivers, family members, friends, or a counselor, it is important to have someone that will listen to and support you. Do not be afraid to ask for help. Communicate with your friends and family so they are aware of your situation and suggest specific things people can do to help you. If this isn't possible you can hire professional [respite care](#) to provide temporary caregiving while you rest and recharge.

It's important to educate yourself. Knowing more about MS symptoms, side effects, and treatment options can help you feel more confident and in control. It will enable you to participate more fully in your partner's healthcare decisions, and adapt more easily to changes in their treatment plan. Be open to [new technologies](#) that can help you care for your loved one. Try attending an MS function. Organizations like the National MS Society host [educational events](#) all over the country. These events are places to learn more about MS and meet other caregivers.

Good communication is key to decreasing caregiver burden. Attend doctor's appointments and discuss your loved one's plan of care with health care professionals, including risks and benefits of treatment options. Being able to express your needs during these visits is important. Be sure you understand the information you are given and don't hesitate to ask questions, if you need to. Communicating with your partner about their needs, as well as yours, can help maintain a healthy relationship with them. It also enables you to effectively inform clinicians about changes in your loved one's health and behavior, as well as better participate in health care decisions.

Staying organized can help keep stress to a minimum and free up more time to do the things you enjoy. Ways to stay organized might include keeping a journal to track your partner's MS symptoms or medication side effects, among other things. Calendars can be useful for appointments, or to keep track of when to give medications. Keep a list of important phone numbers handy. Organize medical information so it is up-to-date and easy to find. In general, it's a good idea to make sure legal documents are in order.

Caregivers frequently forget to take care of themselves. The phrase, "you can't pour from an empty cup" rings very true in this circumstance. If you don't take the time to attend to your own needs, you run the risk of becoming depressed, having feelings of resentment toward your loved one, or losing other relationships. These are just a few consequences of putting your own health and wellbeing second to your role as a caregiver. Maintain your physical health by eating well, and getting plenty of sleep and exercise. Make time for your medical checkups and other appointments. Your mental health is important, too. Schedule time for yourself to refresh and do things you enjoy. If stress is a problem, a variety of therapies might help, including massage, prayer, yoga, or music therapy. Other activities that may help to stay grounded are exercising or simply spending time with a family pet. It's important to watch for [signs of depression](#) and don't delay getting professional help if you need it. Above all else, keep a sense of humor and don't be too hard on yourself, it helps to lighten the stress of the moment and long term.

There are a number of excellent resources for caregivers that offer information and support free of charge. Founded in the late 1970's, the [Family Caregiver Alliance](#) (FCA) is the first community-based nonprofit organization in the country to address the needs of caregivers. FCA's [Family Care Navigator](#) provides state-by-state resources for caregivers, including respite providers. The National Multiple Sclerosis Society (the Society) hosts the [MS Navigators](#) program which also connects those providing MS care to valuable resources, such as emotional support services, and wellness strategies. In addition, the Society offers a helpful guidebook, [Caring for Loved Ones with Advanced MS: A Guide for Families](#), which covers every aspect of MS, from reducing stress to management of MS symptoms. The [Caregiver Action Network](#) (CAN) is a nonprofit organization that provides education, peer support and resources to family caregivers across the country. CAN resources include an online caregiver [forum](#). This is a good resource if you want to share a piece of advice, or if you feel isolated or depressed and want to talk with others going through the same experience. Featured in our [August 2017 newsletter](#), Can Do MS offers the [Embracing Carers webinar](#) series. This informative series contains 3 relevant webinars addressing such topics as managing mood and cognitive changes in your loved one, prioritizing your emotional and physical wellbeing, and building a satisfying partnership.

In the event of an emergency on an airplane, an oxygen mask drops in front of you. The first safety instruction is to put your own mask on before assisting anyone else. The same principle applies for caregivers. Self-care is one of the most important, and yet one of the most often forgotten, things a caregiver should do. When your needs are taken care of, the person you care for will benefit, too. The day-to-day wear and tear of being an MS caregiver can really add up. By taking steps to educate yourself about MS, keep open lines of communication with your loved one and their healthcare providers, reduce stress and take care of yourself, you'll find your burden may be lighter and you'll have an easier time taking care of your loved one.

