

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



YOU ARE NOT ALONE

*Resources and Coping Tips for
Care Partners of People
With MS*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN).

Provided through an educational grant from Celgene.



“No matter how old you are, when you go out into the world it is best to hold hands and stick together.”

— ROBERT FULGHUM, WRITER



Consultants:

Deborah M. Miller, PhD, LISW

Constance B. Easterling, MSN, APRN, MSCN

MS EMPOWERMENT SERIES



Developed by Delaware Media Group in conjunction with the International Organization of MS Nurses (IOMSN)

Publishers: Joseph J. D’Onofrio, Frank M. Marino

Writers: Katherine Wandersee, Nancy Monson

Art Director: James Ticchio

Welcome, Care Partners

If you are providing care for someone you know with multiple sclerosis (MS), you probably didn't plan to have this role.

Caring for a person with an illness or disability is a responsibility that might build gradually over

time, or arise suddenly and unexpectedly. The care partnering role often feels rewarding and important, but just as often it can be lonely, stressful, and overwhelming.

Informal (unpaid) care partners are estimated to provide 80% of care to persons with MS. Whether it is for a spouse, parent, sibling, son/daughter, or another relative or close friend, the tremendous support family care partners provide often goes under-recognized. Many care partners say they don't always get updated information from the healthcare team and are not treated like a full partner in their loved one's care. And most experience stress related to their care partnering role that affects their own health.

As a family counselor and MS specialist at the Mellen Center for Multiple Sclerosis at Cleveland Clinic, I work closely with patients and their care partners to help them adjust to their new lives with MS. For care partners, it is a life



filled with new challenges and many frustrations, but it can be rewarding as well. That is why it is so important for care partners to recognize their own needs, to enable them to give their time, energy, and support to another.

This MS Empowerment Series brochure has been developed in association with the International Organization of MS Nurses (IOMSN) to offer important information and resources to people providing informal (not licensed) care for someone with MS. We hope the ideas and resources in this brochure will help you maintain your strength and peace of mind in ways that allow you to continue to give much-needed support to your loved one with MS.

Deborah M. Miller, PhD, LISW

Professor of Medicine at Cleveland Clinic Lerner College of Medicine and Case Western Reserve University
Social Worker
Mellen Center for Multiple Sclerosis at Cleveland Clinic
Cleveland, OH



YOU ARE NOT ALONE

Someone you love has been diagnosed with multiple sclerosis (MS). It may be your life partner, a close friend, a parent, a child, or a sibling, but things have begun changing for you both. The person with MS is now a person with a chronic illness, and you are an MS care partner.

The Importance of MS Care Partners

In MS, as in many areas of medicine, there has been a shift toward providing patient-centered care. This means listening to people with MS and focusing on treatment goals that are important to them, rather than following standards set for everyone with the disease. And while healthcare providers are listening to patients more, they also need to listen to care partners, says Deborah M. Miller, PhD, LISW, a social worker at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic, because they often have the best understanding of the day-to-day issues affecting people with MS.

Care partners perform a wide range of daily tasks, from helping to prepare and give medications for MS and other conditions to assisting with bathing, dressing, and going to the bathroom. They may take their parent or child to physical or occupational therapy appointments, or help a friend with an exercise program. They are often the first to observe or report a prob-

About MS Care Partners

MOST
are spouses

53%
are male

More than
90%
live with the
person with MS

The average
duration of
providing care is
13.2
years

**ABOUT
HALF**
spend over 20
hours per week on
care-partnering
activities

10%
can't work
because of their
responsibilities

28%
needed mental
health services
for themselves
during the past
12 months

**OVER
HALF**
say they want
information on
how to find time
for themselves



Most care partners do the job out of devotion and love for someone they hold dear, but the impact of care partnering is profound for both people.

lem with a treatment or a change in the health status of the person with MS.

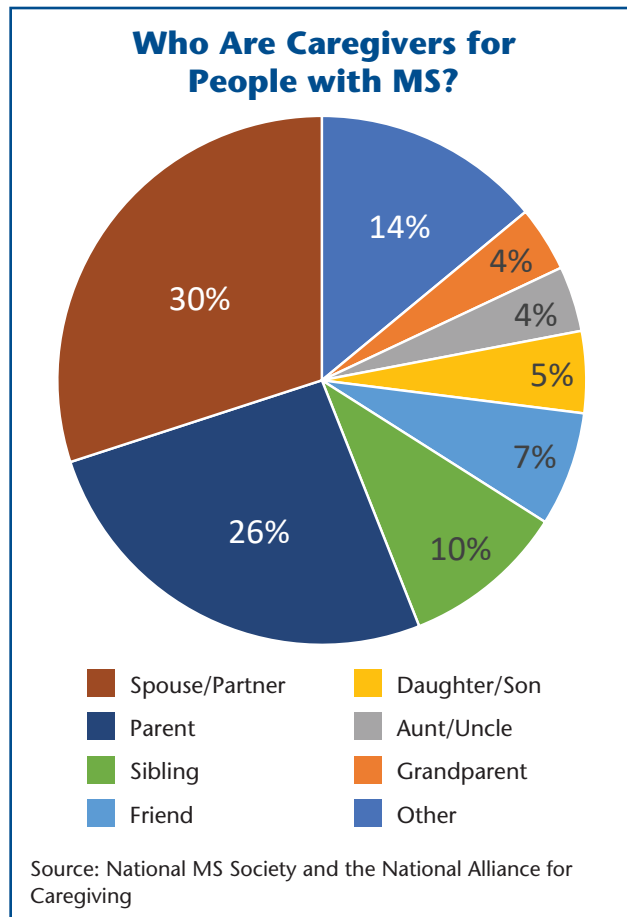
Becoming a care partner to someone with MS is something that people may anticipate in the distant future, but the role often comes on people sooner than they thought it would. In addition, research conducted by the National Multiple Sclerosis Society (NMSS) and the National Alliance for Caregiving found that 48% of 421 care partners who completed a survey felt they did not have a choice in assuming care for the person with MS.

The Unexpected Challenges of Being a Care Partner

Most care partners do the job out of devotion and love for someone they hold dear, but the impact of care partnering is profound for both people. Their roles shift in ways that put extreme stress on the relationship and on their individual lives.

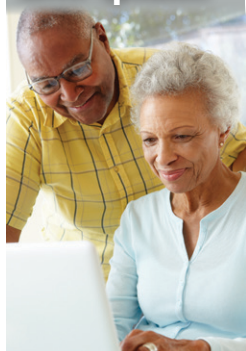
Relationship Changes

Suddenly, when you are in full charge of the daily care of other people, they become dependent on you for things they once did



Relationship Challenges for MS Care Partners

With Spouses



- Change in balance of partnership
- Loss of companionship
- Restricted social life
- Loss of shared activities
- Loss of intimacy
- Added responsibilities for a shared life
- Loss of spousal income

With Adult Children



- Pain of having a disabled child
- Loss of anticipated retirement
- Sharing one's space again
- Renegotiating the parent-child relationship
- Caring for a grown child instead of being cared for

With Parents



- Responsibilities beyond their capabilities (for younger care partners)
- Managing a parent's intimate care
- Feeling guilty about leaving home
- Needing to "parent" the parent
- Loss of parental guidance

for themselves. Resentment and frustration can build on both sides, and you may feel like you are losing the relationship you once had (see page 10). Spouses experience changes in their partnership roles and intimacy. Parents who have a son or daughter with MS often feel pain about having a child with a chronic illness and disability and watching them suffer. In addition, they must renegotiate the parent/child relationship over time and help children transition to caring for themselves as they reach adulthood—or even caring for their children as adults. Those caring for a parent with MS must shift from having a parent, to parenting their parent.

Stress and the Care Partner

General studies of care partners show that caring for a person with a chronic illness raises the chance of becoming sick or injured yourself. Not surprisingly, care partners often suffer from multiple physical and psychological ailments—and they often try to ride them out. Many don't eat well or exercise. They don't see friends as often as they did before they began care partnering. A quarter of care partners report that their own health is only fair or even poor, and three-quarters say they are not seeing the doctor as often as they should. Between 40% and 70% suffer from depression.

Looking specifically at care partners for people with MS, a survey of over 1,300 people conducted by NARCOMS, the North American

Q&A

Tips on Successful Care Partner Relationships



Constance B. Easterling,
MSN, APRN, MSCN
Clinical Coordinator,
MS Care Center
Neurological Services
of Orlando, FL

Q: What are some of the foundations of a successful care partner relationship?

A: Successful care partner relationships begin with a strong foundation of love and respect. Often, care partners are spouses or family members who provide encouragement to the individual with MS by focusing on their positive attributes and strengths. It is helpful when care partners begin by learning as much as they can about the disease process, treatments, and potential care needs. The best care partners are motivated, even on “bad” days, to keep life’s activities as normal as possible and help plan special activities that are in that “bucket list.” Being a resource to the individual with MS may mean keeping the daily schedule, attending healthcare appointments, and communicating with nurses and physicians about any concerns and needs.

Q: In your years as an MS nurse, what examples have you observed of successful care partner relationships?

A: One of my patients has her husband serving as her care partner. During their 40-year

marriage, he has made a life commitment as her care partner to keeping his wife healthy and happy despite the challenges of MS. They travel and plan activities together while attending to her daily needs. He keeps a journal of all appointments, insurance issues, and changes he sees in his wife’s health. When they come to appointments, they often laugh about the small things that happen every day. Importantly, he takes time for himself at least once a week to golf or to meet with other care partners.

Q: What are some ways that care partners can enhance communications with the healthcare team?

A: When possible, the individual with MS should introduce his or her care partner to the MS nurse and other members of the healthcare team. Let them know the importance of the care partner’s role in daily care and activities. The healthcare provider will want to know the care partner’s specific relationship to the individual with MS—whether he or she is a spouse, friend, or family member. The provider should also know whether there are any limitations to the relationship. Ask questions openly at each appointment. Be honest, open, and specific to make the most of the limited time during the appointment. Also, be sure the office staff has documented the best way to reach the care partner, and confirm that care partners will be able to discuss health status and care decisions if they call the office and identify themselves.

Men Versus Women: How They Respond to Caregiving Stress

Men

- Find it more difficult to talk about their feelings
- Are less likely to ask for help
- Tend not to take advantage of available caregiver resources and programs



Women

- Are more likely to neglect their own health
- Are less likely to get out of the house for a while
- Often don't take breaks from caregiving duties



Research Committee on Multiple Sclerosis, showed that depression, headache, stress, and anxiety occurred much more often among MS care partners than in the general population.

Financial Worries

In addition to the physical and emotional strains of providing daily care for a loved one with MS, care partners have to assume much greater financial responsibility. It may simply be in the form of organizing and managing bills, or it may extend much further, to helping pay for medications and mounting medical costs as well as basic food, clothing, and shelter. In many relationships, the household income may be sharply cut by MS disability. And often, the care partner has to take time off from work or stop working entirely to provide full-time care for a loved one, creating an even greater financial burden.

Know Your Tipping Point

It's important to know when you are reaching your limits—and to seek help. People who assume the care for another person may also be taking care of children and other family members, and managing work obligations. Their own needs come at the bottom of a long list of other responsibilities, and they hold off on taking care of themselves.

Tips for Self-Care

The first step in caring for yourself as a care partner is to acknowledge your feelings about

your situation. It's not uncommon to feel depressed, resentful, sad, angry, guilty, or confused—or to have a mix of those feelings. You might feel that it is your job and your job alone to care for your loved one, but that's not true. You don't have to remove all of the independence from your life to be a good care partner. Next, identify yourself to others and especially to your healthcare providers as a care partner, so they understand your issues. Discuss with your partner what you would like help with and try to get his or her buy-in. Also, set realistic expectations for yourself and your loved one—accepting help and losing some of your privacy can be a difficult adjustment for you both. You want to maintain your partnership and make important decisions together.

Assess what only you can do, and try to get help with other tasks. For instance, it doesn't affect your loved one if you have someone else get the groceries or do some cleaning.

Tasks you can outsource

- Cleaning
- Grocery shopping
- Picking up prescriptions
- Laundry
- Errands



Many family members and friends want to help care partners and people with MS, so keep a list of errands and tasks you need done—and accept offers to help. When asking for help, be specific with your requests of friends and family about what you need and when. Train alternate caregivers in what might be needed, as well as about medications and equipment your partner uses.

Beyond that, take care of your physical and mental health by following these guidelines:

Eat right. Try to eat healthy foods at regular times and avoid overdoing on snacks and alcohol.

Exercise. Maintaining a regular fitness routine that consists of going for a walk, going to the gym, or playing a group sport will help you feel better emotionally as well as physically.

Get enough sleep. Seven to eight hours of rest per night is a key management tool for coping with stress. If you don't get enough sleep at night, try to take naps when your loved one sleeps.

Spend time outside of the house. It's easy to think that, because your loved one has physical limitations, you are both trapped in the house. Actually, it's good for both of you to get out as frequently as you can, by taking small trips to the library, the supermarket, restaurants, the movies, and visiting friends and family.

Spend some time apart. Your loved one needs to engage with people other than you, and you need to preserve your sense of independence by taking time regularly for your own activities, support groups, and friendships.

Think Respite

No one person can continue doing all of the work of a care partner without taking time out for themselves. If they don't, they will burn out quickly and not be able to care for their loved one anyway. Just as athletes have players who come in to take their place when they need to rest, care partners can ask for a respite—a break from caregiving. Respite care services are available in a number of ways to temporarily take over your care duties for a few hours, a few days, or even a few weeks. You can, and should, call on these services to help when you are too sick, too busy, or too overwhelmed to take care of yourself and someone else.

Locating Respite Care Providers

Listed below are some organizations that can help you find local providers of respite care:

ARCH National Respite Network and Resource Center

<https://archrespite.org/respitelocator>

Family Caregiver Alliance (FCA)

www.caregiver.org

National Alliance for Caregiving

www.caregiving.org/resources/



Types of Respite Care

Respite care is an important part of your care support system. Three main types of respite services are commonly available. Depending on your needs, you may want to utilize one or a combination of all three services.

The most personal type of care is an **in-home provider**. This can be a friend or family member who volunteers or in some cases may be paid to help out temporarily. Home health agencies can also provide paid respite care that ranges from personal care to skilled nursing services.

Community-based care is often an inexpensive option for short-term support and assistance to people with MS who do not need extensive medical care. Local adult daycare centers can provide a range of activities and support for people with MS to help them stay busy and



socialize while their care partners get a little time off.

For longer breaks requiring 24-hour coverage for a few days or even weeks, patients with MS can stay in **residential facilities, short-term assisted living facilities, and nursing homes** to ensure their needs are met while care partners take time away for other things (including a vacation).

Financial Assistance for MS Care

Depending upon the situation, people with MS can get financial assistance from their home state and other sources to pay for equipment and services, which may sometimes include care partners. Pending legislation is seeking to

increase the programs available, and each state has different rules for benefits, coverage, and eligibility. Sources of assistance may include:

- **Medicare** (<https://www.medicare.gov/>), which covers 80% of the cost of medical equipment, such as wheelchairs and walkers, as well as part-time or infrequent home health services from registered nurses, physical therapists, and social workers. Medicare can be used for respite care, but does not provide for the services of a full-time nurse or family care partner.
- **Medicaid** (<https://www.medicaid.gov/about-us/contact-us/contact-state-page.html>), which may cover many of the expenses associated

Care Partner Resources Outside the Field of MS

There are good resources to be found from advocacy organizations outside the field of MS.

The Alzheimer's Association

(www.alz.org/help-support/caregiving) has excellent information and resources for caregivers. The website is divided into sections for early-stage, middle-stage, and late-stage caregiving, and provides videos on caregiver training and caregiver health.

The American Association for Retired Persons (AARP)

has an extensive array of resources on its website. Check the Family Caregiving section (www.aarp.org/AARP/caregiving) for resources such as how to hire an aide how to be paid as a family caregiver, and understanding Medicaid coverage.

with caring for people with MS, including help with daily home care (cooking, cleaning, and other activities), home health services and personal care, transportation to medical care, and respite care. All 50 states and the District of Columbia offer self-directed Medicaid services for long-term care. In some states, that may include hiring a family member to provide care.

- **Paid family leave to provide home care** (www.dol.gov/general/topic/benefits-leave/fmla). As of 2019, 1 in 6 workers were covered by employers for paid family leave, and four states offered government-sponsored family-leave insurance, with more states scheduled to start between 2020 and 2024.
- **Military veterans.** More than two-thirds of US states and districts offer funds to help veterans pay for goods and services to support their medical needs, including assistance with

cooking, bathing, dressing, feeding, using the bathroom, and prosthetic devices. Veterans may use their benefits to pay a family member who performs these tasks for them (https://www.va.gov/GERIATRICS/pages/Veteran-Directed_Care.asp). In addition, veterans are entitled to 30 days of respite care per calendar year (www.va.gov/GERIATRICS/pages/Respite_Care.asp).

- **Insurance providers** may or may not offer long-term health insurance benefits to pay for a family member or spouse to be a care partner. Check your individual policy for details.

Other Useful Resources for MS Care Partners

National Family Caregiver Support Program

www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program

National MS Society: Living Well With MS

www.nationalmssociety.org/Living-Well-With-MS/Relationships#section-3

Relationship Matters: A Program for Couples Living with MS

www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Resources_Support/FY19-FINAL-RELATIONSHIP-MATTERS-WORKBOOK.pdf

Email: couplesprograms@nmss.org Tel: 800-344-4867

Well Spouse Association

www.wellspouse.org





3 University Plaza Drive, Suite 116
Hackensack, NJ 07601

Tel: (201) 487-1050
Fax: (862) 772-7275

iomsn.org
Email: info@iomsn.org