

Circle of support



Having a team of support can help people with MS live more powerfully. Here's how to expand your network and resources.

by Maureen Salamon

Sometimes it takes eight phone calls before Shelley Peterman Schwarz finds a ride to her next hair appointment.

Having lived with primary-progressive multiple sclerosis since 1979, the 68-year-old Wisconsin resident now uses a three-wheeled scooter to get around. She also taps a lengthy roster of paid and volunteer helpers—topped by her husband of 45 years, Dave—to keep her fully immersed in a life that includes a busy career as an author and motivational speaker.

The level of assistance Schwarz requires, encompassing almost all personal care, could prove intimidating to the support partners of many people with MS—particularly those whose increasing needs, years or decades after diagnosis, find them continually asking for help from the same people. But Schwarz, a grandmother of five, just considers it an opportunity to interact with a greater variety of friends, neighbors and community members.

“I have a long bench of helpers... if one can't do it, I call another,” Schwarz says, though she acknowledges that many in her situation don't feel they have a similar abundance of resources and support. However, there are many ways to expand one's support network and give others a chance to help, too. Read on to discover how.

Needing help but not wanting it

“People are too busy; they aren’t trustworthy.”

“Things won’t get done the way I want.”

“My MS will get worse if I don’t stay active and do everything myself.”

These are among the many reasons individuals with MS may decide not to ask for help, particularly if the disease’s progression requires greater assistance as time passes. Supportive tasks may be physical in nature—such as assisting with cleaning, cooking, laundry, transportation or personal care—but can include emotional, social and financial help as well. But the prospect of asking for help with such needs, experts say, can feel like personal weakness, creating a toxic blend of emotions such as shame, anger and denial.

“People with MS want to maintain their independence, and they want to not ‘give in’ to the illness,” says Peggy Crawford, PhD, a Brunswick, Maine-based psychologist who has worked with people with MS for more than two decades. “However, it’s probably not the best coping style, seeing MS as your opponent,” adds Dr. Crawford, who recently co-led a [Can Do MS](#) webinar on the topic of Flying Solo with MS. “You can be the captain of the team, but MS is going to be one of your players.”

Once a person with MS acknowledges the need for ongoing aid, perhaps with the help of a medical professional, or with the support of family and friends, it’s then easy to fall into a rut of depending on the same people—whether spouse, children, parents or other loved ones—to help again and again. It’s a phenomenon that Dr. Crawford notes is “incredibly common” for people with MS or other disabilities.



Matt Cavallo leaned heavily on his wife, Jocelyn, during three exacerbations of his relapsing-remitting MS. This made Cavallo feel guilty, a common emotion

among people who ask for help. Photo courtesy of Matt Cavallo

Sometimes, asking for help leads the person with MS to feel guilty—either for constantly relying on one or two people, or for not contributing more. Matt Cavallo, 38, leaned heavily on his wife during three major exacerbations of his relapsing-remitting MS that he has experienced since being diagnosed in 2005.

“At certain points, my wife has had to take care of me from a grooming, dressing and toileting perspective like she would our babies,” says the father of two young boys. He found the shift in roles disquieting and guilt-provoking.

Overcoming guilt

This sense of guilt is natural, experts say, but it need not go unchallenged. Regardless of lost abilities, people with MS still have much to offer. What they can contribute may be different from before, or might seem insignificant, but these contributions of time or talent can lighten the load for caregivers and help balance close relationships.

“The emotional power of a relationship can be what keeps that balance in place,” says Deborah Miller, PhD, a staff social worker at the Mellen Center for Multiple Sclerosis Treatment and Research of the Cleveland Clinic. “It might be that a person with MS can’t cook the meal, but if it would be a help, he or she can plan a week’s worth of menus so the person going shopping only has to make one trip. It’s going to be unique with each family, and they need to communicate openly about it.”

Schwarz tries to concentrate on what she can offer that’s unique to her abilities, finding that her value to loved ones extends far beyond her physical strength.

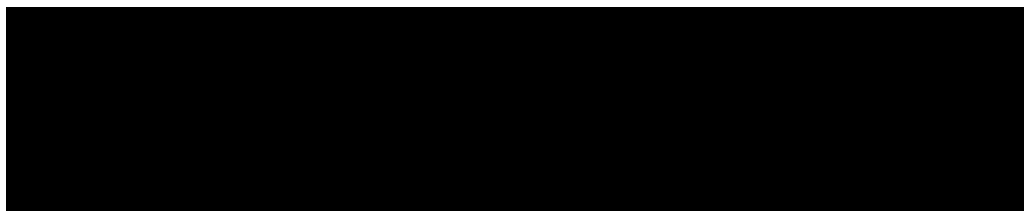
“I offer to help if someone is planning a party, making some calls for them,” she says. “Some of my friends come over and help me cook; I buy all the supplies and they take home meals for their family. I listen to them, and sometimes I think that’s the most important thing of all.”

Schwarz also advocates that people with MS unselfishly give space to spouses and other primary caregivers, pointing out that a bit of freedom for them can also serve to equalize the push-pull of everyone’s needs.

“My husband is retired and takes classes at a university, belongs to a stock club and plays poker. He has his own guy friends, and I encourage him,” she says. “And when he’s away, my girlfriends stay over and we have a slumber party. We’ve always respected each other’s need for our own space.”

Cavallo has addressed the uncomfortable shift in roles with his wife by spending more time on “dates” and more romantic activities when his MS exacerbations ease. This vital

reconnection strategy, Dr. Miller says, “acknowledges a couple is going back to their marital relationship and not the ‘crisis’ relationship.”



Expanding your resources

Not only can continually leaning on the same few helpers cause resentment for caregivers, Dr. Crawford says, but it’s also unhealthy for individuals with MS in most cases.

“I often see that when people put all their eggs in one or two baskets [of helpers], they feel frustrated or angry if the usual person can’t help them,” she says. “Then they become tough people to help. They don’t show a lot of appreciation for the help, which is important to do.”

Being flexible in allowing people to choose how to help, on their terms, is the first step in learning to accept help from more people, Drs. Crawford and Miller say. But after this, they suggest trying new ways to expand your resources so you’re not always asking the same people for help. For example:

- **Tap into local religious, social or civic groups you’ve been involved with.**

“Whoever you interact with on a regular basis is someone who can potentially lend a hand,” Dr. Crawford says. Two women from Schwarz’s temple helped her with physical and occupational therapy exercises, for example.

- **Set up a regular schedule for predictable tasks such as paying bills, picking**

up prescriptions or grocery shopping. With a list of all your needs, it's easier to identify who in your network can be responsible for each activity. "It's good to have assignments or dates scheduled among many support partners," Dr. Miller says. The online service Lotsa Helping Hands lets you post requests for assistance with specific tasks, and people in your network can sign up on a calendar.

- **Hire help for extremely personal tasks such as showering or dressing,** as Schwarz does, to maintain a more balanced relationship with close family members and friends. "I think it's really healthy to have more than one source of support," Dr. Miller says, "especially if it's a partner they count on for a lot of other needs." Be wary, too, of involving children in personal tasks that may not be suitable.
- **Connect with a local home care agency to line up a temporary fill-in helper,** in case the primary caregiver becomes ill, needs to travel or just needs a break.
- **Hire a local retiree to run errands or do odd jobs.** "It's not the same thing as having a friend do it for free," Dr. Miller says, "but having a person in your neighborhood who could use a little extra cash can be a great resource." Online services can be another source of help. For example, TaskRabbit matches people who need work done with others in the same neighborhood who are qualified to do it. Many grocery stores also offer online shopping.
- **Research respite and chore services offered by the National MS Society** to help periodically with personal care and household chores. Call an MS Navigator at 1-800-344-4867.

Maureen Salamon is a New Jersey-based writer.

Visit the [National MS Society's Carepartners Resources](#) page for additional tips and advice for family and friends of people with MS.

To connect with other carepartners with similar experiences, log into the carepartners discussion group on [MSconnection.org](#).

Related articles

Read "[Becoming carepartners](#)" for more on how to create a balanced relationship with MS in the mix.