

MULTIPLE SCLEROSIS FOUNDATION



MAGAZINE

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The Circle of Care

Caregivers' Night Out
Winners





Multiple Sclerosis Foundation



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Statement of Purpose

The purpose of the Multiple Sclerosis Foundation's publications is to empower those affected by MS to make the most educated decisions concerning their healthcare. We do not advocate or endorse any specific treatments, healing modalities, or practitioners. The material in this publication is for informational purposes only. For specific advice, please consult a healthcare professional.

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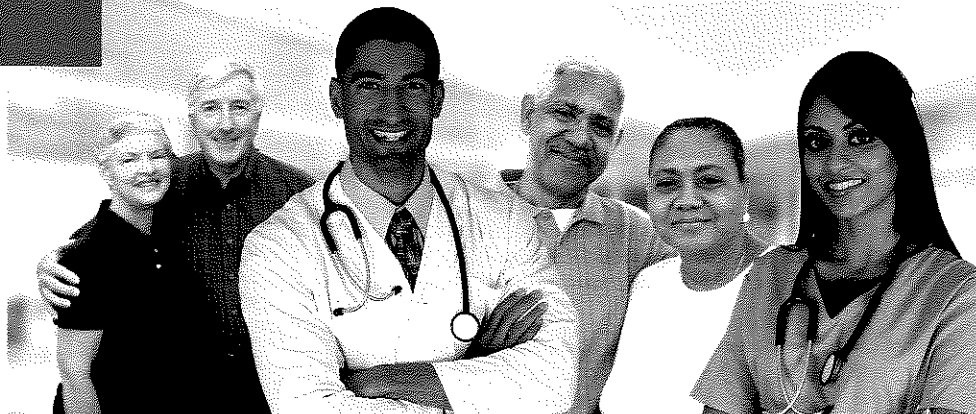
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Stay Afloat: Build a “Caregiver Colony”



"Intentional families" help us to survive the MS floodwaters

By Darbi Haynes-Lawrence, Ph. D

It is no surprise that people who have chronic illnesses are going to need a helping hand now and again. MS is a chronic, progressive disease, and let's face it, some days we need that extra care.

To make sure we get the help we need, we must be prepared for relapses or other issues that arise. I encourage people to get a supportive caregiving system in place early, so when a relapse or major issue occurs, we have our team at the ready.

Collective buoyancy

When I think of a caregiving team, it reminds me of a story in the news not too long ago. During recent floods in the southern states, newscasters warned people to be careful about what might look like a clump of soil floating in the water. The reason? They were floating mounds of fire ants! When fire ants are in a flood, they band together and form a living raft. By holding tight to one another they become buoyant and are therefore able to survive the floods. If someone were to push on this floating mass, they would surely suffer the ants' bite, but the ants would not sink. If the ants didn't stick together this way, their colonies would not survive.

Let's compare those fire ants to those of us with MS. When a 'flood' – or for us, a relapse

– strikes in our lives, how do we survive it? The world doesn't stop simply because we are experiencing difficulties with our disease. We need to band together with our 'colony' to stay afloat.

Very often, we lean intently on our spouses or partners for assistance. They tend to be our first line of help. Sometimes, we may also lean on our children or our parents as our caregivers. Depending on how deep our 'flood waters' are – how much help we need – this may be enough. But we do need to consider it carefully. Family systems theory (a form of human behavioral science that looks at the inter-relationships and inter-connectedness of a family) tells us that we can overburden relationships, causing burnout. In other words, if we lean on one family member for constant care, this can cause chronic stress and burden on the relationship. Frequently, this causes the relationship to burnout, or end.

Keeping us afloat

However, we can choose to build caregiving teams that extend far beyond just blood relatives. In my house, we like to think of this as creating an "intentional family."

The members of our intentional caregiving family are not only relatives and friends.

These intentional family members can be anyone who takes part in helping keep us afloat.

This can include, for example:

- Neighbors, who might bring a casserole or ask if we need anything when they're going to the store
- Coworkers, who pick up the slack when we're out sick
- Our medical team, including pharmacists, who answer questions and help us get treatments we need
- Parents of our children's friends, who assist with ride sharing to and from school, with after-school events, and who also watch our children while we attend a doctor's visit, or simply need to rest
- Local services we can count on to make life easier - think grocery delivery services such as 'Insta-cart' or Wal-Mart's same-day pickup.

These intentional family members can be anyone who takes part in helping keep us afloat.

While it is important that we have our intentional caregiving family established prior to a relapse or a time of need, it's equally important to remember we can provide care, too! For many of us, our MS waxes and wanes. When we aren't in need ourselves, we can be a part of someone else's intentional caregiving family. For example, I have damage from relapses that makes it difficult for me to walk, but I can still find many ways to provide care to others, even if it's just calling to check on how they're doing. This give-and-take caregiving relationship benefits everyone

involved.

Like those fire ants, during a relapse or time of need, lock arms with your intentional caregiving family to stay afloat. Once the storm passes for you, be prepared to assist someone else who is weathering their own storm.

Caution in Using Children as Caregivers

In a recent study by my colleague and I, we discovered that the intentional caregiving family included spouses, partners, parents and grandparents, and, finally, children. While children can be a help for us during a time of relapse, I caution against overburdening children with providing care to their parents. Make sure to select only caregiving tasks that are appropriate to their age and relationship to the person receiving care. For example, asking a child to assist with brushing a parent's hair or tying a parent's shoes is fine. Asking a child to assist a parent in bathing and toileting may not be. Asking a teen to be responsible for cooking is age-appropriate. Asking an elementary school aged child to cook hot meals could put the child in danger. If you are not sure whether something is a reasonable and appropriate task for your child to aid in your care, ask their pediatrician.

