

MS Perspectives™

Volume 8, Issue 2

Practical Insights on
Multiple Sclerosis



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TAKE CARE

Caregiver

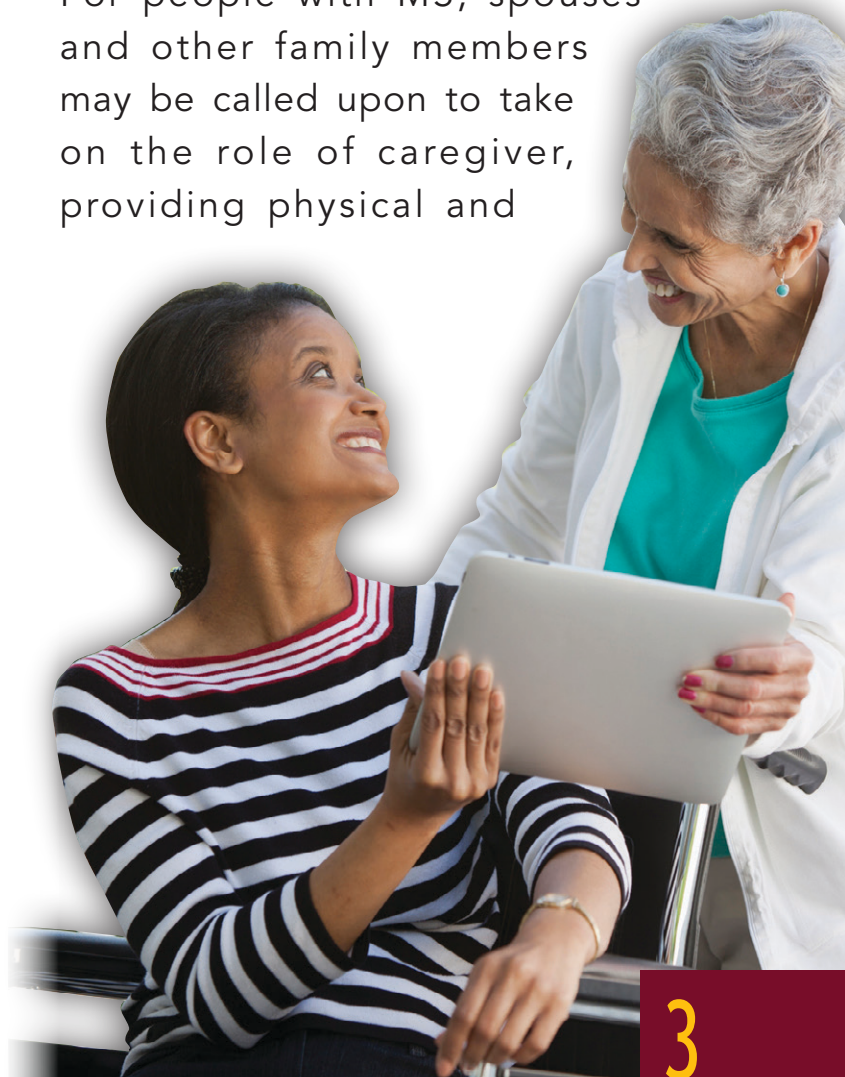
Larry Oswald, 72, has cared for his daughter, Caroline, for 19 years as she has fought progressive multiple sclerosis (MS), a disease her mother also had. Diagnosed at 18, Caroline was mobile until around the age of 30, but has progressively worsened over the years. "She has had stormy, unpredictable relapses," he says, "and multiple, unpredictable symptoms." When she was first diagnosed, Larry took her to the Shepherd Center in Atlanta, 200 miles away from his home in South Carolina, seeking the best care he could find for his daughter. Now 47, Caroline lives in a skilled residential nursing facility, where Larry visits her nearly every morning. He makes sure all of her medical needs are met and that she has a good lunch before returning home.

Larry feels that his role as a caregiver has strengthened his faith. He has chosen to make MS the centerpiece of his life, for his daughter's sake, even retiring early to care for Caroline. Yet he has also remarried and tries to set aside leisure time for himself. "I have

a good support group in my family, my church, and my community. I take it a day at a time," he says. "It takes a lot of patience and perseverance to be a caregiver, but you can cope."

The Caregiver's Dilemma

For people with MS, spouses and other family members may be called upon to take on the role of caregiver, providing physical and



emotional support, particularly as MS progresses. Although the disease and its symptoms are highly unpredictable and individualized, over time, people with MS may require more help with physical tasks, such as getting out of bed, using the toilet and bath, eating, dressing, and other activities of daily living. They also often need help with mental tasks, such as remembering to take their medications, pay bills, and keep appointments.

These activities can be time consuming and exhausting for caregivers, even those who perform the role out of love and devotion and find it rewarding. Caregivers may end up depressed or anxious themselves, and often have little time to themselves or to enjoy life. This is a serious concern, since chronic stress and depression can increase the risk of heart disease, cancer, and diabetes, and can even lead to early death for caregivers. Depression and anxiety can also affect their ability to give good care. They may forget to administer medications on time and find it difficult to perform the tasks necessary to caregiving.

FYI

Did you know that...

- *There are an estimated 65.7 million Americans acting as caregivers for family members who are ill or disabled.*
- *Caregivers are at risk for chronic stress, anxiety, depression, guilt, resentment, and poor health themselves.*
- *Taking time for yourself and safe-guarding your mental and physical health are the best things you can do for yourself as a caregiver and the person for whom you're caring.*

Women and those caring for difficult people are most at risk for mood disorders. The more tasks caregivers have to perform and the more hours they spend with a disabled patient with MS or another chronic, progressive disease, the more likely strain will occur. Having a poor relationship with the patient, being in poor physical or psychological health, and not having enough social support can also increase caregiver stress, according to research.

Working as a Team

Bruce and Anne Rainey, both in their 50s and married for 27 years, have gone through a lot together: Infertility, breast cancer, prostate cancer, and, since 2003, MS. “We both have MS,” says Bruce. “Anne got the diagnosis, but it affects us as a family. We are a team.” Anne’s course has been stable, although she has some memory issues. “She can tell you what happened 10 years ago, but she can’t remember what needs to be done today or what happened yesterday,” he notes. She doesn’t have a good sense of time and has lost her sense of smell, so Bruce retired recently from his job to be with her and make sure she stays safe. On occasion, he assists her with giving herself injections of her disease-modifying therapy (DMT).

“I consider myself her caregiver—I help her with her shots and remembering her appointments. We can’t be as active as we used to be, but we still have a good life together,” he says. “MS is part of what we do every day—we get up, brush our teeth, take a shower, and Anne takes her medication.”

Be Kind to Yourself

You can be a good caregiver and still take care of yourself. In fact, the better you care for yourself, the better a caregiver you’ll be. Follow these tips.

- **Get educated.** “Understand the disease, what can happen, and how to manage it,” advises Kate Upshur, LCSW, a care coordinator at the MS Center of Saint Louis in Chesterfield, Missouri.





afford to hire help. Ask your children, siblings, or close friends to do specific tasks or errands, or to commit to regular meetings with the person with MS so you can get a break and do something fun and interesting. A strong social support network is one of the most important buffers against caregiver strain.

- **Find other caregivers.** Contact organizations such as:
 - the **Family Caregiver Alliance-National Center on Caregiving** (www.caregiver.org, 800-445-8106);
 - the **Caregiver Action Network** (<http://caregiveraction.org/>); and
 - the **Well Spouse Association** (www.wellspouse.org/).Also contact organizations listed on page 7 for more information and local groups you can join.
- **Ask for help.** You don't have to do everything yourself, even if you can't

- **Investigate adult daycare programs,** visiting nurses, Meals on Wheels, and home healthcare assistance. "You can also investigate respite care, which doesn't just mean institutional care," says Upshur. "Different levels of care are available, such as in-home care when you need to get away for a few hours." If you are considering respite care, ask the agency you contact if it has the ability to send the same caregiver to the house each time so you don't have to train a new person at every visit.

- **Give yourself permission to feel frustrated, angry, resentful, tired, or ashamed.** You will go through the gamut of emotions as a caregiver. That's why it's important to connect with other caregivers and health professionals, says Upshur. "They

can validate what you're feeling and experiencing."

- **Keep up with your own healthcare.** Get preventative healthcare examinations, and ask for counseling or medication if you feel you are suffering from caregiver stress or burnout.

Support Programs for MS Disease-modifying Therapies (DMTs)

Aubagio,[®] Genzyme Corporation:

www.aubagio.com/ms-one-to-one,
855-MSONE2ONE (855-676-6326)

Avonex,[®] Biogen Idec:

www.avonex.com/join-biogen-support/,
800-456-2255

Betaseron,[®] Bayer HealthCare:

www.betaseron.com/beta-nurse-support,
800-788-1467

Copaxone,[®] Teva Neuroscience:

www.copaxone.com/shared-solutions,
800-887-8100

Extavia,[®] Novartis:

[www.extavia.com/info/PatientSupport/
Patient-support-program.jsp](http://www.extavia.com/info/PatientSupport/Patient-support-program.jsp),
888-NOW-NOVA (888-669-6682)

Gilenya,[®] Novartis:

www.gilenya.com/c/ms-pill/go-program,
800-GILENYA (800-445-3692)

Lemtrada,[™] Genzyme:

[www.lemtrada.com/resources-and-support/
lemtrada-support](http://www.lemtrada.com/resources-and-support/lemtrada-support),
855-MSONE2ONE (855-676-6326)

Plegridy,[™] Biogen Idec:

www.plegridy.com, 800-456-225

Rebif,[®] EMD Serono/Pfizer Inc:

www.ms lifelines.com, 877-447-3243

Tecfidera,[®] Biogen Idec:

[www.tecfidera.com/join-biogen-
support/](http://www.tecfidera.com/join-biogen-support/), 800-456-2255

Tysabri,[®] Biogen Idec:

www.tysabri.com/support,
800-456-2255

MS News, Support, and Self-Help Groups

MS Views & News

www.msviewsandnews.org

MS World

www.msworld.org

Multiple Sclerosis Association of America

www.msassociation.org, 800-532-7667

Multiple Sclerosis International Federation

www.msif.org

Multiple Sclerosis Foundation

www.msfocus.org,
888-MSFOCUS

National Multiple Sclerosis Society

www.nationalmssociety.org,
800-344-4867

PARENTING ADVICE FOR PEOPLE WITH MS

Parenting children can be challenging under any circumstance. Add in a chronic, unpredictable disease, and the equation instantly becomes more complicated, both for the parent and the children.


“An illness like multiple sclerosis (MS) forces a shift in family dynamics,” explains Robert E. Godsall, PhD, Director of Outpatient Neurorehabilitation/Neuropsychiatry Clinics at the MS Institute of Shepherd Center in Atlanta, Georgia. Frequently, if the onset of the disease is sudden rather than gradual, children may be required to take over a lot of activities that parents used to do,” he notes. “There’s a positive side of this in that kids learn skills that will serve them well into adulthood—but that’s only if they are performing tasks that are age-appropriate. You can’t ask a 13-year-old child to balance the family checkbook.” On the other, less-positive side, kids need to be protected, he says, and taking over caregiving and housekeeping roles shouldn’t be done

at the expense of them having normal social lives and school experiences.

Do You Tell Your Kids You Have MS?

Children may have difficulty making sense of what is happening to their parent with MS, who can have subtle symptoms such as fatigue and



A photograph showing a woman with long brown hair smiling warmly at a young boy with dark hair. They are in a kitchen, with the boy looking at a large stainless steel pot on the stove. The woman is leaning in towards him, and they appear to be engaged in a conversation. The background is slightly blurred, showing a white wall and a hint of a window.

cognitive changes, or more noticeable symptoms such as walking impairments that require the use of assistive devices. “I think it is best to educate children about MS, even young children, so they have something to work with,” says Dr. Godsall, a position that is backed up by research showing abnormal psychological adjustment is related to factors such as children not understanding the illness, lack of social support, family dysfunction, poor psychological health of the parents, and increased severity of the illness.

Teens appear to be at greater risk for psychological and social problems than younger children, but all kids are at risk. “If they don’t know what’s going on, young children in particular will begin to fantasize that their Mom or Dad may be dying and get very anxious,” says Dr. Godsall. He suggests explaining to the child that you (or the other parent) has an illness and that everyone in the family may have to chip in and help Mom or Dad when they don’t feel well or when they’re tired. When they do help out, children should be given extensive praise so they don’t feel invisible or that their contribution to the family is unappreciated.

Sandy, 48, of Suffolk, Virginia, has always tried to be open with her two children, who were young when she was diagnosed, about her disease. “I’ve had a couple of bad relapses that lasted about two weeks, so I couldn’t hide it from them,” she says. “The older they got, the more I could explain the disease to them and the more they could understand. And I stressed that even if I didn’t recover fully from a relapse, which I sometimes didn’t, I would always be there for them.”

Likewise, Denise Clarke, 46, of Virginia Beach, Virginia, has also been up front with her kids about her relapsing-remitting MS, which was



electrical wire, where MS eats away at the outside of the wire.”

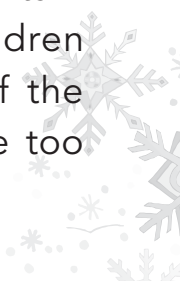
Caregiving Risks Can Endure for Kids

Although research is sparse in this area, children appear to be at risk for anxiety and depression both in their youth and when they mature if they have a parent who is clinically depressed, is a substance abuser, or has a chronic illness such as MS that requires them to take over caregiving duties. Children are also at risk for anxiety and depression as adults if parents put them in the middle of a stressful spousal relationship and expect them to assume adult roles.

Open lines of communication are vital to the psychological well-being of parents and children, both of whom may internalize the stresses they are feeling. Kids might resent having to take on chores that their friends aren't required to do in their homes, or feel embarrassed by or afraid of their parent's illness. They may feel they can't depend on their parent with MS due to the sudden and unpredictable nature of symptoms that can disrupt social plans.

“It's best if the family can maintain some order or structure and children are still allowed to be children. If the roles you need kids to take on are too

diagnosed when her two boys were quite little and before the birth of her daughter. “I don't make a big production about my disease,” she says. “Injections have always been part of my life and I do them in private at night, but the kids knew about them, and I explained things to them about MS when they asked. I gave them bits of information at a level I thought they could understand. For instance, I told them my nervous system is not quite right. I compared it to an



much for them, bring in a caregiver, grandparent, or babysitter to take over," Dr. Godsall advises. Also be sure to maintain family activities, such as nightly dinners and outings, including vacations and trips to the movies, aquarium, or zoo. And allow children to develop a normal social life that includes school clubs, sports activities, and friendships. (Local chapters of the National MS Society, by the way, sponsor camps for kids of parents with MS to help them cope and have fun away from their families.)

"I was very good at scheduling my work life, my kids' needs, and my housework when my children were young," recalls Sandy. "My husband was also very supportive. He would help the kids with their homework or get them to bed if I wasn't feeling well."

With the proper balance of responsibility, communication, and freedom to be a child, most children of parents with MS can grow up to be resilient and have satisfying lives. "I try to be

a good example to my kids of how to cope with a chronic disease and manage my life," says Denise. "I am a very positive thinker. When I was first diagnosed, it was pretty scary, but it could have been worse. It could have been a terminal illness like cancer."

Sandy believes that her MS has helped her kids have empathy for other people and to be grateful. "We all adjusted to my MS, I got on medication as fast as I could and I got a good healthcare provider, and we just went along with our lives, she says. "I had my pity party and I moved on, for the sake of my kids. We didn't let it crush us as a family."



Ask the Clinician

Q. My child was just diagnosed with MS. What can I do as a parent to help her?

Two pediatric nurse practitioners respond

A. It's important to express to children that things are going to be okay and to work together as a family to make their lives as normal as possible. Try to get kids back into school soon after an exacerbation and work closely with the school to get the services they need so they're not excluded from activities, including sports. The Office of Disabilities will help to create a plan that can include academic accommodations and support, modifications for physical education class, and access to home schooling, if necessary. This way, if children must miss a school day for a doctor's visit or testing such as an MRI scan, they won't be penalized. And if they have relapses and miss several days of school, a plan for home schooling can be put in place quickly, rather than children having to wait weeks to receive services.

I also advise parents to let kids do normal things like hanging out with friends or going to summer camp or

college. Check out the Teen Adventure Summer Camp in Rhode Island for youth with MS, which I helped to create, at www.stonybrookchildrens.org/specialties-services/clinical-programs/multiple-sclerosis. Teens come from all over the United States and the world to attend this one-week program, which is free of charge and staffed by nurses, social workers, and recreation therapists. We create a living-and-learning environment for kids, and practice strategies to cope with their MS that they can use at home, such as how to deal with the heat and still be active. We created the camp because we realized that many kids with MS don't know other kids with the disease and they feel isolated. The camp is a place to meet friends living the same life, share stories, and grow together. **[Editor's Note:** There are other camps for kids and teens with MS held nationwide; visit the National MS Society's website for information.]

Also check out the many programs the National MS Society offers for children with MS, as well as written resources for kids and parents, such as:

- **Keep S'Myelin.** www.nationalmssociety.org/Resources-Support/Library-Education-Programs/For-Kids-Keep-S-myelin.
- **Kids Get MS Too: A Guide for Parents of a Child or Teen with MS.** www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure_Kids-Get-MS-Too-Parents-Handbook-current-as-of-11_10_14.pdf.
- **Managing School Related Issues: A Guide for Parents of a Child or Teen with MS.** www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Managing-School-Related-Issues_-A-Guide-for-Parents-with-a-Child-or-Teen-Living-with-MS.pdf.
- **Students with MS & the Academic Setting: A Handbook for School Personnel.** www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Students-with-MS-and-the-Academic-Setting_-A-Handbook-for-School-Personnel.pdf.
- **Your Education Rights as a Student with MS.** www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Your-Education-Rights-as-a-Student-with-Multiple-Sclerosis.pdf.

MSNationalFiles/Brochures/Brochure-Your-Education-Rights-as-a-Student-with-Multiple-Sclerosis.pdf.

Of course, while you want to encourage your children to be as engaged in

school, social, and sports activities as they feel up to, you also want to have a backup plan in place in case there is a problem. For instance, if a child is going off to college, you

want to find a neurologist close to the school who can care for your child if he or she has an issue. I suggest making an appointment with the neurologist prior to the start of school and introducing your child to this doctor, as well as asking your home neurologist to update the new neurologist on your child's medical history.

— Maria Milazzo, RN, MS-PNP
Pediatric Nurse Practitioner
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- *Pediatric MS affects about 5% of US children.*
- *Approximately 5% of adults with MS had their first symptom as a child.*
- *Most kids are diagnosed around the age of puberty, possibly due to the increase in hormone production at that time.*
- *More adolescent girls than boys are affected.*

A. If at all possible, families need to seek out a pediatric MS specialist or specialized center to provide care for their child. The specialists and centers are where your child will get the most accurate, up-to-date treatment options and support. There are nine centers nationwide and they have the most expertise in this field and can offer you and your child the most resources (see the box on page 15).

In addition, seek social support for your child through the MS Society's local chapters and online groups—both have groups for kids and teens with MS. It's important for your child to know that he or she is not alone.

Treatment can be difficult for kids and teens to handle. We use the same disease-modifying treatments (DMTs) in children as we do in adults, but they are used "off-label." This means that the research done to date suggests

they are safe and effective, but the drugs haven't been specifically approved by the Food and Drug Administration for kids.

Most kids are prescribed injectable medications, and the reaction to this treatment is very individualized. Many children do well with injections from the beginning, especially if they're well-prepared about what to expect. Others are afraid of injections and doctors' offices in general. Parents can be needle-phobic, too. If you are one of these people, you need to think about who is going to be responsible for giving your child the injections he or she needs at the time they need to be administered. It could be a mom, a dad, a granny, the school nurse, a nurse friend who lives down the street, or you might need to take the child to the doctor's office. You need to make arrangements for that, and have a backup plan in case the designated person gets sick or is too busy to give an injection.

DMT adherence issues can be a problem, especially with teens because of side effects that interfere with their normal lives:



Yolanda Harris, MSN,
PNP-AC, MSCN



For instance, the interferons (Avonex®, Betaseron®, Extavia®, Plegridy™, and Rebif®) can cause flu-like symptoms, while glatiramer acetate (Copaxone®) can lead to injection-site reactions. Teens may think they are like Superman, and that they don't need their medication. From a developmental standpoint, they may not have the maturity to realize the medication is helping them to avoid exacerbations. So from the time of

diagnosis, parents need to encourage their children to own their disease. They also need to foster independence and the ability to provide self-care.

— Yolanda Harris, MSN, PNP-AC, MSCN
Dual Option PNP Faculty
Neurology Nurse Practitioner
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Pediatric MS Centers

Nine pediatric MS centers have been recognized by the National MS Society as providing comprehensive care to children with the disease. The centers are also doing research and are on the cutting edge of pediatric treatment. If at all possible, experts recommend taking your child to one of these centers for evaluation and care.

ALABAMA

UAB Center for Pediatric-Onset Demyelinating Disease
Children's Hospital of Alabama
Birmingham, AL
205-996-7633

CALIFORNIA

University of California San Francisco (UCSF) Regional Pediatric MS Center
San Francisco, CA
415-353-3939

Pediatric Multiple Sclerosis Center
Loma Linda University
Children's Hospital
San Bernardino, CA
909-835-1810

MASSACHUSETTS

Partners Pediatric MS Center
Massachusetts General
Hospital for Children
Boston, MA
617-726-2664

Pediatric Multiple Sclerosis and Related Disorders Program
Boston Children's Hospital
Boston, MA
617-355-2751

MINNESOTA

Mayo Clinic Pediatric MS Center
Rochester, MN
507-293-0378

NEW YORK

Pediatric MS Center
Jacobs Neurological Institute
Buffalo, NY
877-878-7367
PEDMS@thejni.org

Lourie Center for Pediatric MS
Stony Brook Hospital
Stony Brook, NY
631-444-7802
info@pediatricmscenter.org

TEXAS

The Blue Bird Circle Clinic for Multiple Sclerosis
Texas Children's Hospital
Houston, TX
832-822-5046



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