

The parenting puzzle



How can you manage your kids—and your MS?

by Maureen Heaney

Being a parent requires a person to assume many roles—cook, chauffeur, event planner, lion tamer—and sometimes the responsibilities can feel endless. At the best of times, parenting is still challenging. But when you are also dealing with the physical, cognitive and emotional issues that accompany multiple sclerosis, parenting can seem utterly overwhelming.

“Fatigue is my worst enemy right now,” explains Sarah Keitt, a 44-year-old mother of two in Woodbridge, Va., who was diagnosed with relapsing-remitting MS in 2000. Her biggest concern, she says, is that her children, ages 8 and 9, will miss out on experiences because of her disability. “I think every mom struggles with ‘mommy guilt,’ but adding MS to the mix just makes it worse.”

Michael Wentink Jr., a 37-year-old father of two in San Antonio, Texas, who blogs about his MS experience at MSconnection.org/blog and at mjwentink.com, had a fantasy of what fatherhood would be like prior to his 2008 diagnosis. But his physical limitations interfered with his plans. “I had envisioned leading an active lifestyle with my kids and looked forward to being involved with their sports teams,” says Wentink. But instead, he continues, “extended periods of standing or walking can wipe me out.”

Rosalind Kalb, PhD, vice president of Clinical Care at the National MS Society, suggests that parents allow themselves to think of new or different ways to interact with their kids. “Find activities and strategies that might work for you.”

Wentink has done just that. “Since my diagnosis, I’ve started to enjoy many less-physical activities. I now bake and do puzzles with the kids, and I love that they are so engaged in these activities,” he says. And they also find other ways to stay active. “We go on family walks, our kids play sports, and my wife certainly steps up, too, taking the children on longer walks, and even a little running, at a local park.” That kind of flexibility can lead to greater happiness and success for parents and children alike.

Keeping it real



**Sarah Keitt
Diagnosed in
2000, this mom
has learned to be
gentler with
herself when
facing her
limitations.**

Whether a parent is dealing with fatigue, weakness, visual impairment, cognitive difficulties or any other symptom of MS, it’s best to identify and manage these issues upfront, says Deborah Miller, PhD, a social worker and associate professor of medicine at the Mellen Center for Multiple Sclerosis Research and Treatment at the Cleveland Clinic. For example, Dr. Miller says, “Many parents say they feel tired when the kids get home from school, just when snack and homework time starts.” With this awareness, parents could try to arrange their schedules so they can rest a bit earlier in the day and conserve energy for later.

Keitt says she’s learned not to make too many promises about outings, and always has a low-key backup plan in mind that’s still fun for the kids, like having a movie-and-popcorn day at home. And when it comes to group activities, like being a scout leader or a classroom mom, Keitt says she manages her energy by setting limits. “I just don’t have the cognitive stamina to organize anything beyond my family,” she says. “Birthday parties have become less extravagant, and play dates are limited to one or two kids,” she says.

“Parents often underestimate what kids are capable of dealing with,” notes Peggy Crawford,

PhD, a clinical psychologist and assistant professor at the University of Cincinnati. “Talk to them about MS in an age-appropriate way, and feed them more information as their ability to understand grows,” she says. Explain to your children that fatigue or mobility or visual issues may disrupt plans, but also reassure them that you will try to find a backup person to get them to an outing, or that postponed plans will be rescheduled.

However, while learning that plans sometimes change is an important life lesson, kids may still feel disappointed. “Tell them this makes you sad, too,” explains Dr. Kalb. “Kids understand sadness.”

But kids also understand guilt, so it’s important to avoid overcompensating for your MS by not enforcing rules. “From an early age, focus on consistency and strong discipline,” just as a parent without MS would, advises Dr. Miller. “Parent in such a way that kids know your expectations.”

Helping hands



**Sharon Dodge
Investing in some
“me time” goes a
long way, says
the mother of
three.**

An important item in the toolbox for parents with MS is the ability to seek out and accept help from others, whether it’s asking someone to drive your child to an after-school activity on a day when your vision is bad, or to help you get dinner together when you’re just too fatigued. Having a spouse pitch in is incredibly valuable, but if that’s not possible, try to identify other people who can provide support, such as other parents, friends or family members.

“With a husband who is often deployed for long amounts of time with the Navy, having close friends who know what I have been going through and who are willing to help has been key,” says Sharon Dodge, a Pearl Harbor, Hawaii-based mom to a 20-year-old son and 15-year-old twin daughters. “I always wanted to be able to say, ‘I can do this!’ but some days, I cannot. It

took me a while to realize that's OK."

Dodge, who was diagnosed with MS in 1996, says she also enlists her children's support. "Everyone volunteers what they will be responsible for around the house, to help out Mom," she says.

Chores are a great way for children to learn life skills, too, Drs. Crawford and Miller agree. But kids also need opportunities just to be kids, and parents need to know where to draw the line when asking for assistance. "It's important to leave room for developmentally appropriate activities and interactions outside of the house," explains Dr. Miller. "Parents should never make their child their primary support person or caretaker," Dr. Crawford adds. (If you're concerned that your children may be doing too much, call an MS Navigator at 1-800-344-4867 to explore ways to get additional support.)

Instead, kids should be responsible for simple tasks that add up, like putting things back where they belong. "A lot of time and energy is wasted searching for misplaced items," Dr. Kalb says. "An organized home can help minimize that." Also, keeping a family calendar can help everyone stay on track and reduces the cognitive demands on the parent with MS. "Families should review the calendar together at the beginning of each week, and kids can help to remind parents of upcoming events," says Dr. Crawford.

The kids are all right



**Michael Wentink Jr.
The father of two does fewer physical activities with his kids to conserve energy.**

Even when he follows the experts' advice, Wentink says he still feels guilty about what he can't do, like when his son's coach asks for volunteers to help during sports practice. "I don't tell everyone that I have MS. But I feel that, as a dad, I'm expected to do more physical

things and I worry what people think about the fact that I'm not getting involved," he says.

Keitt says this affects her, too. "On good days, I can be the most fun and active mom. On bad days, I'm lucky if I can manage half of what needs to get done. I constantly feel that I should be doing more," she says.

It's a reminder that the task of managing expectations—yours and your kids'—is ongoing. "Most people create a picture in their mind of the kind of parent they want to be, centered around specific activities they think they need to do with their kids," explains Dr. Kalb. "But parents need to realize that their job is much broader than these things. It's more important to create a safe and loving environment in which kids can grow and learn." Take a moment every day to acknowledge that you are often doing a better job than you realize.

Taking care of the caregiver

Good emotional health is also critical to functioning well as a parent, so find self-care measures that work for you. "There were times when my husband was deployed that I felt overwhelmed," says Dodge, who found that a little "me time" could go a long way. "I took time to do yoga, have coffee with a friend. It made all the difference to put a little focus on myself."

Connecting with others can ease the burden, too. Keitt finds it helpful to have positive friends to talk with about how hard parenting can be. If you are feeling isolated, visit [MSconnection.org](https://www.msconnection.org) to interact with other parents with MS, or call an MS Navigator at 1-800-344-4867 for information about parenting resources and support groups in your area.

However, more severe emotional issues may require professional help. "With issues like mood changes, kids often think that they did something wrong," explains Dr. Crawford. Consult your healthcare provider about treatments or therapies that can help you manage mood changes or other symptoms affecting your family.

The silver lining

While being a parent with MS certainly can bring challenges and disappointments to families, there can be some positive aspects, too. "Families with MS can experience a level of closeness, trust and an ability to communicate that is very rewarding," explains Dr. Kalb. "This is due to the unique ways in which they work together because mom or dad has MS."

Children can benefit from seeing a parent overcome obstacles. "Part of growing up is adapting to unexpected situations that you don't want," explains Dr. Miller. "It is important for parents to communicate that life is full of bumps, and for parents to be a guide as to how to manage these bumps and turns."

"The nature of MS is that it is unpredictable, so do what you can, when you can, and forgive yourself for everything else," says Keitt. And when parents learn to be compassionate toward

themselves, children learn to be compassionate with others—perhaps the most valuable life lesson of all.

Maureen Heaney is an East Northport, N.Y.-based freelance writer and mother of two. She was diagnosed with MS in 2011.

For resources and tips for talking with your kids about MS, visit [Parenting with MS](#).

Download [Keep S'myelin](#), a newsletter for kids and parents, or call an MS Navigator at 1-800-344-4867 to ask for a subscription.

For more information on when and how much to disclose to children about your MS, read [The Disclosure Dilemma](#).