

Parent with MS;

TODDLERS

on Board



Julie Evans hangs out on the hammock with her two preschool-aged sons Will (left) and Sam (right).

The five-year-old refuses to pick up her toys. The three-year-old is whining for juice. Dinner needs to be fixed. Laundry is piling up ... and **Supernanny** is just a TV program. When a parent has MS, there are no ordinary parenting challenges.

By nature, preschoolers run till they drop, are unable to do many physical tasks for themselves, and are years from being able to understand concepts like chronic disease or invisible symptoms. All parents balance many things along with raising their children. There's the household to

stand. You can say, 'My legs are too tired. I need to sit down a lot today.'

When fatigue, vision problems, numbness, or spasticity get in the way, "Give children limited options," Crawford suggested. "Say, 'I can't do this right now, but let's do that.' Offer a back-up activity so you're not always saying no to them. Sometimes breaking activities into parts works: 'We can make cookies, but we'll make the dough today and we'll bake them tomorrow.'"

One mother Crawford knows keeps special books, games, and videos in her bedroom. They are only for the days when

B Y M A R T H A J A B L O W

keep in order, and often a full- or part-time career as well. A parent with MS may have all of these obligations—and the burden of managing whatever MS brings.

Establishing limits for parent and child

"My kids don't understand when I say 'Mommy's foot hurts'," said Julie Evans, mother of five-year-old Will and two-year-old Sam. "It doesn't make sense to them. My pain isn't the result of anything they can see. When they fall down, they know what 'hurt' is, but they can't see what's causing the pain I have."

"You can't explain MS to a preschool-age child," said Peggy Crawford, PhD, clinical psychologist and director of health psychology at Cleveland Clinic's Mellen Center for Multiple Sclerosis Treatment and Research. "But you can talk about function using words they under-

she's exhausted and needs more rest. Her children can climb on her bed and they can be together with these special things.

Giving children limited choices "teaches good life lessons," Crawford said. "It teaches them that they can't have everything they want exactly when they want it—but there are other choices."

Becoming an energy miser

Fatigue, an all too common MS symptom, is especially difficult for parents of preschoolers. Jill Peterson, mother of three-year-old Zachary, said, "The first two years were really rough. With all the sleep interruptions and physical effort of lifting and carrying him, I was always tired. Since he started walking, it has become easier. He can do more for himself. But some things can be a bit of a drain or difficult when I'm tired, like getting him in and out of the car seat. Zachary can't do it completely

by himself yet. I can manage, but when my husband is around he always does it.

"It's all about energy conservation. I'm capable of meeting most physical demands, but if I try to do everything, I'm in trouble. I've learned to scale back, especially in the afternoons. My fatigue is not just the all-over-the-body kind, it's mental fatigue, too. I don't think as clearly and I'm more emotional.

"Self-care is incredibly important," Peterson summed up. "It's easy to lose yourself when caring for a young child. My husband is supportive and minds Zachary while I exercise or relax. That helps me keep my energy up."

Julie Evans laughs when she tells her secret fatigue weapon: "Starbucks every morning!" Evans works as a freelance writer after her boys go to bed. "Fatigue is not something I can separate out from MS or being a single mom who works at home with odd hours."



Kids as young as two or three will enjoy the Society's special newsletter for kids. There are stories about other children, cartoons, games, puzzles, facts about MS, and a special parent's pull-out section in every issue. Older children will like the interactive version on the Society's Web site (www.nationalmssociety.org/Keep%20S%27myelin.asp). Just call your chapter at 1-800-FIGHT MS and ask to be put on the **Keep S'myelin** mailing list.



Aliyah Rivera helps her father, Rod, make a wish.

Kim Neeper has a more regular job. She teaches first grade. And her now two-year-old, Jonathon, is extremely active. "I like to do things with him, but I try not to go overboard," she said. Neeper job-shared the last school year, working Mondays, Wednesdays, and every other Friday. "As long as you are loving, that's all preschoolers need," she said, resisting "supermom" peer pressure. "Kids don't need to be in every playgroup or go to every wonderful place."

Anti-exhaustion measures

"Parents who manage their own fatigue do better," Crawford said. These strategies can help forestall a meltdown:

■ **Manage your time.** "Alternate more physically active days with less active ones. Combine errands so you don't go to the store more often than necessary. Plan a quiet day at home for less tiring activities. If you go to a mall, take the stroller. It helps with balance and gives you a place to stow things rather than carry them. The child can ride or walk alongside."

The Riveras: Mary, Rod, Angelina, and Aliyah.



■ **Plan ahead.** “Look at the whole day and move things around ahead of time to head off problems. One mother with severe fatigue really wanted to walk up to the corner to meet her child’s school bus each afternoon. She was able to do it by resting after lunch and then cooling down by icing herself before time to meet the bus.”

■ **Problem-solve by engaging your children.** “Don’t be afraid to give your toddlers tasks. Chances are they will love it. A mother of several kids was running herself ragged doing laundry until she figured out a system. She gave each child a different colored plastic basket, then taught them to sort and cart their own laundry to their rooms—and put it away!”

The art of being consistent

“Regularity is extremely reassuring to pre-school kids—the same mealtimes and bedtime, the same people around,” Crawford advised.

Peterson finds that consistency helps

both Zachary and herself. Although he’s old enough to walk upstairs, he tries to get carried. “I have to stick to what I said. I’ll tell him, ‘We can walk up together and hold hands.’ Or I’ll walk up the stairs and just leave him at the bottom.

“I think there are long-term consequences if I give in when I’m tired and carry him when he doesn’t need to be carried. I notice when I go through a few days of fatigue, he’ll push, testing the limits. Of course,

that’s a three-year-old’s job: to test the limits. But if I give in, he’ll push the limits even more because I’m not being consistent and he senses the limits aren’t real.”

Pain management

“I’m not an effective mom if I can’t control my pain,” Evans said. During both pregnancies, she stopped taking her disease-modifying drug and a seizure medication that is sometimes used to treat MS pain. After each birth, her pain symptoms became unbearable. She stopped breastfeeding and went back on both medications. It was a smart trade-off. Now her symptoms are better controlled, although occasionally when Will is romping, he’ll accidentally bump into her left ear, which gives her a sharp pain.

“Taking a little pain medication throughout the day may be better than taking fewer larger doses,” Crawford suggested. “You may need to talk with your doctor about changing your medication

schedule so your pain is under good control during the high-stress times, like supper and bath time.”

Evans’ major issue is her disease-modifying drug. The medication gives her a head-crushing headache and nausea. “The next morning the kids come bouncing in, and I say ‘Mommy doesn’t feel well.’ Sometimes I growl at them and I’d like to take it back,” she reported. Moreover, her five-year-old wants to see her give herself a shot. “I’ve chosen to shoo him away,” she said. “If the older one comes in, the younger one will want in, too. My two-year-old would be just like a cat milling around.”

“Most parents who self-inject do it when little ones aren’t around or at night after they’re asleep,” Crawford said. “It’s not an issue of secrecy. It’s distracting to have kids around.” Some toy doctor sets might relieve this a little. The children will give injections to everything in the house until the idea is exhausted.

Keeping it all in perspective

“I work out. I lift weights three days a week,” said Radames (Rod) Rivera, father of five-year-old Angelina and three-year-old Aliyah. “I’ve got to take care of myself. Working out helps a lot as a stress reliever.” As a customer service supervisor for an airline, Rivera is on his feet all day. “When I come home, I’m pooped and the girls want to play.”

Rivera was diagnosed with MS well before the birth of his children. “I was scared of having children at first, scared that I might not be able to pick them up. But I found I could do everything they need me to do.” And he does a great deal—bathing the girls, putting them to bed, doing laundry, and driving Angelina to her preschool three days a week. His wife, Mary, works nights and weekends as a nurse. He works from noon to 8:30 P.M., Sunday through Thursday. “Our



Julie, Will, and Sam spending quality time together.

“



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—Peggy Crawford, PhD

schedules are hard,” he said. “Being with the girls is great, but my wife and I are just ‘hi-bye’ these days.” Still, Rivera looks ahead with a smile: “The girls aren’t going to be three and five all that long.”

The fear factor

Some parents worry that their children will be frightened by MS. And they could be. “If kids see a parent fall,” Crawford said, “it scares them. Adults aren’t supposed to fall down. After a fall, a child may stay close and monitor the parent’s movements.

“A preschooler may not exactly understand MS but may be very empathic,” she explained. “I know a four-year-old who asks his mother if she needs to sit down and rest. He’s very aware his mother has difficulty walking. His concern doesn’t necessarily mean that he’s anxious or overburdened. Raising compassionate kids is not a bad thing!”

Crawford says it’s important not to assume that problems like bedwetting, nightmares, or temper tantrums are attributable to MS. These are common developmental concerns. “Some people tend to think that every behavior problem is related to MS. Usually it’s not,” she said.

How much should a parent tell?

Parents often wonder how much to tell their preschoolers about MS. Mary Elizabeth McNary, the mother of five-year-old

twins, believes in full disclosure. She was diagnosed with MS a decade before Aidan and Aisling were born, so they’ve always known that “Mommy can’t run and Mommy can’t drive.” And because McNary is an MS vocational rehab counselor, her children may hear more about MS than most kids.

“We’ve been very matter-of-fact about it from day one. So now, when we go to the park, they’ll tell other children, ‘My mom has MS, so she can’t run. Her brain doesn’t get the message to her feet. It’s not her fault.’”

A preschooler’s acceptance of difference can be the foundation for a better understanding of people in general. “They see difference as neither good nor bad, just different,” said Kim Koch, manager of National MS Society family programs, who edits *Keep S’mylein*, the Society’s newsletter just for children.

Last year, Julie Evans took Will to his chapter’s MS Walk. “We told him it was to raise money for people who have the same disease as me. I was surprised, but it didn’t spark any questions. He saw people with canes and wheelchairs and it didn’t scare him. The exposure was good for him. I’m going to take him again this year.” ■

Freelance writer Martha Jablow is a frequent contributor to *InsideMS*.