

Grandparenting with MS



The bond grandparents share with their grandkids is more important than physical abilities.

by Shara Rutberg

“First Mate” Mary Munger looks over the back of the pontoon boat at her three grandchildren, tucked together into a three-seater inflatable tube that’s attached by a rope to the back of the boat. The kids float on the waters of Lake Fenton in Michigan like three little frogs on a neon rubber lily pad.

“Ready?” Munger calls to them from her perch on the boat’s deck. Munger, 66, was diagnosed with multiple sclerosis in 1986.

Their chins bobbing over the edges of their Little Mermaid and Sponge Bob life jackets, the kids nod excitedly. Mary’s husband, “Captain” Dean Munger, raises the throttle and steers the boat away from the dock, towing the kids into another afternoon of splashing, bouncing and swimming. Mary plays a critical role as spotter, keeping an eye on the kids and translating their hand signals to Dean, who needs to keep his eyes ahead to pilot the pontoon.

For Mary, enjoying a rich relationship with her and Dean’s seven grandkids—who range in age from 2 to 12—doesn’t require a 26-foot pontoon boat, though it is one of her favorite ways to connect with them. She also loves napping with 4-year-old Parker, who enjoys snuggling with Grandma. No life jackets required.

As people with MS grow older and become grandparents, they may be concerned that their

symptoms could interfere with their ability to engage with their grandchildren. And though the extent of mobility and cognitive challenges varies widely among individuals with MS, there's no need to worry, says David Rintell, EdD, a child psychologist at Partners Pediatric MS Center at Massachusetts General Hospital.

"The most important thing about grandparenting is the very special relationship that's possible between grandparent and grandchild, and none of it requires physical activity," Dr. Rintell says. "The specialness is about someone who is not your parent who is just crazy about you. Simply hearing about a grandchild's day and letting the grandchild know how much they mean to you is most important. Almost no one with MS is unable to do that."

Talking about it

Talking with kids openly about MS helps build the foundation of a close relationship, according to both Dr. Rintell and Deborah Miller, PhD, a social worker at the Cleveland Clinic Mellen Center for Multiple Sclerosis. "It's important to give a name to the condition and to explain that is why the grandparent can't walk, etc.," says Dr. Miller. The explanation should be appropriate to the child's developmental level, Dr. Rintell adds. "It doesn't need to be overly complicated and shouldn't be overly negative. For example, you could say to a young child, 'My legs don't work very well. They used to work better, but they don't now. It's because of an illness I have called MS.' "

The questions kids ask about MS tend to cluster around a few common themes, so do some thinking ahead of time about how you will answer, Drs. Rintell and Miller suggest. For instance, they might ask if MS is contagious. (No.) They might worry you will die from it. (Not likely.) And they might wonder if they'll get it, too. (Not likely.) Speaking from experience, Mary Munger advises: "Just be honest, keep it simple and keep a smile on your face."

Drs. Rintell and Miller stress focusing on the positive rather than the negative and not acting as though you're "disabled;" instead, you have a condition you manage. "If a person uses a mobility aid, it's vital to normalize that," says Dr. Miller. "For example, say, 'You use your bicycle to get places faster; I use my wheelchair to get places faster so that I have more time to spend with you.'"

If you've had MS since your grandchildren were born or before, the symptoms of the disease will seem normal to them. But for grandkids who may not visit frequently, using Skype, FaceTime or other video chat technology to show them your condition can be a helpful way to prepare them for a visit and take away "the fear of the unknown," says Miller.

Help breaking the ice

Vanita Oelschlager's husband, Jim, has MS and uses a scooter. To help their grandchildren and others understand and talk about the disease, Oelschlager, a children's book author, wrote **My Grampy Can't Walk** (VanitaBooks, 2008). "I wanted to show that even though someone can't walk, there are so many things he can do," says Oelschlager.

The brightly illustrated picture book, aimed at kids ages 4 to about 7, begins: “My Grampy can’t walk. He has Multiple Sclerosis Which is a disease, Or ‘MS’ if you please. He uses a wheelchair To go fast as a breeze.” Grampy is shown cruising in his chair, tie flying behind, leaves fluttering in his wake.

Oelschlager’s follow-up book, **The Electrifying Story of Multiple Sclerosis**, (VanitaBooks, 2015) is written for an older audience and has exercises kids can do to help them understand a grandparent’s condition. For example, kids can walk around with pebbles in their shoes, to feel their feet go numb. They can try to open the fridge door while there’s a chair blocking the way, to understand mobility and strength challenges.

“Kids love going for rides on the scooter,” says Grampy himself, Jim Oelschlager, who sometimes spins donuts on his scooter to break the ice in places like airports where kids who don’t know him may be leery.

Munger agrees. “Little kids are always intrigued by my scooter,” she says. Kids also love to try out her cane, which she’s decorated with smiley faces and rhinestones.

Building the bond

Difficulty with symptoms such as mobility, hand function, cognition and fatigue can shape the ways the family spends time together but doesn’t have to affect the relationships. Still, there may be activities you’ve always dreamed of doing with your grandchildren that you simply can’t do now.

In those cases, Dr. Rintell suggests looking for related activities. For example, if you’re unable to take your grandchildren hiking, you could teach them how to take pictures of nature, draw it or tell them stories about experiences you’ve had outdoors.

Having a special activity to do together, like playing a certain board game or reading from a particular book series, can help grandparents and grandchildren bond, says Dr. Miller. “Or it can be as simple as the grandparent sharing stories about what the child’s parents were like when they were growing up,” she says.

To avoid disappointing your grandchildren, you need to be realistic when planning activities and be mindful of fatigue levels, says Dr. Miller. For example, don’t plan a walk in the middle of the day in summer. “Under-plan activities, rather than over-plan,” she says. “You can always scale up.”

Munger has found one activity all her grandchildren like to do: help her. Whether it’s a push when her scooter gets stuck in grass, or handing her items she’s dropped, they’re pleased and proud to be able to help.

What about babysitting?

Is it OK for grandparents with MS to babysit? It depends entirely on the physical and cognitive abilities of each grandparent, say Drs. Rintell and Miller. A grandparent who has difficulty

with fine hand movement may still be able to hold an infant grandchild with the help of another person and supporting pillows. “I have one client who is a grandmother with some mobility impairment, who is still able to provide nearly full-time care for her grandchild,” because of the closeness of their relationship and the level of respect and discipline she’s established, Dr. Miller says.

You and your adult children need to discuss whether you can safely protect your grandchildren, Dr. Miller says. And your kids may need to talk with your grandchildren about what to do if you fall asleep, fall down or have some other medical issue. The important thing is to keep the lines of communication open.

Whether you’re spending time together babysitting or with other family members, the most important thing is to make the time about being together with the grandchild, not about MS. Whether a grandparent uses a wheelchair or has slurred speech should not be the focus, she adds.

“Children do not look at you and see a disability. All they see is Grandma or Grandpa, and the love you have for them and that they share,” says Munger.

“Grampy” Oelschlager agrees. “I learned long ago that the most important thing for a grandparent to do is to help grandchildren eat ice cream,” he says. “And you can do that from a wheelchair.”

Shara Rutberg is a freelance writer in Evergreen, Colorado.

Having discussions about a grandparent’s abilities and challenges can be difficult. For help framing these conversations, or to request resources, call an MS Navigator at 1-800-344-4867.

For more on family discussions about MS, visit [nationalMSSociety.org/familymatters](https://www.nationalMSSociety.org/familymatters).