Tips for explaining the disease

by Shara Rutberg

Sarah Quezada’s kids, Lola, 10, and Julian, 8, were frustrated, disappointed and angry. One summer day a few years ago, the family was at the town fair in Ontario, California, where they had hoped to spend the afternoon. But the temperature climbed higher than expected, clobbering Sarah, who lives with multiple sclerosis. They needed to leave early.

In the Quezada family car, indignant young voices piped up from the back seat:

“I’m so mad at you, MS!”

“Yeah, you ruined our day, MS!”

“I’ve always been really open with my kids about my MS,” says Quezada, 40. Her kids, now 13 and 11, “know they can get mad at MS for messing up our plans.” She says living with the disease is almost like living with another person in the house — one she’s glad her kids can get angry at. They’re able to focus their frustration on the disease, not their mother.
Sarah Quezada is forthcoming about her MS with her kids.

Talking to your children about your MS can be challenging. But honest and open lines of communication can help kids and the entire family process and live with the disease and become closer as a result.

When it comes to talking about MS with your kids, “honesty is the best approach,” says Lucille Carriere, PhD, who works with people living with MS at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, Nevada.

Kevin Byrne, who lives with MS, agrees. His daughter, Eleanor, 12, has never known him without MS.

“Trying to hide something from her would be a huge disservice to her and to myself,” he says. Keeping her completely in the loop helps her understand how MS prevents him from
doing certain activities with her.

“It also lets her understand how I overcome things,” he says. Insight into his challenges lets his daughter see and appreciate how he overcomes obstacles. “These are always great teaching moments,” he says.

He captured some of them in his children’s book, “My MS & E.”

**The diagnosis conversation**

While it’s important to give yourself time to process your diagnosis, don’t wait too long before talking to your children about it, say the experts.

“Most parents believe their kids don’t know what’s going on and all kids do,” says Rhoda Olkin, PhD, who trains therapists and specializes in working with people with disabilities as clinical professor of psychology at the California School of Professional Psychology at Alliant International University. She also maintains a private practice.

Spend some time preparing before bringing up the subject, Carriere says. “Think about some talking points, about what you want them to know,” she says. “What [symptoms] have they seen that you can help put into perspective?” Consider their age and maturity level. Plan a time to talk when you can have their full attention, when they’re not tired or hungry or in the middle of watching their favorite TV show. And, if you have more than one child and they are at different maturity levels, speak to each of them separately.

**Adjust for age**

When Shabanese Barrick’s 4-year-old daughter, Brynlee, notices her mom needs to sit down, she asks: “Is your boo-boo OK?”

“I don’t expect her to fully grasp what’s going on with my MS,” says Barrick, 31, “but I wanted to explain it to her in a way she would understand. In the toddler stage, kids relate to hurt and pain in terms of boo-boos, so I told her that Mommy has a boo-boo and it lives inside her.” When she’s really tired or not feeling well, Barrick tells Brynlee that her “boo-boo is really hurting today. Of course, she immediately asks if she can put a Band-Aid on it,” Barrick says with a laugh.

Barrick told Brynlee that her “Band-Aids” are things like extra rest and medicine. Talking to her daughter about the disease on her level helps prevent fear when symptoms do flare up, Barrick says.

How you talk to a 5-year-old about MS is different from how you’d talk to a 15-year-old, Carriere says. Many parents find comparing the nervous system to a damaged electrical cord delivering inconsistent signals is a helpful strategy, says Erin Martin, a social worker and founder of Caregiver Collaborative who has worked at camps for families with MS. Her father lives with MS, and the electric cord comparison is how she first began to understand the disease. Puppets and books also can be helpful tools.
When Moyna John-Caraballo, 31, spins her 5-year-old, Micah, around and around until both collapse dizzy and laughing, she tells him, “That’s how mommy feels sometimes.” Explaining invisible symptoms like vertigo can be tricky, especially as Micah is autistic, so “I try to be as creative and playful as I can and make it as simplistic as I can. You have to meet them where they are,” in terms of comprehension, she says.

Moyna John-Caraballo with her son Micah.

Adjust the complexity of the conversation as the children get older. “Remember, this is not a one-time conversation,” Olkin says. “Especially due to the nature of MS, with so many ups and downs, there are things you will continually need to talk about,” Carriere says.

As Byrne’s daughter grew older, he got deeper into the details, from mobility to injectable medications. “There is nothing about my disease that scares her because I don’t put anything into a different category that she can’t know about,” he says.

There are no hard and fast rules about how much to tell your child at what age, say the experts. “You don’t want to provide so much information that it gets overwhelming and scary,” Martin says. “You want to find the sweet spot. Parents know when their kids’ curiosity...
has been satisfied.” Follow their lead and answer their questions.

**Answering the most common questions**

Here are the top questions kids ask about a parent’s MS — and how experts suggest answering.

**“Will I catch it?”**

“Let them know that it is very, very unlikely that they are going to develop MS,” Carriere says. “When they are old enough to understand, you can put numbers behind that. Children of parents who have MS only have a 5% chance of also developing MS.”

**“Will you die?”**

While life expectancy for people with MS is shorter by about eight years, due to many factors, this information is generally not helpful to kids, Olkin says. Instead, say, “No, this is not going to kill me.”

**“Why did this happen?”**

We do not know why people develop MS, so the answer to this question can be the first time a child faces the fact that bad, random things can happen to people — and the first time they face the unknown. “Remember, this can be very scary,” Olkin says.

**The un-asked questions**

Kids have questions they don’t yet know how to ask. You should anticipate them, Olkin says. A big question young kids don’t ask is: “Is this my fault?” When kids are young and haven’t yet reached the developmental stage where they learn empathy, their worldview is focused on them, so they naturally believe everything happens because of their actions, Carriere explains. It’s critical to make sure children understand that a parent’s MS is not a result of anything they have done.
Kevin Byrne, who lives with MS, and his daughter Eleanor.

Kids also avoid directly asking questions around whether they will have to care for their parent or if they should remain geographically close, says Olkin. “It helps to explicitly tell them that yes, you can still go to sleepaway camp, and you can still go away to college. You will not have to take care of me.”

During your conversations, remember to include positive things. For example, if you mention activities that you may longer not be able to do, also mention activities that you will still be able to participate in.

Take what’s called the social model perspective when talking to kids, Olkin says. “That means the problem isn’t that mommy can’t climb the stairs, the problem is that there isn’t a ramp,” she explains.

Secrets and sharing
For various reasons, not everyone wants to disclose their diagnosis outside the family. This can be tricky with children. Asking kids “to keep secrets can be really hard on them and may make them feel shameful,” Martin says. Reasons for discretion, like job-related issues, can be complicated for kids to comprehend. Help them understand the concept of privacy by talking about something they might have done, like wet the bed, that they may not want others to know about. Be clear and specific about who they can tell.

Make sure they also know they always have someone who they can talk to about their
parent’s MS. Experts encourage parents to connect with other parents living with MS, through online and in-person groups and activities, as well as activities designed to help families talk about the disease. It helps with everything from finding new phrases to use to describe symptoms to providing a sense of connection and easing feelings of isolation, Carriere says. These types of activities don’t need to be serious. For example, one summer camp activity, relay races wearing goggles with soap-smeared lenses, helps give kids an idea of vision challenges parents may experience, Martin says. Or join in on events like Walk MS, the annual event Sarah Quezada’s kids call the “orange parade.”

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The National Multiple Sclerosis Society has a variety of resources about MS for different age levels. Find more information on families affected by MS.