

Kids Talk

You can—and should—speak to your children about your neurological condition. Here's how.

BY LISA PHILLIPS

ids don't miss much. Even if they're too young to understand everything about multiple sclerosis (MS), epilepsy, head injury, muscular dystrophy, or migraine headaches, you probably won't be able to hide it from them.

And there's no reason to. Experts and parents agree that openness is the best policy, at virtually every age.

Be Honest

It's usually not a good idea to try to hide your condition, no matter how difficult it may seem to tell your child about the diagnosis.

"It may mean going outside the comfort zone of normal family conversation," says Kim Koch, director of family and support programs at the National Multiple Sclerosis Society. "But for the family to function as a normal unit, kids need to learn about your disorder. It's going to be there for the long haul, so it's important to talk about it."

She says staying silent won't prevent kids from suspecting that something is amiss. "Kids have creative imaginations," she says. "They'll create diseases because they don't have a name for it. They'll come up with something worse."

Above all, don't lie. "You can simplify things or leave details out according to your child's age, but don't tell them everything's fine," says Adam Bender, M.D., an associate clinical professor of neurology at Mount Sinai School of Medicine in New York, NY.

Pick the Right Moment

Pick a calm time and place for the conversation, and make sure your child isn't in the middle of homework or a video game or some other distraction. Arrange for your spouse or partner to be there for assistance and reassurance.

Choose a time when you're not in acute distress. For example, you won't be able to explain migraines patiently and clearly if you are

66 Your kids may need to understand why you tire easily, but they don't necessarily need to know their chances are of inheriting your condition. **99**

suffering from a severe headache, says A. David Rothner, M.D., a pediatric neurologist at the Cleveland Clinic in Ohio.

Stay Calm

It's important to move beyond your own fears, says Dr. Bender. "You need to feel comfortable, because children pick up on nonverbal messages very well," he says.

If you are particularly nervous about the conversation, contact the local chapter of a non-profit advocacy organization for your disorder, suggests Kim Koch of the National Multiple Sclerosis Society. Often, chapter representatives and volunteers can offer their expertise to help you develop a "script" for talking to your kids. Educational materials developed for children, such as the National Multiple Sclerosis Society's "Keep S'myelin" newsletter and "Timmy's Journey," a cartoon about a young boy learning about his father's MS, can be helpful too.

Use Their Questions as Your Guide

Children will let you know what level of information they're ready for by the questions they ask. Don't discourage questions, and ask them whether there's anything else they want to know as you're finishing the conversations, says Dr. Bender.

"If you pick up on the slightest bit of curiosity or concern, give them the opportunity to talk about it," he says. "Let the child let you know about how much they're ready to hear."

To get the conversation started, you can ask them what they already know about your disorder, says Dr. Rothner. Like all of us, children sometimes have preconceived notions or fears that are far from reality. They may need to be reassured that migraines aren't fatal or that seizures will subside.

Don't Overwhelm Your Child

Your kids may need to understand why you tire easily or can't fix their toys. But they don't necessarily have to be in on the intricate details of medical procedures or know what their chances are of inheriting your neurological disorder, especially if symptoms are unlikely before they become teenagers or adults.

Koch advises parents to become well educated about their diagnosis, but they don't have to share everything about the disease with their children. "Parents should not present the worse-case scenario, things like wheelchairs or hospitalization, which are very scary to kids," Koch advises. "They shouldn't jump to extremes."

There's also no reason for children to know, for example, that they have a 50 percent chance of inheriting migraines from a parent. "They'll be sitting around waiting for them to

happen," Dr. Rothner says.

If children ask whether they will get headaches, you can tell them that it's possible, but emphasize that most children don't get migraines. "Stay positive and reassuring," Dr. Rothner says.

Accentuate the Positive

Sharon Dodge, a Maryland mother with MS, celebrates advances in medical research and advocacy with her three children.

Even difficult images and incidents can have a positive aspect. Audrey Nelson, a mother in Eau Claire, WI, tells her children the long hairline scar she got from surgery following a traumatic brain injury is "the place where the doctors put me together." Rob Roozeboom, who has limb girdle muscular dystrophy, regularly treats his children to rides on the motorized scooter he uses to get around.

Trust Your Child to Accept You

Roozeboom secretly feared that one day his children would be embarrassed to be seen with him because he wasn't a "he-man, a superman"—especially if he had to use a wheelchair. Then his five-year-old son Jager said to him, "Daddy, if you end up in a wheelchair, can I ride with you?"

"I said, 'Buddy, you have no idea what that means to me, to know you love me for me," Roozeboom remembers.

Parents are often surprised at how accepting kids are of their condition, says Jacqueline A. French, M.D., director of the clinical trials consortium at New York University's Comprehensive Epilepsy Center in New York, NY. "I don't see many kids who don't want to be with their parents because of their disorder," Dr. French says. "If I see anything, it's parents who complicate their relationship with their children by worrying about these things."

Prepare for Emergencies

Teach your children how to dial 911 in case of a medical emergency. Some children can master this skill as early as five, but the typical age is usually eight or nine.

Work with your children to develop an age-appropriate strategy in case of a seizure, fall, or other circumstance that may require medical attention. Make sure your children are not only



capable of, but also comfortable with, performing the necessary tasks. If they aren't, develop a support system with trusted friends and neighbors who can step in if you're disabled.

Know that Kids Want to Help

The first time Roozeboom's son Jager helped him put his pants on in the morning, he had to choke back conflicted feelings about the role reversal. "I thought, I'm supposed to be helping him," Roozeboom recalls.

Instead Roozeboom let Jager know how proud he was. "I said, 'You did awesome! You did it better than mommy!' He was proud as a peacock."

Though Roozeboom wishes he didn't need the help, he sees the way helping benefits his son. "It's good to see him know what it means to assist someone else," he says.

Dr. French says kids who grow up with parents who have a serious disorder tend to become responsible and very involved in their parents' care. She's seen these "mini-nurses" as young as age six.

"They're often hyper-responsible before their time," Dr. French says. "They call the office to ask why their mom's not doing well. They get very involved."

But avoid relying on your child too much, too soon. Even when children want to help, avoid shouldering them with adult-level responsibilities, such as giving shots, managing

TIPS FOR YOUNG CHILDREN

Keep It Simple

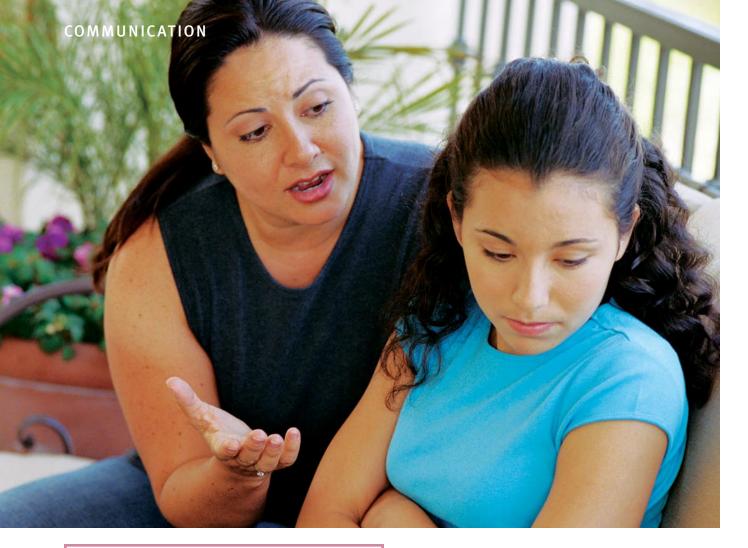
Preschool children may only need to know the most basic information: "Daddy has trouble with his balance and needs to be careful here"; "Mommy has a headache and needs to rest."

Use age-appropriate explanations. A common tactic parents with MS use to explain their illness is to wrap their finger in a blanket and tell their children that the finger is the nerve and the myelin is the blanket. They can remove some of the blanket to talk about the wearing away of the myelin coating on the nerve.

Take Age-appropriate Cautions

If you have epilepsy or another disorder that may leave you suddenly unaware of your surroundings, make sure you have someone else around to help with toddlers. "It doesn't take long for them to wander off or get into something dangerous," Dr. French says.

Another precaution she recommends is to feed and change babies on the floor to prevent them from falling or being dropped.



TIPS FOR TEENS

Satisfy Their Curiosity

The teen years may bring more challenging questions. They'll learn genetics in high school biology, which may raise questions about their risk of getting what you have. Precocious children may ask about hereditary factors as early as nine or 10.

Again, use their inquiries as a signal that they're ready for the information. If you don't know their risk of getting your disorder, research the answer with your child.

Monitor Internet Use

Dodge's 13-year-old son looked up "stem cell research" on the Internet and stumbled upon Web sites generating rumors about researchers using aborted fetuses to collect stem cells. When he asked her about it, she took the opportunity to explain that though the Internet was a wonderful research tool, not every Web site is credible.

Be sure to encourage your Internet-savvy teens to ask you about anything they don't understand. Teach them how to identify reliable sources of information, and guide them to helpful Web sites (see Resource Central, page 37). And set up their computers so you can monitor what Web sites they've been visiting.

medication, or helping out on the toilet, says Koch. "Hire help or look for other family members or friends who could fill that role," she advises.

Encourage Peer Support

Sharon Dodge's three children, ages nine through 13, have benefited enormously from attending Discovery Weekends run by the National Multiple Sclerosis Society. The weekends feature art therapy and other programs that encourage kids to express their feelings about their parents' MS. Most importantly, Dodge says, "Kids get to socialize with other kids and talk about their common experiences."

Never Blame Your Child for Your Disorder

Most importantly, avoid outbursts like "You stressed me out so much I had a seizure" or "You gave me a migraine." It's harmful to make kids feel they have a negative impact on your disorder, or to try to control them or make them feel guilty with your illness, says Dr. French.

Lisa Phillips is a freelance writer and the author of Public Radio: Behind the Voices (CDS Books/Perseus, 2006). Visit her at lisaaphillips.com.



For more information about how to talk to your children about your neurological condition, see Resource Central on page 37.