

"Sometimes, I'm mad at the MS"

How parents with MS - and their kids - adapt and get stronger

By Avril Roberts

Jean-Luc Lemire was a bit older than other kids the first time he hit the ice. He was six, going on seven. His dad Rick pulled his truck up alongside the skating rink, rolled down the window and had a chat with the rink attendant. While Jean-Luc laced up his skates inside the truck, Rick wheeled his scooter down the ramp. When Jean-Luc joined him, Rick told him to hold onto the scooter's armrest.

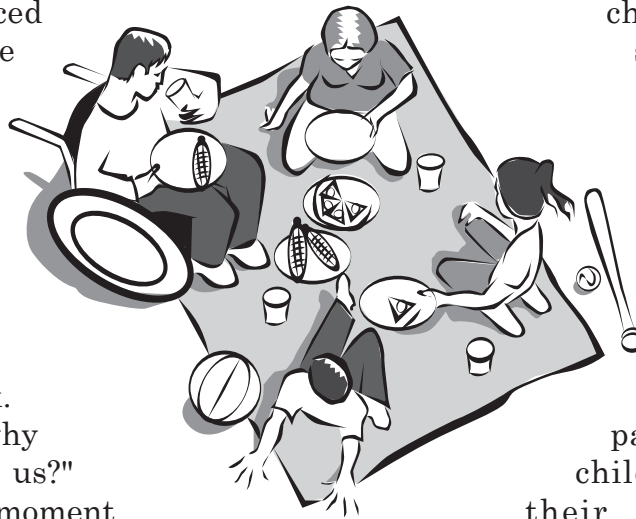
As the skating lesson ensued, people craned their necks to take a look. Jean-Luc asked, "Dad, why are they all looking at us?" Rick was silent for a moment, then answered, "Because we're the best." Father and son had found a creative way to achieve one of the milestones of Canadian childhood while overcoming a potential obstacle of parenting with MS.

Parenting is a difficult job under any circumstances but parenting with MS has extra challenges such as dealing with the physical, emotional and other aspects of MS on top of the pressures of being a good parent; finding ways to meet one's own needs when there are other family members' needs to take care of; and sharing information about MS with children without overwhelming or scaring them.

For the child, there are challenges as well. For instance, how to be a kid like other kids your age, while living with the effects of your parent's MS on you and the rest of the family; wondering if your parent is going to be okay

and still be able to care for you; or seeing the physical and emotional toll MS takes on your parent and feeling helpless that you cannot do anything to prevent it.

Research shows that the impact of a parent's MS on children's emotional and social development is powerful - and more widespread than parents tend to acknowledge. The areas where a parent's MS has greatest impact include children's ability to talk about their emotions and fears, the family's participation in fun activities, children's behaviour, and their social activities with friends. Children are also sensitive to the effects of MS on their parents' relationship and experience uncertainty in not knowing what to expect with such an unpredictable disease.



continued on next page

The top eight questions children ask parents about MS:

- What is MS?
- Can it be cured?
- Do people die from it?
- Can I catch it?
- Did I cause it? (young children)
- Will I get it? (adolescents and teens)
- What will happen?
- Why do you have to go to the hospital?

Carli, 16



Carli has three brothers: one older; two younger. When she was nine, her parents told the children their mother had MS since she was a teenager. The symptoms weren't visible, so Carli didn't worry about it. "I didn't know what it was. It didn't really affect me at the time."

Carli started noticing it as her mother's symptoms got worse, affecting her mobility, vision, ability to drive, and the activities they did as a family. Bike rides and hikes are out but a trip to the science centre is still do-able.

At home, Carli and her brothers took on little chores like making their own lunch for school. She considers herself a little more independent than her friends. "I kind of organize my own life, make my own appointments, get myself places." And thinks that's probably just her character anyway.

She feels, sometimes, that she is missing out on some of the things teenage girls do with their mothers. "Not major life-changing things but little things, like going shopping, going away for a weekend to Buffalo, New York. But we can't do anything about it, so I don't dwell on it." Instead, she throws herself into sports - rugby, basketball, soccer and cross-country skiing. "I love doing it. It gets my frustrations released. I feel really good afterwards."

The most difficult thing for her as a teen is "seeing the changes and dealing with what you don't have with your parent compared to what your friends have." On the other hand, she says, "It may be easier for me to look at things in perspective and not freak about things that don't really matter."

continued from previous page

For the most part, children cope and adjust relatively well when a parent has MS. However, it is important that families develop effective strategies to counter the potential negative effects of a parent's MS. Research indicates that the stronger the family, the better they are able to cope with MS; the less strong the family, the more negative the impact.

How to be a good parent with MS

According to Dr. Rosalind Kalb, a clinical psychologist and director of the Professional Resource Center of the National Multiple Sclerosis Society (USA), one of the keys to being a good parent with MS is to re-think one's image of what it means to be a good parent.

"If a man's image of a good father is one of being able to play ball, coach sports or be physically active with his kids, and he is not able to do that, he may have to change his definition about what being a good father is about. The same is true for mothers. People have a picture of what it is to be a good mom. If those activities become difficult and a woman has to give them up, she may have to think about different ways to be the kind of parent she wants to be."

Dr. Kalb recommends that parents think about what really goes into good parenting. "What is it you think kids need? Do you need to be standing up to do those things? Can you provide love, security and comfort, and good mothering and fathering, in a variety of different ways that you might not have considered before?"

Another consideration for parents with MS is to try not to become so overwhelmed with one's own feelings of frustration that they spill out inappropriately onto the children.

How to talk to children about MS

Be open. Children know something is going on even when you don't tell them. If you don't give them factual information, their vivid imaginations will fill in the blanks. When children have good information, it helps them put a boundary around their fears, so they know what are real issues and what are not real issues. It also helps them avoid blaming themselves, as children tend to do when things go wrong.

By talking about what is going on, parents give children a vocabulary to ask the questions they have. Most importantly, when parents share information about what is happening in their own lives and how they are coping with it,

they give children a model of how family members support each other's efforts to meet life's problems. As a result, when children run into problems in their own lives, they are more likely to share them and be open and honest with their parents because that is what their parents have modelled.

Give age-appropriate information in a way that the child can handle. Every child has a different learning style and processes information differently, so it may not be appropriate to sit children down together and give them a lecture on MS. Figure out how each child uses information, then try to find the right tool.

For example:

- sitting with a parent and reading a story about MS
- playing a game where they learn about MS
- attending an MS Society chapter meeting or other event where they learn about MS in a social setting with other children
- watching a video on MS by themselves and then asking questions

Take advantage of MS Society resources

The following resources can help parents and children communicate about MS:

- **Family-friendly, interactive websites with chat rooms and games**
 - www.msforkids.com
 - www.msforteens.com
 - www.msforparents.com
- **Age-appropriate publications**
 - *My Mommy has MS* (for young children)
 - *Myelin is Getting on My Nerves* (an activity book for children)
 - *Don't Lose Your Balance* (for teens)
 - *How to Talk About MS with Your Children*
 - *Benjamin: My Mum is Special*



MS information and support
mssociety.ca
1-800-268-7582

Jean-Luc, 18



As a young child, Jean-Luc thought his dad was a lot faster than other dads. "He didn't need to walk. He had his own wheels." When he was 10, he realized his dad was different because he had an illness. It didn't worry him because his father reassured him he was always in good hands. Also, his mother was there to help.

When hockey teammates asked why his father sometimes used a wheelchair, he would say, "My dad has a disease called multiple sclerosis and it takes him more time to walk than usual." His friends were also concerned about him. "They always wanted to know if MS was transmissible to a child."

When he hit high school and began to understand more about MS and how it affects the body, he began to lose his cool. "I was angry that my dad was the one affected. I wished it had affected someone else."

Participation in the MS Society's Growing Up Strong project put him in touch with other teens whose parents had MS. They reviewed the content of the MS Society's educational material for children and teens and met periodically over the phone. For the first time, Jean-Luc realized he was not alone. "Sometimes, I was mad at the illness, and then I would find at the other end of the telephone someone else who was going through the same thing."

A friend his own age was recently diagnosed with MS. Jean-Luc believes his inner strength and experience will come in handy when his friend calls on him for emotional support.

Things to keep in mind

- **Prepare answers to the basic questions that every child has no matter how young or how old.** Keep explanations simple and try to answer in a calm and reassuring manner.
- **Be aware that just because children don't ask questions, doesn't mean they don't have questions.** Find gentle ways to

continued on next page

continued from previous page

elicit a child's concerns or to let a child know that it is okay to express them.

- **Know that the symptoms children have the hardest time understanding are mood swings and cognitive changes.** They can feel the effects but cannot see them. It is good to talk frankly about the invisible symptoms of MS.
- **Be prepared to talk again and again and again.** Children need more and different kinds of information as they get older.
- **Recognize that a child's reaction may not be all about the parent's MS.** For instance, if a teen is pulling away and being more private and not engaging as much in family activities, it may be that the teen has some concerns or feelings about the parent's MS or mobility issues, or the teen may just be doing what is developmentally appropriate for a teenager.

Dr. Rosalind Kalb: "It's always tricky to get teenagers to talk about what's on their minds but creating an environment where it's okay to express some of these feelings is probably the best strategy a parent can try."



Dr. Rosalind Kalb

Rick Lemire: "Be very keen to listen to the child's demands and inquiries because, no matter what, the child is reaching for help and support."

Avril Roberts is a Toronto-based health writer with an interest in neurological disorders.

Sources:

Dr. Rosalind Kalb, a clinical psychologist and director of the Professional Resource Center of the National Multiple Sclerosis Society (USA)

Cristina Toporas, project manager, National Client Services, MS Society of Canada

Rick Lemire, a parent with MS

MS Society booklet, *How to Talk About MS with Your Children*

Andrea, 36



Andrea was 15 when she and her brother learned that their mother had just been diagnosed with MS. Her first reaction was to research it.

Then she asked, "What about us? Will we get it? The doctors told us probably not. The risk is very low."

Their mother's MS was progressive and aggressive, so Andrea and her brother had to grow up fast. "We had to learn how to live day by day, not knowing what tomorrow would bring." With a catch in her voice, she recalls, "There were times when my mom was too sick to be there for me emotionally. It was hard, during those formative years, knowing there was a potential she might not be around for a very long time." Her mother died at 55, in 2001.

By then, Andrea was a mother with MS herself. She's trying to create positive experiences for her daughter, who has just turned seven. She tells her, "Mommy uses the walker sometimes because of her MS. Or, mommy takes her needles three times a week. It's a treatment that helps mommy walk better than she might without taking it."

She shares her feelings even when she's having a bad day, saying, "I feel sick today or I feel frustrated that I can't be any different." It's her way of explaining that living with MS isn't easy.

For MS Awareness Month, Andrea will do a presentation on MS for her daughter's Grade 1 class, in the hopes it will spark her daughter's interest while she is surrounded by friends. When her daughter asks her first MS question, Andrea knows where she's likely to be. "I'll be driving, and I'll hear this little voice from the back-seat of the car."

This special insert was made possible through an unrestricted educational grant from

