

Kids To Parents! Kids To Parents!

By Patty Nelson

Michelle broke down in tears. This was her first time at the York, Pennsylvania MS newly diagnosed support group, and her greatest concern was not for herself but for her two daughters, seven-year-old Samantha and three-year-old Alexis. Those of us with children of our own knew exactly what she was feeling. We had all experienced the same fear, grief, and guilt over the great loss we believed our children would experience because of our illness. As mothers and fathers, we all want to give our children a happy, carefree childhood with every possible opportunity. And, most of all, we want to be able to give the best of ourselves to our children. Michelle feared that her MS would make that impossible.

In the days and weeks after meeting Michelle, I couldn't stop thinking about her. I was flooded with the memories of emotions I've had over the years regarding my own four children and how my MS was impacting their lives. I wished that I had had someone to give me perspective and reassurance right after my diagnosis. I needed to know then that my kids would be okay, that they might even become better people because of their mother's struggle with a chronic illness.

Let's ask the kids

Of course, the moms and dads in our support group could tell Michelle how our children have coped but I wanted to ask the kids themselves. After all, who knows better than they do? So I rounded up six kids (two of whom are my own) and we sat down in my kitchen to talk. Boy, did they have a lot to say!

The group included my two oldest: Chris (19 and a college sophomore) and Rebecca (17, a high school senior); my friend Amy's two oldest: Rob (11 and in sixth grade) and Elizabeth (13 and in eighth grade); and my friend Claudia's two oldest: Amy (15, a high school sophomore) and Nicole (17, a high school senior). To give a little background, all six of

them have lived with a parent who has MS for three to eight years—which took them through some important developmental milestones.

I asked them what they would most like to say to Michelle and to other parents who have just been diagnosed with MS. After a lot of talking, they agreed that these four things had been the most important to them.

1. HONESTY, FIRST AND LAST

Chris remembers the day we sat him and his sisters down to tell them about my MS diagnosis. At the time, he was thinking, "Parents always try to protect their kids and sugar-coat things and I always hated that. I wanted to make sure I knew the bottom line, which for me was 'Are you going to die?'"

All six of the young people who talked in my kitchen believe that it is always best to be straight with kids, to talk on their level, and not try to protect them from the truth.

All six of them knew that something was seriously wrong before their parent was diagnosed. They appreciated that their parents respected them enough to tell them the truth about the diagnosis. Having their questions answered honestly and not dismissed gave each of them a solid foundation. Open communication with their parents strengthened them to face the future. It also comforted them. They knew that they could bring up future questions and their parents would respond honestly.

Amy and Nicole's parents actually showed the MRI pictures when telling their kids about the diagnosis. As Nicole described it, "It helped a lot to be able to visualize it."

2. IT'S OKAY TO BEHAVE LIKE NORMAL KIDS

All six kids spoke of feeling guilty when they fought with their siblings or behaved selfishly. They recounted times when their parents told them that their behavior was adding stress to the home environment and then reminded them that stress can bring on an MS flare-up. (Translation: you're about to be responsible for your mom getting sick!)

I have to confess that I've said things like this too.*

[* Editor's note: While everyone agrees that stress makes people feel awful, there is no compelling scientific evidence that stress is related to the onset of attacks or the worsening of MS.]

Now that Chris is away at college, he looks back over the past few years. "I should have helped out more than I did when I was living at home," he said. He feels he somehow let us down and his initial response is feelings of guilt. All these kids have shown an incredible ability to rise to the occasion when more was required of them. We parents with MS and our spouses must remind ourselves almost daily that our kids need our permission to just be kids. We should never blame them for symptoms or disability. MS is the cause of the problems.

3. NO PITY! WE ARE MORE RESILIENT THAN YOU IMAGINE

As Rebecca put it, "I don't like having to tell people [about my mom's MS] because I don't like getting pity. It's not a pity issue. It's just something you live with and it's nothing to be pitied for."

These six kids actually expressed their belief that they have grown in some ways as a result of their mom's MS.

Nicole described her new independence this way: "I now have no problem running the washer and dryer or the dishwasher. If Mom's sleeping and it's 4:30 and everyone's getting hungry, I'll just start something for dinner. I'm more independent now than I ever was before."

Then Amy told about a friend who came over to their house and was shocked at all the things Amy and her siblings do themselves. The friend asked if she could mow one strip of the lawn and was so proud of herself when she discovered she could actually do it. Amy, Nicole, and their brother take turns mowing the lawn every summer and never think of it as a big deal.

4. **BEING THERE FOR US AND HAVING A POSITIVE ATTITUDE IS MORE IMPORTANT THAN YOUR PHYSICAL ABILITIES**

Elizabeth and Rob talked about playing less tennis because their mom can't play anymore. They weren't sorry about it. They would rather go together to places where she's never left out. Elizabeth spoke for both of them when she said, "I don't think she could be any better of a mom! She's our mom!"

When I asked if they felt that MS had changed their mothers, Nicole said, "She's just Mom! I think I might even have a better relationship with her than I would have otherwise!" Amy responded, "I'm happy with the way she is." Rebecca spoke directly to me and said, "I've always been really close to you and I don't think that's changed at all."

The take-home message

Amy, Claudia, and I realize how blessed we are to have these amazing children who support and encourage us daily. However, there will come a day when our kids will prepare to leave home and begin their own lives. Chris has already begun this process. Will they feel that their choices are restricted because we have needed their help at home? Will they worry about what will happen to us when they leave? We all want our kids to feel free to follow their dreams, but they can sometimes feel overwhelmed by a sense of responsibility for us.

It's important for us parents to take the initiative to develop outside support systems so our kids can feel free to live their own lives to the fullest. When Chris left for college, knowing that I still had a great support system intact freed him to go without worrying about who would be here to help me.

In addition to family support, I have received much-needed outside support over the years from my National MS Society chapter and the MS newly diagnosed support group of York. Society staff members are

there to encourage us and direct us to available resources to meet home-care needs and other challenges that may arise.

A good MS self-help group is a place to learn about solutions that have worked for others. A group provides friendship as well. In fact, I feel blessed to have the strong support of my family and the amazing people I've met in the support group and on the staff of my chapter. All it takes is a phone call to **1-800-344-4867** and you will be connected to the chapter nearest you.

Thanks, kids, for sharing your experiences and perspectives so openly and honestly. You are an inspiration!

Patty Nelson is a family-based therapist in York, Pennsylvania. Diagnosed with MS in 1994, she started the MS newly diagnosed support group of York in 1997. She has been married to Paul for 24 years, and they have four children. The Central Pennsylvania Chapter named her Mother of the Year in 1998.