

PARENTING

Talking to my daughter

by Amy Gurowitz

I believe that children give themselves the time they need to learn—and that’s something we can learn from.

My daughter, Madeline, has always accepted my differences, because she doesn’t know they are differences. And she doesn’t know that the reason for some of them is I have multiple sclerosis. She knows that Mommy doesn’t walk as fast as Daddy, and can’t pick her up now that she is a “big girl.” But that’s not too different.

When it came time for potty training a few years ago ... well, I don’t pee the way most women do. I was nervous as I started what I thought would be a long explanation with, “I use a straw, a catheter, to help me pee, while you can just pee right into the potty.” She just said “Oh.” And walked away. That was all she needed to know.

I struggled with this. MS is an unpredictable disease, and the me that Madeline knows could change tomorrow. She wasn’t going to ask, so I felt pressured to figure out a way to explain.

When Madeline was watching “School House Rock,” I heard the start of a song I know so well—“There’s a telegram for



Amy and Madeline

you, ma’am, and the message is clear ...” I thought this animated lesson on the central nervous system was just what the doctor ordered. A start to the conversation I’d been looking for. When the song was over, I paused the DVD.

“Madeline ...”

“Yeah, Mommy?”

“Do you know how sometimes Mommy gets tired and can’t walk too far?”

“Mmm-hmm.”

“That’s because sometimes my telegrams don’t get delivered.”

“Oh.”

“It’s because I have multiple sclerosis.”

“OK. Hit play, Mommy.”

And that was when it occurred to me—it wasn’t the groundbreaking lesson I’d imagined, but she got the message she was ready to hear.

Living with MS, there is a lot of information I need to

absorb quickly—to educate myself intellectually at the same time I try to deal with something—something very difficult—physically and emotionally. I had to learn the way I need to learn.

It finally hit me. Madeline was doing naturally what I had to teach myself to do; to learn at the right pace, both cognitively

and emotionally, for me.

When Madeline starts the next MS conversation, it is her pace, not mine, that will determine the exchange. And should my symptoms change or become more apparent to her, I will continue on with a dialog that is always a work in progress.

We’ll learn—and teach—at the right pace for the both of us.

Amy Gurowitz was diagnosed in 1988 when she was 20. She received her master’s degree in Educational Technology from New York University and, using her combined knowledge of learning theory and living with MS, is developing **MS Soft Serve**, a Web site that puts the user in control. Among other volunteer activities, Amy was a juror for the Moving Forward Film Festival at the National Conference. (See page 20.)

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