

Speaking of Illness

The benefits of discussing your condition with family and friends.

Unaddressed

almost always

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fears about

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hen I was in elementary school, the father of one of my friends started using a wheelchair due to progression of multiple sclerosis (MS). I had never really noticed that there was anything wrong with him till then. "Why is your Dad in a wheelchair?" I whispered to my friend. "He has MS," she whispered back. She tried to explain to me what that meant, but I was still

mystified and a little frightened. Later that day, my friend's mother talked with me about MS. Her honesty, patience, and good humor allayed my fears and enabled me to be a better friend. I have often thought of her when I have had to explain an illness to patients and their family members and to my own friends and family.

Her approach was totally consistent with the advice given in our "Kids Talk" story in this issue (page 26): Give as much information as the person you are speaking with wants, in a way that he or she is able to understand. Although this story focuses on talking with children about a parent's illness, it is important not to neglect the issue of talking with children about a sibling or friend's illness as well.

My daughter has a friend Susie [not her real name] who has epilepsy. For a time in elementary school, Susie's seizures were fairly frequent and anxietyproducing for the other children. I got

some wonderful materials about seizures and epilepsy from the Epilepsy Foundation that were targeted to elementary-age children. My daughter read them and shared them with her teacher. I helped the teacher (with Susie's and her parents' permission) talk with the other children in the class about seizures and epilepsy. We discussed:

- ▶ What it is—a condition that can be treated
- ▶ What it is not—contagious or caused by something bad that a child with seizures had done
- ▶ What to do if someone has a seizure—try to help the person to the floor, lay him on his side, and never put anything in the person's mouth

This led to a discussion of other illnesses the children or members of their family had. One little boy told an especially poignant story. "I've never told any of my friends this," he said, "but Susie is not the only kid who has to take medicine. I do, too." He went on to tell us, "Remember at the beginning of the year when I was always bad and could never sit still?" The rest of the children nodded.

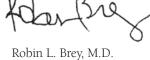
and none of them laughed. "Well," he said proudly, "now I take medicine that helps me sit still and do my work. Now I'm getting good grades." Of course, the little boy's "trouble sitting still" had been diagnosed as Attention Deficit Disorder (ADD) and the medicine he was talking about taking was Ritalin, a drug commonly used to treat ADD at the time.

One point made in "Kids Talk" deserves special emphasis: When it comes to illness, whether in a parent or peer, fear is almost always worse than the actual situation. In fact, this is one of the very things that motivated the American Academy of Neurology to develop Neurology Now. We believe that everyone deserves to have all of the accurate information they need to understand their own or a family member's illness and to be able to make the best decisions for their health. If you have a story or advice about talking with a child, family member, or friend about your condition, please share it with us. And

since we don't have room to print all of the great letters our readers send us, don't forget to check our Web site at neurologynow.com. We are able to post many more of them online.

actual situation.

My very best,



Editor-in-Chief

