Setting Limits: Teaching a child with CFIDS to take responsibility

By Mary Robinson

Originally published in The CFIDS Chronicle, May/June 1999

I am the mother of two children with CFIDS. My son was struck ill in the fourth grade and remained ill through middle school. He is now in a state of recovery, and we are feeling optimistic that it will be permanent. My daughter began showing symptoms by age 4 and is now in the third grade and struggling on a daily basis with this illness. My husband and I are fortunate, as is our other daughter, to be in good health.

From watching our children, and working closely with Dr. David Bell, we have learned many things about coping and living with this illness when it invades your family. There are probably as many ways to deal with this issue as there are families dealing with CFIDS. If our experiences offer any ideas for parenting your children, then I am happy to have shared our journey.

When our son first began showing signs of CFIDS we didn’t know what to do. Along with the many medical questions and school issues that came to mind there was also the question of how to handle his activity. He had always been very active in sports and the outdoors. Should we now limit what he was allowed to do when he felt well? Should we enforce a set activity limitation to try to ward off the bad spells that usually followed overexertion? We didn’t know what to do, so we turned to Dr. Bell for his opinions. He encouraged us to treat our son as normally as possible. If he didn’t feel well, then treat the symptoms and offer him all the support and care he needed to get through that time. But on the days that he felt he could tolerate more vigorous activities, he suggested that we encourage him to do so.

In our experience, we found that when we tried to force limitations on our two children, they only resented us for it. So instead we encouraged them to monitor their own activity. They learned to take breaks when *they* felt the need, to turn down invitations to outings they knew they could not tolerate, and to also partake in other things that were worth the price they might have to pay later on. We always support them in these decisions, which is sometimes hard to do. They are the ones that have to learn to listen to their bodies, and experience is the best teacher. But there are also days that they do overextend themselves, and often the payback is a disappointing setback.

When I have discussed this approach to activity with my son and daughter they have both said that they do not want us imposing limitations on them. When we have done this, it made them feel worse than they already did. My daughter once told me that while she is feeling good, it is like she doesn’t have CFIDS. She is able to just be a normal kid for a while, and she needs that time, even if it is only a few hours. My son agreed that when he was ill, it was hard enough to have to give up the time to illness when the symptoms flared up. But he did not want to limit his activity too much and miss out, on those rare opportunities when he was feeling well, on just being a kid.

Do not misunderstand me on this issue. We do not take a totally back-seat approach, and we are not beyond worrying about our decisions. This past year our son is back to normal activity with school and sports. We pray all the time that as he continues to add activities, his body stays on the road to recovery. So far, it has. But with our daughter, if we feel that she is setting herself up for a setback, we gently remind her what may happen if she engages in the planned activity. We suggest ways that she can keep her plans without overdoing it. We sit down and talk together when she is concerned about what she should do. Last night was one such time. She had felt terrible in the morning but felt better later in the day. She desperately wanted to play baseball with her brother and sister. But she didn’t want another major setback today. I could have just told her she couldn’t play, but that would have only had her resenting me. So we discussed what special things we could do if she chose to stay indoors with me. Nothing was as good as being outdoors.

It’s the child’s choice

"OK, then," I said, "Go out and play for a little bit knowing you will probably pay the price later. You need to decide which is worse, the price of not feeling well, or the price of staying in mad all night because you didn't go out and play." She thought it over, and decided that she could go out and bat and have someone else run the bases. She did, she loved it, and she had no setbacks because of it. So we try as much as possible to help her out and, in the end, we let her know that these decisions are hers to make, and we support her in whatever she decides.

As a parent, this has been one of the hardest things for me to do—to just stand back and watch my children race around and be active knowing how they may wind up feeling as a result. However, this attitude has helped them to dispel the "invalid" mindset that some people with this illness can develop. It offers them a perspective on their life that has more hope and less disruption. I think it made the years of illness easier for my son, and disrupted his life less, than if we'd imposed more limits. He has memories of doing normal things during his worst years, and those are the only things he chooses to remember. I am so grateful he has them. I pray my daughter will be able to look back on her childhood and be able to pull out some wonderful memories of times she felt like any other kid.

Encouraging school attendance

Another issue that is very difficult to undertake is the issue of school. Some children with CFIDS have been able to stay in school for full days with a few modifications, while others have required home tutoring or chosen to homeschool, as leaving the house was not possible due to the severity of their symptoms. Dr. Bell encourages attendance at school whenever possible in an attempt to minimize the disruption of the normal social development of the growing child and adolescent. For this reason, we have always encouraged our children to attend whatever amount of school they could tolerate without setbacks. It may be a 40-minute science class at the intermediate level, or a 30-minute snack break and teacher read-aloud at the elementary level, but at least it gets our children into school to be with their peers.

I asked my son, who is now in the ninth grade, how he felt about the choices we made for him in relation to school. He remembers the times he made it to school. He said that while he knows he was homebound for months at a time, his memories are of the days that he did manage to get to school to be with his friends. By touching base a little bit every day when he was able, he minimized the social disruption of feeling like a total outsider. When he began to tolerate nearly normal activity after years of very limited social activity, he went through the developmental levels very rapidly. As a 14-year-old, he made friends with boys several years younger than he and rapidly grew out of these friendships until he was most comfortable with others his own age. It was fascinating for my husband and me to watch as he fast-forwarded through four years of socializing—the giggles, to the sports, to the times just visiting with friends—in four short months. He picked up where he left off when CFIDS struck and ended where he would have been had CFIDS not invaded his childhood.

Trust your child

As we sit back now and look at our children, we are happy that we have been able to assist them in the challenges they have faced in coping with this illness. Because they have been given control of how to utilize their limited energy, they have been able to maintain control of an important part of their life. This has helped them in small ways to feel normal. We hope and pray that the day soon comes that our daughter will enjoy the same level of recovery that our son is experiencing and that his recovery lasts. We hope that all of you who are struggling with these same decisions for your child may find peace in knowing you are not alone, and that these are difficult choices to make. Trust in your child, and have faith that you are doing the best that you can.