

CFIDS Association of America

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Kids Coping With CFIDS:

Children Explain What it's Like to Live with CFIDS

By Lynn Vanderzalm

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While it is hard for anyone to deal with CFIDS, it is particularly hard for kids. They face the physical, emotional, relational and spiritual pressures without the maturity that comes with life experience. Their debilitation prevents them from being involved fully in crucial developmental years of their lives. Most of them are too sick to attend school or be involved in the activities that help children define their gifts and abilities.

Listen to their insights about their losses, their coping strategies and their needs.

Grieving and Accepting the Losses

"The hardest part of living with CFIDS," reflects our daughter, Alisa, whose eight-year battle with CFIDS began when she was nine years old, "is accepting all the losses. The symptoms, pain and debilitation are hard, but I've learned to live with those. I've lost the ability to have a social life, to be part of my friends' lives. In a way, I've lost my self, my personality, my people-person self. Most teenagers "find themselves" in their teen years, but since I've lived such a limited life, without being able to taste other things, I don't really know who I am. I've lost part of my real self."

"The losses have been hard," admits Christina Volkens, who has struggled with CFIDS for nine years. "I've had to give up going to school, and that also means not being in choir, honor society, musical performances. If I hadn't gotten sick, I would be singing in school musicals with my friends. It's hard for me to go and watch the performances because I want to be part of it so much. I don't feel jealous of the kids, but I do feel sad that I can't be part of it."

"I think I lost a sense of stability when I got sick with CFIDS," says Becky Moore. "Before I got sick I never doubted that God would take care of me. It never occurred to me that I'd get sick as a teenager. I just assumed that I would go to medical school, get a practice and have kids. But now all of that is uncertain. I may not be well enough to go to medical school. Dealing with the unknown future is the worst part of this illness."

Thirteen-year-old Brooke Volkens misses not being able to be a normal kid. "I couldn't handle gym class at school today, so I had to sit it out. I could see my friends having a great time. I just had to sit because the pain was so bad."

Timmy Volkens, who became ill with CFIDS when he was five years old, has a growing sense of loss in his life. "When I was in kindergarten and first grade, I was able to go to school half-days. When I'm in the hospital with pneumonia, I'm out of school more, and it's hard to go back to school. I wonder if the kids will tease me or if I'll get sick again. I love school and get good grades, but it's just hard to get back in with my friends after I've been so sick. That makes me sad."

Beth Waysek, who has been severely debilitated by CFIDS for five years, says, "Living with CFIDS is like having my life taken away, losing the ability to do what I used to, losing the ability to think clearly. Knowing that I may never get my mind back to where it used to be is a horrible thought. Relationships with my former friends have changed.

They call me with their problems because I listen, but their problems are so superficial that I become frustrated. My peers and I are headed in the same direction, but we are on very different tracks. I don't go to school, so I've lost that whole life, the academic challenge, the hanging out after school with friends, the prom, all of it. I've handled my losses with prayer, and that has helped. I've grieved about the losses; I've cried. But then I decided I had to accept that my life is different. It's not going to be the same. I'm not like everyone else. I can't feel bad about it; I have to move on."

Kids' Coping Strategies

"When I was the sickest, I kept a journal," offers Alisa Vanderzalm. "I wrote about what I was feeling. I remember screaming into my journal when I finally came to grasp that this illness may be with me for the rest of my life, that it's not something I can ignore. Now when I reread the journal, I can see obvious places that I have grown."

"One of the major things that helps me cope with my illness is my contact with other young people with CFIDS," says Ann McErleane. "Interacting with other people who share my needs and questions and feelings through what is now the CFIDS Youth Alliance (see page 12) was a major turning point for me. I don't know how I could have made it without that base of support."

"Because I have been unable to read," adds Nancy Masoner, who has been unable to attend school for the past four years. "I listen to books, magazines and newspapers on tape, and I watch educational videos."

"I try to stay hopeful," says Craig Maupin. "Many days I don't even think about my illness, even though I still am quite debilitated. I have faced the fact that I may never recover fully from this illness, but I don't want to force myself to accept the illness completely. I want to continue to hope that at some point I will be able to function enough to go to college, get a job and get married."

What CFIDS Children Need From Others

When I spoke to the children, I said, "If you knew that doctors, teachers, friends, friends, parents and youth-group leaders would listen to you, what would you say to them?" These are their responses.

1. *Believe us.* Believe that we are sick, even though we may look fine. Our symptoms wax and wane and we have little control over how we will feel from day to day. We are not school phobics or hypochondriacs. Don't tell us the pain and debilitation are not real because you can't see evidence of our pain on diagnostic tests.
2. *Trust us.* Most of us are responsible, bright, capable people. Before we got sick, many of us were honor students. Trust that we want to be excellent students, but we can't. Sometimes our brains fog over, and we can't remember even simple things.
3. *Help us trust you.* We need to know that you are for us and not against us. We need to know that you will be there for us. We need to know that you will not use this illness to punish us or to make an example to others. Youth-group leaders need to know that we struggle with our faith; sometimes we question whether life is worth living. Stay involved with us, even though we may not be able to come to youth-group meetings or activities.
4. *Try to understand us.* We struggle with a powerful and complex illness. We won't bore you with all the details of what we know about our illness, but we need you to try to understand some of the dynamics of our illness so that when we need to say no to something, you won't be puzzled that we can't be involved.
5. *Accept us.* We don't expect you to understand us completely; we don't even understand ourselves sometimes. But accept that we are debilitated, and help us have as normal a life as possible. Accept that we will be sick some days and not others. Accept that we will be deeply discouraged at times.
6. *Stay with us.* We are probably not going to recover tomorrow or next week or next

month. We may not recover next year. Don't let that frighten you. We are not going to die, but we may have relapses and become quite a bit sicker. We have come to accept that, and we need you to accept that too. Commit yourself to stay with us for the long haul. If you are in charge of our medical care, don't abandon us when you don't have the answers. We would rather have you cry with us and tell us you don't know what to do than send us home pretending we'll be better next week.

- 7. *Keep in touch.*** Check in with us and let us hear the school gossip. When we are housebound, you may be our only link to the normal world. Call us, even if it's just for a five-minute chat.
- 8. *Be our friend.*** Realize that we aren't always going to be able to go to a mall or to a movie, but we still have a lot to offer a friendship. In fact, sometimes kids with CFIDS can offer a deeper relationship because we are there to talk. Many of us have gone through some pretty rough things. We have been forced to think about a lot of things, so many of us can offer deep spiritual awareness and insight into life and others.
- 9. *Put up with us.*** When we are sickest, we can get very crabby. We don't mean to be crabby, but it takes so much energy to live with this illness. Remember that most often we are not crabby with you; it's the illness.
- 10. *Send us cards, letters or notes.*** If we are housebound or bedridden, communicate with us through the mail or the phone. Send us encouraging cards. Make us a tape of greetings from friends at school or from our youth groups at church. Make a videotape of a party or meeting you're having. Help us stay connected to your world. Leave us messages on our answering machines.
- 11. *Make us laugh.*** Help us keep perspective by making us laugh. Send us cartoons or funny videotapes. Tell us the funny things that have happened in your life.
- 12. *Encourage us.*** Tell us when you think we are doing a good job of coping with this illness. We can't compete in sports or perform in drama or music, so we don't have the normal access to affirmation. Let us know that our strength, perseverance and courage are important to you.
- 13. *Pray for us and with us.*** More than anything, we need to know that you stand with us in asking for God's help as we struggle with all the losses and changes CFIDS brings to our lives. Let us know you pray for us, and pray *with* us too.

This article is adapted from Lynn Vanderzalm's book, Finding Strength in Weakness: Help and Hope for Families Battling Chronic Fatigue Syndrome.