CFIDS Association of America

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The Challenges of Parenting a Child with CFIDS

By Lynn Vanderzalm

Originally published in The CFIDS Chronicle, Winter 1996

A friend asked me, "Lynn, what is harder for you: having CFIDS yourself or being the mother of a child with CFIDS?"

Without needing to think about my response, I answered, "It's much more painful to watch Alisa struggle with CFIDS than it is to battle my own symptoms, despite the fact that at times I have been 80 percent debilitated."

While coping with the pain and confusion of CFIDS - not to mention the physical, emotional and relational losses - is difficult for us as adults, it is even tougher for children. Our daughter, Alisa, was nine when she first became ill with CFIDS. Now, almost eight years later, she has been sick nearly half of her life. Last year we faced our most difficult year with her CFIDS. In addition to the imbalances in her immune, neurological and endocrine systems and her sleep/wake cycle, her body also developed a chemical imbalance that caused depression. Already exhausted from fighting CFIDS for years, she has no emotional energy to cope with all of these challenges. The depression became so severe that one night she took an overdose of medication, hoping to end her struggle.

In *Finding Strength in Weakness: Help and Hope for Families Battling Chronic Fatigue Syndrome**, I wrote that the only fatal symptom of CFIDS is suicide. When I wrote that sentence, I wrote it as information. Now I know it as reality. For Alisa and our family, CFIDS has become a life-threatening illness.

My husband and I grieve as we watch Alisa lose critical stages of her life. We are pained to see her navigate the treacherous waters of adolescence without the physical health or stamina to maintain equilibrium. We agonize as we see her, some days too sick to even enjoy a phone call from a friend. We grieve as she looks to her future and sees her dreams die.

We are not alone. Those of us who are parents of children with CFIDS feel the heartache as we watch our children fight pain and exhaustion when they should be fighting their opponents on a sports field. We see them crippled by illness when they should be bouncing through the carefree days of childhood. We see their minds hampered by brain fog when they should be sharpened in classrooms with their peers. We see them confined to beds and couches when they should be developing their self-esteem on the stage, in groups or in leadership positions. We see them struggle with friendships when peer relationships are so important for their growth. We see them dependent on us when they should be trying out their wings.

As the years pass, we grieve that our children are not getting better and we face the grim reality that they may never fully recover. We grieve deeply when they go into relapses. We grieve our own helplessness.

But gradually we must come to a point of acceptance. This is the way life will be, and we must make the best of it. We make the necessary changes and commit ourselves to our children's wholeness in the midst of a broken situation. In doing so, we model for our children how to face adversity and how to integrate the illness into our lives.

As we attempt to be effective parents of our children who have CFIDS, we can give them several gifts: our trust, our support and encouragement, our love, our commitment to their growth, our commitment to bring balance to their lives and our commitment to protect and advocate for them.

- **Trust your child.** Because I carry CFIDS in my body, it was easy for me to trust Alisa when she reported strange symptoms which seemed to wax and wane from day to day and even hour to hour. I knew what she was feeling. I have great respect for the parents who do not have that firsthand experience. The unusual dynamics of CFIDS can be very frustrating for parents if they don't know their children and if they don't know the effects of CFIDS. It's imperative for parents to read reliable information about CFIDS, especially as it relates to children. Trust is also important as CFIDS children get older and make more of their own decisions about school, activity level, treatment and relationships. In his book The Doctor's Guide to Chronic Fatigue Syndrome, Dr. David Bell says, "The family struggling with CFIDS must function well. There needs to be good communication between parent and child, appropriate behavior control and above all, trust."

- **Encourage and support your child.** "The best gift I can give my child with CFIDS is summarized in three words: encourage, encourage, encourage," says Sharon, a PWC whose daughter also has CFIDS. "That means I try to understand her, empathize with her, let my anger go. That means I accept her for who she is right now, not for what she could have been without CFIDS. That means I give her my time, my hugs and other expressions of love. That means I do special things for her and praise her for even the little things."
- **Guard your child's self-esteem.** "Children with CFIDS have to endure a lot, not only physically but also emotionally as they face doubt and insensitivity from other people," says Cyndi, a PWC whose five children also have CFIDS. "When Mandy was hospitalized at a pain center, several neurologists who worked on her case did not believe CFIDS was a valid diagnosis and their disbelief showed in their attitudes. They said some devastating things in front of Mandy. I confronted them, but they didn't stop. Finally I made sure that her medical charts stated that no doctor could discuss his or her feelings about CFIDS in front of Mandy. That was the last thing she needed as she fought unbearable head pain and seizures for weeks."
- **Commit to your child's growth**. One family's commitment to their child's growth expressed itself in their choice to drive a 40-mile round trip and pay full tuition at a private Christian school so that their son, who has CFIDS, could attend a few classes there because that's where his social network was, that's where his learning disabilities were accepted, and that's where he could find wholeness.
- **Compensate for the losses.** One of the significant ways my husband, Bas, and I have committed ourselves to Alisa's growth during her years of CFIDS is by compensating for the things she has lost. As parents, we are the guardians of our child's whole person - not only her physical well-being, but also her emotional, relational, mental and spiritual well-being. Our goal is to keep a balance in her life. When CFIDS robbed Alisa of her ability to take drama classes and be involved in drama clubs, we worked to balance that loss by renting videos of classic dramas, getting videotapes of her school's drama performances and trying to take her to a few major theatrical productions. That wasn't easy. We would rest up for days ahead of time so that we could sit through a three-hour performance of Les Miserables, then we would crash for days afterward. Alisa will tell you we almost cried when the theater elevator was not working and we had to climb four flights of stairs to get to our seats at The Secret Garden on her 14th birthday. She was so nauseous we thought she was going to lose her food several times. We can laugh about it now - well, almost - but then we thought we weren't going to make it. But 10 years from now Alisa will remember the magic of the drama production and music, and we hope she will forget how sick she was.
- **Advocate for your child.** One of the major gifts we can give our children with CFIDS is to advocate for their needs. Advocacy means representing them, explaining their situation and, if necessary, fighting for their rights with the medical community, the school district and school personnel, as well as friends and family.

A parent who has done extensive work as an educational advocate for children with CFIDS is Karen Lang. Karen, who also has CFIDS, began her work as an advocate for her son, Calen. She writes about their family's experience with the educational system in "Calen's Story: A Child's Journey Through CFIDS," in the Winter 1994 issue of The CFIDS Chronicle. (This article and other helpful information is available in the Association's "CFIDS in Children" packet; see item 6020 on page 64.)

Karen shares several suggestions for parents working with school districts on behalf of their children with CFIDS. "Approach the district with an attitude of cooperation but with the knowledge that your CFIDS child is entitled to special services under Section 504 of Public Law 94-142."

If your child has CFIDS, your job as a parent takes on new dimensions. Learn all you can about the illness. Find other parents who can encourage you when you are sure you can't do this another day. Give your children all the love and support you can as they navigate the treacherous waters of life with a debilitating, frustrating and frightening illness. Advocate where you can, and confront when you must. Hang in there. Your child needs you.

If your child despairs of life and becomes suicidal, enlist all the help you can. Find immediate support from psychiatrists and counselors who will help your child deal with the immediate losses he or she faces. Keep yourself emotionally and spiritually healthy. Lean on your friends, your family and your faith. We are happy to say that God spared Alisa's life, but her battle is not over. Neither is ours. And neither is yours. May God give you strength in weakness.

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

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