



Social Beings

For adolescents and teens with CFIDS, **maintaining social relationships with their peers** can be difficult. This article offers **practical tips** parents can use to help facilitate meaningful social interactions for their children.



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When CFIDS, which ranks among the most devastating chronic illnesses in our country, strikes our youth, it can be both physically and socially crippling. Children who fall ill before having really experienced life outside the safety net of home may never know how to venture out to make friends or know the joy of participating in social activities with peers. Even when CFIDS doesn't strike until the teen years, social repercussions are still common, with many teens finding that they are misunderstood and alienated because of their illness.

While CFIDS usually strikes children during adolescence, it can surface as young as elementary school. Like their adult counterparts, children find that the severity of their symptoms can range from mild to disabling. Some can attend school; others cannot. Fortunately, for those who can manage school attendance, it's often possible to work out accommodations with your school that allow children to be part of extracurricular activities. Parents with children who are struggling just to keep up with the demands of their schoolwork are often very reluctant to see limited energy reserves going to extracurricular activities instead of academics. I don't advocate that extracurricular activities be a priority over academics or school attendance, but a reasonable balance can be achieved. Human beings are social beings, and extracurricular and social activities are as critical to your child's development as mastering the intricacies of algebraic equations or understanding the economic, political and societal forces that led to the Civil War.

It's very common for doctors to encourage their young CFIDS patients to engage in whatever activity they feel they can manage. CFIDS specialist Dr. David Bell, a leading expert on pediatric CFIDS, encouraged our children to partake in activities that were really important to them. He didn't advocate routinely choosing extracurricular activities over school, but did encourage us to give our kids a say in what activities they felt they could handle.

As parents, this was a very difficult thing for us to learn. In the early years of dealing with this illness, I was afraid that if given the opportunity, my son and daughter, who both have CFIDS, would choose fun activities over necessary things like schoolwork, but they both proved me wrong. They never faked feeling bad to stay out of school and, with prodding, have made schoolwork a priority when they were up to it. We have worked together, and they have made good sound decisions. As a parent, it's hard to tell your daughter she can go to the mall and the movies with a friend on Saturday when you know she was wiped out for two days the last time she did that and missed a day of school. But what truly amazed me was that from the age of around 10, my kids usually made very good choices.

Younger children will certainly benefit from some dialogue with you about the pluses and minuses of various choices, but it's important for them to know you support them and will do whatever you can to help them be successful on these social outings. My children have been able to go on school field trips by riding in the car with me behind the school bus. That way they can leave when they need to and not be forced to sit on a noisy bus all the way home. Having a cell phone has also increased my teens' independence and confidence in venturing off on their own because they know they have a safety net an easy phone call away if it's needed.

Many teens battling the fatigue of CFIDS discover that giving up involvement in drama, sports, music or other activities is more crippling than the illness itself. In order to avoid making such a sacrifice, students and parents should work with their school to make acceptable accommodations. For instance, if your child can't manage both PE

TIPS FOR HELPING YOUR CHILD FIND SOCIAL OUTLETS

There are a variety of ways children can become involved in social interactions with their peers. The amount of activity they can tolerate will depend on their level of illness. Some children are able to do about anything they would like, while others find that any outing requires a huge payback. Here are some suggestions and tips:

■ **Know your rights.** Children with CFIDS are protected under Section 504 of the Rehabilitation Act of 1973, which assures that children cannot be discriminated against due to their disability. If they are unable to come to school full time due to their illness, they still must be afforded the opportunity to participate in extracurricular activities to their ability level.

■ **Request a special education evaluation** to determine eligibility for an IEP (Individualized Educational Program). States vary on how they define education in the IDEA (Individuals with Disabilities Education Act), but in New York and Ohio for example, the social aspect of a child's life is included in the definition. This was a big help to my family in developing an educational plan for our daughter, Meg, who is a PWC. She has a social goal written into her IEP that mandates she be encouraged to attend social functions at the school.

■ **Don't waste money.** Since it's difficult to plan ahead without knowing how your child will feel on a given day, focus on some activities that require only a short-term commitment and don't require advanced registration or preregistration fees.

■ **Encourage your adolescent to search for some activities that "fit" the waxing and waning typical of this illness.** For instance, Barnes and Noble has a high school literary society that meets once a month at local book stores to discuss a promoted book. A new topic is covered each month, and there's no expectation of attendance at each one. So if your teen is unable to attend some months because of the illness, it's not an issue.

■ **Don't forget the benefits of new technology.** Cell phones with text messaging capabilities and a home e-mail account help kids with CFIDS feel less isolated. Instant Messaging or "IM" can be a great way for teens to stay connected to other kids with CFIDS, and to school friends. I am fast learning that many teens rely on IM to communicate with each other.



■ **Be an advocate at school.** Some schools and teachers are more accommodating than others in allowing partial involvement, but if it's important to your child, do all you can to make participation a reality. Chorus and band programs, various sports, drama productions, school dances and other special events are all things our children can do according to their energy levels.

■ **Empower your child.** By the time children reach adolescence, they should be encouraged to take part in decision making about what activities to engage in and how to spend their precious energy reserves. Don't assume they'll make bad decisions. With your guidance, they can find an appropriate balance between academics, social activities and other priorities.

and cheerleading, but wants to stay on the squad for the social benefits, ask the school if cheerleading can fulfill the PE requirement for graduation. Engage your child's doctor in this fight if necessary. A compelling letter from an outside expert like a physician can sometimes carry more weight than a parent's appeal.

It can be exhausting to educate all the teachers, school counselors, coaches and administrators your child comes in contact with about CFIDS, especially since the cast of characters changes each new school year, but the effort usually pays off. After all, it's hard for school personnel to understand why your child needs special accommodations if they know nothing about the illness and its impact on cognitive and physical functionality.

Some teens are sensitive about asking for special accommodations at school and prefer extracurricular activities outside of the school arena. Others are homeschooled because of the illness and must search out opportunities for social interaction. One homeschooled teen I know found a soccer team in her community. "I scheduled my entire life around soccer games, practices and tournaments," she told me. "We had practice every day for at least an hour and a half, and then we usually had at least one game on the weekend. Honestly, it killed me to play soccer. I would come home from practices and games literally unable to do anything, including eating or talking.

"Some doctors told me to quit soccer," she acknowledges, "but Dr. Peter Rowe at Johns Hopkins encouraged me to do as much as I could. I think that because I was exercising so much, it really helped keep my neurally mediated hypotension symptoms to a minimum in terms of the light-headedness and dizziness. Because my leg muscles

were so strong, they were able to keep the blood pumping more fully. But I also had negative ramifications. Because of the terrible fatigue and other symptoms, I was more prone to injuring myself and had some severe postexercise malaise. Yet soccer was one thing that helped me to still feel normal. It gave me something to dream about, work toward and feel good about."

Sometimes, though, a teen is just too ill to participate in the sport they love. Courtney Page, who was on the basketball team prior to the onset of CFIDS, was unable to play after she became sick. She was, however, able to stay on the team, ride the team bus to the games and be with the team in the locker room at halftime. She said this social contact was very important to her, even though everyone on the team didn't understand her illness.

Considering everything kids with CFIDS have lost to this illness—and their diminished control over their own bodies, which just won't behave and function normally—I think it's important to give them control over what we can. This is especially true with teens, who will soon be young adults making decisions on their own without our help. We must prepare them to make good choices and to realize they often have options about ways to engage in an activity. It's not always all or nothing. Learning to make choices about what activities to skip and which to do, when to go full out and when to sit out part of the activity, or when to schedule rest beforehand to have enough energy to participate in a cherished activity are important life skills for people with CFIDS. Giving them this responsibility is also a lesson in self-advocacy. We won't always be by their side when they face family, friends, college professors, employers and their medical team.

Chronic illness often causes feelings of isolation and alienation even in well-adjusted adults. For young children and teens, the impact can be even more severe. As parents, it's our job to help them find fun and meaningful ways to engage in social interactions with their peers. Whether it's a school activity, scouting, volunteering at the local Humane Society, joining a teen book club or inviting a friend over to watch a DVD, social activities are critical to adolescent development and self-esteem. ■



Mary Robinson is the parent of two children who have CFIDS, one of whom has recovered. An educator by training, Robinson has become an expert on the special education needs of kids with CFIDS and led a support group for youth with CFIDS and their parents for several years. She coauthored A Parents' Guide to CFIDS with Dr. David Bell, Jean Pollard, Tom Robinson and Bonnie Floyd. Robinson is the co-founder and coowner, along with Rebecca Moore, of the Pediatric Network for CFS, FM, OI (www.pediatricnetwork.org). Families that want a place to "talk" and share ideas are invited to visit the network and join a forum of more than 250 members. Robinson can be reached at mary@pediatricnetwork.org. She is pictured above with her daughter, Meg.