

Lyme disease in children and adolescents: parenting dilemmas

by Sandy Berenbaum, CSW-R, BCD

I'm writing this as an introduction to the topic of "Parenting Dilemmas," and hope to address this topic further in future issues of the Lyme Times. This is the first time I've specifically focused on "parenting dilemmas" and I encourage readers to contribute by writing letters to the Editor of the Lyme Times. I'd also like to see other psychotherapists participate in this discussion, so that a body of knowledge becomes available on how to help parents deal with the non-medical side of Lyme disease in children and adolescents.

Parents of children who have been diagnosed by a Lyme-literate doctor are often relieved. The child has had symptoms for months or years, and has seen many doctors, who have given false direction, or no direction, and the child has remained ill. It would appear as though the hard part is over, now that there is a diagnosis and treatment plan.

By the time they have found this doctor, the parents usually know enough about Lyme to realize that, at this stage, it will not be a quick fix. Treatment is likely to take many months, sometimes longer. The medical decisions, the most important ones, have begun, but for the parents, the decisions are far from over. This complex, poorly understood illness produces other dilemmas for parents. It is important that the Lyme-literate community (physicians, psychotherapists, educators, nurses, support group and task force leaders) recognize these dilemmas, and provide support for the parents of these young Lyme patients and their families.

After the child is diagnosed by a Lyme-literate physician, his parents come to realize how little accurate information on Lyme disease is out in the community. They often immerse themselves in the literature, particularly some of the excellent websites, and come to a basic understanding regarding what their

child is going through, and are ready to provide support and advocacy. This can lead to a sense of isolation for parents, when they realize how little is known in the general community about Lyme, and some dilemmas surface.

In this article, I'd like to address three areas in which parent dilemmas are common: 1) a family's primary support group, 2) the child's moods and behaviors, and 3) the child's school.

Dilemma #1 – Dealing with primary support group (extended family, close friends)

We know the complexities of Lyme disease and coinfections. Patients don't necessarily "look sick", symptoms come and go, moving from one part of the body to another, the intensity of symptoms can be extreme or subtle. It is therefore difficult for those who have not had previous experience with this illness to understand and appreciate what is going on. Lack of understanding, and judgmental remarks on the part of family members and friends often lead parents to question how much contact they can or should have with those close to them. This is a heart-wrenching dilemma for many.

It is important for parents to read widely and deeply regarding the illness, and to have simple materials available (like the ABCs of Lyme,

carefully selected Lyme Times articles, and "The Basics") for those close to them. If local cable TV stations show the Lyme videos, family members should view them, and educate themselves. Family members need to be encouraged to respect boundaries with their loved ones, providing support and not criticism, even if they don't really understand what the issues are that this child and his family are facing.

Families of children with Lyme have a lot to deal with. Support from those close to them, giving encouragement and in some cases, concrete help, can eliminate the isolation that the family might feel, and ease the burden. How sad it is when a family of a child who is ill needs to distance themselves from loved ones because of a lack of understanding and acceptance.

Dilemma #2 – Dealing with the child's moods and behaviors

Where children with Lyme are concerned, behaviors may not simply be choices a child makes. The behaviors may be symptoms of the illness, normal flares of the symptoms induced by the medications, or side effects of the medication itself. Parents struggle with the questions regarding accountability of a child for his behaviors.

Lyme disables many children, but parents certainly do not want to further disable their child by not having appropriate expectations of him, or by denying him the natural and logical consequences of his actions. Herein lies the dilemma.

For example, if a child has a rage outburst, to what extent is it under the control of the child? What response should parents have? What messages do they give their child?

Whether or not the child is ill, the message is that the outburst is not acceptable. If the child is *not* ill, the child has more responsibility to change the behavior on his own. With the child whose Lyme disease might be a factor, there is more of a

need to focus on the *reasons* for the behavior, and environmental changes that might need to be made while the child is ill. Depending on the child's age, the parent can encourage the child to become more aware of how he is feeling, and identify the triggers of the behaviors, in order to prevent the reactions.

My co-therapist and I have developed a "two-track" approach, in working with children with Lyme. We suggest that parents keep in mind two ideas, or two tracks, that need to be considered simultaneously – 1) the child is ill, and negative behaviors might be a part of the illness, and 2) the child needs to be encouraged and directed to behave and function at an age-appropriate level.

Here's an example of a response that serves both tracks. A child with neuropsychiatric Lyme disease has a friend over, and has a major outburst in front of the friend. If the parent knew that the child's behavior was willful and under the control of the child, the parent might simply send the guest home, and send the child to her room, with the clear message that the behaviors are not tolerated, without delving into it any further. If the child has Lyme, however, particularly with diagnostics supported by neuropsychological testing and/or a brain SPECT scan, there's a strong likelihood that the outburst, or some aspect of it, was *not* under the child's control. The dilemma for the parent then is, "How do I *know* whether my child had control, or whether it was part of the illness? What message do I give her, and what actions do I take, as a result of the outburst?"

A major problem is that the parents cannot really *know* to what extent the child has control. However they should not presume that the child had *complete* control. So this dilemma calls for some deeper thought on the part of the parents than would be required if the child were not ill. However, the

behavior still calls for a parental response.

One option for the parent is to address both children, saying, "Susie is not having a good day. It's best if she doesn't have company right now. Sometimes Lyme disease causes kids to behave this way." This is protective of the child, and of her relationship with her friend. The parent is not blaming the child, but she is also not allowing the situation to get worse, by eliminating further contact between the children that day. She then takes the friend home. This is the logical consequence of the child's behavior.

A talk with Susie after her friend leaves, might yield some information about what happened *before* Susie had the outburst, "The TV was so loud, that it made me feel jittery," etc. Teaching Susie, even at a young age, to make connections between her behaviors and precursors to it might help her to gain control, by removing stimuli or circumstances that lead to outbursts *before* they happen. Parents could then set guidelines for when a friend comes over, and which friends are good company, while their child has this set of symptoms.



Whether or not the child is ill, the message is that the outburst is not acceptable, but in the case of the child who is not ill, the child has more responsibility to change the behavior on her own. With the child whose Lyme disease might be a factor, there may be more of a need to focus on the reasons for the behavior, and environmental changes that might need to be made while the child is ill.

Dilemma #3 – Dealing with the school

The school can present an array of issues for the parents of a child with serious Lyme disease symptoms, depending on how Lyme-literate or Lyme-open the school administrators, teachers, and other school professionals are. The degree of support varies from school to school, and from district to district, and, at worst, can be a nightmarish experience for parents.

The best situation exists when the school believes the parents and doctor, providing supports to meet the child's changing needs (as I discussed in the "Time for Lyme" video). In this situation, the child feels safe and protected, yet challenged in school, and one source of potential stress is removed from the parents.

Even in this situation, there are dilemmas for the parents and doctor. These include: determining when the child's workload can be increased, when he can return to school if he has been on homebound instruction, when to go from part-day to full day – these are judgement calls that may be difficult to make.

When a school is supportive, these judgement calls are, however, much easier. The school becomes a part of the team that adjusts supports at every step of the way. If the system is fluid, and the child is given an academic load that meets his abilities at a given point in time, there's less of a problem for the

parents and child. If he is welcomed back to school when his parents and doctor determine that he is ready, with the understanding that if his symptoms get worse, he will be out again, it creates far less of a dilemma for the parents.

However, if the system is rigid and once the child is back, the administrators says he'd better remain at school, it's harder for the parents to make the decision to allow him to return to school, or to move up from part-day to full-day. Parents are torn between what they know would be better for their child's health, and their not wanting to make waves at a school that is not a supportive environment for children with Lyme. They fear that, if they fight the system too hard, their child will harrassed and judged, and that the attitudes of staff will make their child very uncomfortable in the school environment. If the school is rigid, the parent might therefore be inclined to ask the child to "tough it out". At times, this results in children relapsing, under the pressure of a school day that's too long or too rigorous.

An important question we need to ask is, "Why is the school not being supportive?" They may simply lack information. The parents and Lyme support community can provide information, in a congenial way, to help the school understand and appreciate the serious nature of this illness, as well as the specifics of how it effects this child. Some schools are open to in-service training by Lyme-literate educators, doctors, psychotherapists. Educators who participate in this training can pass information on to their colleagues. [Note: In New Jersey, Lyme disease education is mandated, for both students and teachers. Other states should follow New Jersey's lead, and pass similar legislation.

In some cases, Lyme disease education has been offered, or resources have been provided to the school, yet administrators or teachers

have refused to believe the parents or the materials and have made determinations or taken actions that are counterproductive. The Lyme community needs to build resources that will back parents who are dealing with these schools. Perhaps there needs to be a network of Lyme-literate parent advocates who attend school meetings with parents, so that they don't have to participate in these often-intimidating meetings alone.

These parenting dilemmas highlight the importance of having community resources and support for parents of children who are seriously impacted by Lyme disease. Although Lyme disease is a medical illness, there is far more to this illness than we find in medical literature and discussion.

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Suggested resources:

- ABCs of Lyme – available through the LDA
- Time for Lyme video – (see order form on page 52)
- A Controlled Study of Cognitive Deficits in Children With Chronic Lyme Disease – Felice Tager, et al
- The Basics - Lyme Disease Association of Southeastern PA
- Also see lymetimes.org for articles in back issues

New Jersey Law

Public Law 18A: 35-5.1 (1992) The Commissioner of Education, in consultation with the Commissioner of Health, shall develop curriculum guidelines for the teaching of information on the prevention of Lyme disease within the public school health curriculum. The guidelines shall emphasize disease prevention and sensitivity for victims of the disease. The Commissioner of Education shall periodically review and update the guidelines to insure that the curriculum reflects the most current information available.

Public Law 18A: 35-5.3 (1992) The Commissioner of Education, in consultation with the Commissioner of Health, shall also provide curriculum guidelines for the training of all teachers who instruct students with Lyme disease which emphasizes the special needs and problems of students with the disease, in order to provide information about how best to teach those students. Each school district shall annually provide training to all teachers who instruct students with Lyme disease, based upon the guidelines.

This law was passed through the efforts of the national Lyme Disease Association (LDA), formerly the Lyme Disease Association of New Jersey. LDA conducts regular inservice training workshops for teachers in compliance with this legislation.