



REFLECTIONS ON LYME DISEASE IN THE FAMILY

Ideally, the family is a safe, protective, nurturing unit in which a child develops and grows. The early years are demanding for parents, who, in addition to bonding with their child, must make daily decisions that are vital to their child's life and growth. In contrast, the adolescent years are emotionally challenging, as parents struggle to remain connected, supporting their children's bid for independence, while protecting them from making sometimes disastrous choices, as the child struggles to develop her own ideas and direction.

Let's add Lyme disease to this picture. Parents of children with Lyme disease carry an enormous burden, far greater than those outside the Lyme community are likely to understand. They worry about accuracy of diagnosis, selecting the right doctor and treatment approach, paying for treatment that is very costly, and the complexities of identifying and advocating for educational supports that may be necessary for a child to make it through school.

Other members of the family may be ill as well, often the case with Lyme disease. Aside from the increased financial burden, there is the stress of trying to meet the needs of *several* Lyme disease patients in one family. It is particularly difficult when one of those Lyme patients is a parent, and when the ill parent suffers from neuropsychiatric problems!

Given the complexity and unpredictability of symptoms, and the inadequate understanding of this illness in the greater community, parents often find that they do not have the support of family and friends, as they struggle to cope. Unwittingly, some well-meaning family members may make comments that undermine parents, even challenging the medical decisions that they make. At times, family members mistakenly attribute the child's symptoms and behaviors to willfulness on the part of the child, or inadequate structure and limits on the part of the parents. Failing to appreciate the complex, debilitating nature of this illness, they do not acknowledge the struggle the family is going through, and are therefore not a reliable source of support. This reality in the life of the family of a child with Lyme can be particularly disappointing and painful!

Behavioral problems are not uncommon in children with chronic Lyme. If the child is subject to rages or other severe psychiatric symptoms, this increases the stress level in the family, and makes the family's day to day life far more complex. Lacking the support and help they would have hoped to get from their family and friends, parents truly feel isolated. They are often out on a limb with their child, but they are also out there *alone*.

Where a young child is concerned, although his parents do their best to help him feel safe and protected, hiding their worries and fears, the child surely senses that something is very wrong. Parents can't help but worry about whether their child will ever fully recover. What might the residual damage be...to his body, to his brain, to his experience of life? On some level, the young child is keenly aware that he is *not* growing up in the carefree environment that peers may be experiencing. Worries certainly permeate the household. Even deciding whether to allow a child to go on a school field trip, or give permission for a teenager to go hiking with friends may be a struggle for parents, who worry that their child, already very ill, might be re-infected. A sense of normalcy is lost.

Where the adolescent is concerned, a primary issue is how to support the teenager in her efforts to individuate and move toward independence, while taking appropriate precautions for treating the illness. The physical and emotional dependency of a sick teenager may delay or interfere with the

task of individuating. Or, the teenager, supported by inaccurate information that is all around them, may separate by challenging the Lyme diagnosis or treatment, and refusing to go to the doctors or take prescribed medications. In denying their illness, teenagers may even come to believe that their symptoms represent *who they are*, as they lose touch with the fact that these symptoms are caused by a *treatable medical illness*. They may therefore see themselves as lazy, not very bright, quick to anger, moody. And, in the process of individuating, they might not believe the evidence their parents and doctors present that these are merely symptoms of the illness, and *not* a manifestation of who they *really* are. How terrifying this is can be for parents!

A child's illness may call on parents to grow in unaccustomed ways. Parents may find themselves thrust into situations beyond their own comfort level, needing to be more assertive with previously trusted school and medical authority figures or more conciliatory with insurers and others, in order to achieve important goals. The needs of their children often push parents far beyond their comfort zone in these areas. It is important that parents recognize where that comfort zone is, and work to move beyond it, for the sake of their child, and his recovery.

In this complex, demanding world, we need to have compassion, empathy, and understanding for those who are struggling to raise children who have chronic Lyme disease. If we can appreciate the challenges that face them, and respect their decisions, perhaps we can make their world a little bit brighter.

Parenting Strategies from the Trenches

After years of helping parents, children, adolescents and families deal with some of these issues, I have developed the following strategies, to help parents ease their journey:

- Maintain a problem-focused approach as you make decisions about diagnosis, doctors, and treatment.
- Work at developing a consensus between you and your child's other parent, whether or not you are still together!
- Stay focused on current problems to be solved, and keep worries on the back burner.
- Explain what's going on to your child in concrete, age-appropriate terms.
- Maintain your credibility with your child by being truthful.
- Be careful with the words you use. Avoid words like "psychotic episode", "manic", or "incurable". Lyme disease is a scary illness. Keep your words from making it scarier.
- Be firm when you need to be, but give choices when you can, lots of choices.
- Establish and maintain protective boundaries, protecting yourself and your child from family members and friends who doubt your judgment and parenting decisions. Let others know what they can and cannot say.
- Build a supportive network - educate your family and friends about Lyme, but don't overload them. Remember, this is *your* issue, not *theirs*.
- Be open to support, but make it clear that you're *not* open to being second-guessed. Allow people to help in concrete ways when you're overwhelmed. Let them make meals, pick up the kids, or shop for groceries..

- Psychotherapy or family therapy, with a Lyme-knowledgeable therapist, can be an important adjunctive treatment, to help you and your children get through the hard times without residual damage. The model I use is helping Lyme patients and their families go from being victims, to survivors, to thrivers. There's nowhere that this model is needed more than with families coping with Lyme disease.

Sandy Berenbaum, LCSW, BCD
Family Connections Center for Counseling
Offices in Brewster, NY and Southbury, CT
(203) 240-7787

*Published in Lyme Times Children's Treatment Issue
#42 – Summer, 2005*

© 2005