We in the Lyme world all know that tick-borne diseases are caused by complex organisms that can affect just about any part of the body, and we realize that the key to getting well is finding a Lyme-literate doctor, obtaining an accurate diagnosis, and comprehensive, efficacious treatment. While treating the medical aspect of the disease is paramount, for children and adolescents with chronic Lyme disease, medical treatment alone is often not enough. Many of these children have Lyme-related psychiatric symptoms or educational impairments. Their serious symptoms, combined with the duration of the illness often leads to gaps in their development. Their isolation can leave them lonely, and inhibit their ability to interact with peers. These issues are best addressed through the coordinated efforts of a team.

Children and adolescents with chronic Lyme, often meet the DSM criteria for one or more “mental illnesses”—anxiety disorder, depression, anorexia nervosa, AD/HD, as well as disorders in which behavioral problems manifest—oppositional defiant disorder, conduct disorder, and for some, psychosis. Even though the “mental illness” may be due completely to Lyme, the serious psychiatric symptoms cannot be ignored. For many, psychiatric medications are essential, in managing the symptoms during treatment, including the complex issues of managing symptom flares (Jarisch Herxheimer reactions), brought on by the antibiotics. Thus there is a need for involvement of Lyme-literate psychiatrists who treat children.

These “mental illnesses” carry a constellation of issues. The
anorectic children, for example, often have an aversion to certain foods, or a rigid pattern of eating, and there is an obsessional quality to their thinking, about food and exercise. Some put a pathological spin on suggestions doctors make for a “yeast free” diet while on antibiotics, some refuse to take any medications by mouth. Weight gain typical of some Lyme patients terrifies the anorectic, and pathological weight loss brings them comfort. These issues need to be dealt with in individual and family therapy, to keep the anorectic child safe and healthy during the acute phases of the illness and Lyme treatment.

Anxiety is another symptom common to children with Lyme. The anxiety presents for many in their fears about school failure, even as their cognitively impaired brains struggle to succeed. It takes a Lyme-literate team to deal with the anxious child with Lyme—the medical doctor who treats the illness, the psychiatrist who prescribes the medication for anxiety, the psychotherapist who teaches the child and family strategies for dealing with the anxiety, helps the child learn to think in a different way (cognitively-based therapy is helpful here), and the Lyme-literate school team who provides support and accommodations for the child who has impairments that affect learning. The school nurse or guidance counselor can provide a brief respite, and support, for the anxious child, in the middle of the chaos of the school day.

Behavioral problems are often due simply to the infection in the brain, and will resolve as the illness is treated comprehensively. However, the treatment could take a long time, and the behaviors need to be addressed and managed during these difficult times. Intervention and support of a Lyme-literate psychiatrist and psychotherapist, as well as involvement of a parent advocate who develops a plan for managing behaviors in the school setting can make a significant difference in the life of the child and the family. Traditional “behavior plans” are often not effective,
when the behavior is driven by an infectious cause.

Attention needs to be paid to the tasks of the various developmental stages the child with chronic Lyme is going through. The most difficult stage to manage is adolescence, where the Lyme patient may deny the illness and resist treatment to be “normal”, in an attempt to individuate. At this stage, some will self-medicate the Lyme symptoms with street drugs. If the child has been ill for a long time, it may be difficult to distinguish between symptoms of the illness and who the child really is. It is helpful if these symptoms are addressed in therapy, as well.

Part of the work of childhood is to develop social skills, to learn how to interact with others. Children learn that at home, in their communities, in school, on the ball field. When a child is ill with chronic Lyme, often her exposure to others is very limited. Some children have been on homebound instruction for months and years, not even having the school community to interact with. Socialization needs can be addressed in therapy, and for those who are seriously ill, some social experiences can be built into their week.

CONCLUSION AND RECOMMENDATIONS

While physicians who treat Lyme are focused on diagnosing and treating the medical illness, it is also important to recognize that there is more to treating the child with Lyme than ridding the body of infection. We need an integrated approach that includes doctors, nurses, psychiatrists, psychotherapists, neuropsychologists, educators, and advocates. It is important that we are aware of each other’s roles, and communicate regularly.

The impact of Lyme disease on children and adolescents is not just a medical issue. By working together to support and treat the whole child, we can help our children achieve more than physical health. They can become resilient, life-loving,
successful people, and put the nightmare of the Lyme years behind them.

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