

EDUCATIONAL ACCOMMODATIONS FOR LYME DISEASE

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Lyme disease is caused by infection with the spirochetal (cork-screw shaped) organism *Borrelia burgdorferi*, which is transmitted by the bite of an infected deer tick. It is most often an acute illness with flu-like symptoms that responds well to three to six weeks of high-dose oral antibiotics. However, some cases are difficult to diagnose because the presenting symptoms are subtle or atypical, and some cases do not respond adequately to antibiotic treatment. In these cases, the illness can persist for months or years, interfering with social, emotional and intellectual development. The severity of the illness can vary from a chronic fatigue condition accompanied by intermittent pain, to a state of complete debilitation. To properly recognize and address the needs of children with Lyme disease, teachers and other educators should be familiar with the nature of the illness and its physical, cognitive, and psychological impact.

The physical symptoms most common in Lyme disease are joint and muscle pain, fatigue, headache and sleep disturbance. However, almost any body system may be affected, including gastrointestinal, cardiac, endocrine or visual systems. Neurologic symptoms can also occur, particularly sensitivity to light or noise, dizziness, and tingling or numbness in the extremities or the face. In small children, irritability and moodiness may be the earliest indication of illness. In others, a period of frequent or recurrent upper respiratory infections or viral illnesses marks the early stage of the illness. Less frequently, Lyme disease can cause psychiatric symptoms, such as anxiety, with panic attacks, phobias or obsessive compulsive symptoms, depression, or thought disorder.

Lyme disease also causes cognitive dysfunction. Most often these are impaired attention and concentration, slowing of mental and motor processing, impaired retrieval of information from memory, impaired word retrieval or verbal fluency, problems with planning, organizing and sequencing of ideas, difficulty with visual scanning and auditory tracking, and problems with certain kinds of reasoning, particularly causal reasoning, decision making and "seeing the big picture." The severity of the cognitive impairment tends to correlate with the severity of other symptoms, particularly and the level of fatigue and malaise, and is similarly variable.

The symptoms of Lyme disease tend to fluctuate widely in severity, day to day, week to week and even within a given day. Changes in medication may produce a worsening of symptoms, known as a Herxheimer reaction. Some patients experience a cyclical flare-up, often every four weeks, and during times of stress, hormonal changes and seasonal weather changes. The medications for Lyme can cause gastrointestinal upset and loss of appetite.

The fatigue of Lyme disease can get through the school day or completing homework impossible. Pain is distracting and upsetting. Irritability can lead to behavioral and social problems. Sleep disturbance make it very difficult to get up for early classes. Falling behind on assignments and being unprepared for tests can cause significant stress. Chronic illness can result in social withdrawal, decreased physical stamina, a decline in self-esteem and decreased academic motivation.

Lyme-related cognitive impairment will interfere directly with learning and academic performance. Impairment of attention and concentration results in poor absorption of information from classroom teaching, difficulty with reading and reading comprehension, difficulty completing assignments and studying for tests. Problems with retrieval of information from memory can interfere with performing on tests and class participation. Problems with visual scanning and writing interfere with copying from the board, note taking, and keeping track of homework assignments. Editing of written work and accuracy in math computations may also be affected. Slowed processing or thinking interferes with completing assignments and being prepared for tests. In children with pre-existing learning or attention problems, these will be significantly exacerbated in Lyme disease.

Frequent absences interfere with continuity of learning and result in gaps in the knowledge base. Children who miss a significant number of days consecutively qualify for home tutoring. Children who are very ill and are unable to attend school at all need to be home tutored for long periods of time. This should be scheduled for two hours, three to five times a week, at a time of day that the child tends to feel best, often early afternoon. Although the child may not be well enough on some days to do much in the way of work, the tutor attend anyway and do whatever is possible, even if it is chatting with the child about past lessons, movies or current events. Otherwise, there will likely be frequent cancellations, which will cause frustration for the tutor and isolation for the child.

The child should return to school as soon as he or she is able, on a part time basis. A shortened day as well as a shortened week should be considered. A late start to the day is often helpful, because sleep disturbance is so common. A rest period during a study hall may also be necessary. For other children, arriving late and leaving early will both be necessary. A week with Wednesdays off works well for some children with very limited stamina, whether the attended days are full-length or not. Although this type of schedule is tricky to work out on a practical level, it represents the “least restrictive environment” for a child with chronic Lyme disease, who would otherwise be unable to attend classes at all.

For children who are able to attend class full time or close to full time, other accommodations will likely be necessary. These can often be done under a Section 504 plan, with arrangements made at the building level, rather than at the district level. Accommodations helpful for children with Lyme disease include: Preferential seating, not necessarily in the front of the class, extended time for classroom and standardized tests, a scribe when a lot of handwriting is necessary, clarification of instructions, multiple choice format to aid information retrieval,

provision of a word bank for writing assignments, a calculator for math tests, assignments presented in written form, class notes and curriculum outlines provided, an extra set of text books to keep at home, a laptop available for note taking and written work, keyboarding instruction, instruction in organizational and time management strategies as well as test-taking and study skills, and multimedia approaches to supplement reading assignments (e.g. films, video lectures and other internet resources). Assignments must be adjusted in length to account for slowed processing, so that, when possible, they can be completed in the time it takes other students.

Children with longer-term illness should be evaluated and monitored by the Special Education team and should have an Individualized Education Plan. Specialized assessment, including neuropsychological evaluation should be utilized as needed. Periodic academic testing should be done to identify lags in specific skill or knowledge areas. The social and emotional impact of the illness must also be carefully monitored and addressed; supportive counseling is often necessary.

Adequate rest and limited stress are critical to the successful treatment of chronic Lyme disease. Thus it is critically important that the student with Lyme be given appropriate and adequate educational support, whether they are able to attend classes or not, during the course of their illness. Meeting the needs of children with chronic Lyme disease presents a unique challenge for school districts, one that requires close communication and cooperation between parents, educators and medical professionals.