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Lyme Disease

Lyme disease is caused by a spirochetal (corkscrew-shaped) organism called Borrelia burgdorferi. It is transmitted by the bite of a deer tick. The deer tick is much smaller than the familiar dog tick and is very hard to see on your body, particularly because it tends to find hairy places like the scalp or groin. The deer tick got the Lyme organism by feeding on a white tailed deer or on a field mouse that was infected with it.

At the site of the bite, a distinctive rash occurs, that is red and round, often with a central clearing so it looks like a bull's eye. Even more distinctive than the shape is the fact that the rash expands, becoming a larger circle. It appears within a week or so of the bite and then goes away, but you're still sick. Many people never notice the rash. The symptoms of Lyme disease area usually flu-like aches and pains, joint and muscle aches, and fatigue. However just about any symptom can be caused by Lyme, including headache, stomach or digestive problems, heart palpitations, vision changes, and so on. Sleep disturbance - problems falling asleep or staying asleep, are very common, as is mood disturbance - irritability, depression or anxiety.

In Lyme disease, a frequent complaint is "brain fog", or cognitive dysfunction, that interferes with school or job performance. Because Lyme disease can be difficult to diagnose, and sometimes to treat, people are often sick for many months, or even years, rather than just a few days or weeks as in many infectious illnesses. As a result, people cannot just climb into bed and sleep, but must try to function, and they find that many tasks are difficult or impossible due to impaired concentration, memory, and so on.

A number of research studies have looked at the nature and extent of the impairment in information processing that occurs in Lyme disease, and have found that the *executive processes* are selectively affected. That is, the "brain fog" of Lyme disease looks much like an acquired attention deficit disorder. It is *not* ADHD, because by definition this involves problems that were there from an early age. But the processing deficits are similar, because the same circuits seem to be involved.

Other chronic illnesses can cause similar deficits. Whenever we are sick, our immune system gets into gear to manufacture and dispatch specialized cells to attack and kill the invading organism - a particular type of bacteria or virus. In order to fight the infection, the immune system needs all the energy it can get, so it slows or shuts down all non-essential body processes, like digestion. That's why when we are sick we don?t have much appetite and all we want to do is go to sleep. You may have noticed that when you are sick with a bad cold or virus, you can?t concentrate or think as well as usual. If you've ever dragged yourself into work when sick, you probably found that you couldn't get much done. You couldn't make decisions, solve problems or contribute good ideas at the meeting.

Apparently, the higher level brain functions, or information processes that we have been talking about, are not that important, according to your immune system, relative to the workings of your heart and lungs, for example. Neither are the digestive functions, which can be slowed down for a few days. So these nonessential systems are put into "power-saver mode" while the immune system directs energy resources to battling the bad guys. Your brain is on "brown out", and the highest level, most widely communicating circuits, the Executive processes - the control center - are the first to go.

Most people get Lyme disease and either never experience symptoms, because their immune system handles it, or respond well to a few weeks of antibiotic medication, with full resolution of all their symptoms. But a small percentage of people who get Lyme disease do not respond to treatment, and become chronically and seriously ill, requiring many months, if not years, of treatment. It seems that there are either two kinds of Lyme disease or two kinds of Lyme disease sufferers. Because the laboratory tests are unreliable, the diagnosis must be made by a knowledgeable doctor who takes a detailed history and does a careful examination.

Unfortunately, many doctors do not know or understand this and rule out a diagnosis of Lyme because a blood test comes back negative. Also unfortunate is that many doctors believe that after two or three weeks of antibiotic treatment you cannot possibly still have Lyme disease. These doctors may not offer an alternative explanation for your persistent symptoms, and leave you to feel like you are either crazy or faking. However, a recent large scale and carefully controlled by Brian Fallon, M.D. at Columbia Presbyterian, showed that patients with persistent Lyme disease who had been treated with the standard course of antibiotics, but who continued to have symptoms, got better when treated with three months of intravenous antibiotics. Both physical and cognitive symptoms improved. Hopefully, this study will make it easier for people to get additional treatment when they need it.

Children with Lyme are particularly difficult to diagnose and treat, because they often can't understand or

communicate what they are feeling. Children who are very tired and obviously unwell need to be seen by a doctor and carefully worked up, like an adult. But in children the only other symptom may be a change in behavior, an increase in irritability, temper outbursts or tantrums, or crying over seemingly little nothing things that normally would not upset them. The problem is that children often go through periods like this, as they grow and change and face new challenges, like toddlerhood, the start of school, or the approach of adolescence. The presence or absence of fatigue seems to be the critical factor.

Children with chronic Lyme experience processing deficits just like adults, and these cause problems with school performance. Many times, these children have subtle processing deficits or learning or attention problems that have never been identified but are developmental in nature. That is, they have always been there, but perhaps the child has been able to compensate and do alright in school. But Lyme disease makes them worse, adding its own brain fog, bringing the mild difficulty to the level of a big problem. In these cases it is important to tease apart the Lyme from the developmental issues, so that after the child is treated, continued difficulties are not mistaken for continued symptoms and persistent infection.

Educational Accommodations for Children with Lyme Disease

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 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 correlates with the severity of other symptoms and the level of fatigue.

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 flare-up every four weeks, during times of stress or before or during menstruation. The medications for Lyme can cause stomach upset and loss of appetite.

The fatigue of Lyme disease can make getting 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

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, a a word bank for writing assignments, a calculator for math tests, assignments presented in writing, 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, multimedia approaches to supplement reading assignments and minimized homework..

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.

Vitamin D - Too much of a good thing?

Current research suggests that Vitamin D is a hormone that is central to the function of the immune system, and that ingesting foods supplemented with Vitamin D leads may be contributing to the epidemic of chronic inflammatory illness, including post-treatment or chronic Lyme disease. Vitamin d is being added to more and more foods, and it is becoming nearly impossible to purchase Milk without added Vitamin D - even milk labeled "no hormones added" !

To read more on this topic, see: Vit D: the alternative hypothesis

or visit: http://bacteriality.com/

More to come on this topic...

ATTORNEY GENERAL'S INVESTIGATION REVEALS FLAWED LYME DISEASE GUIDELINE PROCESS

Important links to Lyme disease information websites:

The Lyme Disease Association: www.LymeDiseaseAssociation.org

The Lyme Disease Foundation: www.lyme.org

Columbia University Medical Center's Lyme and Tick-Borne Diseases

Research Center: www.columbia-lyme.org

Lyme Network: www.lymenet.org

CDC Lyme page: www.cdc.gov/ncidod/dvbid/Lyme

Lyme Info: www.lymeinfo.net

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