



KIDS AND LYME DISEASE

HOW IT AFFECTS THEIR LEARNING

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Introduction: There is an urgent need for Lyme disease education and awareness in the schools throughout the United States. In addition to the "ABC's of Lyme," and the new "Time for Lyme" video, Lyme professionals - physicians, psychotherapists, neuropsychologists, need to be seeking opportunities to provide in-service training to schools, so that teachers and other school professionals understand and appreciate the difficulties that face kids with Lyme every day. We need to call on the schools to help these children, and education is the key.

The following is a presentation I gave to the Northern Dutchess County (NY) Support Group in November 2002. Perhaps it will provide ideas for other presentations to Lyme groups and schools around the country. Every child with Lyme disease should feel understood and supported, and be successful in school. Lyme disease may be a handicap that some children have, but it should not be an insurmountable obstacle.

When my colleague, Lynne Canon, and I started our private practice 16 years ago, we did so with a commitment to providing psychotherapy and family therapy to adolescents and their parents. For five years, we did just that, with no thought that a medical illness might be at the root of the psychiatric, behavioral or learning problems some of these kids might have.

Then, in 1991, a client was referred to us who had a profound effect on us, and on our practice. I will call him "Jim".

Jim was a 15 year old boy who refused to go to school. He was paranoid, fearing that people were out to get him as well as his family, and he could not sleep at all. His parents reported that he had been an honors student up to a few months prior to our first session, but now, when he *did* go to school, he failed every test he took. He appeared to be physically fit and well disciplined. He was even skilled in the martial arts.

On Intake, we asked standard history and family history questions. We found Jim to be a very verbal and engaging young man, obviously bright, and a deep thinker. We saw agitation, restlessness, and anxiety, as well as the paranoia reported by his parents.

Toward the end of our initial interview, we asked about his hobbies. With great enthusiasm, Jim told us about his volunteer work at an environmental center here in Dutchess County, and of his hopes for a career involving environmental studies.

Jim was a real puzzle to us. We were faced with a set of symptoms and functional problems that made no sense, even in examining his history. Realizing that there had been *a dramatic onset of symptoms at a particular point in time*, and that Jim had spent so much time out of doors in what we now see as the Lyme capital of the universe, we referred him to his family doctor for a Lyme assessment.

His pediatrician took a titer, which came back "negative", (any of you parents have that experience?) indicating to *this doctor* that Lyme was not a factor! *That road appearing closed*, we continued to see Jim, as well as his parents, and watched a steady decline in Jim's functioning. He could not go to school, and was placed on home teaching. His parents and we were completely baffled.

As Jim's symptoms got worse, we thought he might have to go into a psychiatric hospital. In a *last* quest for a possible medical answer, we suggested that his parents take him for a consultation to a pediatrician who we knew to be Lyme-knowledgeable.

On the day that consulting doctor saw Jim, he called to tell us that he had made a CLINICAL DIAGNOSIS of Lyme disease, a diagnosis based on Jim's clinical symptoms, NOT on a blood test. The doctor prescribed Ceftin, a drug that crosses the blood brain barrier, attacking spirochetes that were in the brain.

Within *three days*, Jim's paranoia disappeared. He admitted to having had hallucinations, and they too were gone. He was now sleeping 14 or more hours a day, and for the first time, had joint pain, as part of a Jarisch Herxheimer reaction to the antibiotics, a reaction in which the symptoms temporarily get worse. Thus began Jim's long struggle with what turned out to be chronic Lyme disease.

Jim went from being a teenager who could not attend school, could not participate at all in the educational process, was failing all tests, to a good student at one of the best colleges in the New York State system. He went from being a very sick kid, who was on homebound instruction for a year and a half, to a college graduate. He was helped by a supportive family, a Lyme-literate doctor, who treated him effectively, a school administrator who accepted the fact that he was, indeed, ill, and a school system that provided accommodations, to help him succeed.

Most of you know that Lyme disease is a multi-system illness. Someone with Lyme can have joint pains, heart problems, stomach problems, any kind of physical manifestation. I'd like to focus this evening on the neurological and neuropsychiatric problems, the ones that have the greatest effect on learning, and the ones that lead to the greatest misunderstandings between parents and school professionals.

Most common with children and adolescents who have chronic Lyme are intense headaches that can last for days, cognitive, attentional and mood problems, profound fatigue, and difficulty sleeping. Many kids have problems with vision, or visual and auditory overstimulation. Some have a sensitivity to fluorescent lighting.

Some of these symptoms may be very subtle, so it is difficult for the teachers to realize that they are dealing with a sick child, rather than a child who is daydreaming, or simply trying to avoid his school work.

Once a child has been diagnosed, and is undergoing treatment, there are problems produced by the treatment itself. High doses of antibiotics and other medications the child may be taking can produce gastrointestinal problems. The child may be uncomfortable, and complaining a lot, particularly of stomach aches. Since young children sometimes complain of stomach aches to avoid academic projects (I remember my stomach hurting in 3rd grade every time I had to speak

in front of the class), it's hard for teachers to discern whether the problem is avoidant behavior, or the result of illness.

Another problem, of course, is the flare of the symptoms when the Lyme spirochetes are being killed off by the antibiotics. A teacher who doesn't know much about Lyme disease has a difficult time realizing that with this illness, once the medication is started, the child will periodically feel worse, and have more, rather than fewer, symptoms. My sister-in-law used to say to me, during my Lyme treatment, when I told her how bad I felt - "Oh, that's right - worse is better", but that's a hard concept for people who are not personally affected by Lyme to grasp.

Other problems include the frequent need for medications (sometimes at school), the fatigue caused by the illness itself, or as a result of the lack of sleep, the demand on the child's time for long car trips to doctors who are Lyme specialists (some kids are even travelling to New Haven, CT, a 4 hour round trip).

Another big problem can be that these very sick kids *don't look sick*. The extent of the child's illness is not reflected in what the teacher sees.

Another, and very important, way to look at kids with chronic Lyme is to look past their symptoms at their functional impairments. It's the functional impairments that give us the language necessary to figure out what these kids need *in school*.

If you have a medical problem, you ask yourself and your doctor two questions:

1. What do I need to do to get better, to get well?

(This question addresses how to get your health back completely, or as completely as possible)

2. What do I need to do in the meantime, to compensate for my current functional impairments?

(This addresses what in school jargon amounts to "accommodations", enabling you to function on the best level you can, hopefully the need will only be short term.)

You break your leg. Before you broke your leg, you were able to walk, to drive, to go up and down stairs. You go to the doctor. He develops a treatment plan - puts a cast on your broken leg, tells you what not to do while it's healing. You get rides to work, maybe use a wheelchair at home, someone else in the house does the laundry, if the washer and dryer are on a different level. You have a long term plan and a short term plan. The long term plan is to get permanently better. The short term plan is for "accommodations."

If a child breaks her leg, the same process is put into place -- the doctor establishes the long term plan, by "treating" the broken leg. A note from the doctor, gives the child "accommodations" in

school as part of the short term plan, giving her an elevator pass, having someone carry her books, compensating for her "functional impairments."

What's different about Lyme? First, if Lyme is chronic, you probably don't know *when* you got sick. Your symptoms crept up on you, until you finally found a doctor who put the puzzle pieces together, diagnosed you, and began treatment. (You *know* when you broke your leg!)

When you got the Lyme diagnosis, a light bulb probably went off in your head. You remember when you were well. You had years of life experience of health, physical and mental. You know what your brain was like before your first symptom. You want to get back to that point, and that is your goal, restoring health and restoring functioning.

For a child, here is the profound complication - she had *little or no life experience before Lyme*. One of my clients is in 5th grade. Her doctor speculates that she's had Lyme since the age of 4. What do she and her parents know about her cognitive abilities, her attentional abilities, *before* Lyme touched her life?

This is the problem for so many kids. They have *no baseline*.

Having *no* memory of a tick bite or a rash, they really don't know when normalcy ended, and Lyme began. Or, even if they *do* remember, they were so young when they got bitten that there was no evidence of their ability to do schoolwork and to concentrate before the illness began. It's not clear to them how competent they would have been had they not gotten Lyme disease. It's a very puzzling picture for these children, and hard for them to be self-confident, in the face of this illness.

Now, let's look at some of the FUNCTIONAL IMPAIRMENTS in children and adolescents who have chronic Lyme disease?

One can see functional impairments at home, in school, and among the peer group. The child's physical problems, unpredictability of symptoms, and feelings of helplessness can lead, IN SOME KIDS, to a self-focused view of life, understandable given what these kids are trying to cope with.

I'd like to show you a slide that I used in a presentation at a Lyme Disease Association medical conference. It highlights what some of the functional impairments are, and points to how the school can help.

In this chart (*See Slide #1*) I give an example of some of the common impairments we see:

- Fatigue
- Problems Sleeping
- Lethargy
- Attentional problems, such as distractibility, impulsivity, problems focusing

- Depression or anxiety, including obsessional thinking or racing thoughts, "brain never stopping" (thinking constantly)
- Problems with eating (due to gastrointestinal symptoms, either from the Lyme itself, or secondary to the antibiotics.)
- Behavioral problems, severe at times
- In adolescent girls, by the way, PMS symptoms can be QUITE severe, as well.

Let's look at some of what the functional impairments might LEAD TO.

We can see the process here. The functional impairments that are the *original* problems produced by Lyme (and when I say Lyme, I include, of course, the co-infections) result in further problems for the child. (*see the second column*)

- Poor school attendance
- Chronic lateness
- Incomplete assignments and tests
- Behavioral problems at school
- Withdrawal from peers (particularly when peers fail to understand how sick the Lyme patient is)
- Situation-induced mood problems (aside from the mood problems coming from the infection itself)
- Weight gain or loss, at times, dramatic
- Mood swings, inappropriate verbal outbursts, increasing conflicts in all settings

(In general, kids and adolescents do not have a high degree of frustration tolerance. We all know that. Lyme disease severely challenges the child's already-limited resources)

What, then, might the child do to COMPENSATE for what is going on?
(these are what I call the "self-selected solutions")

All that I have discussed so far is *distressful* for the child. She may try to cope with all of this by doing any of the following:

- As school performance falls, and they're less involved with activities, Lyme patients might shift to a lower-functioning peer group, cut classes, and, in the extreme, they might drop out of school (if over 16), to avoid the frustration of dealing with academic demands
- For the kids with GI problems, they might severely limit their food intake, or begin gorging and purging

- Self-Medicating
 - For energy, or to self-treat the attentional problems, they might use stimulants or cocaine
 - To calm them down, or to keep them from thinking about all that is going on, alcohol, marijuana or other drugs might be chosen

I have seen all of the above in adolescents with chronic Lyme in my practice.

Any of the functional impairments can lead to any of the results, and to any or all of the self-selected solutions.

Functional impairments in school are often very significant, and call on the educators to develop creative plans to help the student with Lyme succeed. Without the support of the school, the best efforts of the parents might not be enough to keep a kid on track, in school, and successful!!

What THERAPEUTIC SOLUTIONS might we offer, to help deal with the FUNCTIONAL IMPAIRMENTS?

Please note that these solutions do NOT directly connect with any particular item in the previous column.

There are different categories of therapeutic solutions, but for now, I'd like to focus on what the school can do. They can make the difference between success and failure for a child with chronic Lyme.

We see several listed on this slide. I'll mention others later. They DO WORK, and most of them are not very costly for the district or the state:

For example,

- The length of the school day
- Time school day begins and ends
- Length of homework assignments
- Length and location of tests
- Physical education requirements
(as well as other accommodations)

I'll just mention briefly another important area where there can be therapeutic solutions, the home front:

Always keep in mind that when your child has chronic Lyme, he needs to be both SUPPORTED and ENCOURAGED. It's important that you base your expectations of him on how he is able to function, on a day to day basis, but you don't want him to feel like, or function like, an invalid. Have expectations of him, but keep them in line with where he is in his medical treatment, as well as whether he's having a good day or a bad day.

Some families need help dealing with children with Lyme, particularly if it effects their brain, and their school functioning. That is where psychotherapy and family therapy can be helpful. Therapy can serve an important role for kids and families with chronic Lyme, but it's important to find a therapist who is at least Lyme-open, if not Lyme-literate. The kid and the parents should be involved, in a combination of individual and family therapy. The therapy should be concrete, focusing on the problems.

Now lets look more specifically at school.

As I mentioned earlier, cognitive problems are common with kids with Lyme disease, as are attentional problems.

Kids with chronic Lyme might find it hard to retain new information. Lyme also can effect receptive and expressive language, visual-spatial processing, abstract reasoning, processing speed. Just as Lyme disease can effect any part of the body, it can effect any cognitive process.

These kids may appear to be distracted easily, have poor concentration, appear scattered, have just about any symptom of attention deficit disorder. Or if the child had ADD *before* she got Lyme, her ADD symptoms are often exaggerated by the illness.

These symptoms might be intermittent and transitory, given the nature of Lyme disease, making it even more difficult to develop an education plan. When I speak to teachers' groups, I tell them that when they have a child with chronic neurological Lyme in their class, the child may appear learning disabled one day, seem normal the next. She may act like she's got ADD on another day, and may appear withdrawn and fatigued the next. It's a real challenge for the classroom teacher!

So what can be done to educate these children?

First lets look at the issue of free and equal public education, a wonderful and radical gift our democracy has given us.

Free and equal public education gives all children a right to an education in this country, this state, this county. The law protects the disabled through *entitlements*, to level the playing field, so that they can benefit from an education, just as those who are not disabled can. There are state and federal bodies of law that provide for those entitlements, and they are available to all those who are disabled. They are not granted at the *discretion* of *anyone* - the teacher, administrator, school superintendent!!

Some of these benefits are costly. There is always a push on the part of those responsible for balancing budgets to protect our tax dollars. There is always controversy regarding which programs should be prioritized. The result is that not all entitlements are easily gotten by those entitled to services. But parents of kids who are seriously ill with Lyme disease need to know that these entitlements exist, and that it is **YOUR CHILD'S RIGHT TO HAVE ACCOMMODATIONS, AS LONG AS THERE IS EVIDENCE THAT THEY ARE NECESSARY.**

I'd like to discuss three stages of supports the schools can provide. Most children will only need the first stage, and when a school is cooperative, coming from an understanding that these children are indeed ill, and that the school can be a partner in their recovery, the first stage might be all that is needed.

The first stage is "Informal Educational Supports." These are supports that can be given to children without any formal plans, without classification, without formal meetings.

A school administrator, for example, knowledgeable about the child's illness, and the resulting impairments, might carefully select a classroom teacher or teachers that can develop flexible schedules for a child, permanently excusing a percentage of the required homework, giving extra time for testing, seating a distractible child near the source of instruction. These teachers give support and encouragement, without blaming the child for erratic performance.

Depending on their teaching styles, some teachers have an easier time providing this flexibility than others, and if the administrator realizes this, and appropriately matches the child's unique needs to the particular teacher, problems can be avoided from the beginning. Late assignments can be accepted, without penalty, misspelling on tests that are not spelling tests can be excused.

There is no battle ground here between the school and the parents. All are partners in providing this child with the education she deserves, and there is little if any cost to the school district, or to the state.

There are two reasons why informal accommodations don't always work.

The first is that the school refuses to believe that this child, who looks healthy, or is laughing with his friends in the hall, is in fact sick. Parents should certainly be prepared with documentation, to back their assertion that their child has an illness that effects her learning - clear detailed letter from the treating doctor, neuropsychological evaluation, even brain SPECT scan, if there is one. The child has a right to an education, but the school has a right to the evidence that a medical problem that effects learning DOES exist.

The second reason that informal supports might not work is that the child needs more than can be provided without a formal plan. If this is the case, a 504 committee needs to be convened, and a 504 plan is put into place.

Section 504 is Federal civil rights legislation. Under it, a child with a disability has a right to accommodation to compensate for the disability. And, as I said earlier, it *is* an entitlement.

By law, a letter from the treating physician should be all that is needed in order to convene a 504 meeting, and develop a 504 plan. This is the easier of the two types of accommodations to put into place, and usually leads to a quicker meeting, therefore accommodations begin more quickly.

If the 504 does not seem to be working, if it does not provide for adequate accommodations, then a parent can request the Committee on Special Education to meet. A child with a health problem qualifies to be classified *Other Health Impaired*, an IEP (the plan for the child), is put into place, and supports are written into the plan. Supports available with an IEP that are not usually available under 504 include Resource Room, regular counseling for the child with a the school social worker, and school psychological evaluation every three years, as long as the child remains classified.

Here are some of the accommodations that might be put into place, and how I've seen children helped by these accommodations. Some may require that a neuropsychological evaluation document the particular learning problem that leads to the need for the accommodation.

- Unlimited time for testing - a child is afforded extended time to take tests. Some children with Lyme have problems with the speed of processing information. These children get exceedingly anxious, trying to take a timed test. This accommodation removes the anxiety, literally gives them enough time to think.
- Separate testing location - this is appropriate for children who have problems with focusing and concentration, and are easily distracted. There are fewer children taking the test, in a quiet location.
- Tests read to student - this is for students who have particular verbal learning problems, in which their auditory learning is less impaired than their visual learning.
- Excused from a percentage of their homework. Children with profound fatigue, who have a difficult time just getting through the school day, benefit greatly from having less work to do at home.

Keep in mind that *more* school work is not necessarily *better*. If a child is fatigued and has problems with memory and organization, of what use is hours worth of homework, at the end of the school day, or on the weekend? Of what benefit is increasing the child's anxiety by requiring that he/she perform equal to the children who are well? Are they really being treated equally, if the child who is well can do the work in 1/4 to 1/2 the time as the child who is ill? Shouldn't the sick child have at least an equal right to down time, time to relax, and recover, to face the next learning challenge?

There are long lists of accommodations, designed to fit the needs of disabled children. Those with chronic Lyme, where documentation supports the problems and the need, are entitled to

these accommodations. Those who say it gives these kids an edge, rather than levelling the playing field, have never known someone with chronic Lyme. I suggest to those people that if these accommodations provide an edge for these kids, then so do hearing aids and eyeglasses. Ask everyone with those disabilities to do their work without those particular accommodations, as well!!!

One more thing - you parents have a very important job in this process with the school - advocating for your child.

Meetings with the school professionals can be very intimidating. They've got formats to follow, protocols, guidelines required by law to follow, for the very design of the meeting. They are used to these meetings. You are NOT - often leading to a very uncomfortable situation for parents.

Go into the meeting prepared. Take your documentation, know what your child's needs are, and DON'T GIVE UP!! If you don't get support from the school the first time around, find a support group for parents of classified kids, attend meetings, network with parents who have been dealing with their children's schools for years. They have an expertise in education law, and they are very willing to help you. Someone from the group may even be willing to attend the meeting with you. You are entitled to bring anyone you wish. Take advantage of it.

It's not always an easy path, but you already know that about Lyme disease. It's unfortunate that yet another part of the environment can be so difficult to negotiate for families with Lyme, but for right now, until there is a greater understanding of Lyme in the education community, that's the way it is. So just remain in your child's corner, and don't give up!!