

Neuropsychological Evaluation & Treatment Services, P.C.

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THE ROLE OF NEUROPSYCHOLOGICAL TESTING IN CHILDREN WITH LYME DISEASE

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The cognitive problems associated with Lyme disease and other tick-borne illnesses include difficulty with: 1) attention and concentration, 2) speed and efficiency of processing information, 3) learning and memory, 4) auditory processing and language expression, 5) planning and organization and 6) multitasking. These cognitive symptoms have a significant impact on learning and school performance.

Children with Lyme disease may have difficulty sustaining attention in the classroom, answering when called on by the teacher, completing home work assignments and taking tests. The result is that children with Lyme disease frequently get poor grades and consistently perform below their innate intellectual ability. Our recent research has shown that mathematics and reading scores of children with Lyme disease are often significantly lower than their verbal and non-verbal intellectual abilities.

Cognitive weaknesses have a direct impact on a child's self-confidence and self-esteem and put children at risk for maladaptive behaviors and disruptions in peer and family relationships. It is, therefore, essential to identify the cognitive symptoms experienced by the child and to initiate appropriate interventions, such as cognitive remediation, and provide academic accommodations to address these problems.

The purpose of the neuropsychological testing is to assess cognitive functioning and to understand how existing cognitive weaknesses impact the child's ability to manage demands of everyday academic, family and interpersonal life.

A child should be referred for a neuropsychological evaluation to assess cognitive functioning and to make education and treatment recommendations as soon as a Lyme/TBD diagnosis is made. Having this information early in the process allows parents, teachers and medical specialists to better understand a child's cognitive strengths and weaknesses. The knowledge derived from the evaluation often verifies or enhances information about the child's developmental, cognitive and behavioral functioning and allows medical treaters, teachers and parents to make the necessary changes to maximize the child's academic, emotional and interpersonal functioning.

The neuropsychological or neurocognitive evaluation is conducted by a licensed psychologist who has specialized training in neuroanatomy and brain-behavior relationships. This person is referred to as a neuropsychologist. Due to the complex nature of Lyme disease it is also important the child be evaluated by a neuropsychologist with a specialty in tick-borne illnesses.

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Pre-evaluation steps include completion of a history form by the child's parents or legal guardians and review of medical and academic records and previous evaluations.

The first evaluation session begins with an in-depth clinical interview with parents and child. Consideration of family factors and interactions is important to understand how the family system is impacted by Lyme disease. Following the clinical interview, testing is initiated. The testing schedule will vary according to child's medical condition, medication regimen, and energy level. For children with Lyme disease it is best to perform the evaluation over several days as they typically do not have the stamina to sustain more than a few hours of testing at any one time. To maximize a child's performance during the testing, it is important to monitor fluctuations in attention and concentration, and physical and mental stamina and provide refresher breaks whenever necessary. Generally, neuropsychological testing takes eight to twelve hours divided over two to three sessions. An additional ten to fifteen hours of the neuropsychologist's time will be required to analyze the test data, prepare the final report and conduct the feedback session.

The neuropsychological evaluation consists of a battery of standardized, age-normed tests that allow for the comparison of a child's test performance with that of other children in his/her age group. It also provides for a profile of a child's strengths and weakness across a variety of skill domains. Those domains include:

- Verbal and Non-verbal Intellectual/Conceptual Abilities
- Visual Discrimination
- Visual-Spatial Skills
- Visual-Motor Skills
- Graphomotor Skills
- Fine Motor Skills
- Sensori-Motor Skills
- Attention and Concentration
- Information Processing Speed
- Auditory Processing
- Language/Oral/Written Communications Skills
- Memory
- Academic Skills
- Higher Level/Conceptual Reasoning
- Executive Abilities (problem solving, planning, organizing and prioritizing)
- Emotional State/Traits
- Behaviors

Scores on tests across these domains allow for the comparison of the child's performance relative to his/her innate intellectual ability as well as to same age peers. The profile of relative strengths and weaknesses can be used by the neuropsychologist to determine the appropriate interventions that will maximize the child's functioning. Recommended interventions are, for example: breaking tasks into smaller parts to make tasks more manageable, developing step-by step plans for organization of tasks, working on tasks at a slower pace to improve accuracy, extending task time limits, developing multi-modal and hands-on learning tasks, employing repetition to improve recall and using cues to increase recognition of learned information. Such interventions and strategies will maximize a child's ability to utilize his/her innate intellectual skills and experience success.

At the end of the final testing session, a one-hour feedback session is conducted to provide preliminary findings and initial impressions about the child's strengths and weaknesses and to answer any immediate questions. Upon the completion of the report, a feedback session is conducted with the parents and the child. Parents are also encouraged to invite whomever else they wish to participate in the session. At this session, the neuropsychologist reviews the child's cognitive strengths and weaknesses and discusses how they may impact the child's life. Areas addressed include academic, social, emotional, family and interpersonal relationships and extracurricular activities. Recommended treatments and strategies are discussed to utilize areas of preserved strength and to ameliorate the areas of documented difficulty or discord.

Treatment typically involves several modalities:

- Cognitive Remediation: A treatment intervention that was originally designed for individuals who had sustained a brain injury and is now widely used for individuals who are affected by any neurological impairment, attention deficit disorder or other illness compromising cognitive functioning. This therapy helps the child cope with his/her cognitive deficits by learning compensatory strategies to improve functioning. These strategies allow the child to maximize innate intellectual skills and to help restore self-confidence and self-esteem. Cognitive remediation is provided by an experienced psychologist trained in neuropsychology and one who understands the interaction between brain function and the behavioral aspects of everyday life.
- Individual Psychotherapy: Most often, the treatment plan will also include psychotherapy to help the child process the significant losses experienced as a result of the devastating effects of Lyme disease (reduced attendance at school, reduced interaction with friends and classmates, reduced ability to engage in sports or hobbies, depression, mood changes, emotional rages, and anxiety).
- Family Therapy: Lyme disease affects multiple systems of the body. Just as each system in the body responds to the infection, so too the family system responds to the disruptions in spousal, parental and sibling roles. Lyme disease disrupts all aspects of a child's life and compromises interpersonal relationships. It is therefore critical that the child and the family come together in a common understanding of the nature of the disease and what each member of the family can do separately and collectively as part of the family system to support the child. The child's decline in personal functioning is impacted by the frustrations and burdens that the illness places on those s/he needs most for support. The findings of the neuropsychological evaluation can be used to help educate those individuals actively involved in the child's life. This will help them better understand the nature and complexity of the deficits and how they can best interact with the child so that stress on the external systems can be reduced and more positive academic and interpersonal roles can be reconstructed. Furthermore, as is often the case, more than one family member may be suffering from Lyme disease. This makes family therapy all the more critical to help restore a sense of well-being in the life of the family.
- Education of School Officials and Academic Accommodations: Children with Lyme have difficulty functioning consistently in their daily life. Reductions in their level of physical and mental energy require that they revise and reduce the demands of their participation in activities at school, in sports and with family and friends. Academic

accommodations must be put in place to assist them in their functioning at school. These accommodations may include: reduction in their academic schedule, home tutoring, reduced subject assignments, provision for extended school absence, limits on school hours, extension of time limits for school tasks and tests, and allowance for reduced participation in physical education, individual and team sports and other extracurricular activities. Teachers and other school officials need to be aware of the undulating nature of Lyme disease. A child may appear to be functioning well one day or for part of the day and then may be so debilitated by a sudden onset of Lyme symptoms that s/he will have to go to the nurse's office or leave school. Repeated tardiness and/or absences must be expected and allowed.

The neuropsychologist often serves as an advocate for the child when dealing with school systems and teachers. At the request of parents or school officials a neuropsychologist can serve as a consultant to participate at on-site school meetings or be available by conference call to discuss in depth the child's strengths and weaknesses and assist in formulating and implementing academic accommodations. The Lyme literate neuropsychologist can also serve as a consultant to school systems to design and implement academic and environmental accommodations to support the needs of students with Lyme disease. This most often involves design and implementation of 504 and Individual Educational Plans (IEP) to conform to federal and state statutes.

- Education of Medical and Mental Health Specialists: Some medical and mental health professionals may not be aware of the neurocognitive and neurobehavioral problems of a child with Lyme disease. They may inadvertently or incorrectly ascribe the child reduced functioning solely to an emotional problem thus, doing a disservice to the child. A thorough neuropsychological report can assist medical and mental health professionals to understand the organic basis of the child's difficulties as well as to provide assistance in addressing the child's needs. Often children with Lyme disease will require specialized audiological and/or vision tests to more acutely diagnose sensory reductions often seen on the neuropsychological evaluation. Identification of these sensory changes associated with Lyme disease is critical in maximizing academic performance.
- Re-Evaluation: A one-year neuropsychological re-evaluation is commonly recommended to assess treatment effectiveness, the status of the child's neuropsychological strengths and weaknesses and to make revisions in the treatment plan based on the tests results.

Summary: The value of the neuropsychological evaluation is that it provides the necessary information that can lead to improvement in academic performance, participation in sports and recreational activities, social and family relationships, mood and behavior and increased self-confidence and self-esteem.