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## **THE ROLE OF NEUROPSYCHOLOGICAL TESTING IN CHILDREN WITH LYME DISEASE**

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The neuropsychological problems commonly associated with Lyme disease and other tick-borne illnesses have a significant impact on learning and academic achievement. These problems may include difficulty with: 1) attention and concentration, 2) speed of information processing, 3) visual discrimination, 4) visual-spatial analysis, 5) memory, 6) auditory processing and language expression, 7) planning and organization, 8) multitasking, 9) mood regulation and 10) behavioral control.

As a result of these problems, children with Lyme disease often have school-related difficulties and frequently perform below their innate intellectual ability. They may have difficulty sustaining attention, answering when called on in class, completing homework assignments and working within time constraints. In addition, because of frequent absences, they miss important learning and social opportunities. Our recent research has shown, for example, that mathematics and reading scores of children with Lyme disease are often significantly lower than their innate intellectual abilities.

Similarly, these problems have a direct impact on self-confidence and self-esteem and put children with Lyme disease at risk for disruptions in peer and family relationships. It is, therefore, essential to identify existing neuropsychological problems and to initiate appropriate interventions, such as cognitive remediation, and to provide academic accommodations.

A neuropsychological evaluation delineates a pattern of existing strengths and weaknesses in cognitive, emotional and behavioral functioning. This information will clarify how strengths and weaknesses impact a child's ability to manage demands of academic, family and interpersonal life. Furthermore, cognitive weaknesses have a direct impact on self-confidence and self-esteem and can put a child at risk for maladaptive behaviors and for disruptions in peer and family relationships.

The neuropsychological evaluation is conducted by a neuropsychologist, a licensed psychologist trained in neuroanatomy and brain-behavior relationships. Due to the complex nature of Lyme disease it is preferable that the child be evaluated by a neuropsychologist with a specialty in tick-borne illnesses.

A child should be referred to a Lyme literate neuropsychologist to assess cognitive and behavioral functioning as soon as a Lyme/tick-borne disease (TBD) diagnosis is made. Documentation of a child's cognitive strengths and weaknesses and clarification of emotional and behavioral functioning is essential in making educational and treatment recommendations. This information allows medical and school personnel and family to initiate interventions and make the necessary changes to maximize the child's academic, emotional and interpersonal functioning.

Pre-evaluation steps include completion of a history form by the child's parents or legal guardians and review of provided medical and academic records and previous evaluations. The first evaluation session begins with an in-depth clinical interview with parents/guardians and the child. Consideration of family factors and interactions is important to understand the impact of Lyme disease on the family. Following the clinical interview, testing is initiated. Testing usually takes eight to twelve hours divided into three to four testing sessions over several days.

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The length of the testing sessions varies according to a child's stamina and ability to concentrate. To maximize performance, it is important to monitor fluctuations in attention and concentration and physical and mental stamina and provide refresher breaks whenever necessary. 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 report consists of a review of medical, educational and family history, an extensive discussion of tests results, recommendations for treatment and evaluations by other specialists and academic accommodations. For example, a child may require an audiological or neuro-optometric evaluation to assess sensory reductions. Identification of these sensory changes associated with Lyme disease is critical in maximizing functional performance.

The neuropsychological evaluation consists of a battery of standardized, age-normed tests that provide a profile of a child's strengths and weakness across a variety of skill domains. Those domains include:

1. Verbal and non-verbal conceptual and reasoning abilities
2. Visual discrimination
3. Visual-spatial skills
4. Visual-motor skills
5. Graphomotor skills
6. Fine motor skills
7. Sensori-motor skills
8. Attention and concentration
9. Memory
10. Information processing speed
11. Auditory processing
12. Oral and written communications skills
13. Academic skills
14. Executive abilities (problem solving, planning, organizing and prioritizing)
15. Emotional factors
16. Behavioral factors
17. Interpersonal and Family factors

The profile of relative strengths and weaknesses can be used by the neuropsychologist to determine the appropriate functional and academic accommodations that will maximize daily performance. Recommended accommodations are, for example:

1. Breaking tasks into smaller parts to make tasks more manageable.
2. Developing step-by step plans for organization of tasks.
3. Working on tasks at a slower pace to improve accuracy
4. Extending time limits for assignments and tests.
5. Developing multi-modal and hands-on learning tasks.
6. Employing repetition to improve recall.
7. Using cues to increase recognition of learned information.
8. Open book tests.
9. Supplementing chalkboard and lecture information with printed handouts.
10. Calling on a child in class only when his/her hand is raised.

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 completion of the report, a final feedback session is conducted with the parents/guardians, the child and any other individuals the parents wish to invite. 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 interventions, additional evaluations and compensatory strategies are discussed.

#### Treatment Modalities:

1. Cognitive Remediation: Cognitive Remediation is recommended for individuals who are affected by any neurological impairment, attention deficit disorder or illness compromising cognitive functioning. This intervention is designed to help develop strategies to compensate for neurocognitive weaknesses with the goal of functional improvement. Such 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 with expertise in the relationship between brain function and behavior in everyday life.

2. Individual Psychotherapy: Psychotherapy is often recommended to help the child process the significant losses experienced as a result of the devastating effects of chronic Lyme disease. The medical problems associated with Lyme disease often necessitate school absence, reduced interaction with peers, loss of friends and reduced ability to engage in sports, hobbies and extracurricular activities. As a result, a child with Lyme disease may feel isolated and alone. In addition, psychotherapy may be necessary to address depression, anxiety, mood changes and emotional rages that are often seen in children with Lyme disease.
3. Family Therapy: The stress of Lyme disease disrupts many aspects of a child's life and compromises interpersonal relationships. Disruptions in family relationships are common as individual family members attempt to address the demands of the disease. Family therapy can be helpful to address differing perspectives and to understand the impact of Lyme disease on family life. Moreover, the functional decline exacerbates the frustrations and burdens on family members. As is often the case, more than one family member may be suffering from Lyme disease and this adds additional stress to the already overburdened family structure. This makes family therapy all the more critical to help restore a sense of well-being in family life and to develop a sense of resilience in the face of challenging circumstances.
4. Consultation with School Officials and Academic Accommodations: Children with Lyme disease 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 at school, in extracurricular activities and in activities with family and friends. Teachers and 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 an onset of Lyme symptoms that he/she will have to go to the nurse's office or leave school. Repeated tardiness and/or absences must be expected and allowed. Academic accommodations must be provided to maximize school performance. These accommodations may include, for example:
  - Reduction in academic schedule.
  - Home tutoring.
  - Reduced subject assignments.
  - Provision for extended school absence.
  - Limits on school hours.
  - Extension of time limits for assignments and tests.
  - Allowance for reduced participation in physical education, sports and other extracurricular activities.

The Lyme literate neuropsychologist often serves as an advocate for the child. At the request of parents or school officials the neuropsychologist can serve as a consultant to participate in on-site school meetings or be available by conference call to discuss the neuropsychological evaluation and assist in formulating and implementing academic accommodations. This most often involves design and implementation of a 504-plan and/or an Individual Educational Plan (IEP) in accordance with federal and state statutes. The Lyme literate neuropsychologist can also serve as a consultant to school systems to help develop accommodations to support the needs of students with Lyme disease.

5. Consultation With Medical and Mental Health Specialists: The Lyme literate neuropsychologist can assist medical and mental health professionals in understanding the neurocognitive, neurobehavioral and emotional manifestations of Lyme disease and provide assistance in addressing individual and family needs.
6. Re-Evaluation: A one-year neuropsychological re-evaluation is commonly recommended to assess treatment effectiveness, changes in neuropsychological strengths and weaknesses and to make any necessary revisions in the treatment plan.

Summary: The neuropsychological evaluation provides the foundation for a program of interventions and accommodations that can lead to improvement in cognitive, behavioral and emotional functioning. These improvements can enhance academic achievement and contribute to more satisfying family and social relationships and increased self-confidence and self-esteem.