

A Multidisciplinary Approach to the Care of a Child with Multiple Sclerosis

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Pediatric MS is more common in the present day

About 5 - 10% of MS patients are diagnosed before the age of 18 (mean age: 11-14 years) Approximately 90-95% of children are determined to have a relapsing-remitting course



MS doesn't just affect the body. When a child or teenager has the disease, it can influence every aspect of their life:

Academic Performance: ❖ Coordination for IEP or 504 Plan with school Extended test taking time Delayed memory recall skills May miss a significant amount of school due to relapse and/or treatments Self Image: Chronic diagnosis Injection sites * Responsibility of medication management * Responsibility of symptom management * Transition of care to adult Neurology Injection anxiety **Pediatric Neurologists**

Neuropsychologist

- Performs specialized cognitive testing to determine a patient's cognitive profile.
- Provides recommendations for school and home accommodations to maintain or improve current cognitive abilities to succeed in independent life skills.

Nurse Practitioner

- * Provides primary, in-person, disease-specific education at time of diagnosis.
- * Educates patients and families about MS prophylactic medications, including goals of treatment, technical aspects of injections, and side effects.

Study Coordinator

- Notifies patients and families of the database and specimen projects.
- ❖ Obtains informed consent from willing participants. Assists Dr. Gorman in the collection of clinical research information (i.e. patient identification, chart review, questionnaire completion).
- Enters data into the databases.

Psychologist

- ❖ Meets with patients for a comprehensive psychological evaluation including an examination of risk and resilience factors for adaptively coping with the
- ❖ When a patient/family appears to be struggling, will assist in finding them appropriate follow-up psychological support either at Boston Children's Hospital or in their community.

Family and Peer Relationships:

- Social activities missed due to relapse
- * Residual symptoms may make keeping up with peers difficult, both socially and cognitively
- * Frequent injections, working into social activities to continue feeling included
- · Residual symptoms from initial presentation and/or relapses
- Feels as though unable to keep up with peers and participate in social events
- ❖ Feels different than peers due to increased responsibilities that accompany diagnosis

Specialty training in Pediatric Neurology and

Pediatric Multiple Sclerosis

At

Boston Children's Hospital we approach these challenges with a **Pediatric Multidisciplinary Team**

Education Specialist

Works with families and schools to translate Neuropsychology test results into specific educational accommodations (IEP's/504 Plans).

Social Work

- . Helps to connect patients and families with hospital and community
- Provides support and guidance with insurance plans
- ❖ Assists patients and families with transition to adult care providers.

Primary Nurse

- ❖ Assesses patient with family then collaborates with team to develop a plan of care to reach optimal goals.
- Educates patients and families on topics such as disease, medications, recurring symptoms, and follow up plans.
- ❖ Coordinates care for acute attacks and prophylactic treatment in a home care setting to prevent patient from requiring inpatient hospitalization.

Resource Specialist

- * Works with and instructs teenage patients who have been diagnosed with MS for more than 1 year, along with a parent.
- Serves as a peer contact for newly diagnosed patients and their parents, thus providing a unique patient and family perspective.

Until every child is well"