

What is it?

A Paediatric Neuromuscular Clinic is a specialty service for children with neuromuscular disorders, and their families. Assessments, education, training of care providers, recommendations for equipment, treatment options, school adaptations etc. are available and individualized according to the needs of each child.

Which professionals are involved in the visit?

The Paediatric Team is usually an interdisciplinary group of professionals with a wide range of experience. Staff members may evaluate the child alone, or together with other therapists. The professions on the team who may see the children are: physiotherapist, occupational therapist, speech pathologist, physiatrist (medical doctor with a specialty in physical medicine and rehabilitation), clinical dietitian, and psychologist and education consultant. A rehabilitation assistant or clinic coordinator may also be involved in the appointment; she/he is the one who coordinates the clinic appointments with parents ahead of time.

A representative/volunteer from Muscular Dystrophy Canada may also be present during the clinic appointments. This person is available to meet with families, and is an invaluable source of information, as they are familiar with the challenges faced by people with neuromuscular disorders and their families. They may also provide linkages to MDC Chapters and families in the community who have similar situations to allow them to connect with each other and share in experiences.

How long does a clinic visit take?

The clinic visit may last for an hour or two, or it might take the full day. This depends on the therapists that the child needs to see, and upon the specific type of appointment needed. If the child needs to rest during the day, staff will usually be able to find a suitable room for this purpose. Families should plan on being at the clinic for at least half of the day in most instances. Special needs for meals or transportation should be communicated prior to the visit.

How often will a child need to participate in a clinic appointment?

Children with neuromuscular disorders should be evaluated at least once per year. It might be more frequent depending on the condition and which other professionals are involved in caring for the child. By having a full clinic review with a selection of team members on a yearly basis, it is hoped that problems may be detected early, and perhaps prevented from worsening by modifying equipment, positioning, nutritional supplementation, etc. Optimum health with a neuromuscular condition is our goal for the child.

What can we do to prepare the child for the clinic visit?

Children should be told that several different people will see them. They will ask the child to play, or show them how they do normal functions in their daily life. There will be questions for the parent/caregiver and the child to answer, and perhaps a private interview with parents or caregivers. Most of the evaluation is by examination and observation, and is not considered to be invasive. The most important point to tell the child is that the staff is there to help him/her be the best they can be at home, school, and in the community.

What can we expect after the visit is completed?

Usually there is a "wrap-up" meeting with all professionals and caregivers involved with the child. Recommendations for maximizing strengths and overcoming or minimizing weaknesses will be discussed, and families will have an opportunity to ask questions of the various team members.

Then, in a few weeks parents will receive a report, which describes the evaluation done by each professional as well as the recommendations made and any further action that is needed. Copies of this report will be sent to the child's family doctor or paediatrician, to the school, to your community therapists, etc. with your permission. In this way, the people who are involved with the child on a regular basis will be able to read the suggestions and contact the clinic if there are any questions.

Who can answer my questions?

Contact us at:

Muscular Dystrophy Canada - Services
Western Canada office - 1-800-366-8166
Quebec office- 1-800-567-2236

Ontario & NU office - 1-800-567-2873
Atlantic office - 1-888-647-6322