

# Managing School-Related Issues: A Guide for Parents with a Child or Teen with MS



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## **COVER PHOTOGRAPHY**

Paul Pinsler

*Hand in Hand*

Paul has been taking photographs since he was sixteen years old, starting with a Kodak box camera. When Paul became really serious about his photography he took several photography courses and began to shoot as a freelancer doing both commercial and party work. Paul joined a camera club where the competition and critiquing from the more experienced and published members really helped to develop his skills and photography both from the technical as well as artistic perspective.

Paul's merchandising and marketing business positions allowed him to travel the world and his equipment traveled with him. Paul was fortunate to be able to visit many countries in Europe and Asia as well as major portions of Canada and the United States, photographing when time allowed.

About 15 years ago Paul was diagnosed with multiple sclerosis. Although Paul says he has slowed down a little, his passion for photography continues. Even though he has MS, his friends tell him that he is a "glass half full" person and the poem on Paul's website expresses his outlook for photography and life.

Paul donates fifty per cent of the proceeds made from the sale of his photography to the MS Society of Canada.

To see more of Paul's work, please visit his website at  
**[www.theperfectpicturesite.com](http://www.theperfectpicturesite.com)**

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## Foreword

Parents of children with MS often report feeling frustrated, overwhelmed or even helpless about how to help their children. The task of gathering appropriate information to prepare parents to help their children cope and advocate for them at school seems to be a daunting task. The goal of this handbook is to provide you with tips on parenting a child living with MS and offer tools and resources for you to be your child's best advocate. You will learn more about how your child's MS may impact his/her school life, as well as proactive strategies that you and your child can use to manage MS.

## SECTION 1 Advocating for your Child

### Parenting a Child with MS

What is the true definition or "job description" of a parent? We know that parents are legally responsible for their children until they are 18 years old, but what does that mean? How much "common sense" is involved in parenting and how much is learned? When we think of parenting, we think of meeting a child's basic needs first: food, shelter, clothing and safety. Unfortunately, for parents with children who have a chronic illness, even meeting basic needs can be challenging at times. Having a child with a chronic illness can present certain obstacles for children and parents.

Parents are generally aware of their child's needs and stressors. A good approach for parents is not to always try to solve the child's problems, but provide empathy and tools to help their child along the way. Parents are not perfect; they are aware of their own emotions and problems, and how their own emotional state may adversely impact their relationship with a child. This kind of awareness is achieved by having a strong support network of people and appropriate resources. Good communication with your child is essential. Connecting with your child requires a continuous open dialogue about how your child is doing. However, good communication also means accurate communication.

It is easy to rely on "small talk" within the family, using the shortest dialogue possible, especially with adolescents. You may choose to speak with your child on a regular basis or wait for "the right time" to broach a delicate subject. Whatever you choose, it is important to ask your child what is the preferred way to communicate, and always keep in mind your child's developmental capacity and what is age appropriate.

It is important to establish a trusting relationship so your child does not fear approaching you with problems. Your child must feel safe to bring up difficult topics without fear, guilt, or shame.

It is also important for you to know that you are not alone. *Children and Teens with MS: A Network for Families* is a support network that provides multiple program options for families living with a child or teen who has been diagnosed with multiple sclerosis. This program is a collaboration between the MS Society of Canada and the National MS Society (NMSS) in the United States.

You can contact the MS Society at [kidswithms@mssociety.ca](mailto:kidswithms@mssociety.ca), or by calling **1-866-922-6065** or contact the NMSS at [childhoodms@nmss.org](mailto:childhoodms@nmss.org), or calling **1-800-344-4867**.

## **You as Your Child's Advocate: Navigating Your Child's School Life**

You now also have the job of helping your child's school to understand and respond to your child's needs. It is helpful to keep in mind that teachers and administrators, like most other people, will have an easier time recognizing and responding to symptoms they can easily see and understand (e.g., walking difficulties, balance problems or tremor) as compared with less obvious symptoms like fatigue, cognitive changes or bladder/bowel concerns. The more you understand the symptoms your child is experiencing, the better prepared you will be to help others understand them. Also, do not hesitate to ask your health care team to provide suggestions for interacting with your child's school.

It is important to remember that each child may deal with MS symptoms differently. In order to get a full appreciation of your child's MS, consider your child's lifestyle before illness.

- What has changed?
- How much has changed?
- What does "change" mean to you, your child, and your family?
- How big of an issue are the new stressors?

## **Stressors Related to Chronic Illness<sup>1</sup>**

- What the illness/diagnosis means to the child/adolescent and family
- Diagnostic and treatment procedures
- Impact of ongoing symptoms on day-to-day activities
- Change in physical appearance
- Compliance with the demands of treatment
- Interrupted schooling
- Difficulty planning family outings and holidays
- Financial burden
- Sibling stress

## SECTION 2

### Child Development – Ages and Stages

#### Aspects of Chronic Illness by Developmental Stage

As a parent, it is important to evaluate and understand your child's developmental stages including issues that may arise during each stage. This information will help your own understanding of how MS can affect your child's development and will also be helpful when you must explain to others how MS has impacted your child's life.

Keep in mind that in addition to dealing with MS, developmental issues have a large influence in your child's life. These issues affect how your child may think and feel about socialization, peer acceptance and self-esteem. Developmental issues may also affect how your child understands MS and how s/he deals with treatments. S/he may want to fit in and not appear different, or may be worried about what peers think. Therefore, your child may choose not to let peers know s/he has MS or may be resistant to using a mobility device such as a cane, wheelchair or scooter.

The following is an overview of the various stages of child development and the potential impact of MS.

#### Young Children: 3-5 years old

Multiple sclerosis in children can significantly impact a young child's development, personality, or self-image. This is a complex stage, because it is such an early stage in development. Even minor life events can alter the developmental trajectory. At this stage, your role is to provide encouragement and reassurance as your child explores the world, while also setting limits, and providing guidance.<sup>2</sup> It may be difficult for parents to stick to their parental role of discipline and balance it with nurturing their child. It is also challenging to balance protecting a child and letting a child be a child, allowing them to experience a "normal" childhood. These issues exist in all stages of development.

When a child is newly diagnosed at this stage, it is common for parents to struggle with setting limits and boundaries due to the desire to comfort and nurture the child. And while extra nurturing to help your child feel safe and secure is natural and essential, setting boundaries is equally important. Boundaries also allow your child to feel safe and secure, while preserving the parental role (caring for the best interests of your child). Parents need to demonstrate that things are still under control, that the family structure still exists, and that when the child feels good, s/he can do what other children do. Young children take cues from their parents when learning how to cope with changes. If parents are anxious, often children will be too.

Some suggestions to help your child develop adaptive coping strategies include:

- ➔ Share information appropriate to their level of understanding.
- ➔ Answer questions matter-of-factly without giving more information than they can absorb.
- ➔ Be alert for changes in behaviour that may signal your child is feeling stress.

## School-aged Children: 6-10 years old

School-aged children begin to seek independence from their parents—while at the same time, still depend on them. They are getting ready to be more independent and become individuals; yet they are unsure and will at times act immature, in other words, act “like a baby.” This can be a clue to parents about their child’s level of confidence. At times, they may also need re-direction.

Some suggestions to help a school-aged child cope with their illness include:

- ➔ Listen carefully to what they say – or do not say – and look for ways to encourage talking about what is on their mind. Talking about their worries is a way of reducing fear and helping children feel that you understand them.
- ➔ Reassure that your child’s feelings are normal.
- ➔ Provide direction to foster healthy development.

### For example:

“I see that you’re very interested in doing \_\_\_\_\_. I think you might also like doing \_\_\_\_\_ as well.”

Dealing with a chronic illness is confusing for children in this age group because the natural developmental instinct is to graduate toward independence. Children with MS in this age group are sometimes in situations where they need to be more dependent on their parents, which conflicts with their natural drive to seek independence.

## Adolescents

Early adolescence: 10-13 years old

Mid adolescence: 14-17 year old

Late adolescence: 18-20 years old

In this stage, adolescents are becoming individuals. There is a natural drive to be independent (which can be scary in itself), and facing MS can increase anxiety. A critical component of this stage is the involvement in their own medical care and treatments. This is a component of independence that is important to encourage and support.

In addition, treatment regimens (like giving injections) can conflict with normal developmental challenges such as body image issues. Teens tend to be focused on physical changes occurring in their bodies. They may have fears related to MS and may have concerns, e.g. injection site reactions will be visible and result in embarrassment among their peers. Beginning a **transition plan** would make this stage less mysterious and would be beneficial to both adolescents and parents.

Some suggestions to help adolescents cope with their illness include:

- Be alert for signs of depression that seem beyond normal adolescent withdrawal. Changes in mood are common in MS, but can sometimes be difficult to notice because of the overlap in symptoms between depression and MS (e.g. fatigue or lack of energy, a general slowing, changes in sleep patterns, inability to think clearly). Sometimes feelings of depression present as acting out at home or at school rather than appearing as withdrawn or sad behaviour.
- Promote honest communication. Teens often worry about the important people in their lives and often do not want to burden them. They may not be open about things that are bothering them, such as a new physical symptom or thoughts they are having about themselves.
- Provide opportunities for support that go beyond the family such as self-help or support groups and other community programs.

### **For example:**

Your child may be interested in participating in the online community for youth living with MS:  
[www.someonelikeme.ca](http://www.someonelikeme.ca)

## **Normal Child Development Stages and Phases All Kids Go Through**

### **Why is it important to understand normal child development?**

It is important to understand the normal challenges children face in order to recognize and help your child or adolescent if s/he is having difficulties that extend beyond what is normal.<sup>3</sup>

## General Development Sequence – Infancy to Young Adulthood<sup>2</sup>

STAGES	DEVELOPMENTAL TASKS
<b>Infancy</b>	<ul style="list-style-type: none"> <li>• Infants depend on their caregivers for food, warmth and affection.</li> <li>• With parents and caregivers providing for physical and emotional needs, infants will develop a basic sense of trust in their caregivers and the world.</li> </ul>
<b>Toddler</b>	<ul style="list-style-type: none"> <li>• Toddlers try to become more independent—walking, talking, using toilets and generally doing things for themselves.</li> <li>• Self-control and autonomy (self-governance) begin to develop during this stage.</li> <li>• If encouraged and allowed to explore, experiment, make mistakes and test limits, toddlers will develop autonomy, self-reliance, self-control and confidence. If not, they may begin to doubt their abilities and may feel ashamed of their behaviour.</li> </ul>
<b>Preschooler</b>	<ul style="list-style-type: none"> <li>• Pre-schoolers become more engaged in social interaction with people around them.</li> <li>• They will try to find balance in the ability to control impulses and childish fantasies.</li> <li>• If provided with encouragement to pick and choose their own activities, they will develop a positive view of themselves. If they are not allowed to make some of their own decisions, they may feel timid or even guilty when taking steps toward independence. They may come to believe that it is wrong to be independent, refrain from new activities and allow others to make decisions.</li> </ul>
<b>School-age</b>	<ul style="list-style-type: none"> <li>• School-age children make the transition from the world of home to school and peers.</li> <li>• They learn to make things, use tools and acquire the skills to be productive at school.</li> <li>• Many kids experience receiving feedback from outsiders about their accomplishments for the first time.</li> <li>• If they can discover pleasure in learning, being productive and seeking success, they will develop a sense of competence. If they do not, they may develop a sense of inferiority and feelings of inadequacy.</li> </ul>

## General Development Sequence (continued)

STAGES	DEVELOPMENTAL TASKS
<p><b>Adolescence</b></p>	<ul style="list-style-type: none"> <li>• At adolescence, children will begin asking, "Who am I? Who do I want to be?"</li> <li>• Their task is to explore, test limits, become autonomous from parents and commit to an identity or sense of self.</li> <li>• One can only establish an identity after trying out various roles, behaviour and ideologies.</li> <li>• Failure to achieve a sense of identity results in confusion about one's role and effectiveness in life.</li> </ul>
<p><b>Youth (Young Adults)</b></p>	<ul style="list-style-type: none"> <li>• During this stage, the young adult must learn how to form intimate relationships, both in friendship and love.</li> <li>• It may be difficult to establish intimacy if one has not developed a basic sense of trust or a sense of identity.</li> <li>• The alternative to developing those intimate relationships results in alienation, isolation, a fear of commitment and an inability to depend on others.</li> </ul>

## SECTION 3

### MS and its Potential Impact on School Life

Multiple sclerosis is an unpredictable disease. Symptoms can come and go without apparent reason or warning, and no two people experience MS symptoms in exactly the same way. Likewise, some symptoms are clearly visible (like weakness causing walking problems) or less visible (like fatigue or cognitive concerns). It is not possible to predict when symptoms will occur or what parts of the body will be affected. Your child may require **special accommodations** in the school setting to support their educational needs.

Examples of how MS can affect children and adolescents in school:

- Symptoms such as fatigue, depression or bowel/bladder problems can decrease a child's interest in socializing. Children may also feel embarrassed or have difficulties with their mood and/or self-esteem, which directly impact socialization.
- Blurred or double vision may impact reading, writing and/or attention.
- MS can affect a broad range of thinking skills. Thus, reasoning, processing, attention span, information processing, concentration, learning and memory may be impacted.<sup>5</sup> Acute attacks or residual symptoms can cause numbness, weakness, fatigue, poor posture or coordination difficulties, all of which can affect handwriting and typing.
- Heat sensitivity can limit participation in physical activities while in a warm environment.

MS symptoms can change from week to week. It is essential to recognize what symptoms your child experiences in order to prevent on-going problems in school. Likewise, school personnel need to understand that symptoms come and go without warning, so accommodations need to be in place, even when symptoms seem to diminish for a time.

While most MS symptoms remain relatively mild and manageable for most children, they can significantly impact and limit daily activities for some children. It is critical that every effort is made to recognize and address these problems before they have a significant impact on a child's school experience. Therefore, it is essential that children with MS and their parents know what signs may indicate emerging difficulties in school life.

#### **For example:**

A neuropsychological assessment can help identify areas of strengths and weaknesses your child may experience. Please contact your **provincial ministry of education** for more information.

Diagnosis of MS in the pediatric population can have a unique impact on children’s cognitive abilities and school performance. This is particularly true for younger children who have an active disease before mastering their core educational building blocks.<sup>6</sup> A child whose learning process is disrupted prior to learning specific skills such as mathematics or sentence structure might develop deficits as compared with those who have mastered these subjects.<sup>7</sup>

## School Work

### Learning and Memory

MS can affect cognitive functioning. Reasoning, processing, attention span, information processing, information retrieval and other thinking abilities may be impacted. The following table includes a selected list of cognitive abilities as they relate to schoolwork. Becoming familiar with these may help you to better understand or interpret psycho-educational or neuropsychological reports.

COGNITIVE ABILITIES AS THEY RELATE TO SCHOOL WORK	
<b>Fluid Reasoning</b>	Learning ability that can influence the speed and amount that someone learns, and ability to manipulate and use information in a reasoning process. This is important for reading, solving problems and generating solutions.
<b>Crystallized Knowledge (learned)</b>	Learned and stored knowledge and experience (e.g., vocabulary, spelling, ability to read, social studies).
<b>Short-Term Memory</b>	The ability to hold information for a short period of time, for example, remembering a locker combination within the first 20 minutes it is assigned.
<b>Long-Term Associative Storage and Retrieval</b>	The ability to store information for a long period of time and the ability to recall that information when it is needed. This ability is important in school where students are constantly required to recall information that they learned days, weeks and months before.
<b>Visual Processing</b>	The ability to process information that was received visually. This involves visual recognition and memory for visual information. This ability is necessary for tasks such as copying notes from the chalkboard, processing slides, video, etc.

<b>COGNITIVE ABILITIES AS THEY RELATE TO SCHOOL WORK (Continued)</b>	
<b>Auditory Processing</b>	The ability to process information that was received orally. This involves sound recognition and memory for auditory-verbal information and is important for understanding classroom instructions, following directions, etc.
<b>Information Processing Speed</b>	The speed at which mental processes occur. This cognitive ability can affect a range of other thinking skills and is heavily related to test taking skills and rapid comprehension (e.g., grasping concepts quickly in the classroom) - an important part of school.

## Coping with Cognitive Symptoms

Whether a child is having difficulty with vision, motor skills or memory, the parent should focus on how s/he can cope with his/her symptom(s). Specifically, the focus should be on helping a child come up with strategies to achieve challenging tasks.

**For example:**

My child has \_\_\_\_\_ symptom(s).

- Have I seen him/her using a different way to get a task done? (e.g., using the opposite leg to kick a ball, counting on fingers when s/he didn't usually use this method, etc.)
- When I teach my child a new way to get a task done, can s/he produce better results?
- Once my child learns a task (even if it takes a while), can s/he reproduce the task alone? If s/he can't do it by him/herself, can s/he do it with assistance? How much help is needed?
- Does this mean s/he will need more structure in the classroom?

## Life at School

Children spend a large part of time at school. School can be seen as their workplace. They go to school every day to learn new academic information. However, school life is not just about books, pop quizzes and homework. It is not just about academic performance and standard tests. School is also where much of socialization occurs; kids learn about social skills and interpersonal functioning through interaction with their peers.

## Academic and Social Demands All Children Face<sup>4</sup>

LEVEL	ACADEMIC	SOCIAL
<b>Preschool</b>	<ul style="list-style-type: none"> <li>• Readiness Skills</li> </ul>	<ul style="list-style-type: none"> <li>• Taking turns</li> </ul>
<b>Primary Grades (JK – 2<sup>nd</sup> ±)</b>	<ul style="list-style-type: none"> <li>• Numerical Skills</li> </ul>	<ul style="list-style-type: none"> <li>• One to one, small group sharing</li> </ul>
<b>Intermediate (3<sup>rd</sup> ± to 6<sup>th</sup> ±)</b>	<ul style="list-style-type: none"> <li>• Subject content mastery: for example “I can name each Canadian province and territory.”</li> <li>• Application (homework)</li> <li>• Competition (tests)</li> </ul>	<ul style="list-style-type: none"> <li>• Formal Groups (ie. Scouts/Guides)</li> <li>• Gangs (Us vs. Them)</li> </ul>
<b>Junior High/ Middle School (6<sup>th</sup> ± to 9<sup>th</sup> ±)</b>	<ul style="list-style-type: none"> <li>• Study/organizational skills</li> <li>• Time management</li> <li>• Early abstract thinking</li> </ul>	<ul style="list-style-type: none"> <li>• Peer influences</li> <li>• Dependency and independency conflicts</li> <li>• Egocentrism surges (tendency to think everything evolves around them)</li> </ul>
<b>High School (9<sup>th</sup> ± to 12<sup>th</sup>)</b>	<ul style="list-style-type: none"> <li>• Advanced cognitive skills, e.g. critical thinking</li> <li>• Past/present/future links</li> </ul>	<ul style="list-style-type: none"> <li>• Understanding their place and involvement in the community (sociocentrism) surges</li> <li>• Larger community horizons</li> </ul>
<b>Post High School (Grade 12 on)</b>	<ul style="list-style-type: none"> <li>• All of the above</li> <li>• Functional vocational skills</li> </ul>	<ul style="list-style-type: none"> <li>• Responsibility for self and others</li> </ul>

## Socialization

Developmentally speaking, no matter which stage we focus on, developing social skills is critical<sup>2</sup>, and school is where the majority of this development occurs. What happens during the school day carries over into time at home, which can dictate children’s behaviour there. While little is known about the specific effects of MS on socialization, we do know that overall, children with chronic illness are at a greater risk for difficulty with socialization than children without chronic illness. It has been found that among children with chronic illness, those with more obvious physical limitations or disabilities have more difficulty with socialization due to feeling isolated and different from their peers.

Unfortunately, for many children and adolescents with MS, school life as it relates to socialization can become difficult for various reasons such as:

- Changes in cognitive functioning which can lead to feelings of inadequacy and a sense of not being able to “keep up with” their peers. Feeling different than their peers or even experiencing teasing from their peers.
- Frustration or embarrassment because school personnel often don’t understand MS symptoms (such as fatigue, decreased vision, and frequent bathroom use).
- Low self-esteem and/or embarrassment, causing a low desire to socialize due to physical limitations (if any) and/or other symptoms.
- Compromised drive towards independence, because the nature of the disease can require increased dependence on parents, caregivers and teachers or others may feel the need to protect the young person and limit independent activities.
- Anxiety, which can be emotionally internalized (withdrawal) or externalized (acting out), because of the uncertainty that comes with MS.

It is important to remember, that while chronic conditions leave a child more vulnerable to social problems, the presence of a condition does not invariably lead to social problems. It is also important to understand that healthy peer relationships may actually be protective to the well-being of children/ teens with chronic conditions, and therefore positive peer relationships should be encouraged and supported by parents and caregivers.

## **Emotional Impact**

Having a chronic illness, such as MS, can impact children and adolescents’ emotions in various ways. Differences in cognitive abilities may cause changes in the ability to do everyday tasks, such as recalling a locker combination, completing homework or doing a classroom assignment. Even changes to a school schedule, transportation requirements and changes in how a child gets around school can impact his/her emotions. It is possible that children with MS who have changes in cognitive functioning have a greater emotional impact from the disease on their lives. This may be due to children often feeling left behind or not feeling “as good” as other children due to difficulties in academics or feeling a loss in ability and frustration because they were previously highly successful students. This may affect their self-esteem and self-view. Without intervention, this can result in a greater gap between a child’s actual level of functioning in school and where s/he should be based on chronological age. There may be other emotional hardships that may originate from social situations that are unique to schools and other places where children socialize.

## Teasing

Teasing and/or bullying in schools has become an increasing problem and has garnered more attention in communities nationwide. Children with chronic illness are an at-risk group for teasing and bullying. The following is some general information about teasing that will help you to prepare your child for possible encounters with bullies at school.<sup>8</sup>

### Why Children Tease

- Attention—teasing is an effective way of getting negative attention.
- Imitation—some children mimic or model what is happening to them at home by acting the same way to others at school.
- Feeling of superiority or power over others.
- Peer acceptance.
- Lack of understanding normal differences among people.
- Teasers want to provoke anger, frustration or make their victims feel weak or inadequate, often with the subconscious goal of making themselves feel powerful.

### Strategies Parents Can Teach Children about Teasing

These strategies can be used alone or in combination. Role-play with your child and have him/her come up with examples and scenarios.

<b>Self-Talk</b>	Encourage children to come up with phrases that they can say to themselves when they are in a teasing situation (e.g., “Even though I don’t like this teasing, I can handle it.”).
<b>Ignore</b>	Displays of anger or tears often invite more teasing. It is more effective for children to ignore the teaser.
<b>Visualize</b>	Especially for young children, visualizing words “bouncing off” of them helps them imagine not having to accept what is said.
<b>Reframe</b>	Change your child’s perception about the negative comment. For example, “Four eyes, four eyes, you have four eyes.” The child being teased could respond, “Thanks for noticing my glasses.”

## SECTION 4

# Working with the School System to Get Support for Your Child

## Interventions, Adaptations, Accommodations and Consultation

Each **provincial ministry of education**, municipal or regional school board and school will vary in the types of interventions, adaptations and accommodations they provide; the information provided in this section offers an overview of the various types of accommodations and interventions offered across Canada and are intended to be used to help guide you through the school system. Your child's teacher can help to identify any issues s/he may be experiencing at school. Once problem areas have been identified, necessary steps can be taken to improve your child's learning experience, whether this involves an intervention, adaptation, accommodation or further consultation with school staff or allied health care professionals.

### Accommodation

Accommodation is something you can discuss and negotiate with your child's teacher(s). Simple accommodations may be very informal and made at the classroom level while more complex accommodations may involve formal assessments and negotiations at the school board level. Each school board establishes, maintains and implements a general education intervention procedure. Interventions are implemented on school premises for students whose classroom performance is adversely affecting educational outcomes. In other words, because a child's school performance is suffering, the child would not meet educational milestones.

When school personnel, a parent (or guardian) or the student has concerns regarding his/her academic performance, physical abilities and/or social/behavioural adjustment, the procedure usually looks like this:

- ➔ The school principal, principal's designee, or the classroom teacher is contacted and referral is made to a designated school-based team. This team would create general educational accommodations.
- ➔ Soon after the referral is made, the school-based team meets to plan strategies for resolving the problem or concern.
- ➔ A general educational accommodation plan is developed and implemented.
- ➔ Parents receive a copy of this plan.
- ➔ A follow-up meeting should be scheduled to determine the success and/or progress of the accommodation.

What you may expect from a follow up meeting:

- The general educational accommodation plan may be re-designed and/or the duration can be extended to see whether the existing plan will continue to work.

AND/OR

- The group will discuss and initiate a psychoeducational evaluation or physical assessment (e.g., need for a writing aid or accommodations to a physical education program). If the group decides that an evaluation is necessary, a copy of the general educational accommodation plan should accompany the referral when it is sent to the Special Education Office.

## Your Child's Education History

If necessary, be prepared to give your child's educational history to the school-based team.

- Did your child have an educational assessment (psychoeducational testing) before being diagnosed with MS?
- Have you or anyone who knows your child (e.g., teacher) had concerns about his/her learning?
- Has your child received, or does your child currently receive, any educational services (formal or informal) at school?
- What are your child's current concerns at school?
- What symptoms get in the way of your child's schoolwork and life at school? Have specific examples ready.

## Accommodations and Interventions

### Individualized Education Program (IEP)

The term IEP refers to a written document developed and implemented by a team, outlining a plan to address the individual learning needs of students. This plan should be tailored to your child's academic and medical needs in school. When you are thinking about types of accommodations, think of what would help your child function better at school physically (if they have motor function symptoms) and/or academically (if they have cognitive symptoms). For children and adolescents moving on to another school, a transition plan, which is part of an IEP plan, should be in place. Students about to start high school or who are already in high school should have a transition plan as well.

Ensure the school maintains up-to-date and detailed health information on your child with specific care instructions in the event of any medical problems that may occur at school. The file should contain a medical history, any other health-related issues as well as contact information for parents, emergency contacts, pediatricians, neurologists and anyone else that might need to be contacted. Parents also need to be mindful of school resources and policies. If there is a school nurse, s/he needs to be involved with the process, as s/he may need to be trained for some of the procedures.

## Examples of Accommodations and Interventions

Keep in mind that accommodations are individualized for each student's needs. It is impossible to provide a comprehensive list of all possible accommodations because each student is different and has unique learning and/or medical needs at school.

### Examples of General Accommodations

- A multiple-choice test, if your child has trouble remembering and/or recalling information.
- Provide a second set of books to be kept at home if your child experiences significant fatigue or other motor limitations.
- Preferential class seating if your child's symptoms include visual problems, attention deficit, or bladder/bowel problems.
- Bathroom pass and/or extended bathroom time if your child's symptoms include bladder and/or bowel control problems.
- Frequent breaks if your child's symptoms include fatigue or difficulty concentrating.
- Modify homework assignments – this is helpful for children who experience extreme fatigue and have problems with writing.
- Portable air conditioner or fan to be carried from class to class if the school does not have air conditioning.
- Step stool for bus access.
- Slant board to prop up books/binders/papers for better vision.
- Clear colored ruler to highlight sentences in books.
- Lockers to be opened with keys rather than combinations.

### Formal Accommodations

#### (may require special permission from school board)

- Extended test-taking time. This is extremely useful during province-wide testing. These accommodations typically include "stop the clock" breaks for bathroom visits or for taking breaks when extreme fatigue occurs.
- Relocation of classrooms – for children with fatigue and/or physical disabilities that affect gross motor skills.
- Aid for students with visual impairments (e.g., a reader).
- Laptop computer for taking notes and tests or using computer software such as *Dragon Naturally Speaking*—a voice activated program that types what you speak.
- Psychological services.
- School health services.

## Special Education Intervention

- ➔ Occupational therapy for those with fine motor and/or visual needs.
- ➔ Speech/language therapy and audiology services.
- ➔ Psychological services.
- ➔ Physical therapy.
- ➔ Therapeutic recreation/adaptive physical education.
- ➔ Mobility services and/or medical services for diagnostic or evaluation purposes only.
- ➔ School health services by a school nurse or other qualified personnel.
- ➔ Social work services.
- ➔ Parent counseling and training.
- ➔ Educational assistant to support needs in the classroom.

## SECTION 5

### Coping Skills and Strategies

#### Coping with MS symptoms

Learning coping skills and strategies to overcome troublesome symptoms can be empowering and beneficial when facing challenges in the school setting. Both parents and children can benefit from learning these skills.

**Parents** benefit because they feel that they're helping their child.

**Children** benefit because they feel that something can be done about what they often feel they have no control over.

- Talking about an exacerbation/attack can be anxiety provoking and difficult for parents to bring up with their child. Keep in mind, however, that talking about these issues, as challenging as they are, makes it less scary for your child.
- Have open discussions and encourage talking about ways to reduce, or cope with, the effects of the disease and its related disabilities. Involve your child or adolescent when developing coping strategies.
- Talk to your child or adolescent about anticipated physical effects of MS and how it is treated.
- For younger children and early school-aged children, create "what if" plans and talk about different scenarios that could occur for your child when you are not around. If certain symptoms have occurred previously and then went away, talk about how s/he would handle this symptom if it occurred again in school.
- Older children and adolescents should be encouraged to generate some coping strategies on their own; often this increases the chances that they will use these strategies when necessary.
- For some adolescents and older school-aged children, the effects of having a chronic illness conflicts with the natural desire to be independent. They begin to feel a loss of control in their lives. This is sometimes described as a feeling that "someone else" or "something else" is "controlling" their life.
- A chronic illness such as MS can sometimes interfere with time spent with peers at school, which is a child's primary social environment. Self-esteem issues related to acceptance and concerns about being accepted by others are intensified by chronic illness and related treatment needs.

Additional support such as support groups and/or therapy/counseling can help parents, the child and his/her sibling(s) cope with MS.

### **Sometimes it helps to role play with your child:**

“Let’s say you’re in school during lunch in the cafeteria, and all of a sudden you notice your vision becomes blurry just like it did a few months ago. What would you do?” Keep in mind that you’re not quizzing your child. Play out different types of scenarios for your child in order to help him/her to feel less anxious. Help prepare your child to cope with the symptoms on his/her own.

### **Here are some ways to help your child feel more independent:**

- ➔ Involve him/her in health-related discussions (such as concerns about MS or treatment choices).
- ➔ Teach him/her self-care skills.
- ➔ Encourage him/her to monitor and manage his/her treatment needs as much as possible.
- ➔ Encourage and support the development of coping skills to address problems or concerns related to MS that might arise.

### **Here are some ways to help your child feel more safe and prepared to socialize:**

- ➔ Encourage spending time with friends.
- ➔ Discuss concerns about disclosure – what to share, and what not to share with friends.
- ➔ Encourage humor.
- ➔ Encourage and assist friends in being supportive.

## **Transitions**

### **Youth with chronic illness face a number of important transitions:**

- ➔ A developmental transition – from childhood to adolescence to adulthood.
- ➔ A situational transition – changing schools or educational services.
- ➔ A transition from relative health to living with a chronic disease – depending on the progression.

## **What Will Happen to Me?**

The fear of an unknown future has been found to be one of the most challenging stressors that children and adolescents as well as parents face. Living with a chronic illness further complicates this normal stressor. Children find it very difficult to understand that illness or life outcomes cannot be predicted—it is virtually impossible to tell a child exactly what impact MS may have on each aspect of his/her life. Even though MS is unpredictable, talking about the future with your child/adolescent can help to alleviate some of the fear of the unknown. If a transition plan already exists through your child’s IEP, you can also modify it to add in personal/social life issues or make the transition plan longer—say for ten years instead of five. Transitional plan simply means being prepared for anticipated change(s) that will occur (e.g., changing schools from elementary to middle school, moving, etc.). Each child is unique in his/her future needs, and parents together with the child are often the best authors of transition plans. It may be comforting for your child to know that an adult is thinking ahead with them.

## Goal of a Transition Plan

- To provide educational and health care services that are uninterrupted, coordinated, developmentally and psychologically appropriate. This needs to be in place prior to, and throughout transitioning into, a different school and/or developmental stage.
- Planned and facilitated with involvement of the child or adolescent, in order to equip him/her with the knowledge and skills to face each new stage in his/her life.

## Transition Planning Checklist for Parents

### FIRST STAGE TRANSITION – Preschool to third grade

The child is being introduced to the world. The child begins to take part in group social activities and is preparing to attend school.

#### Self-advocacy

- Support your child to be as independent as s/he is ready to be (e.g., washing hands, getting dressed, etc.).
- Help your child verbalize what s/he wants or needs by “using your words.”
- Have a list of names and, if possible, pictures of your child’s health care providers for him/her to look at, to promote familiarity. Talk about when you and your child saw them last and when you will see them next.
- Encourage your child to ask questions during each health care visit. If a child is too shy or scared during the visit, ask him/her to whisper questions in your ear, which you can then relay to the provider on his/her behalf.
- Discuss MS and treatments your child needs (discuss with your child’s health care team first). Have pictures available and use developmentally appropriate examples to explain concepts. You can ask your health care provider(s) for examples if needed.
- Discuss and demonstrate (by role playing) how to seek help from others.

#### Psychosocial Support

- Provide your child opportunities to take part in social activities, peer involvement and structured play to resemble the school setting.
- Start talking about supportive relationships (e.g., teacher, family members, guidance counselor, etc).

## Educational Planning

- Identify schools that may be appropriate for your child. Ask yourselves, what kind of school fits our overall values, religion, educational beliefs, and my child's needs?
- Discuss restrictions that may (or may not) interfere with your child's educational or recreational activities.

## Health and Lifestyle

- Create a binder or a large folder to keep all medical records, and use a separate one for your child's school records.
- Have discussions with family members about how MS might impact each of you.
- Make sure that you, as a parent, have adequate social support with whom you can talk about your feelings and concerns about the future.

## EARLY STAGE TRANSITION – Fourth Grade to Seventh Grade

At this stage the child can begin to participate in his/her own care. Skills are supported and practiced at home with the family.

### Self-advocacy

- Educate your child by describing MS, its symptoms and treatments in basic terms.
- Review findings, news and new information with your child.
- Encourage your child to ask questions during each office visit to support development of independence.
- Discuss the medications and treatments your child needs, including side effects (discuss and consult with your child's health care team first).
- Discuss how to seek help from others. Have your child discuss when, how and from whom to seek emergency and medical help.

### Sexual Health

- Discuss the change of puberty, differences and similarities in comparison to peers, and any impact of puberty on the child's health condition.
- Talk to your health care team about where children and parents can obtain information about sex education.

## Psychosocial Support

- Support your child's drive for independence. Supporting independence should be balanced with appropriate structure.
- Talk to your child about social activities, peer involvement and supportive relationships.

## Educational Planning

- Talk about your child's responsibilities at home (e.g., chores) and at school (e.g., homework, clubs, etc.)
- Discuss restrictions (real and hypothetical) on your child's educational or recreational activities.

## Health and Lifestyle

- Ask your child or pre-teen about smoking, use of alcohol and street drugs.
- Discuss impact of smoking, street drugs and alcohol on health, treatments and general well-being.
- Make sure you, as a parent, have access to supportive persons to discuss your feelings and concerns about the future.

## MIDDLE STAGE TRANSITION – Eighth Grade to Tenth Grade

Here you and your adolescent will gain an understanding of the transition to, and expectations of, adulthood. The younger adolescent practices skills, gathers information and sets goals for participating in his/her care.

## Self-advocacy

- Discuss strategies to access accurate information about health conditions and treatments with your child's health care team (e.g., support groups, internet, library, and condition-specific health associations).
- Discuss appointment times and dates with your adolescent, and let them help make decisions about scheduling appointments.
- Encourage your adolescent to check-in for their own health care appointments.
- Encourage your adolescent to learn about medication and practice having a prescription re-filled.

## Sexual Health

- Provide your adolescent time to meet alone with their health care providers to discuss any questions or concerns about sexuality-related issues. Parents can meet with the provider separately to raise any additional concerns.
- Discuss importance of using contraception.

## Psychosocial Support

- Prompt your adolescent to create and verbalize positive goals for self and health.
- Encourage your adolescent to join a school club, a community or peer support group, or attend camp.

## Educational and Vocational Planning

- Focus on school, favorite subjects, plans for high school and even college or university, and ideas for careers.
- Have your adolescent visit school counselors to talk about career prep courses or volunteering in the community.

## Health and Lifestyle

- Discuss plans for driving; identify any restrictions with your adolescent's health care team.
- Discuss issues of body image, importance of exercise, concerns regarding dieting, and weight gain or weight loss.
- Encourage and help find support outside of the family to enhance your child's support system. If professional help for mental health concerns is appropriate, ideally, the adolescent should choose who they would like to see such as a psychologist, social worker, counselor, etc.

## LATE STAGE TRANSITION – Eleventh and Twelfth Grade

The older adolescent uses independent behaviours (as much as possible) to move into the adult world.

### Self-advocacy

- Discuss choices for medical care and community services (e.g., going away to college or university, summer program, etc.).
- Encourage your teenager to maintain a personal health record book for medical/dental appointments, health information, treatments, and health care providers (including names and telephone numbers).
- Encourage your teenager to contact the health care team directly when s/he is experiencing new symptoms or health issues.
- Parents and teens meet with the health care team separately to discuss concerns.

### Sexual Health

- Discuss sexual capabilities, fertility and sexual vulnerability with your adolescent.
- Give opportunities for the adolescent to address sexual issues privately with the health care provider.
- Discuss importance of using contraception.

## **Psychosocial Support**

- Identify needs related to living away from family (e.g., going away to college/university).

## **Educational and Vocational Planning**

- Discuss employment options and plans for health care benefits.
- If choosing college/university, discuss available health care services, educational services (should be discussed in the very last IEP the adolescent had while still in high school), transportation, living arrangements and impact on health condition.

## **Health and Lifestyle**

- Discuss impact of smoking, street drugs and alcohol on health, treatments, and general well-being.
- Discuss issues of body image, concerns regarding dieting, weight gain or weight loss and the importance of exercise.
- Provide opportunities for older teens to discuss emotional topics. Listen for clues suggesting emotional problems, depression, thoughts that life is not worth living or urges to hurt oneself.
- Encourage and help find additional support outside of the family for extra support. If professional help for mental health concerns is appropriate, ideally, the adolescent should choose who they would like to see, such as a psychologist, social worker, counselor, etc.

## APPENDIX I

### SAMPLE LETTER REQUESTING SPECIAL EDUCATION PROCESS AND ASSESSMENT

(Today's date)

TO: Mrs. Joan Smith (school principal's name)  
123 Main Street (school's address)  
Anywhere, Manitoba A1B 2C3

RE: Ellen Jones (student's name), a student in the 5th grade class taught by  
Ms. Camryn Graves (teacher's name)

I am writing to you because Ellen has been recently diagnosed with multiple sclerosis. I am formally requesting that the school begin its special education process, including initial assessment for eligibility.

Thank you very much for your attention and kind assistance.

Sincerely,  
Robert Jones (parent or guardian of student)

Contact Information:

987 Any Street (parent or guardian's address)  
Anyplace, Manitoba A1B 2C3  
(123) 456-7890 (parent or guardian's phone number)  
email@address.com (parent or guardian's e-mail address)

## APPENDIX II

### SAMPLE ACCOMMODATION PLANS (IEP)

A thorough plan contains:

- 1) Concrete information about the child's disability;
- 2) Specified actions for teachers to take that will impact their attitudes, knowledge and behaviours;
- 3) Strategies for promoting the child's self-concept and minimizing possibly embarrassing situations;
- 4) Ways to support the child's autonomy and decision-making regarding his/her health care needs.

#### Sample Plan #1:

Accommodations that are necessary for (child's name):

1. Provide (child's name) teacher information on pediatric MS.
2. Provide (child's name) the book titles necessary for reading in advance, so there is ample time to order them on tape and work through the assignment.
3. Only call on (child's name) in class (to read aloud, or offer an answer) if she is raising her hand.
4. Permit written assignments to be done with dictation software and submitted in a typed format.
5. Give extended time for, or shortened assignments in, reading, spelling and written expression.
6. Where possible, avoid "classmate checking" so not to embarrass her with peers.
7. When possible, provide written notes or worksheets to minimize the amount of material that needs to be copied.
8. During tests, be available to read words, sentences, or to paraphrase questions as needed.

#### Signatures and Indication of Agreement:

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Parent or Guardian Signature

Date

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School Principal Signature

Date

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School Teacher Signature

Date

## EMERGENCY CONTACTS

Mother's/Guardian Contact Information:

Home Phone #:

Cell Phone #:

E-Mail Address:

Father's/Guardian Contact Information:

Home Phone #:

Cell Phone #:

E-Mail Address:

Child's Primary Care Provider:

Work Phone #:

Pager #:

Child's Other Health Care Provider:

Work Phone #:

Pager #:

## Sample Plan #2:

Accommodations that are necessary for (child's name):

1. (Child's name) shall be permitted to use the bathroom without restriction.
2. An extra set of clothes is allowed to be stored on the school premises/in their locker.
3. (Child's name) will be permitted to participate in all field trips and extracurricular activities (such as sports, clubs, and enrichment programs) without restriction and with all of the accommodations and modifications set out in this plan, where feasible.
4. If (child's name) is affected by fatigue or exacerbated symptoms at the time of regular or standardized testing, he will be permitted to take the test at another time without penalty. If (child's name) needs to take breaks to use the bathroom during a test or a classroom assignment, s/he will be given extra time to finish the test or assignment without penalty.
5. (Child's name) will not be penalized for absences or tardiness required for medical appointments, illness, visits to the office or time necessary to manage his MS-related symptoms.
6. (Child's name) will be granted an "Office Pass" that he can use at any time and place during school activities in order to get the care he needs on an immediate basis.

7. Each teacher who is directly involved in the care of (child's name) will receive a packet of information about pediatric multiple sclerosis.

**Signatures and Indication of Agreement:**

\_\_\_\_\_  
Parent or Guardian Signature Date

\_\_\_\_\_  
School Principal Signature Date

\_\_\_\_\_  
School Teacher Signature Date

**EMERGENCY CONTACTS**

Mother's/Guardian Contact Information: \_\_\_\_\_

Home Phone #: \_\_\_\_\_ Cell Phone #: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

Father's/Guardian Contact Information: \_\_\_\_\_

Home Phone #: \_\_\_\_\_ Cell Phone #: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

Child's Primary Care Provider: \_\_\_\_\_

Work Phone #: \_\_\_\_\_

Pager #: \_\_\_\_\_

Child's Other Health Care Provider: \_\_\_\_\_

Work Phone #: \_\_\_\_\_ Pager #: \_\_\_\_\_

## APPENDIX III

### RESOURCES & LINKS

#### Multiple Sclerosis

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##### **Multiple Sclerosis Society of Canada**

The mission of the MS Society of Canada is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life. We provide quality programs and services across Canada to those affected by multiple sclerosis to achieve the highest possible quality of life while living with the daily challenges that MS presents.

In addition to supporting Canadians whose lives are impacted by MS, MS Society volunteers and staff also provide information and support to health professionals, employers, and the general public.

**Toll Free: 1-866-922-6065**

**Website: [www.mssociety.ca](http://www.mssociety.ca)**

##### **National Multiple Sclerosis Society (USA)**

The National MS Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

**Website: [www.nationalMSSociety.org](http://www.nationalMSSociety.org)**

##### **Children and Teens with MS: A Network for Families**

Children and Teens with MS: A Network for Families is a North American support network that provides multiple program options for families living with a child or teen who has been diagnosed with multiple sclerosis. This program is a collaboration between the MS Society of Canada and the National MS Society (NMSS) of the United States.

**Toll Free: 1-866-922-6065**

**Website: [www.mssociety.ca](http://www.mssociety.ca)**

##### **Someonelikeme.ca**

An online community for young people living with multiple sclerosis; either with a diagnosis of MS or a personal connection to MS.

**Website: [www.someonelikeme.ca](http://www.someonelikeme.ca)**

## Family Support

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### **Canadian Association of Family Resource Programs**

Promotes the well-being of families by providing national consultation and resources to those who care for children and support families and provides a network of family resource agencies.

**Website:** [www.frp.ca](http://www.frp.ca)

### **Canadian Child Care Federation (CCCF)**

CCCF provides Canadians with information about early learning, child care knowledge and best practices to help families promote healthy growth and development of their children.

**Website:** [www.cccf-fcsge.ca](http://www.cccf-fcsge.ca)

### **Caring For Kids (Canadian Paediatric Society)**

Caring for Kids is designed to provide parents with information about their child's health and well-being.

**Website:** [www.caringforkids.cps.ca](http://www.caringforkids.cps.ca)

### **Growing Healthy Canadians**

This guide offers a rich source of information as well as a unique perspective on how best to promote the well-being of young people.

**Website:** [www.growinghealthykids.com](http://www.growinghealthykids.com)

## Accessibility and Technology

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### **Inclusive Design Research Centre (IDRC)**

The IDRC is a research and development centre at the Ontario College of Art and Design University (OCAD) in Toronto, where an international community of open source developers, designers, researchers, advocates, and volunteers work together to ensure that emerging information technology and practices are designed inclusively.

**Website:** [www.idrc.ocad.ca](http://www.idrc.ocad.ca)

### **Special Needs Opportunity Window (SNOW)**

SNOW is an accessible interactive site that unites community members and organizations to engage with resources, current events, upcoming conference, online courses and social networking groups on projects related to accessibility and inclusive design.

**Website:** [www.snow.idrc.ocad.ca](http://www.snow.idrc.ocad.ca)

### **Tetra Society of North America**

A non-profit organization that recruits skilled volunteers to create customized assistive devices for people with physical disabilities.

**Website:** [www.tetrasociety.org](http://www.tetrasociety.org)

## **Post Secondary School**

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### **Canadian Alliance of Student Associations (CASA)**

CASA is an alliance of students associations and student unions that represents and defends the interests of post-secondary students to federal and inter-provincial levels of government.

**Website:** [www.casa.ca](http://www.casa.ca)

### **Canadian Federation of Students (CFS)**

CFS works to ensure a high quality system of post-secondary education that is accessible to all. Within the Federation there is a Constituency Group for Students with Disabilities.

**Website:** [www.cfs-fcee.ca](http://www.cfs-fcee.ca)

### **National Education Association of Disabled Students (NEADS)**

NEADS is a consumer organization that provides information on services and programs for students with disabilities nationwide and advocates for increased accessibility so that students with disabilities have equal access to post-secondary education.

**Toll-free:** 1-877-670-1256

**Website:** [www.neads.ca](http://www.neads.ca)

## **Government**

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### **Public Health Agency of Canada – Division Childhood and Adolescence**

The Division Childhood and Adolescence is a focal point for policy development, research, and strategic analysis of trends regarding broad determinants of health regarding children and youth in Canada.

**Website:** [www.phac-aspc.gc.ca/hp-ps/dca-dea/index-eng.php/](http://www.phac-aspc.gc.ca/hp-ps/dca-dea/index-eng.php/)

## Provincial Ministries of Education

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**Government of British Columbia - Ministry of Education**

Website: [www.gov.bc.ca/bced](http://www.gov.bc.ca/bced)

**Government of Yukon - Department of Education**

Website: [www.education.gov.yk.ca](http://www.education.gov.yk.ca)

**Government of Alberta - Ministry of Education**

Website: [www.education.alberta.ca](http://www.education.alberta.ca)

**Government of the Northwest Territories - Department of Education,  
Culture and Employment**

Website: [www.ece.gov.nt.ca](http://www.ece.gov.nt.ca)

**Government of Saskatchewan - Ministry of Education**

Website: [www.education.gov.sk.ca](http://www.education.gov.sk.ca)

**Government of Manitoba - Department of Education and Training**

Website: [www.edu.gov.mb.ca](http://www.edu.gov.mb.ca)

**Government of Nunavut - Department of Education**

Website: [www.edu.gov.nu.ca](http://www.edu.gov.nu.ca)

**Government of Ontario - Ministry of Education**

Website: [www.edu.gov.on.ca](http://www.edu.gov.on.ca)

**Government of Quebec - Ministry of Education, Recreation and Sports**

Website: [www.mels.gouv.qc.ca/gr-pub/m\\_englis.htm](http://www.mels.gouv.qc.ca/gr-pub/m_englis.htm)

**Government of New Brunswick - Department of Education  
and Early Childhood Development**

Website: [www.gnb.ca](http://www.gnb.ca)

**Government of Prince Edward Island - Department of Education  
and Early Childhood Development**

Website: [www.gov.pe.ca/education/](http://www.gov.pe.ca/education/)

**Government of Nova Scotia - Department of Education**

Website: [www.ednet.ns.ca/](http://www.ednet.ns.ca/)

**Government of Newfoundland and Labrador - Department of Education**

Website: [www.ed.gov.nl.ca](http://www.ed.gov.nl.ca)

## APPENDIX IV

### COGNITIVE/NEUROPSYCHOLOGICAL EVALUATIONS

A cognitive/neuropsychological evaluation may be a part of your child's treatment plan. A baseline evaluation is highly recommended with testing repeated periodically (particularly at transition stages) to monitor progress. These evaluations are very helpful for all parties involved.

- For children and adolescents, this testing provides an opportunity to understand how their brain works—which tasks are easy for them and which are hard. This can help them find strategies and ways to get around cognitive symptoms that may occur.
- For parents, this testing provides an opportunity to understand how MS affects their child's behaviour and thinking. This can help parents learn how to better communicate with their children, support them with their homework/assignments and advocate for school accommodation if needed.
- For health care providers, this testing serves to evaluate a child's cognitive status, and changes over time, and can be part of the process of monitoring disease evolution. It tells the health care provider if intervention is needed.
- For schools, this test can aid in assessing overall cognitive function of the child and identifying cognitive issues that require academic accommodations and added educational supports. Strategies for enhancing cognitive strengths and addressing specific cognitive challenges can be developed based on the test results.

### Types of Tests Given and What They Evaluate

#### Cognitive/Neuropsychological Tests

When people hear "cognitive testing," they immediately think of IQ/Intelligence tests. This is only true in part. Cognitive testing measures the ability to succeed in school. Neuropsychological testing evaluates different parts of listening, visual and motor skills, as well as attention, different kinds of memory, speed of responses and use of strategies. These abilities are dictated by different parts of our brain. So, by finding out how our brains work, we can also find out which area in our brain is affected by MS disease.

The most important part of this test is understanding how your child solves problems. This is often more important than the end result of the test because it is more helpful to understand how someone comes up with their answers than what their score was on a particular test. Cognitive testing should be repeated over time. In a nutshell, neuropsychology provides a way to understand how MS might impact behaviour and learning and how this might affect your child at school.

## **Behavioural Assessments**

Some of these assessments evaluate purposeful, goal-directed and problem-solving behaviours. These are used to estimate how a child will do in a classroom or social setting. This type of assessment has components that seek input from the child, teachers and parents. Other assessments examine the psychological functioning of the child.

## **Developmental/Psychosocial Assessments**

Developmental and psychosocial assessments evaluate levels of functioning out in the world—in their own environment on a daily basis. These assessments are usually done through in-depth parent interviews. Typically, a child's capabilities in communication (what s/he understands and what s/he says), daily living skills (what s/he can do to take care of her/himself), socialization (how s/he gets along with others and how s/he plays), and motor skills (how s/he gets around physically) are examined.

## **Frequently Asked Questions about Cognitive/Neuropsychological Testing**

### **What is involved in preparation for the test?**

There is no advanced preparation for cognitive testing. Neuropsychological evaluations can range in length from a "screening" measure (less than 1 hour) to an "intermediate" assessment (1 to 3 hours) to a "comprehensive" assessment (4 or more hours). The most accurate results are obtained if the child is well rested and is not hungry. If a child becomes too tired, the neuropsychologist may recommend that the tests be given during several short appointments, instead of one long session.

Cognitive testing should be conducted when the child is not on a steroid treatment, as it may interfere with neuropsychological status.

### **What do the test results mean?**

The test results show how a person performs when given different tasks that examine different facets of cognitive ability. This correlates with success in school. The result can be most useful when used as a tool to evaluate a child's cognitive ability to inform parents and kids about their range of abilities. The results can emphasize areas in which children can do well, ones that are more difficult, and those that may require supportive help. Nobody has a perfect brain! These results can be used to formulate school-based interventions to make any difficulties more manageable.

## APPENDIX V

### GLOSSARY OF SCHOOL-RELATED TERMS

**Accommodations**—Interventions and/or modifications in the school setting designed to help the student compensate for any difficulties in learning.

**Achievement Tests**—Measures of learned knowledge in academic skills (such as reading, writing, math and science).

**Assessment (or psychoeducational assessment)**—Process of identifying needs to assist in educational planning, which includes classroom observation, record review, interviews (including parents, teachers, and others as needed), and tests.

**Assistive Technology (AT)**—A piece of equipment or system that helps kids with disabilities compensate for their disability.

**Cognition**—High level functions carried out by the brain including comprehension and use of speech; visual perception and construction; calculation ability; attention (information processing); memory; and executive functions such as planning, problem-solving and self-monitoring.

**Cognitive Impairment**—Changes in cognitive function that place an individual's level of performance below the expected range for his/her age. Some degree of cognitive impairment occurs in approximately 50-60 percent of people with MS, with memory, information processing and executive functions being the most commonly affected functions. See Cognition.

**Cognitive Rehabilitation**—Techniques designed to improve the functioning of individuals whose cognition is impaired because of physical trauma or disease. Rehabilitation strategies are designed to improve the impaired function via repetitive drills or practice, or to compensate for impaired functions that are not likely to improve. Cognitive rehabilitation is provided by psychologists, neuropsychologists, speech/language pathologists and occupational therapists. While these types of specialists use different assessment tools and treatment strategies, they share the common goal of improving the individual's ability to function as independently and safely as possible in the home, school and/or work environment.

**Disability**—As defined by the World Health Organization: a disability (resulting from an impairment) is a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being.

**Discrepancy**—Difference between two abilities (usually indicated by tests that are designed to measure different abilities).

**Duty to Accommodate**—In education there is a duty to accommodate the needs of students with disabilities to allow them to access educational services equally, unless to do so would cause undue hardship.

**Inclusive Education**—Inclusive education refers to the placement of children of varying abilities within the same classroom. This concept is based on the belief that every child should have the opportunity to be educated in the least restrictive environment in which his or her needs may be appropriately addressed.

**Individualized Education Program (IEP)**—A written document developed and implemented by a team, outlining a plan to address the individual learning needs of students.

**Informed Consent**—Agreement in writing from parents that they have been informed and understand procedures and potential outcomes (permission from a parent or guardian is voluntary).

**Modification (as used in the school system)**—Changes in the delivery, content, and/or instructional level of a subject or test.

**Neuropsychologist**—A psychologist with specialized training in the evaluation of cognitive functions. Neuropsychologists use a battery of standardized tests to assess specific cognitive functions and identify areas of cognitive impairment. They also provide remediation for individuals with MS-related cognitive impairment.

**Occupational Therapist (OT)**—Occupational therapists assess functioning in activities of everyday living including dressing, bathing, grooming, meal preparation, writing and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coordination, (3) adaptations to the home and work environment, including both structural changes and specialized equipment for particular activities, and (4) compensatory strategies for impairments in thinking, sensation, or vision.

**Referral**—Written request for assessment to see if the child meets eligibility criteria for special education and related services to benefit from his/her general education program.

**School Psychologist**—A psychologist employed by the school board who is specialized in evaluating a student's learning potential, identifying learning disabilities, and recommending appropriate interventions and/or accommodations at school.

**Special Education**—Specifically designed instruction to meet the needs of eligible students whose educational needs cannot be met through modification of the regular instructional program; provides for a range of options for services available to students enrolled in public schools.

**Speech-Language Pathologist (SLP)**—Speech-language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a SLP for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

For a list of MS related or medical terms please see the Glossary of Terms in the MS Society publication, *Kids Get MS Too: A Guide for Parents* <http://mssociety.ca/en/pdf/kidsgetmstoo.pdf>

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## How to reach the MS Society of Canada

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### Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.