



*The National Multiple Sclerosis Society...
One thing people with MS can count on.*

KIDS GET MS TOO: Questions and Answers

*A Publication of the Multiple Sclerosis Society of Canada and
the National Multiple Sclerosis Society*

This FAQ is available in both U.S. and Canadian versions.
This is the Canadian version.

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Introduction

Kids Get MS Too: Questions and Answers is an information guide on pediatric multiple sclerosis for MS Society staff and volunteers, parents of children with MS, health professionals and others with an interest in this topic. Information in this handbook was adapted from *Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS (2003)*.

This guide is brought to you by *Young Persons with MS: A Network for Families with a Child or Teen with MS*. The Network is a collaborative effort of the Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (NMSS).

We hope this material will be a useful and to-the-point resource. If you have other questions that you would like to see answered in this material, or if you have any comments on the present material, please e-mail us at kidswithms@mssociety.ca.

If you have questions or would like further information on your child's MS, please contact the National Information Resource Center of the MS Society at 1-866-922-6065 or e-mail kidswithms@mssociety.ca. For further information on the *Young Persons with MS Network* you may also contact childhoodms@nmss.org or 1-866-543-7967.

The Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (NMSS) are proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information, consult a qualified physician.

Neither the MS Society of Canada, nor the National MS Society approve, endorse or recommend products, therapies, services or manufacturers. The Societies assume no liability whatsoever for the contents or use of any product or service mentioned.

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.

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.

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GENERAL QUESTIONS ABOUT PEDIATRIC MS

1 What is MS?

Multiple sclerosis (MS) is an unpredictable, at times disabling, disease of the central nervous system (CNS). MS is thought to be an **autoimmune** disease that affects the CNS, which is made up of the brain, spinal cord, and optic nerves.

When a person has MS, the immune system, which usually works to protect the body from disease-producing organisms, mistakenly attacks the body's own tissue. The primary target of this attack is **myelin**, the protective coating around the nerve cells in the CNS that facilitates nerve conduction. The nerve cells themselves can also be damaged. The attacks on myelin produce scarring at multiple sites in the CNS, and it is these scars that give the disease its name. The scars, in turn, begin to slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS.

2 Do children get MS? How common is MS in children?

MS is usually considered to be a disease of young adults. However, a few studies indicate that about 2.7-5% of individuals with MS are diagnosed before their eighteenth birthday. The majority of children with MS are between the ages of 10 and 17, but some have been diagnosed younger than five years of age, as early as three or four years old.

Many adults with MS report experiencing recurrent symptoms in childhood or adolescence that may have been initial manifestations of the disease. This raises the possibility that the diagnosis of MS in children is often delayed until more symptoms occur in adulthood. The more timely diagnosis of patients who develop MS before 18 years of age may lead to an apparent increased incidence of pediatric MS.

3 What causes MS in children?

We do not yet know the answer to this question. The current thinking is similar to what we think about adult onset MS. It is believed that the disease appears in people who have a genetic predisposition, who also experience environmental triggers such as an infectious agent in the environment (e.g., virus or bacterium). Certain genes or combinations of genes seem to make one person more susceptible. While several different viruses and bacteria have been studied for their possible role in MS, the trigger(s) have not yet been found.

4 **Is MS a fatal disease?**

MS is not a fatal disease for the vast majority of people with MS. Most people with MS can expect to live a normal or near normal life span, thanks to improvements in the treatment of symptoms and in MS therapies.

5 **What happens when someone gets MS?**

Misguided immune cells enter the central nervous system (CNS), causing inflammation in the brain, spinal cord, and/or optic nerves. This inflammation can cause damage to the protective myelin coating around the nerve cells, producing scars (also called **plaques** or **lesions**) that interfere with nerve transmission. Some of these scars are responsible for the various symptoms of MS. In addition, patients with MS experience symptoms (such as fatigue and cognitive impairment) that are not directly related to the individual lesion.

Each person's symptoms will vary depending on the particular location(s) where the scarring (**demyelination**) occurs. The possible symptoms of MS include: fatigue, changes in vision, stiffness, weakness, imbalance, sensory problems such as numbness, tingling, and pain, changes in bladder and/or bowel function, changes in sexual response, emotional changes, speech difficulties, and problems with thinking and memory. In the adult population, we have seen that most people develop only a few of these symptoms over the course of their MS and most are able to manage their symptoms in relative comfort.

6 **What are the types of MS in children?**

We see different disease patterns in MS: relapsing-remitting, primary-progressive, secondary-progressive, progressive-relapsing, benign MS and malignant MS. Virtually all children start with a *relapsing-remitting* course, characterized by clearly defined attacks (relapses) of symptoms that subside (remit) on their own or with treatment. During the periods of remission, there are no new symptoms or progression of the disease. Other forms of MS are rarely seen in children.

7 **Is MS in children different than MS in adults? How?**

The symptoms of MS are similar in both children and adults. However, some young persons with MS have symptoms which adults rarely experience. These symptoms include malaise, irritability and low-grade fever at the time of disease.

It is not yet known what the impact of the disease would be on the developing central nervous system of a young person with MS. The early onset of MS may have an impact on learning ability. Children with MS may experience difficulty with school performance, particularly with respect to concentration and short-term memory.

8 Is there a cure for MS?

There is no cure for MS at the present time. Because we do not yet know the underlying cause of the disease, it is very difficult for scientists to develop treatments to prevent it or make it go away. More has been learned about the disease process in MS over the past decade than in all the preceding decades combined. We have also learned a great deal about slowing the progression of the disease and helping people manage their symptoms.

Most people with MS can expect to live very close to a normal life span like everyone else.

9 Will a child with MS become severely disabled?

MS varies greatly from person to person, so it is hard to predict what will happen to your child. The statistics from the adult population tell us that two out of three people with MS remain able to walk, although some may need the help of a cane or other assistive device. It might be reassuring to know that some studies suggest that children progress to secondary progressive MS much more slowly (50% after 23 years) than adults (50% after 10 years). For information on the different types of MS see our website: www.mssociety.ca or consult our publication, *MS: Its effects on you and those you love*.

10 What is new in research? Is there research specific to pediatric MS?

Every day, researchers are learning more about MS in adults and zeroing in on ways to prevent it. MS Society of Canada-funded researchers are targeting areas like repairing or growing myelin, blocking immune system attacks, genetic susceptibility, MRI studies, and health research. There is a new interest in pediatric MS among researchers and clinicians in Canada, Europe, and the United States.

In Canada, the MS Scientific Research Foundation is currently funding a \$4.3 million, multi-centre study of children who have had an initial attack, called a clinically isolated syndrome (CIS). This five-year study, launched in May 2004, will follow the children to find out which ones

go on to experience a second attack, which would then be considered clinically definite multiple sclerosis. This study may also identify the key triggers which cause multiple sclerosis. The Foundation is related to the MS Society of Canada.

11 Is MS contagious? If I have MS, will my child get it too?

MS is not contagious, nor is it directly inherited although research studies now underway suggest that genetic factors make certain people more susceptible to developing MS. The risk is higher in families in which there are several family members who have the disease. The average risk for any person in the general population is one in 750. The risk for the child of a parent with MS rises to one in 40. Although this represents a significant increase, the absolute risk remains fairly low.

12 How is the MS Society of Canada helping families and children with MS?

The Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (US) have joined together to offer a support network called ***Young Persons with MS: A Network for Families with a Child or Teen with MS***. This network provides multiple program options for families living with a child or teen who has been diagnosed with MS. The network assists children with MS (18 or younger) and parents of a child or teen with MS.

13 What programs and resources are available for parents and children with MS through the Young Persons with MS Network?

The Network provides a wide spectrum of programs:

Education: The Network provides educational programs and written materials for children and their parents about childhood MS. The Network also introduces families to specialists working in the field of childhood MS.

Kids Get MS Too: a Guide for Parents Whose Child or Teen has MS is a handbook made available through *The Young Persons with MS Network*. It is written by specialists in pediatric MS, and contains an invaluable breadth of information for parents of children with MS. You can obtain a copy of this handbook from your local chapter, from the National Information Resource Centre or download it from the MS

Society's web site
(<http://www.mssociety.ca/en/pdf/kidsgetmstoo.pdf>).

Mighty Special Kids is an activity book for kids aged 5 to 12 who have multiple sclerosis. The book helps families talk about MS and includes games, interviews with kids who have MS, and family activities. You can request a copy of this booklet from your local chapter, division office, or from the National Information Resource Centre.

Information and Referral: Parents can receive information about MS and local resources from the chapter in their area. For information more specific to childhood MS, families can use a toll free number to learn more about the Network and other available resources.

Emotional Support: Parents can gain emotional support through a variety of programs and services including individual parent or family support and group support programs.

Connecting Families: The Network connects parents through an e-mail list where they can share concerns and information, and develop a support network.

14 Who do I call to sign up for the Network or to find out more about it?

For information specific to Canada, please contact the **National Information Resource Centre Coordinator** of the Multiple Sclerosis Society of Canada:
175 Bloor St E, Suite 700
Toronto, ON M4W 3R9
1-866-922-6065
kidswithms@mssociety.ca

For more information or to register for the Network for Families, please call 1-866-KIDS W MS (1-866-543-7967) or e-mail childhoodms@nmss.org

15 What other resources and publications are available for families whose children have MS?

For information on other publications and specific resources, please contact your local chapter or division office. You may also contact the National Information Resource Centre Coordinator of the Multiple Sclerosis Society of Canada at 1-866-922-6065 or e-mail at kidswithms@mssociety.ca.

Your local MS Society Chapter or Division may also have financial assistance programs for individual diagnosed with MS. Contact our local office for more information on such programs.

16 **Is there a clinic specialized in pediatric MS in Canada?**

The Pediatric MS Clinic at the Hospital for Sick Children in Toronto is the only official pediatric MS clinic in Canada at this time, however several other centres are expanding their interest in pediatric MS. The Pediatric MS Clinic at the Hospital for Sick Children (also known as Sick Kids) provides comprehensive assessment, treatment, education, and support of children and adolescents diagnosed with multiple sclerosis and their families. The clinic takes place twice a month and is run by a team of healthcare professionals with expertise in childhood MS.

For general inquiries about the Pediatric MS Clinic and the services provided, please contact:

Jennifer Boyd, Clinical Nurse
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Phone (416) 813-7738
E-mail:
jennifer.boyd@sickkids.ca

Lynn MacMillan, Clinic Nurse
Phone (416) 813-7355
E-mail:
lynn.macmillan@sickkids.ca

Physicians requesting a consultation with the medical director about medical management of pediatric patients with MS, please contact:

Dr. Brenda Banwell
Phone: (416) 813-6660
E-mail: brenda.banwell@sickkids.ca

DIAGNOSIS AND TREATMENT

17 **How is a diagnosis made in pediatric MS?**

Formal diagnostic criteria specific to pediatric MS are currently being developed by an international working group, of which Canada plays a leading role. Up until now, the criteria for making a diagnosis of MS in children has been the same as that for adults. The doctor must be able to find evidence of at least two separate and distinct neurologic events (attacks), which occurred at least one month apart and in different areas of the brain and/or spinal cord. The doctor must also be able to

rule out all other possible explanations for those attacks and the symptoms they caused. It is important to rule out other childhood disorders.

Here are some of the ways a doctor may try to determine a diagnosis:

- **Medical history** – a careful review of past symptoms and/or medical events;
- **Neurologic exam** – an examination of reflexes and coordination among other subtle neurologic indicators;
- **MRI** -this technology allows the physician to see areas of demyelination in the brain and spinal cord. Repeated MRI scans, done several months apart, are used to show separate episodes of disease activity.
- **Laboratory tests** – Sometimes, additional evidence is needed to show that more than one attack has occurred. Thus, even if a youngster has only had one attack, or is only experiencing one symptom, abnormal responses on these tests can provide evidence of a second area of demyelination in the brain.
 - An examination of the cerebrospinal fluid (CSF) -- a fluid that is made in the brain and normally bathes both the brain and spinal cord, may be helpful in diagnosing MS and ruling out other possible diseases.
 - Evoked potentials (EPs) allow doctors to evaluate how well nerves are sending messages that are “evoked” (stimulated) by various types of stimuli, such as a flashing light. If any of CNS pathways have been injured by demyelination, they will not send messages as quickly as they should.

18 **What are the special challenges of diagnosing MS in children?**

It is not uncommon for children to have a single neurological episode known as acute disseminated encephalomyelitis (ADEM). ADEM most often follows a viral illness or some other event such as a vaccination or immunization. One of the challenges for the doctor is to determine if the current neurological episode is caused by a condition that is likely to get better on its own (such as ADEM), or is the beginning of a chronic disease that requires ongoing treatment. While ADEM presents some symptoms and signs similar to that of MS, youngsters with ADEM are more likely than those with MS to have fever, headache, nausea and vomiting before the onset of their neurologic symptoms. They may also become very irritable or sleepy, or develop seizures.

In short, pediatricians and pediatric neurologists have been reluctant to diagnose MS in children and teens for several reasons:

- ADEM is much more common than MS in childhood.
- MS has traditionally been thought of as a disease of adulthood.
- Childhood MS is seen so rarely by most doctors that the signs and symptoms go unrecognized.

19 Is it important that children and teens be told their diagnosis?

Parents sometimes wonder if they should delay telling their child or teen about the MS diagnosis. There are very good reasons for talking about the diagnosis openly.

- Children and teens know when they don't feel well; they are also very sensitive to their parents' moods and state of mind. Without an open and honest explanation of what is happening, they will use their own imaginations to fill in the blanks—and what youngsters can conjure up with their imaginations is almost always even scarier than the reality.
- Many children, particularly the younger ones, don't have the vocabulary or concepts they need to express their concerns or ask their questions. When parents talk openly with their children about MS, they are giving their children the vocabulary they need to say what's on their minds, as well as permission to say it.
- Additionally, youngsters with MS are going to have ongoing relationships with a variety of healthcare professionals; they are also going to be undergoing periodic medical examinations, evaluations, and tests of various kinds. Open, comfortable communication with these professionals, geared to the child's age and level of understanding, will promote a trusting relationship and help make these experiences less frightening.
- Finally, children and teens need to be included in decisions about their care. When children are included in their own treatment planning, they are more likely to take medication and other therapies that are recommended.

20 Are there treatments available to children with MS?

Yes. Treatments that reduce the number of MS attacks are available to children. The treatments work by modifying the immune system response, which reduces immune activity, thereby decreasing some of

the destructive activity in the CNS. The four main treatments – Avonex® , Betaseron® , Copaxone® , and Rebif® – are injectable medications. They have been shown to reduce the annual relapse rate by approximately 30-35%. There is also an additional treatment called Novantrone® (mitoxantrone), which is used in a very select group of pediatric MS patients who have more frequent attacks associated with early signs of progressive disability. Use of this treatment carries greater risk.

As well as the disease-modifying treatments, there are medications to manage acute MS attacks, such as corticosteroids. The goal of corticosteroids is to improve symptoms and shorten recovery time. Corticosteroids do not, however, change the long-term course of MS or have any known long-term benefits.

Finally, there are medications to deal with many MS symptoms.

21 Who treats children and teens with MS?

Individuals under the age of 18 with MS receive treatment from their pediatricians, family doctors, general adult and pediatric neurologists, and neurologists who specialize in MS. The reality is that very few physicians have much experience with this younger group of patients with MS, and you may or may not have anyone in your area that is familiar with pediatric MS.

If there are no MS specialists in your area, you have a couple of options: You can travel to an MS specialist for a consultation and take his or her recommendations back to your local physician (please see 'Resources' Section for Pediatric MS Clinic contacts). Or your physician can consult with an MS specialist physician by contacting the Pediatric MS Clinic at the Hospital for Sick Children in Toronto.

The important thing to remember is that there are resources available to help you clarify your child's diagnosis, and/or find the best possible treatment.

22 How can we deal with my child's discomfort with needles?

A child's comfort level with needles is closely tied to how health professionals handle the child's introduction to treatment injections. Child-centred techniques by experienced MS clinic professionals help children gain comfort and confidence with the injection process. If a child is taught with appropriate sensitivity, they will be more likely to

accept the need for injections and to stay on the treatment. Ideally, someone experienced in pediatric MS should be involved in the process.

23 Should my child take vitamins if they have MS?

There is no proven role for herbal remedies or vitamins with respect to multiple sclerosis. It is important to remember that too much of a vitamin can be toxic. Each child's nutritional requirements will be different, and your child's primary healthcare professional can best determine what would be most helpful to your child. Recent research suggests that vitamin D might be helpful. This should be discussed with your child's doctor.

24 A naturopath prescribed something to 'boost' my child's immune system. Is this okay?

No. It is important to be wary of alternative therapies, which claim to 'boost' the immune system. MS is an illness in which the immune system appears to be overactive. In theory, boosting your child's immune response could result in further damage to myelin. It is best to consult with your child's medical professional before using any alternative treatments.

25 What is a relapse?

A relapse (also known as an attack, exacerbation or flare up) is a sudden worsening of an MS symptom or symptoms, or the appearance of a new symptom or symptoms, lasting at least 24 hours and separated from a previous relapse by at least one month. Relapses usually last from several days to several weeks, although they may extend into months.

26 What is a pseudo-relapse?

A pseudo-relapse is a temporary increase in symptoms due to an outside stressor. The increase in symptoms disappears shortly after the stressor is removed. For example, someone might see an increase in symptoms during a bout with the flu or during hot weather. As the infection subsides and the person's body temperature returns to normal, the MS symptoms return to baseline.

EMOTIONAL ISSUES

27 **How common is depression?**

We know adults with MS are at a higher risk for depression than the general population or those with other chronic illnesses. This suggests that it may be a symptom of the disease itself, rather than simply a reaction to it. Depression and mood swings can be associated with MS in children. This is why it is important to work with a professional in pediatrics to determine what are normal mood swings and behaviours versus MS-specific ones. It's important to discuss depression and significant mood swings with your child's physician so that appropriate evaluation and treatment can be recommended. These problems are most effectively treated with some combination of education, supportive counselling and medication.

28 **What do we say to our other children?**

Siblings experience a host of feelings when their sister or brother is diagnosed with MS. For instance, they may experience fear about their future: What will happen to our family? Will I get MS? Why is this happening to our family? Will things ever go back to normal? Did I do something to cause this? Siblings may also resent losing their parent's attention and feel guilty about their resentment. Answering their questions in an age appropriate way and including them in conversations about MS may be helpful in their understanding and can contribute to their cooperativeness. Siblings are often quiet about their feelings and may need extra attention to voice what's on their minds.

29 **How do we cope as a family with MS?**

There are many different ways in which a family can cope. It is important to reach out for support. All of us do better when we are connected to others who understand and support us. Keeping the lines of communication open and family meetings are also helpful coping techniques for families. Holding on to hope is a powerful life force that sustains us. If you don't feel hopeful, seek out someone who is. Finally, having a spiritual sense about life can foster a connectedness to others, positive self-perception, and optimism about the future.

30 What is a parent's role in communicating with our child's healthcare professionals?

You and your child need to be able to communicate with the healthcare team. Depending on your child's age, you may have the dual challenge of helping the healthcare professional understand what your child is experiencing and helping your child understand what the professional is doing or saying.

31 What can we do to prepare our child for her/his interactions with healthcare professionals?

Very few of us are relaxed in the doctor's office, but your ability to remain calm and relaxed in spite of all the anxiety you are feeling will help your child to become more comfortable. As much as possible, find out what is likely to occur during the upcoming medical visit and prepare your child for what to expect from the visit. Talk with your child before the visit and find out what will help put him or her at ease. A child or teen-friendly environment can also be helpful in calming any fears your child or teen may have.

32 Adolescence is difficult enough! How do we help our child also cope with having MS?

Teenagers typically withdraw from parents and don't talk much about what's going on. Although it's difficult to separate typical adolescent turmoil from a reaction to having MS, it is possible. Listen carefully to what your teen says and be alert for signs of depression or cognitive problems (memory, attention span). Help your teen talk about what's bothering him or her. Often these conversations happen in the car and while running errands when teens are likely to open up. Counsellors at school, a favourite teacher, or someone your child trusts and respects can also be resources for your child to turn to.

33 What are some signs I should be looking for which tell me my child is having difficulty coping?

You may see changes in your child that could be related to issues of coping, depression, cognitive changes, or are a side effect of any medications he or she is on. Persistent sadness, feelings of hopelessness, a sense of worthlessness, loss of pleasure or interest in activities, sleep difficulties, and significant weight gain or loss are all symptoms of depression that demand attention. Some symptoms of depression such as difficulty with concentration or decision-making can

also overlap with symptoms of cognitive difficulties. A visit with a specialist may help in determining the cause of any challenges your child is experiencing.

34 Where can we go for support? What resources are available?

Your local chapter or division of the MS Society of Canada is knowledgeable about its mental health community, healthcare professionals, education referrals, and can answer questions about insurance. **Young Persons with MS: a Network for Families with a Child or Teen with MS** is also available to help you along the way with information, support and referrals.

35 How do I address my own feelings of inadequacy in dealing with MS?

Fear, anger, sadness, and worry are universal feelings for parents when their child has been diagnosed with MS. Many parents feel guilty and wonder what they did wrong. It is important to understand that there is nothing you could have done to have prevented your child's illness. Parents ride a roller coaster of feelings that is similar to that of their children but with the greater intensity that comes with knowledge and understanding. Know that you are not alone with your feelings. Get involved and learn everything that you can to empower yourself toward this disease which in turn will increase your competency skills.

36 Where do I find a qualified mental health professional?

For appropriate mental health referrals in your area, you may want to consult with your child's pediatrician or family doctor.

COGNITIVE ISSUES

37 What is cognition?

Cognition refers to the high-level functions that are carried out by the human brain. They include a person's ability to:

- Understand and use language
- Have a visual understanding of the world—*visual-spatial functions*

- Perform calculations
- Focus, maintain, and shift attention as needed—*information processing*
- Learn and remember information—*memory*
- Perform complex tasks involving organization, planning, decision-making, and problem-solving—*executive functions*

38 What is known about how MS affects cognition problems in children and teens with MS?

At this time, little is known about the ways in which MS affects cognition in children and adolescents. Fortunately, ongoing research efforts will help enhance our understanding of this important aspect of pediatric MS. Some clinicians have speculated, based on the fact that the child's brain is not fully developed, that children with MS may be especially vulnerable to cognitive impairment.

Clinical experience to date suggests that the frequency of children showing cognitive deficits is similar to adults. Thus, it is important to highlight that not all children and adolescents with MS will demonstrate cognitive problems. While some children and adolescents have no problems, others develop varying degrees of difficulty ranging from mild to moderate.

39 What are some of the cognitive problems my child might experience?

In adult MS, research has shown that approximately 50% of patients experience some cognitive deficits. Sometimes, however, the cognitive changes are subtle enough to escape notice in everyday interactions. For this reason, patients, family members, and healthcare professionals may be slow to recognize these changes. Memory, attention, speed of information processing, and verbal fluency are the most frequently impaired functions. Reasoning, planning, and visual perception are also impaired in some people. Changes can affect your child's performance in school. Older children's ability and interest in socializing with their peers is sometimes affected.

40 What type of progression of cognitive symptoms can we expect?

Cognitive symptoms, much like sensory and motor functions, may fluctuate along with clinical relapses. Just as sensory and motor

functions generally improve following an acute relapse, cognitive skills are likely to as well. Some deficits, however, may remain.

Unfortunately, the overall progression of cognitive problems is not entirely understood at this point. Preliminary findings from individual case studies suggest that in some people cognitive deficits may become worse in as little as a year. In general, however, worsening of symptoms is likely to be related to a number of factors, including the length of time the person has had the disease and the severity of disease activity.

Disease severity may be indicated by the frequency and number of relapses, the total lesion area as seen on MRI, and the particular areas in which the lesions occur. Research suggests that disease-modifying drugs may help slow the worsening of symptoms – including cognitive changes.

41 Can steroid treatments affect cognition?

Steroid interventions used during the acute treatment of relapses are known to affect cognition in adults. For example, problems with attention and memory are common during steroid treatment. However, as with the adult population, these are only temporary medication side effects that will lessen as your child is tapered off of these medications.

42 What is a neuropsychological evaluation?

A neuropsychological evaluation is a comprehensive assessment of cognitive and behavioral functions using a set of standardized tests and procedures. Various mental functions are systematically tested, which may include but are not limited to: problem solving and conceptualization, planning and organization, attention, memory, and learning, language, perceptual and motor abilities, emotions, behaviour, and personality.

43 How do I know if and when my child should have a neuropsychological evaluation?

If your child is reporting or showing signs of cognitive difficulties (such as those mentioned in #39), a neuropsychological evaluation is appropriate. Sometimes your child may not be a good judge of his/her cognitive abilities and limitations. Often family members and/or teachers recognize cognitive problems that are not apparent to the

child. If you or your child's teacher have observed changes in your child's cognitive functioning, a referral to a neuropsychologist will be helpful. The neuropsychological report should include specific recommendations tailored to each child regarding strategies (restorative or compensatory – see # 52) that will help your child overcome cognitive limitations. Look into your private insurance coverage to see if it will help cover neuropsychological evaluations.

44 **Why is a neuropsychological evaluation helpful?**

Even if cognitive changes are not evident, a neuropsychological evaluation may be helpful for several reasons.

- Cognitive changes are often subtle, worsening gradually over time. Therefore, it may be difficult to observe them in casual interactions and a neuropsychological evaluation may be more sensitive to subtle decline.
- Neuropsychological evaluations rely on standard data to make comparisons regarding how well an individual is performing relative to age-matched peers. For this reason, deficits may be difficult to detect in children who are very high functioning. That is to say, those who once had excellent memory, a performance in the "average range" may represent a relative decline for them. Thus, another function of the neuropsychological evaluation is to establish a baseline level of functioning for your child, with which to compare future results should he or she experience any cognitive decline in the future. Deciding to go for a neuropsychological evaluation may be a prudent decision even if a child does not show cognitive deficits.

45 **How common are memory problems for children with MS?**

Among the children reporting cognitive changes, memory problems are perhaps the most common complaint. This likely reflects the fact that memory problems are among the most easily observable deficits and with the most immediate negative feedback. For example, these children will have difficulty remembering conversations and forget to do chores or will be unable to remember teachers' lectures or to keep track of assignments. It is important to note, however, that attention plays an important role here as well. For example, children who have difficulty paying attention will encode and store less information, and thus report poor "memory" for that information.

Neuropsychologists often consider memory as having three components:

- Encoding—which involves the initial learning of the information.

- Storage—which involves holding it there for a period of time.
- Recall—which involves accessing the information at a later time.

Children and adolescents with memory problems may have difficulty with one, two, or all three of these steps. Thus, they may have difficulty learning information, have increased rates of forgetting in comparison to other children, or be unable to report information without cueing or prompting. Children may have difficulty with memory for verbal information (information they hear), as well as visual information (information they see).

Children with deficits in verbal memory will have trouble remembering what they are told—a class lecture, for example. Children with deficits in visual memory may have difficulty remembering where they put their school books or their keys, or may get lost more easily, especially when in unfamiliar neighbourhoods or buildings. This latter point is an important consideration for teenagers who may soon be getting their driver's license.

46 Will my child experience any language deficits?

Language deficits in children and adolescents, like the deficits seen in adults, tend to be quite subtle. They are generally related to speed of information processing and usually involve a reduction in fluency (the speed with which language is produced). As a result, these children may speak more slowly than before.

They may also exhibit “naming” deficits (also referred to as “word finding” problems) in which the word is “on the tip of their tongue” but they can't produce it. Adults or children with these kinds of deficits may say a related (but incorrect) word in place of the target word (e.g., sister rather than brother), or “talk around” the word, using unnecessarily indirect and wordy speech to explain something that could be stated with one or two words. This is often referred to as “circumlocution.” Such language deficits can cause embarrassment and frustration in social situations or when speaking aloud in school.

47 How might the visual-spatial functions be affected in pediatric MS?

The term “visual-spatial functions” does not refer to visual acuity (correctable with eyeglasses), but rather how one's brain interprets and works with visual information. These functions may include the ability to judge angles and distances, and comprehend how objects

relate to one another or are put together. Deficits in these areas can cause trouble with tasks such as reading maps, drawing, and/or building things. These functions have not yet been extensively evaluated in children with MS.

48 How might my child's motor functions be affected?

When MS affects the ability to walk, it is quite apparent. More subtle however, are the problems with fine motor coordination that may be caused by the disease. When manual dexterity is affected, these children may exhibit slowed movements and/or tremors that affect their ability to complete certain kinds of tasks. For example, handwriting may be adversely affected and hobbies such as building models or competing in sports that require fine motor coordination may become more challenging.

49 Will my child become physically disabled if he/she has a cognitive disability?

In adults with MS, level of physical disability is only slightly related to level of cognitive disability. In other words, a person can have significant physical symptoms without any cognitive symptoms whatsoever, while someone with little or no physical impairment can have significant cognitive problems. In fact, cognitive changes can even be the first symptom of MS to appear.

50 How might my child's attention level be affected?

Typically, simple attentional tasks such as focusing briefly to repeat a phone number are not a problem for children and adolescents with cognitive issues related to MS. However, as tasks become more complex, these children may have more difficulties. For example, attentional problems may not be observable in a child with MS who is speaking one-on-one with someone in a quiet environment. Unfortunately, real world environments tend to be more complex. Classrooms are often noisy, with multiple distractions. Children with MS may be at an increased disadvantage when required to focus their attention in the face of distractions.

In addition, these children may have trouble with "working memory"—the ability to hold information in mind while working on it. This ability is necessary, for example, when performing mathematical computations that require "carrying" numbers, or other more complex operations. Also, the speed at which information is processed can be

adversely affected, necessitating longer time to think about responses in general. People with MS may become fatigued very easily when performing demanding tasks (either physical or cognitive). This fatigue may intensify the attentional problems as well as other cognitive deficits.

51 What can be done about my child's cognitive deficits in the school setting?

Academic accommodations refer to modifications in school curriculum, environment, and specialized services in school (or outside of school where necessary) to help the school system meet the needs of the child based on the nature and extent of the specific deficits they have. For example, when children or adolescents display attentional deficits, they are often provided with preferential seating in class (e.g., placing the child near the teacher at the front of the room). This simple accommodation helps the child in two ways. First, it minimizes the distractions the child faces (i.e., the child need not look through a sea of 20 other students to see the teacher). Second, having the child sit up front allows the teacher to more easily monitor the child's level of attention and engagement in the classroom activities. This allows the teacher to reorient the child when necessary.

Due to attentional problems as well as reductions in the speed at which these students process information, modifications to test settings are also common. A child who experiences problems with attention or concentration may perform better when placed in a quiet, distraction-free environment (such as a resource room) when completing tests. Furthermore, extended time limits to complete tests addresses processing speed issues as well as any physical challenges that may exist and allows the child the best opportunity to demonstrate his or her level of mastery of the material. These modifications are often applied not only to classroom tests, but also to standardized examinations.

Memory deficits obviously have serious implications for learning. As these children often display "retrieval deficits" (i.e., poor access to information stored in the brain), they are greatly aided by recognition measures. Therefore, a multiple choice test may be the best format for these children to show what they have learned. Such modifications can often be made for children with memory deficits.

52 What is cognitive rehabilitation and would it be of benefit to my child?

Cognitive rehabilitation refers to behavioural interventions geared toward improving cognitive functioning. Generally speaking, there are two types of strategies employed—*restorative* and *compensatory*. Restorative techniques involve repetitive practice of certain tasks to strengthen the functions involved. Compensatory strategies refer to learning new skills to replace skills that have been lost (e.g., learning to keep lists or use a day planner to avoid forgetting assignments). Also, mnemonic strategies (memory tricks) are often taught to enhance memory functions in various settings.

Cognitive rehabilitation (typically with a neuropsychologist, occupational therapist, or speech-language pathologist) is available at most major medical centres. At this time there are only a few studies supporting the use of cognitive rehabilitation in adult MS and no studies examining its effectiveness in children and adolescents. However, it is expected that these techniques will be effective when specific cognitive functions are targeted and specific skills are taught to address real world problems.

53 How do we prepare for the unknown?

It is important to keep in mind that while a child or adult with MS can experience a change in any of these cognitive functions, many people do not experience any of these symptoms and others may experience symptoms in only one or two functional areas. The key to dealing with cognitive changes is to recognize them when they develop and find ways to minimize their impact on daily life.

EDUCATION ISSUES

54 **What are my child's rights in the education system?**

In Canada, education is the responsibility of each province and territory. Information regarding special education, special assistance, or accommodations within the classroom should be available through your child's school. However, each province/territory has a department or ministry of education which can also be contacted for information on your child's rights. For this contact information, please see either *Kids Get MS Too: a Guide for Parents Whose Child or Teen has MS* (available through the MS Society of Canada), or contact the MS Society of Canada.

55 **Who can advocate for any changes that need to be made for my child at school?**

Your child has a right to an education. As a parent, you may well find yourself needing to advocate for your child in his or her academic setting. With the assistance of healthcare professionals who are providing treatment, you will have the job of helping the school understand and respond to your child's needs. The more you understand the symptoms your child is experiencing, the better prepared you will be to help others understand them.

56 **My teenager plans to go to university. Are there any resources out there for young persons with MS related to financial assistance or accommodation in a post-secondary setting?**

Yes. The National Education Association of Disabled Students (NEADS) provides information on services and programs for students with disabilities nation-wide, including information on financial assistance and accommodations which exist for people with disabilities.

NEADS

Room 426, Unicentre
Carleton University
Ottawa, Ontario K1S 5B6
Tel.: (613) 526-8008 (Voice / TTY)
Fax: (613) 520-3704
E-mail: info@neads.ca
Web Site: www.neads.ca

INSURANCE AND FINANCIAL ASSISTANCE

57 How can I afford my child's medications?

As parents of a child with MS, you know that your child needs health insurance coverage to finance his or her health care. Most people have coverage for their dependent children through their employer-based plans or other group coverage. Nonetheless, parents should be aware that factors affecting their own eligibility for coverage, such as a change of employers or employers' change in health plans, reduction in work hours, marriage or divorce, relocation out of province, or death, can have a major impact on their child's ability to access the care they need. Your goal should be maintaining coverage without interruption, no matter what changes occur in your employment, insurance or circumstances.

58 Is there any financial support available?

The treatment drugs are very expensive and if your private insurance does not cover your child for these medications, your provincial government may help subsidize the cost. The level of reimbursement for the treatment medications and access criteria varies from province to province. For more information, see the document *Overview of provincial government coverage for MS disease-modifying therapies* at www.mssociety.ca. Or, contact your nearest division office at 1-800-268-7582, or your provincial government program office at:

Alberta

Alberta Blue Cross: 1-800-661-6995

British Columbia

Pharmacare Special Authority Process: 1-800-554-0250 or (250) 952-2866

Manitoba

Pharmacare Exceptional Drug Status: 1-800-297-8099 or (204) 786-7141

New Brunswick

MS Prescription Drug Program: 1-800-332-3692

Newfoundland

Prescription Drug Program: (709) 729-6507

Nova Scotia

Special MS Therapy Program MS Clinic: (902) 422-7817

Ontario

Trillium Drug Program or ODB Drug Program: 1-800-268-1154
or (416) 326-1558

Prince Edward Island

MS Program: 1-877-577-3737

Québec

Régie de l'assurance maladie du Québec (RAMQ) – service de l'expertise pharmaceutique:

Québec : (418) 646-4636 (for Quebec Region)

Montréal : (514) 864-3411

Other parts of Québec : 1 800 561-9749

Saskatchewan

MS Drugs Program: (306) 655-8400

The manufacturers of the four disease-modifying therapies have patient support programs and financial assistance programs that might apply to your case. You may want to talk to your MS Clinic nurse about these programs.

While the MS Society of Canada does not assist with any medical expenses, there may be some other financial assistance available through either equipment funding or a special assistance program. For instance, the MS Society of Canada may be able to assist with some transportation costs to a Pediatric MS Clinic, or may be able to refer you to other resources in your province. To find out more, contact the MS Society of Canada at 1-800-268-7582. Please note that services offered by the MS Society vary from region to region across the country based upon local needs and available resources.

59 What is the 'Child Disability Benefit' and will my child be eligible for this?

The 'Child Disability Benefit' is a governmental benefit for low and modest income families to help them with costs of raising children under 18 who have a severe and prolonged mental or physical impairment. Because of the definition of disability in this case, only children with MS who have severe disabilities would qualify for the benefit.

Individual provinces may offer additional benefits. Please contact your division office for information.