



MassGeneral Hospital
for Children

Pediatric Multiple Sclerosis Information Guide

Partners Pediatric Multiple Sclerosis Clinic

MGH Pediatric MS Center
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Welcome

The Partners Pediatric Multiple Sclerosis Center is dedicated to the care of children and adolescents with Multiple Sclerosis and related demyelinating disorders such as acute disseminated encephalomyelitis (ADEM). We are located at one of the world's leading clinical and research hospitals, the Massachusetts General Hospital for Children in Boston, Massachusetts. Our staff specializes in the treatment of children with MS, and is dedicated to providing our patients with state of the art care.

The Partners Pediatric MS Center is a multi-disciplinary clinic. This means that your child will be cared for by a team of health care workers. Our team is led by a neurologist. The team also has a neuropsychologist, school liaison, psychologist, psychiatrist, and nurse. Our neuropsychologist and school liaison worked together to help us find out how your child learns. When needed they can help obtain school accommodations for children. Our psychologist is available to work with children and their families with the assistance of our psychiatrist when needed. In addition, our team has physical, speech, and occupational therapists, neuro-ophthalmologists, and radiologists ready to help in your child's care.

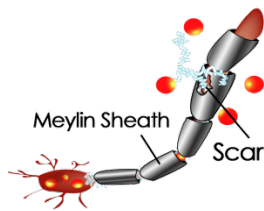
In addition to providing excellent patient care, we also are active in researching MS. Research is important to help us better understand and treat Pediatric MS.

We have been selected as one of nine regional [Pediatric MS Centers of Excellence by the National Multiple Sclerosis Society](http://www.npmssc.org) (www.npmssc.org). We work with the other Centers and the National Multiple Sclerosis Society as part of a network to provide comprehensive care and to conduct clinical research related to childhood multiple sclerosis. We have also established research collaborations with other international Pediatric MS Centers.

We hope this binder will help provide you with helpful information about MS. You may also use this binder to help keep your medical records organized. Please feel free to bring your binder with you to each clinic visit.

About Pediatric MS

Multiple Sclerosis (MS) is thought to be an autoimmune disease that affects the brain and spinal cord. White blood cells, which are part of the body's immune system normally fight infection. In MS, these white blood cells become mis-



programmed or confused and attack the brain and spinal cord. These white blood cells damage the nerves (neurons) and their myelin coating. Damaged myelin forms scars tissue (sclerosis) which gives the disease its name. MS is often referred to as a demyelinating disease. The damage to the nerves and their myelin coating cause the many different symptoms that affect

people with MS. Symptoms include weakness, numbness, tingling, dizziness, and blurred or double vision.

MS affects about 250,000 people in the United States. While MS usually starts in patients 20 to 30 years of age, we think that about 5% of all MS cases start in children or adolescents.

Children with MS experience many of the same symptoms that adults do. However, it can sometimes be harder for children recognize and tell us about these symptoms. This is why it is important for children with MS to have regular exams by a neurologist. We have also found that children can have more frequent relapses than adults.

Care of a child or adolescent with MS requires a multidisciplinary team, which includes evaluation by a neurologist, as well as neuropsychologist and other caregivers. We recognize that MS can affect multiple parts of a child's life. For this reason, we offer supportive services such as physical therapy, psychological support and educational support. We believe these services will be important in each child's long-term care plan. Our goal is to work with your child and your family to find the best way to manage your child's condition.

Clinical Signs and Symptoms

Relapsing-remitting MS is the most common form of MS. Over 90% of children with MS have relapsing-remitting MS. Children with relapsing-remitting MS follow a pattern in which they develop symptoms as part of a relapse. Symptoms get worse over a few days, stabilize, and then usually get better after a few weeks.

Optic neuritis is a common presenting symptom of multiple sclerosis. As a result, patients, may complain of pain with eye movement and decreased vision in the affected eye. Other common symptoms include double vision, numbness and tingling. Parents may observe slurred speech, limb weakness, clumsiness, imbalance as well as bowel and bladder symptoms. These symptoms can completely resolve or one may remain with a partial deficit.

Additional symptoms common to patients with MS include fatigue, heat intolerance, depression, and spasticity. Children can be affected by one or more of these symptoms. Younger children in particular may not readily recognize these symptoms as abnormal, which can lead to delays in diagnosis.

Over time, a relapsing-remitting disease course can convert to a secondary progressive course in which symptoms do not get better or go away. The ultimate goal of therapies in MS is to prevent progressive disability. There is increasing evidence showing that children develop progression slower than adults, however this may vary from patient to patient.

Diagnosis

The diagnosis of MS in children is based on clinical attacks and MRI evidence of typical lesions. The International Pediatric MS Study Group has published consensus criteria which help to guide clinicians in the diagnosis of MS in children and adolescents (see Neurology Journal supplement, April 2008).

MRI imaging of the brain and spinal cord is a valuable tool to establish an early diagnosis and monitor disease progression. MRIs are relatively safe tests which take pictures of the brain and the spinal cord. The MRI pictures shown in **figure 1** demonstrate areas of demyelination (plaques) in the cervical spinal cord and in the brain (**figure 2**).

It can be helpful to have an infusion with a dye called gadolinium given during an MRI through an IV. The dye can help us see if lesions are "active" (have enhancement).

Additional testing may be required to establish the diagnosis of MS. Lumbar punctures are performed to sample the cerebral spinal fluid (CSF) and to examine it for evidence of inflammation. We also look for the presence of oligoclonal bands or an elevation of a test called the IgG index which shows that an immune reaction is taking place in the brain. Visual evoked potentials may be obtained to examine if there is evidence of previous damage to the optic nerve from a demyelinating event. At times, brainstem auditory evoked potentials or somatosensory evoked potential are obtained to examine other information pathways in the brain.

Figure 1

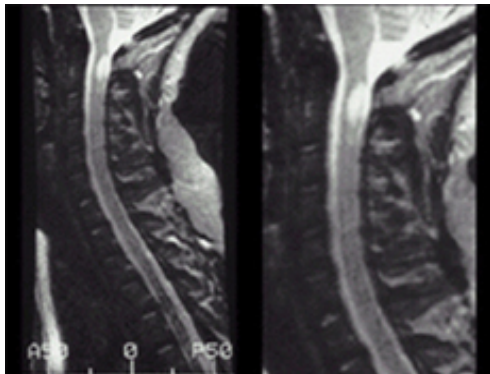
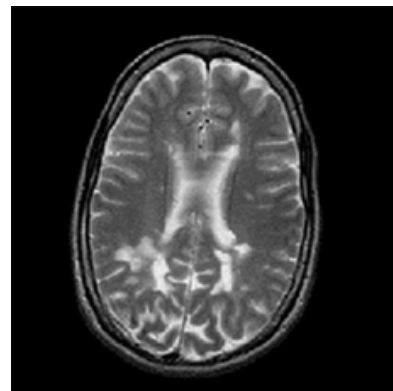


Figure 2



First Pediatric Approved MS Medication

Gilenya is the first medication approved for pediatric use. While we don't know exactly how it works, it is thought to prevent lymphocytes (white blood cells) from attacking the Central Nervous System (brain and spinal cord) by lowering the number of lymphocytes circulating in the blood. Lymphocytes are part of the auto-immune response in MS; they play a role in inflammation and the demyelination (removal of protective covering) of axons.

Gilenya is a capsule that is taken by mouth once daily. It should be taken whole. Do not break, crush, chew, or dissolve before swallowing as this may increase the risk for side effects. It may be taken with or without food.

Prior to starting Gilenya the following tests will be done:

- An EKG (of the heart)
- A blood test for antibodies to varicella zoster virus (VZV). If your child does not have antibodies, they will be asked to get the VZV vaccination prior to starting Gilenya
- Blood tests including complete blood count (CBC), and liver function tests (LFT)
- An eye exam before initiation of Gilenya (and 3-4 months into therapy)

Once the above tests are complete you will then schedule an appointment for a First Dose Observation (FDO). This appointment lasts six hours and is to monitor for signs of bradycardia (slow heart rate) after your child takes the first dose of Gilenya. You will bring the medication with you to this appointment.

Once your child has started Gilenya it is important not to miss any doses. Do not stop taking Gilenya without first talking to your doctor. If stopped for more than two weeks, your child will need another six-hour monitoring appointment in order to re-start the medication.

Common side effects include headache, infections, influenza (flu), diarrhea, back pain, cough, macular edema and an increase in liver enzymes.

Other Multiple Sclerosis Treatments

There are two other major categories of medications available for the treatment of relapsing-remitting MS that are used in pediatric patients. These drugs help in prevent the long-term effects of MS. We have evidence that these medications are safe and effective in children.

The first is called Beta-interferon. Beta-interferons are cytokines that are normally produced by the body. They have been found to have protective effects on the immune system. These drugs are effective in reducing MS relapses and new lesion formation. There are four commercially available Beta-interferon drugs:

1. Avonex (Beta-interferon 1a); given once a week by intramuscular injection
2. Rebif (Beta interferon-1a); given 3 times a week by subcutaneous injection
3. Betaseron (Beta interferon-1b); given every other day by subcutaneous injection
4. Plegridy (peginterferon beta-1a); given once every 2 weeks by subcutaneous injection.

The second category of drug for the treatment of relapsing-remitting MS is called Glatiramer acetate (Copaxone). This is a synthetic drug that is designed to look like the myelin coating in the brain and acts to make the white blood cells more benign. It decreases MS attacks and MRI damage over time. It is given every day or 3 times a week by subcutaneous injection.

There are additional drugs which may be used if the above drugs do not work or are not tolerated. These medications are all designed to help prevent relapses and long-term disability. Your doctor will help you to choose which drug is best for your child.

There are also medications for acute attacks or an MS relapse. The most common medication we use to treat relapses is Methylprednisolone (Solumedrol). Methylprednisolone is a steroid that is given through an IV for between 3-7 days. Steroids help stop an MS relapse, making the attack shorter and less severe.

Injectable Multiple Sclerosis (MS) Medications

Medication:	Avonex	Betaseron	Rebif	Plegridy
Dose:	30 mcg (1/2ml)	250 mcg (1ml)	44 mcg (1/2ml)	125 mcg (1/2ml)
Frequency:	Taken once a week	Taken every other day	Taken 3 times a week	Taken once every 14 days
Route:	Intramuscular Injection	Subcutaneous Injection	Subcutaneous Injection	Subcutaneous Injection
Pre-filled Form Available:	Yes Also available in powder form which requires mixing	No	Yes	Yes
Standard Needle Size:	23 Gauge Needle/Autoinjector	27 Gauge Needle	29 Gauge Needle/Autoinjector	29 Gauge Needle/Autoinjector
Customized Needle Options:	Smaller needles are possible. Please discuss with health care provider	Depth of the needle can be adjusted with auto injector	Depth of the needle can be adjusted with auto injector	N/A
Storage:	Must be refrigerated. Can be stored at room temperature for 1 month	Store at Room Temperature	Must be refrigerated (May be at room temperature for up to 30 days)	Keep in package to protect from light. Must be refrigerated. Can be stored at room temperature for 30 days
Injection Sites:	Upper Thighs Outer Thighs Upper Arm	Upper arm Stomach (abdomen) Upper thigh Buttock	Upper arm Stomach (abdomen) Upper thigh Buttock	Upper arm Stomach (abdomen) Upper thigh Buttock
Common Side Effects:	Flu like symptoms	Flu like symptoms Injection site reactions	Flu like symptoms Injection site reactions	Flu like symptoms Injection site reactions
Rare Side Effects:	Depression Mild Anemia Elevated Liver Enzymes Allergic Reactions	Depression Elevated liver enzymes Allergic reactions Decreased number of white blood cells	Depression Anemia Elevated Liver Enzymes Allergic reactions Decreased number of white blood cells	Depression Allergic reactions Heart Problems Decreased number of white blood cells

Multiple Sclerosis (MS) Medications: Copaxone

	Copaxone 20mg	Copaxone 40mg
Dose:	20mg/mL	40mg/mL
Frequency:	<i>Taken every day</i>	<i>Taken 3 times a week (48hrs apart)</i>
Route:	Subcutaneous Injection	Subcutaneous Injection
Pre-filled Form Available:	Yes	Yes
Standard Needle Size:	28 Gauge Needle/Autoinjector	28 Gauge Needle/Autoinjector
Customized Needle Options:	Depth of the needle can be adjusted with auto injector	Depth of the needle can be adjusted with auto injector
Storage:	Must be refrigerated. (Can be stored at room temperature for 7 days)	Must be refrigerated. (Can be stored at room temperature for 7 days)
Injection Sites:	Upper arm Stomach (abdomen) Upper thigh Hip	Upper arm Stomach (abdomen) Upper thigh Hip
Common Side Effects:	Injection site reactions (redness, pain, itching)	Injection site reactions (redness, pain, itching)
Rare Side Effects:	Immediate reaction following injection lasting 15-30 minutes: including chest pain, anxiety, shortness of breath, palpitations, and flushing.	Immediate reaction following injection lasting 15-30 minutes: including chest pain, anxiety, shortness of breath, palpitations, and flushing.

Other Demyelinating Diseases

There are several other conditions that are classified as "demyelinating diseases". These disorders can occur in patients with MS, or independently:

Acute disseminated encephalomyelitis (ADEM): ADEM can occur in both adults and children, although it is more common in children. ADEM generally appears after a viral illness, or rarely after vaccination. The symptoms of ADEM can resemble an MS attack, although ADEM usually does not recur. There are some recurrent or multiphasic forms of ADEM, which in some cases can be difficult to distinguish from MS. The relationship between ADEM and MS is not well understood, and in approximately 15-20% of cases, patients with ADEM may develop MS later in life. The initial treatment of ADEM often includes steroids and supportive care. Other immunomodulatory agents such as IVIG may be used in refractory cases.

Optic neuritis refers to an inflammatory demyelinating attack on the optic nerves. Symptoms can include blurred or loss of vision as well as eye pain. Optic neuritis can occur in MS patients, or can occur in isolation. In some cases, a first attack of optic neuritis may lead to the development of MS later in life. Steroid treatments are often used to reduce the symptoms of optic neuritis.

Transverse myelitis is an inflammatory demyelinating attack on the spinal cord. Symptoms include back pain, leg weakness and bowel and bladder dysfunction. Transverse myelitis can occur in MS patients, or can occur in isolation. In some cases, a first attack of transverse myelitis may lead to the development of MS later in life. The initial treatment for transverse myelitis is intravenous steroids, however other immunomodulatory agents may be used in refractory cases.

Neuromyelitis Optica spectrum disorders (NMO-SD)

What is NMO-SD?: Neuromyelitis optica, also known as Devic's disease, is an autoimmune disorder in which immune system cells and antibodies mistakenly attack and destroy myelin cells in the optic nerves and the spinal cord. The damage to the optic nerves produces swelling and inflammation causes pain and loss of vision; the damage to the spinal cord causes weakness or paralysis in the legs or arms, loss of sensation, and problems with bladder and bowel function. NMO occurs in two different forms: a single attack extending over a month or two, or a more common relapsing form in which the person experiences multiple attacks.

Who gets pediatric NMO?: Patients usually experience their first symptoms in childhood or adolescence. Patients as young as 16 months have been reported with NMO. The average age for children is 10 years old.

Symptoms of pediatric NMO: Children with NMO usually present with "attacks" of new neurological symptoms appearing within a few hours or days. Children with NMO can have attacks with symptoms of blurred vision, or loss of vision in one eye or both eyes. Other symptoms are weakness or numbness of the arms or legs. Some children experience confusion or extreme lethargy at their attacks. Other possible symptoms including vomiting, fever or seizures.

Laboratory testing: Approximately 65% of children with NMO have antibodies to aquaporin-4 (AQP4), also known as NMO-IgG. AQP4 antibodies are sometimes present at the first symptom, or can appear with time. About 15% of children with NMO have MOG antibodies (see section below). About 15% of children are negative for both antibodies.

Treatment of pediatric NMO: Although there are no FDA approved treatments for adults or children with NMO, children are usually offered immunomodulatory treatments. Attacks are treated with a short course (usually up to a week) of intravenous steroids, or IVIG or plasmapheresis. It is important to prevent new attacks in children with established NMO, and treatment with mycophenolate mofetil or rituximab is usually offered.

Myelin-oligodendrocyte-glycoprotein (MOG) antibody associated diseases (MOG-AAD)

Demyelinating disorders in children: Acute demyelinating syndromes (ADS) in children includes a broad spectrum of clinical presentations including optic neuritis (ON), transverse myelitis (TM), clinically-isolated syndromes (CIS), acute disseminated encephalomyelitis (ADEM) and relapsing forms such as neuromyelitis optica spectrum disorder (NMOSD) or multiple sclerosis (MS).

MOG antibody associated diseases: Myelin-oligodendrocyte-glycoprotein (MOG) antibodies (abs) can be found in the serum in up to one third of all children almost all forms of demyelinating disorders but are found in particular in children with ADEM, NMOSD in the absence of AQP4 abs, recurrent isolated or bilateral ON and in selected patients who do not fit one of the mentioned disease categories.

Children can have widespread involvement of primarily the white matter structures affecting many different areas of the central nervous system including the myelin. Several studies have demonstrated that age of the affected child influences the clinical presentation. Young children have more often the clinical picture of ADEM and adolescents have an inflammation of the optic nerves. Adults may present with transverse myelitis or neuromyelitis optica.

Importantly, studies showed that in children who subsequently develop MS only rarely have MOG abs in serum and if present initially MOG abs do disappear in the course of the disease.

The precise role of MOG abs is unclear and research suggests that the integrity of the myelin sheath is affected leading to a transient functional impairment of nerve conduction in the affected areas. The presence of MOG antibodies can affect diagnosis, treatment choices and prognosis.

MOG antibody testing: If the diagnosis MOG-spectrum disease is suspected in a child the investigation of choice is a live cell-based assay ideally performed a specialized laboratory. Different techniques are used to determine the level of MOG- abs in serum, which every laboratory has to specify in their reports. In a patient with positive MOG antibodies at a first attack, repeat testing every 6-12

months may be considered, and some studies have shown a correlation of persistent positive antibodies with further attacks.

Labs which perform MOG live cell-based assay:

Mayo Clinic:

<https://www.mayomedicallaboratories.com/testcatalog/Clinical+and+Interpretive/65563>

Athena Diagnostics:

[https://www.athenadiagnostics.com/view-full-catalog/n/nmo-spectrum-evaluation-\(aqp4,-cba-reflex-to-mog,](https://www.athenadiagnostics.com/view-full-catalog/n/nmo-spectrum-evaluation-(aqp4,-cba-reflex-to-mog))

Treatment:

Acute treatments: Most children who do present with inflammatory - demyelinating episode associated with MOG abs respond well to high-dose intravenous steroids given for three consecutive days followed by a tapering regime over the following three to four weeks. Children who do have persistent high MOG abs in serum appear to have a higher risk of a relapse. Children with relapses of ON, ADEM, NMOSD seem to benefit in particular from IVIG. In contrast to children with NMOSD and AQP4 or MS the long-term prognosis in children with MOG appears to be better.

Preventative treatments: Approximately 50% of children with MOG-AAD will have a relapsing course. There are no FDA or EMA approved treatments to prevent relapses for patients with MOG-AAD. However, commonly used preventative treatments are:

- Mycophenolate mofetil (Cellcept, Myfortic) - a pill given twice a day
- Rituximab (Rituxan) intravenous infusions - given approximately every 6 months. Dosing may be tailored to B cell counts.
- Intravenous immunoglobulin (IVIG)

Preventative treatment of NMO-SD and (MOG) antibody associated diseases

Cellcept:

CellCept (Mycophenolate mofetil) is an oral immunosuppressant. It inhibits an enzyme in the body that contributes to the production of specific purines. These purines are necessary for certain white blood cells, specifically T- and B-cells, to carry out an attack against offending material. This leads to less damage of myelin and neurons in the brain.

How it's Given

CellCept is a pill that is taken by mouth. It should be taken one hour before or two hours after food for best absorption. Tablets should not be crushed, chewed, or cut and capsules should not be opened. Tablets and capsules should be swallowed whole. A solution is also available for younger children.

Certain medications interact with the absorption of CellCept and should not be given at the same time. These include the following:

- Avoid taking antacids containing aluminum or magnesium (i.e. Maalox®, Mylanta®) at the same time as mycophenolate as these will affect how much drug you absorb. **It should be taken at least one hour before or two hours after taking antacids.**
- Avoid taking calcium supplements or iron supplements at the same time as mycophenolate as these will affect how much drug you absorb. **It should be taken at least one hour before or two hours after taking these supplements.**
- Make sure to contact your doctor prior to starting any new medications

Common Side effects include: increased risk of infection, nausea, stomach pain, diarrhea (increasing the dose slowly reduces these effects), weakness, dizziness, difficulty sleeping and increased liver function tests.

Rituximab:

Rituximab (Rituxan) is an intravenous immunosuppressant. It is an antibody to a population of immune cells called B cells. B cells cooperate with T cells to cause attack on the myelin, neurons or other cells in the brain. Rituximab is used as a treatment for MS, NMO-SD and MOG-antibody associated diseases in children.

How it's Given

- Rituximab is given by intravenous infusion approximately every 6 months. The exact duration between treatments may be tailored to the specific patient and situation. Usually the first dose is administered in two half doses, two weeks apart.
- Rituximab is usually given along with intravenous steroids, antihistamines and antacids to prevent infusion or allergic reactions.
- Rituximab infusions are usually given in an infusion unit by trained nursing staff.
- Make sure to contact your doctor prior to starting any new medications

Common Side effects include: infusion reactions including rash, tiredness, rarely breathing difficulties. Longterm side effects include increased risk of infection, nausea, stomach pain, diarrhea (increasing the dose slowly reduces these effects), weakness, dizziness, difficulty sleeping and increased liver function tests.

Neuropsychological Testing - FAQ's

Why is my child being referred for testing?

Because multiple sclerosis and demyelinating disorders affect a person's central nervous system, there are sometimes effects on cognition and learning. Often there are effects on a person's ability to concentrate, remember, or think for long periods of time. Neuropsychological testing will help identify if your child is experiencing difficulties in any of these areas. The results of testing can be used to help make recommendations for accommodations in school. Even if your child has not experienced obvious symptoms that affect his or her learning, neuropsychological testing is important to establish a baseline of functioning and to monitor your child's functioning and progress over time.

How does the testing process work?

A complete neuropsychological assessment requires gathering and analyzing information about a child or young adult's development physically, socially, cognitively, academically, and psychologically. All patients from the pediatric MS center are tested at MGH through the Learning and Emotional Assessment Program (LEAP). Testing sessions typically last 4 to 6 hours with breaks for your child as needed. The process includes individual administration of intelligence and achievement tests, as well as a number of tests that assess memory, attention, problem-solving, and other areas of functioning often affected by demyelinating disorders. You and your child will also be asked to complete questionnaires about your child's coping and emotional well-being and your clinician will take time to talk with you as well. After testing is complete, a report describing all of the testing results is generated and recommendations specific to your child's needs are provided. Your LEAP clinician will also schedule a feedback appointment with you to review the test results.

How do I schedule the testing appointment?

We will coordinate with the staff at LEAP to schedule the appointment for testing for you. After you receive a phone call to schedule the appointment, you will receive a packet of information in the mail with directions, more information on testing, and a background questionnaire for you to complete. You should bring that with you on the day of testing, along with any evaluations your child may have had previously. Due to the high demand for testing at LEAP and the time set aside by your clinician for testing, if you need to reschedule or cancel your appointment, please do so 5 business days prior to your appointment.

How do I know if my insurance will cover the cost of testing?

We will coordinate with the staff at LEAP to determine whether or not testing is covered by your child's insurance. If it is, you will be responsible for any co-pay required by your insurance. If testing is not covered by your insurance, or you cannot meet the cost of a co-pay, financial assistance is available for qualified families through the Pediatric MS Center.

Who do I call if I still have questions about testing?

You can contact the LEAP clinical coordinator, Darlene Maggio, at 617-643-6010 or Quianna Barnwell at 617-726-2664 if you have questions about scheduling. If you have questions about the testing process, Dr. Ellen O'Donnell is the lead consulting clinician at LEAP for the Pediatric MS Clinic. She can be reached at 617-643-6017.

Tips for Travel

Multiple Sclerosis should not interfere with your ability to travel. However, it is important that you continue to take your medication throughout your trip. To do this, it is important to think ahead and pack plenty of supplies. When possible pack enough supplies for an extra day or two. This will be helpful should your trip be unexpectedly extended.

Call ahead to your MS Medication supplier and ask for an insulated container that you can use to transport your medications. It is ok for all medications to be left at room temperature for at least 7 days, but they should never be heated. Remember to never leave your medication in an empty car or other areas in direct sunlight where your medication may be accidentally warmed.

What to Pack for your Trip

- ❑ Puncture Resistant Container
- ❑ Medication
- ❑ Autoinjector (If applicable)
- ❑ Alcohol Wipes
- ❑ Gauze Pads
- ❑ Contact Information for the MS Center: (617) 726-2664
- ❑ Tylenol or Advil
- ❑ Emla cream (If you used as part of your regular injection routine)
- ❑ Insulated Storage Container to keep your Medication cold if you are on Avonex, Copaxone, or Rebif

Special Considerations for Flying

When flying with your MS medications, it is important to keep your medication and supplies with you at all times in your carry-on luggage. Try to keep all of your syringes and needles together in an easily accessible container so that they are together for security inspection. Please bring a current prescription label with you.

School Nurse Guide to MS

General Information

Multiple Sclerosis (MS) is thought to be an autoimmune disease that affects the brain and spinal cord. Together the brain and spinal cord make up the central nervous system.

White blood cells, which are part of the body's immune system normally fight infection. In MS, these white blood cells become mis-programmed and attack the brain and spinal cord. These white blood cells damage the nerves (neurons) and their myelin coating. Therefore MS is often referred to as a demyelinating disease. Damage to the nerves and their myelin coating causes the neurological symptoms that affect children with MS.

Symptoms Associated with MS

MS can cause a variety of symptoms. These most commonly include symptoms of weakness, fatigue, numbness, tingling, dizziness, and blurred or double vision. Some children with MS also experience cognitive symptoms, which can affect their school lives. Neuropsychologists at the Pediatric MS center monitor for cognitive symptoms. These specialists will help work with your school to develop appropriate educational interventions if needed.

Fatigue associated with MS is a real symptom which can affect school performance. It is often made worse by warm weather. MS related fatigue can come on very suddenly, be severe, and effect a child's daily life. Good sleep hygiene, stress reduction, time management, and avoiding warm weather can help improve fatigue in some people.

MS Relapses or "Attacks"

The majority of pediatric patients have Relapsing-Remitting MS. This means that they experience relapses or attacks during which time symptoms are worse. During an attack or relapse children may complain of increased weakness, fatigue, tingling, dizziness, or altered vision. These symptoms usually last several days or even weeks. Attacks are often treated with corticosteroids, which can help to reduce inflammation improving symptoms. If a child has a relapse during the school day, they should tell their parent or guardian and contact the MS center.

MS symptoms may also be temporarily triggered by hot weather, fever, or infection. These exacerbations are sometimes called "pseudo-exacerbations" and often improve when the underlying cause resolves. Pseudo-exacerbations or pseudo-relapses last less than 24 hours and usually do not require medical care. If a child has sudden symptoms associate with heat, they should drink lots of cold fluids and sit in a cool or air-conditioned room. Often symptoms will resolve in a few minutes or hours. If symptoms continue please contact the child's parent/guardian.

MS Medications

Gilenya is the first medication approved for pediatric use. While we don't know exactly how it works, it is thought to prevent lymphocytes (white blood cells) from attacking the Central Nervous System (brain and spinal cord) by lowering the number of lymphocytes circulating in the blood. Lymphocytes are part of the auto-immune response in MS; they play a role in inflammation and the demyelination (removal of protective covering) of axons.

Gilenya is a capsule that is taken by mouth once daily.

There are two other major categories of disease modifying medications available for the treatment of relapsing-remitting MS in pediatric patients. These drugs help in prevent the long-term effects of MS and reduce relapses. The first is called Beta-interferon. Beta-interferons are cytokines that are normally produced by the body. They have been found to have protective effects on the immune system. There are four commercially available Beta-interferon drugs:

1. Avonex (Beta-interferon 1a), given once a week by IM injection
2. Rebif (Beta interferon-1a); given 3 times a week by SQ injection
3. Betaseron (Beta interferon-1b); given every other day by SQ injection
4. Plegridy peginterferon beta-1a); given once every 2 weeks by SQ injection

The second category of drug for the treatment of relapsing-remitting MS is called glatiramer acetate (Copaxone). This is a synthetic drug that is designed to look like the myelin coating in the brain and acts to make the white blood cells more benign. Given daily or 3 times a week by SQ injection.

While none of these medications are typically given during the school day, children taking a Beta-interferon may experience flu-like symptoms following their injection. These symptoms can be treated with Tylenol and usually resolve within 24 hours of an injection.

Working Together

Staff at the Pediatric MS Center at MGH are committed to working with school systems to provide the best service available to the children we serve. We are happy to answer any specific questions you may have, however, in order to protect our patient's privacy, we do require proper parental authorization. If you have any further questions, feel free to contact the Pediatric MS center at (617) 726-2664.

Contact Information

General Information & Scheduling of appointments & testing
Jacqueline Brown: (617) 726-2664

EMERGENCY PHYSICIAN CONTACT: (617)-726-2000

*Physicians can be paged for emergencies or after hours by calling
(617)-726-2000 and asking to page the pediatric MS pager

Neuropsychological Testing

LEAP Center: 151 Merrimac St, 5th Floor, Boston, MA 02114

Dr. Ellen O'Donnell: (617)-643-6017

Darlene Maggio (scheduling): (617)-643-6010

Pediatric Psychiatry

Dr. Jefferson Prince: (617)-724-5600

Katia Canenguez, Phd., Ed.M.: (617) -724-7399

Pediatric MS Center Nurse

Tracy Popkin, RN: (617) 643-2219

Physical Therapy & Occupational Therapy: (617)-724-0767

Speech-Language Pathology Department: (617) 726-2763

Mass Eye and Ear: (617) 523-7900

Dr Heidary & Dr Rizzo

Infusion Centers

Pediatric Hematology & Oncology Unit:

Yawkey Center for Outpatient Care, 32 Fruit St, Suite 8B, Boston, MA 02114

Scheduling: (617)-726-2737

*For patients under 18yrs

Medical Infusion Center:

Charles River Plaza, 165 Cambridge St, Suite 820, Boston, MA, 02114

Chris Callahan, DNP, RN (nurse manager): (617)-643-2066

*For patients 18yrs and older

Creating A Healthy Diet and Lifestyle



Handout for Children living with MS and their Parents

Partners Pediatric MS Center
55 Fruit St
Boston MA, 02114

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Grain Group

These foods give us carbohydrates, iron, protein, and fiber. Carbohydrates are especially important and give our bodies energy.



Grain Group Foods: wheat, oats, rye, barley and rice. Breads, rolls, bagels, spaghetti, crackers, and other foods from these plants are all in the grain group.

1 serving = 1 slice of bread, $\frac{1}{2}$ cup of rice or pasta, $\frac{1}{2}$ of a bagel or English muffin, 2-4 crackers, or 1 oz of cereal.

Vegetable Group



Vegetable Group foods provide vitamin C, Vitamin A, fiber, folate, potassium and magnesium.

Vitamin C helps our body heal cuts and bruises and fight infections! Vitamin A is important to help you see in the dark and keep our skin healthy. Fiber is important for digestion.

There are countless types of vegetables you can eat in this food group: carrots, green beans, broccoli, potatoes, tomatoes, and squash are just a few.

You need 3-5 servings of vegetables a day

1 serving = $\frac{1}{2}$ cup of cooked or raw vegetables or 1 cup of leafy vegetables

Fruit Group

Fruit Group foods provide vitamin C, Vitamin A, fiber, and phytochemicals (a substance that helps prevent disease).



There are countless types of fruit you can eat in this food group: apples, oranges, bananas, grapes, berries and melons are just a few.

You need 2-4 servings of fruit a day

1 serving = 1 piece of fruit, 1 melon wedge, $\frac{1}{2}$ cup of canned fruit or $\frac{1}{4}$ cup of dried fruit

Milk Group

Milk and dairy products provide calcium, protein, riboflavin and Vitamin B12.



These foods are important to keep your bones strong. They also help your muscles contract and relax and help your body stop bleeding if you are injured.

Children need 2 servings of milk foods a day. Teenagers and young adults need 3 servings.

Milk, yogurt, cheese, cottage cheese, and even deserts like ice cream and pudding are in the milk group.

1 serving = 1 cup of milk, 1 ½ oz of cheese, or 1 cup of yogurt

The milk group is especially important when you are taking steroids for you MS. Steroids make it harder for your body to absorb and keep calcium in your body. That is one reason calcium and vitamin D are especially important for people living with MS.

Meat Group



Foods in this group provide protein, iron and Vitamin B12. Nutrients that help give you lots of energy.

These foods are especially important to your neurologist because help your brain and nervous system work correctly.

Beef, pork, chicken, turkey, fish and eggs are all in the meat group. Don't worry if you are a vegetarian or just don't eat a lot of meat. Beans, peas, peanut butter, and nuts are also in the "meat group".

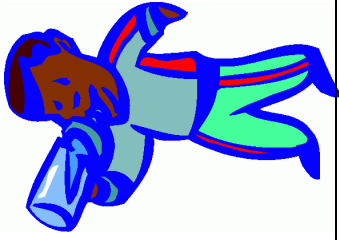
You need 2-3 servings of these foods per day.

1 serving = 2-3 oz of lean meat, chicken, or fish
or

1 serving = 1 egg, ½ cup of beans, or 2tbs of peanut butter

Water & Liquids

Water and liquids are a final part of any good diet. On average, your body is 60% water, so you need to drink lots of it to stay healthy. In general people should drink 8 8oz glasses of water a day.



Hydration is especially important for children with MS during the warmer months of the year. Heat can increase MS fatigue and bring on pseudo-relapses. Drinking lots of liquids can help your body stay cool.

Children and Teenagers should get at least one hour of exercise a day. Exercise can be running around a park, playing a game of tag, or going for a brisk walk.

Exercise can help you in many ways. Exercise can:

- ❖ Reduce Stress
- ❖ Build strong bones and muscles
- ❖ Help children stay at a healthy weight
- ❖ Reduce risk of: Type 2 Diabetes, high blood pressure, and high cholesterol.

Sometime MS can make it harder for you to exercise the way you would like to.

Chapter 2: Exercise

Exercise is very important for all children. Children who learn to enjoy physical activity when they are young are more likely to keep these healthy habits as adults.



Exercise can make our bodies hot, and heat can sometimes cause a brief pseudo relapse. A **pseudo relapse** is when some of your MS symptoms such as tingling or numbness happen very quickly but then last only a short time (less than 24 hours).

Pseudo Relapses can be scary and annoying, but you can help to avoid them **by drinking lots of fluids to keep your body cool while you exercise**. Some children also find a cooling vest helpful. **Cooling vests** can be used during exercise or just during a hot

day to keep your body cool. Ask your healthy care provider about how to get a cooling vest. Finally, remember to listen to your body. If you start to feel “strange” while you are playing or working out, just stop and take a break. Drinking some cool liquids or going into a cool room should help you feel better quickly.

Other times children find it harder to exercise because of more permanent symptoms or disabilities, such as a foot drop or weakness. Physical therapists and occupational therapists can help find fun and safe ways that you can do as much physical activity as your body will allow. Of course, the most important thing is always to keep your body safe when doing any activity.

Chapter 3: Vitamins

Vitamins are important for all of us to help our bodies work correctly. They help us stay healthy and fight of infection. They also help keep our bones strong and our vision clear.



While fruits and vegetables are the best source of vitamins many of us don't eat enough of these healthy foods to get all of the vitamins our

bodies need. For this reason your doctor may recommend a multivitamin.

Multivitamins are made in pill, liquid and chewable forms. They also come in all different flavors including tropical berry, watermelon, and other tasty choices. At the end of this chapter you can find an assortment of multivitamin options for children.

The Food and Nutrition Board and National Academy of Sciences have published recommended daily allowances for all vitamins and minerals. You can find a detailed chart with this information in the back of this handbook. If you aren't sure if your child's multi-vitamin meets these recommendations be sure to ask your doctor or nurse for help.

A Handy List of Common Children's Vitamins



- @ L'il Critters Calcium Gummy Bears with Vitamin D Dietary Supplement 60 ea
 ~Includes 200 IU of Vitamin D! ~



- @ Nature's Plus Animal Parade, Children's Chewable Multi-Vitamin & Mineral Supplement 180 ea
 ~ Includes 400 IU of Vitamin D! ~



- @ Flintstones Children's Complete Multivitamin, Chewable Tablets 150 ea
 ~ 400 IU of Vitamin D! ~



- @ Centrum Kids Complete Vitamins, Chewable Tablets 60 ea
 ~ 400 IU of Vitamin D! ~



- @ Disney Gummies Children's Multi Vitamin & Mineral 60 ea
 ~ Includes 200 IU of Vitamin D! ~



- @ Sundown Marvel Heroes Gummies Children's Multiple Vitamin and Mineral Supplement 60 ea
 ~ With 400 IU of Vitamin D! ~



- @ One-A-Day Kids Scooby-Doo! Complete Multivitamin, Chewable Tablets 50 ea
 ~ 400 IU of Vitamin D! ~



- @ Yummi Bears Vegetarian Multi-Vitamin & Mineral 90 ea
 ~ These Vitamins include 150 IU of Vitamin D! ~



- @ Dr Greene Childrens Chewable Multivitamin/Mineral, Berry 50 ea
 ~ Includes 400 IU of Vitamin D! ~



- @ One-A-Day Teen Advantage for Her 80 ea
 ~ With 800 IU of Vitamin D! ~



- @ One-A-Day Teen Advantage for Him 80 ea
 ~ Includes 400 IU of Vitamin D! ~

Chapter 4: Vitamin D & MS

Vitamin D is a fat-soluble vitamin that helps your body absorb calcium. Vitamin D works with Calcium to keep your bones strong. We think Vitamin D may also be very important for the immune system.



Vitamin D is special because it is the only vitamin that your body can make with the help of sun. All other vitamins you have to eat from foods or multivitamins.

How does Vitamin D affect MS?

Vitamin D is especially important for people who have MS or are at risk for developing MS. Doctors and scientists have found that people with low vitamin D may have a higher change of developing MS. Researchers have also found that people with MS may have more relapses when they don't have enough vitamin D.

At the Partners Pediatric MS Center we check all of our patient's vitamin D levels by taking a small sample

of blood. Your doctor or nurse will let you know if your Vitamin D level is too low. If your vitamin D level is low we will tell you specific vitamin pills to take to help bring your vitamin D level back to the normal range.

How much vitamin D do I need?

In general the American Pediatric Association recommends that all children take 400 units of vitamin D a day. However, your doctor may recommend that you take more vitamin D. Vitamin D can be given as part of a daily multivitamin or as a Vitamin D only supplement. If you or your child is taking a multivitamin be sure to look at how much Vitamin D is in that pill before you give them any additional Vitamin D supplements. If you are not sure or have any questions please call your doctor or nurse and ask for help.

Can I get enough vitamin D from sun exposure?

While the best source of vitamin D is sunlight, it can be very hard for anyone to get enough vitamin D from the sun. It is especially hard to get enough sun for

those of us living in the Northeast. Sunscreen and sunglasses are very important to protect us from skin cancer and other damage the sun can do, but they also make it harder for our bodies to make vitamin D.

The best way to get vitamin D from the sun is to go outside for 20 minutes 3 times a week between 10 am and 2 pm.

Luckily, You can also get Vitamin D from food. Vitamin D is found in Fish and fortified foods, such as dairy products and breakfast cereals.

Below are a few examples of Vitamin D supplements

Nature's Bounty Vitamin D



Nature Made Vitamin D 2000 I.U.



Rainbow Light Vitamin D 1000 I.U. Sunny Gummies



Chapter 5: Herbs & Supplements



Many people with MS and their families are interested in Herbs and other supplements. While many herbs and supplements may have potential benefits, it is important to know they can also have harmful side effects. Herbs can also have interactions with some medications. For these reasons, **if you or your child is currently taking any herbs or is considering taking an herbal supplement be sure to tell your doctor. Your doctor can help make sure that the herbs you are taking are safe.**

The National MS Society has written a detailed guide on herbs and other supplements called "Vitamins, Minerals and Herbs in MS: and Introduction". You can find this handout on their website.

Chapter 6: Smoking and MS

Many research studies have been conducted to investigate the potential dangers smoking has on individuals. Smoking affects overall health, resulting

in complications ranging in a wide variety of areas, from dental health to cardiovascular health.

Research has already shown that smoking is an identified risk factor for multiple sclerosis, but now, there is evidence to support the fact that smoking is related to the progression of the autoimmune disease.

Multiple sclerosis is often associated with pseudo-relapses, in which symptoms come and go based on various factors such as the current emotional state to changing environmental conditions. MS may often advance to a secondary stage - secondary progressive MS - in which symptoms occur more frequently due to the steady deterioration of the central nervous system.

According to researchers from the Harvard School of Public Health, the risk of progressing to the secondary stage was 3.6 times higher for current and past smokers than patients who never smoked (Boyles)

References

For more information on Nutrition and Diet you can look at the US Department of National Agriculture Library:

(Recommended daily Vitamins from this website can be found on the next page)

http://fnic.nal.usda.gov/nal_display/index.php?info_center=4&tax_level=1&tax_subject=242

Other Great References:

Partners Pediatric MS Center web page:
<http://www.partnersmscenter.org>

Mass General for Children web page:
<http://www.massgeneral.org/children/>

National MS Society web page:
www.NationalMSSociety.org

Appendix:

Dietary Reference Intakes (DRIs): Tolerable Upper Intake Levels (UL^a), Vitamins

Life Stage Group	Food and Nutrition Board, Institute of Medicine, National Academies															
	Vitamin A (µg/d) ^b	Vitamin C (mg/d)	Vitamin D (µg/d)	Vitamin E (mg/d) ^{c,d}	Vitamin K	Thiamin	Ribo- flavin	Niacin (mg/d) ^f	Vitamin B ₆ (mg/d)	Folate (µg/d) ^f	Vitamin B ₁₂	Pantothenic Acid	Biotin	Choline (g/d)	Caro- noids	
<i>Infants</i>																
0-6 mo	600	ND ^e	25	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND
7-12 mo	600	ND	25	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND	ND
<i>Children</i>																
1-3 y	600	400	50	200	ND	ND	ND	10	30	300	ND	ND	ND	1.0	ND	ND
4-8 y	900	650	50	300	ND	ND	ND	15	40	400	ND	ND	ND	1.0	ND	ND
<i>Males, Females</i>																
9-13 y	1,700	1,200	50	600	ND	ND	ND	20	60	600	ND	ND	ND	2.0	ND	ND
14-18 y	2,800	1,800	50	800	ND	ND	ND	30	80	800	ND	ND	ND	3.0	ND	ND
19-70 y	3,000	2,000	50	1,000	ND	ND	ND	35	100	1,000	ND	ND	ND	3.5	ND	ND
> 70 y	3,000	2,000	50	1,000	ND	ND	ND	35	100	1,000	ND	ND	ND	3.5	ND	ND
<i>Pregnancy</i>																
14-18 y	2,800	1,800	50	800	ND	ND	ND	30	80	800	ND	ND	ND	3.0	ND	ND
19-50 y	3,000	2,000	50	1,000	ND	ND	ND	35	100	1,000	ND	ND	ND	3.5	ND	ND
<i>Lactation</i>																
14-18 y	2,800	1,800	50	800	ND	ND	ND	30	80	800	ND	ND	ND	3.0	ND	ND
19-50 y	3,000	2,000	50	1,000	ND	ND	ND	35	100	1,000	ND	ND	ND	3.5	ND	ND

^aUL = The maximum level of daily nutrient intake that is likely to pose no risk of adverse effects. Unless otherwise specified, the UL represents total intake from food, water, and supplements. Due to lack of suitable data, ULs could not be established for vitamin K, thiamin, riboflavin, vitamin B₁₂, pantothenic acid, biotin, carotenoids. In the absence of ULs, extra caution may be warranted in consuming levels above recommended intakes.

^bAs performed vitamin A only.

^cAs α-tocopherol; applies to any form of supplemental α-tocopherol.

^dThe ULs for vitamin E, niacin, and folate apply to synthetic forms obtained from supplements, fortified foods, or a combination of the two.

^eβ-Carotene supplements are advised only to serve as a provitamin A source for individuals at risk of vitamin A deficiency.

^fND = Not determinable due to lack of data of adverse effects in this age group and concern with regard to lack of ability to handle excess amounts. Source of intake should be from food only to prevent high levels intake.

SOURCES: *Dietary Reference Intakes for Calcium, Phosphorus, Magnesium, Vitamin D, and Fluoride* (1997); *Dietary Reference Intakes for Thiamin, Riboflavin, Niacin, Vitamin B₆, Folate, Vitamin B₁₂, Pantothenic Acid, Biotin, and Choline* (1998); *Dietary Reference Intakes for Vitamin C, Vitamin E, Selenium, and Carotenoids* (2000); and *Dietary Reference Intakes for Vitamin A, Vitamin K, Arsenic, Boron, Chromium, Copper, Iodine, Iron, Manganese, Nickel, Silicon, Molybdenum, and Zinc* (2001). These reports may be accessed via <http://www.nap.edu>.

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Sample Menu: Pre-school age

(4yo child weighing approx. 36lbs)

Meal	Sample Menu
Breakfast	Milk (not almond milk)— $\frac{1}{2}$ cup Whole grain cereal— $\frac{1}{2}$ cup Cantaloupe, strawberries or banana—4-6 oz. or $\frac{1}{2}$ cup
Snack	Milk (not almond milk)— $\frac{1}{2}$ cup Fruit (melon, banana, berries)— $\frac{1}{2}$ cup Yogurt— $\frac{1}{2}$ cup
Lunch	Milk (not almond milk)— $\frac{1}{2}$ cup Sandwich—2 slices of whole wheat bread with 1-2 oz. of meat and cheese, veggie and dressing (if needed) or peanut butter and jelly Dark-yellow or dark-green vegetable— $\frac{1}{4}$ cup
Snack	Peanut butter (1 teaspoon) with whole wheat bread (1 slice) or 5 crackers or string cheese or cut-up fruit
Dinner	Milk (not almond milk)— $\frac{1}{2}$ cup Meat, fish, chicken, or tofu—2 oz. Pasta, rice, or potato— $\frac{1}{2}$ cup Vegetable— $\frac{1}{4}$ cup

For more sample menus by age group,
visit healthychildren.org

Nutrition Guide for Kids and Teens with MS



MassGeneral Hospital
for Children™



**PARTNERS PEDIATRIC MS
CENTER**

Yawkey Center for Outpatient Care, Suite 6B
Massachusetts General Hospital
55 Fruit St.
Boston, MA 02114
Phone: 617-726-2664

Five Rules to Follow:

#1: Consume appropriate amounts of fiber

- Recommended daily fiber intake for children 2-18 years of age are outlined in the following table:

Age and gender groups	Recommended intake of fiber per day (in grams)
1-3 years old	19
4-8 years old	25
Fiber intake recommendation for boys	
9-13 years old	31
14-18 years old	38
Fiber intake recommendation for girls	
9-13 years old	26
14-18 years old	26

Portions:

Apples/bananas/oranges/strawberries = ~3 grams of fiber
1 cup of raspberries = ~8 grams of fiber

#2: Eat your Veggies

- The recommended serving of vegetables for toddlers to early-school-age children includes one source of vitamin C daily and one source of vitamin A every other day
- Vitamin C intake can be attained through consumption of broccoli or tomatoes and vitamin A intake can be attained from consumption of spinach, sweet potatoes, corn, or squash
- Recent studies have suggested that an increase in vegetable consumption in children with multiple sclerosis decreases relapse rate

AGE	VEGETABLE SERVING PER DAY
12 to 23 months	¾ cup
2 to 3 years	1 cup
4 to 8 years	1½ cups
9 to 13 years	2 to 2½ cups
14 to 18 years	2½ to 3 cups

#3: Avoid Processed/Fast Foods

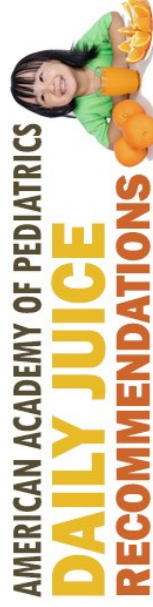
- Processed foods are sources of sodium and saturated fats and therefore should only be consumed if the limits of these are satisfied
- Processed foods are also the source of artificial trans fats, which can be found in some microwave popcorn, some desserts, frozen pizza, etc.



- Opt for fresh, frozen (no sauces or seasonings), or no-salt-added can vegetables as well as fresh poultry, seafood, pork, and lean meat
- Some minimally processed foods such as tuna and roasted nuts, however, can be part of a healthy diet

#4: Limit juices

- It has been confirmed that 100% juice and juice drinks have no essential role in a healthy diet for children and it contributes to excessive calorie intake in children
- Recommendations from the Committee on Nutri-



Age:	Recommendation:
Younger than 12 months	Do not routinely give fruit juice to infants younger than 12 months since it offers no nutrition benefit at this age.*
1 to 3 years	Limit fruit juice to a maximum of 4 ounces per day (½ cup). Do not allow your child to carry a cup or box of juice throughout the day.
4 to 6 years	Limit fruit juice to a maximum of 4 to 6 ounces per day (½ cup to ¾ cup). Do not allow your child to carry a cup or box of juice throughout the day.
7 to 18 years	Limit juice to 8 ounces per day (1 cup).

#5: Get Enough Vitamin D

- Vitamin D insufficiency is associated with an increased relapse rate in pediatric-onset MS patients
- The main food source of vitamin D is oil-rich fish (salmon, mackerel, herring). Liver, organ meats, and egg yolk are also good sources of vitamin D.
- In the US, milk, infant formula, breakfast cereal, and other foods are fortified with vitamin D as well.

Vitamin D intake targets

Infants: 400 IU daily (breastfed and some formula-fed infants require vitamin D supplements)

Children 1-18 years old: 600 IU daily

There is evidence MS patients may need more than the amounts listed above, ask your doctor about your vitamin D levels in order to get a more personalized intake target.

American Academy of Pediatrics: General Dietary Guidelines

- Prioritize consumption of fresh or frozen fruits and vegetables when possible. Develop a list of low-cost sources for fresh fruit and vegetables to support the efforts.
- Avoid processed meats, especially maternal consumption while pregnant
- Consume less than 10% of calories per day from saturated fats
- Consume less than 2,300 milligrams of sodium per day
- Select a mix of foods from the five food groups (vegetables, fruits, grains, low-fat dairy, and quality protein sources)
- Offer appropriate portions

Links for Pediatric MS Patients and Their Families:

1. Partners Pediatric MS Center at MGH:
<http://pediatricmscenter.partners.org/>
2. The National Multiple Sclerosis Society: <http://www.nationalmssociety.org/>
3. NMSS Greater New England Chapter:
<http://www.nationalmssociety.org/Chapters/MAM>
4. Multiple Sclerosis International Federation: <http://www.msif.org/>
5. The Partners MS Center: <http://www.partnersmscenter.org/>
6. US Network of Pediatric MS Center:
<https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Pediatric-MS/Care-for-Pediatric-MS>
7. International Pediatric MS Study Group: <http://www.ipmssg.org/>

Suggestions to Improve Sleep

1. Establish a regular time for going to bed and getting up in the morning and stick to it even on weekends and during vacations.
2. Use the bed for sleep only, not for reading, watching television or homework; too much time in bed can fragment sleep.
3. Avoid naps during the day.
4. Avoid caffeine for four to six hours before bedtime. Caffeine is a stimulant that can make it hard to fall asleep.
5. Don't exercise within four to six hours before bedtime. However, exercising earlier in the day can actually improve sleep.
6. Avoid fluids just before bedtime so that sleep is not disturbed by the need to use the bathroom.
7. Avoid eating a large meal before bedtime, but a light snack might help sleep. Foods containing tryptophan can also promote sleep (turkey, chicken, yogurt, bananas and warm milk); chamomile non-caffeinated tea can also be soothing.
8. Take a hot bath about an hour and half before bedtime. The body temperature then begins dropping rapidly, which may help sleep after that time. (Taking a bath too close to bedtime actually increases alertness.)
9. Do something relaxing in the half hour before bedtime (for example reading, or listening to relaxing music; doing a relaxation exercise or guided imagery, even once you are in bed).
10. Make sure your bed is comfortable and the bedroom is conducive to restful sleep - quiet, at a comfortable temperature, and well ventilated.
11. Do not look at the clock. Obsessing about the time will just make it more difficult to sleep.
12. If you can't fall asleep within 10-15 minutes, get out of bed, go into another room, and do something boring using dim lighting until you are sleepy again. (Don't watch TV or use the computer, which emit too bright a light.)



Relaxation Thermometer



10 - Very tense

5 - Sort of tense

1- Very relaxed - about to
fall asleep

0 - Totally relaxed - sleeping

_____ 's Sleep Plan

Wake up Time: _____

Bath Time: _____

Snack Time: _____

Start Relaxation: _____

Relaxing Activities:

Lights Out / Bedtime: _____

Boring Activity: start after 10-15 minutes of not being able to sleep



Sleep Plan Log

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Wake up Time _____							
No naps							
Bath Time _____							
Snack Time _____							
Relaxation							
Boring Activity							
Time to Sleep							
At least 3							

Rewards: Reward for at least 3 in a day _____

Reward for 5 days in a week w/ at least 3 _____

Reward for 4 days in a row w/ at least 3 _____

Alie's Fund for Children with MS supports children, teens and young adults with MS between the ages of 2-22, by offsetting the cost of the following:

- Educational Needs
 - Elementary
 - Primary
 - Secondary
- Durable Medical Equipment
- Insurance Co-Pays
- Medical Needs
- Personal and Emotional Needs
- Physician Visits
- Referrals
- Respite Services
- Testing
- Transportation

**JOIN THE MOVEMENT
to prove you're stronger than it.**

Programs, Services and Advocacy

Until a cure is found, the National Multiple Sclerosis Society helps people cope with the disease and maintain independence. To accomplish this, the Society offers educational programs, wellness programs, financial assistance, support groups, counseling and referrals. The Society serves as the premier advocate for individuals with MS and their families nationwide.



**National
Multiple Sclerosis
Society**



There is Hope

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn more about options by talking to your health care professional and contacting the National MS Society at www.nationalmssociety.org.



*"Helping to ensure a
brighter future
for kids with MS."*

Alie's Story

Alie was diagnosed with multiple sclerosis at the age of 14. She is currently living her life to the fullest, thanks to her medical team's care and passion. She is grateful for the medications currently available to slow the progression of her disease.



The National Multiple Sclerosis Society served as a critical source of information and support to Alie and her family. The Society referred doctors with expertise in MS care, worked with her schools to allow extra time for exams and guided her college advisors about the intricacies of her life with MS.

Alie is continuously inspired by the efforts of so many people who raise funds to find solutions, so people with MS can live their best lives. Stories from children affected by financial hardship motivated her to start a fund for children with MS.

An estimated 8,000 - 10,000 children have multiple sclerosis in the United States. Children with MS can experience weakness, fatigue, numbness and tingling, vision problems, loss of balance, difficulty concentrating or remembering, seizures and mental status changes.



"It is not possible to measure the impact this fund will have on the lives of those with MS, but it feels incredibly good to be able to help other children with MS."

Alie's Fund for Children with MS provides funds to support children, teens and young adults ages 2-22 who live with MS. These funds will help defer medical and educational costs, counseling and other needed services to ensure a brighter future for those impacted by MS.

Alie's Fund for Children with MS Form for Support

If you are interested in applying for assistance for Alie's Fund for Children with MS, please complete the form and return to:

**3201 West Commercial Blvd., Ste. 127
Fort Lauderdale, FL 33309**

For more information call 954-731-4224 or visit www.nmssflls.org.

Name _____
/ ____ / ____
Date of Birth _____

Age of Diagnosis* _____

Address _____

City, State, Zip Code _____
(_____) _____

Telephone _____

Parent/Guardian Name _____
(_____) _____

Telephone (if different) _____

Preferred way to receive application
 Email _____
 Fax _____
 Mail _____

*Documentation of your MS diagnosis and verification of age is required.



JOSHUA
DIAGNOSED IN 2015



HANNAH
DIAGNOSED IN 2017

RESOURCES FOR CHILDREN AND TEENS WITH MS AND THEIR FAMILIES

MS NAVIGATOR®

The Society's MS Navigators are highly-skilled, compassionate professionals who are supportive partners and help navigate the challenges of MS, unique to each person's situation. They can help you identify and advocate for what you need, when and how you need it — particularly access to services, benefits, and the ability to connect you with a skilled healthcare provider — to live your best life. Connect with an MS Navigator via **email**, visit our **website** and Live Chat, or call 1-800-344-4867 to receive information specific to pediatric MS or to learn more about the resources available to you and your family.

The National MS Society provides direct services, support and resources for navigating your best life through the challenges of MS. Learn more at **nationalMSSociety.org**.

ACCESS TO HIGH-QUALITY HEALTHCARE

Identifying a neurology provider who will partner with you and your child can be a daunting task. The National MS Society has a directory of pediatric providers, by state, to assist you in your search. The clinicians in the directory have experience diagnosing and treating children under the age of 18 who have MS and other central nervous system immune-mediated diseases. Many are also involved in researching pediatric MS.

Access the directory of pediatric providers **online** or contact an MS Navigator for further help.




National
Multiple Sclerosis
Society

1-800-344-4867 | **nationalMSSociety.org**

CONNECT WITH OTHERS

Pediatric MS Online Group for Parents connects parents through an online group where parents can share concerns and information.


 Visit our **website** to register, and then search ‘Pediatric MS Online Group’ to get started.



 **Pediatric MS Alliance Facebook** group for parents with a child or teen with MS.

Oscar the Monkey

Supporting kids and families on their journey with MS.

 **mroscarmonkey.org**

 Oscar the MS Monkey

  @mroscarmonkey

PUBLICATIONS AVAILABLE

Download the publications below from our website.

Kids Get MS Too: A Handbook for Parents Whose Child or Teen has MS is an informational handbook containing a wide range of information pertaining to pediatric MS. The handbook was written by specialists in childhood MS.

Network of Pediatric Multiple Sclerosis Centers E-Newsletter provides a way to keep you connected and informed about the research happening throughout the pediatric focused network. Click here **usnpmsc.org**.



National
Multiple Sclerosis
Society

1-800-344-4867 | nationalMSSociety.org



CADEN, DIAGNOSED IN 2011



HANNAH, DIAGNOSED IN 2017



PETER, DIAGNOSED IN 2015



Kids Get MS Too: A GUIDE FOR PARENTS OF A CHILD OR TEEN WITH MS



**Kids Get MS Too:
A GUIDE FOR
PARENTS OF A
CHILD OR TEEN
WITH MS**

Our MS Journey



Our son, Doug, was diagnosed with MS at the young age of 13. It was the most terrifying experience we had been through. We knew virtually nothing about MS and had to go back into the room to tell our son he had a disease we knew nothing about. The tears didn't stop for days. After a few days, and meeting with several doctors and specialists, we began to learn there was help. They had medication

available. As we researched and learned from some of the best doctors in the country, we began to feel some comfort.

As time progressed and we learned more, we felt empowered. We now focus on what we can do to help Doug stay healthy and feel his best. Doug focuses on exercise, eating healthy, taking his Vitamin D supplements, and never missing a dose of his disease modifying therapy, a doctor's appointment or MRI. He is reminded he has MS for 5 minutes a day as he does his injections. The other 1,435 minutes in the day, he focuses on being 18 and enjoying his life!

I know all too well how scared you might be right now. I promise it gets easier and that you and your child will be able to focus on things other than MS again, just like our family did. Learning about MS is the best way you can feel in control again. I encourage you to use this resource and connect to others who can relate and provide comfort in times of uncertainty. You are not alone—the National MS Society is there to be your supportive partner as you help your child live their best life with MS.

— John and Sarah Roderus

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SECTION ONE—INTRODUCTION AND OVERVIEW

Scary thoughts? ► Quick answers

You've just heard that your child has multiple sclerosis (MS). We're here to help you learn about MS so you can feel confident in helping your child manage this disease. Before we go any further, let's tackle some of those fears you have with some quick answers to help put your mind at ease.

Is my child going to die?	No
Is there a cure?	Not yet
Did I do something to cause this?	No
Can my child give MS to someone?	No
Are my other kids going to get MS?	Probably not
Can my child continue to be active?	Absolutely
Will my child need a wheelchair?	Probably not
Can my child continue to go to school?	Yes

Now that we've gotten those scary questions out of the way, let's expand on these answers and help you feel empowered through knowledge.

What is MS?

MS is a chronic, unpredictable disease of the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. MS is thought to be an immune-mediated disease in which the body's immune system mistakenly attacks normal tissue in the

CNS. This attack is aimed at myelin, the coating around nerve fibers (axons), and the cells that make myelin, which are called oligodendrocytes. The myelin coating around each nerve fiber serves as insulation, much like the plastic coating on an electrical wire. This helps to ensure the efficient transmission of nerve impulses (messages) between the brain and other parts of the body. When myelin or nerve fibers are damaged or destroyed in MS (called demyelination), messages within the CNS are altered or stopped completely.

Who gets MS?

MS is most often diagnosed between the ages of 20 and 50, but, as you know, it is also diagnosed in children and older adults. Nearly one million people in the United States are living with MS. The disease is about three times more common in women than men and occurs in most ethnic groups. It was historically believed to be more common in Caucasians of northern European ancestry, but recent findings suggest that it is equally or possibly more common in African Americans, particularly African American women.

The International Pediatric MS Study Group estimates that less than 5,000 children and teens are living with MS in the United States and less than 10,000 worldwide. There are also another 10-15,000 children and teens with other CNS immune-mediated disorders with symptoms similar to those seen in MS, which makes the diagnosis of MS in children and teens challenging.

The average person in the United States has about one in 750 (.1%) chance of developing MS. For first-degree relatives of a person with MS, such as children, siblings or non-identical twins, the risk rises to approximately 2.5-5% — with the risk being potentially higher in families that have several family members with the disease. While that might seem like a significant increased risk, the relative risk of developing MS

even with a family member with MS is still very low.

What are the Symptoms of MS?

The symptoms experienced from MS result from the damage done to myelin and nerve fibers in the CNS. Since demyelination can occur anywhere in the CNS, a person can experience a range of symptoms. Symptoms vary from person to person and from day to day.

Some common symptoms include:

- Limb numbness and tingling
- Vision changes (blurred, loss of, or double vision)
- Limb weakness
- Poor coordination
- Walking problems
- Depression
- Fatigue
- Concentration or memory problems

Fortunately, most people develop only a few of these symptoms over the course of their MS, and most can manage their symptoms quite effectively.

What Causes MS in Children and Teens?

We do not yet know the answer to this question. The current thinking is similar to what we think causes adult onset MS: that the disease appears in individuals

who are genetically predisposed and then exposed to a trigger in the environment, including:

- Infection with Epstein-Barr virus (mononucleosis)
- Cigarette smoking
- Childhood and adolescent obesity
- Low levels of vitamin D

No one environmental trigger alone causes MS, but they all play a role in making someone with the right genetic make-up more likely to develop MS. Many people who have been exposed to these triggers do not develop MS. We still do not understand why a combination of genetic factors and these triggers causes MS to happen. Scientists are studying the possible triggers, both environmental and genetic, to learn more about the causes of MS.

While studies indicate that genetic factors may make certain individuals more susceptible to the disease, there is no evidence that MS is directly inherited. It's important to know MS is not caused by any factor over which you or your child had any control. MS is not a contagious disease — your child did not “catch MS,” and you do not need to be concerned that your child will give MS to other members of the family or to friends and classmates. There was nothing you did to cause this to happen and, similarly, nothing you could have done to prevent it.

What are the Different Types of MS?

Children with MS exclusively have a relapsing-remitting course, which means there are clear attacks (relapses) of symptoms that subside (remit). During the periods of remission between attacks, there is no progression of the disease. Even though children may experience frequent attacks (possibly more than typically seen in adults), studies have shown that children also seem to have very good, often more rapid recovery than adults.

Other types of MS include:

- Clinically isolated syndrome
- Primary progressive MS
- Secondary progressive MS

If you would like to learn more, you can find information at nationalMSSociety.org/What-is-MS or by calling an MS Navigator® at 1-800-344-4867.

Is There a Cure for MS?

There is no cure for MS at the present time. The important thing to note is that MS is not fatal. Almost all people with MS will live very close to a normal life span and eventually die of “natural causes” (e.g., heart disease, strokes or cancer).

There are many medications approved by the US Food and Drug Administration (FDA) to treat relapsing forms of MS in adults. One treatment, fingolimod (brand name Gilenya®), is also approved for use in children ages 10 and older who have relapsing remitting MS. Many of the treatments approved for adults with relapsing forms of MS are also used off-label for children with MS. Pediatric MS experts have extensive clinical experience with the use of these medications in children, and there is a growing amount of safety and efficacy data for their use. We'll talk more about these treatments in the "Managing MS" section of this publication.

Do Children and Teens Need to be Told Their Diagnosis?

Parents sometimes wonder if they should delay telling their child or teen about their MS diagnosis. No parent wants to cause a child undue anxiety, and every parent would like his or her child to have as carefree and happy a childhood as possible. There are, however, 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 states of mind. Without an open and honest explanation of what is happening, they might use their own imaginations to fill in the blanks.

- Open, honest communication in a family promotes trust and eliminates the need for secrets.
- Children and teens need to be included in decisions about their care. When children and teens are included in developing their treatment plan, they are more likely to adhere to it (e.g. if children and teens get to make the decision of which medication they use, they are more likely to use it as instructed).
- When parents talk comfortably about diagnosis and treatment issues, children feel more secure and less afraid. They know their parents and healthcare team are taking good care of them.
- Children and teens with MS are going to have ongoing relationships with a variety of healthcare professionals, and undergo periodic medical examinations and evaluations. 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.
- Many children, particularly 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.

SECTION TWO— MANAGING MS

Your Child's Relationship with the Healthcare Team

Good relationships with healthcare professionals play an important part in living comfortably with MS. Depending on your child's age, you may have the dual challenge of helping the health professional understand what your child is experiencing, and helping your child understand what the professional is doing or saying.

Very few of us feel relaxed in the healthcare provider's office, and young children may find the diagnostic tests and neurologic exams frightening until they have developed trust in the healthcare providers. Your ability to stay calm and relaxed despite all the anxiety you are feeling will help your child feel more comfortable. To the extent possible, finding out ahead of time what is likely to occur during the visit will help you talk to your child about what to expect.

While teenagers may have some anxiety as well, they may gradually want to handle some of the healthcare provider visits on their own. Those who have been able to develop an open, trusting relationship with their healthcare provider may prefer to be examined and talk to the professional

without you there. This may be very difficult for you, given your own concerns and desire to hear everything that the professional is saying. But your teen's need for privacy and independence is normal. It will also help their transition to managing their own care as an adult easier.

One strategy is to arrive at a three-way agreement between you, your teenager, and the healthcare provider that acknowledges your child's wish for privacy and independence while making it clear that important medical decisions will be made by all of you together.

Because they do not want to "burden" or worry others, older children and teens may not open up about things that are bothering them either physically (such as new symptoms) or emotionally when you are present at visits. Giving teenagers time alone with their healthcare provider allows them to have an open discussion about things they might not otherwise share. After your teenager has had time alone with his or her healthcare provider, you can join them to review the details of the visit and make treatment plans.

In the case of older teens (18 and above), medical decisions are legally theirs to make. The provider will seek your input on medical decisions only with the older teen's permission.

Where to Find Pediatric MS Healthcare Providers

Identifying a neurology provider who will partner with you and your child can be a daunting task. The National MS Society has a directory of pediatric providers, by state, to assist you in your search. The clinicians in the directory have experience diagnosing and treating children under the age of 18 who have MS and other central nervous system immune-mediated diseases. Many are also involved in researching pediatric MS.

If there are no providers with expertise in your area, you can consider traveling to a provider with MS expertise for a consultation and take his or her recommendations back to your local healthcare provider. The important thing to remember is that there are resources available to help you find the best possible treatment for your child.

Access the directory of pediatric providers at [nationalmssociety.org/pediatricMS](https://www.nationalmssociety.org/pediatricMS) or contact an MS Navigator at 1-800-344-4867 for further help.

Treating Pediatric Onset MS

The treatment of MS, in children and teens as well as adults, involves several strategies:

- Modifying the disease course
- Managing relapses
- Maximizing lifestyle interventions
- Managing symptoms

Modifying the Disease Course

There are medications that are very effective at preventing relapses and disability accumulation, which is referred to as modifying the disease course. Starting a disease modifying therapy (DMT) early and staying on it is the best available strategy to manage MS. There are several preventative goals of disease modifying therapies, including:

- Reducing the number of relapses
- Limiting the number of new lesions seen on magnetic resonance imaging (MRI)
- Delaying disease progression

DMTs do not cure MS, and they are not designed to relieve existing symptoms. Sometimes the effects of the medications on the disease are not apparent, especially in the first few months. This can make staying on a medication difficult, particularly for children and teens. It's important that your child be involved in choosing and understanding the goals of a treatment. The medications only work when they are taken as intended. Encourage your child or teen to talk openly with his or her healthcare provider if they are struggling with sticking to the treatment schedule. There are many medication options, and it's most important that your child or teen be on one that he or she will be committed to taking.

More than a dozen disease modifying therapies are approved by the U.S. Food and Drug Administration (FDA) to treat adults with relapsing forms of MS. In May 2018, the FDA approved the use of the oral MS therapy Gilenya® (fingolimod, Novartis AG) for the treatment of children and adolescents 10 years of age or older with relapsing MS.

Many of the medications used for adults with MS have been studied in children with MS in different centers throughout the world, and a wealth of experience has accumulated among many clinicians caring for children and adolescents with MS. Healthcare providers rely on published study findings as well as their own clinical judgment to adapt the treatments with FDA approval in adults for their younger patients. Work with your healthcare provider to determine the best treatment option for your child.

Due to the changing landscape of disease modifying agents currently available for MS, the specific treatments are not discussed here. For more information on the available therapies, visit nationalMSSociety.org/DMT.

Managing Relapses

Relapses, also called attacks, flare-ups and exacerbations, are periods of new or a recurrence of old symptoms that last in a constant fashion for 24 hours or more. Other things, like a fever,

getting overheated or a urinary tract infection, can also make old relapse symptoms worsen—this is called a pseudo-relapse. To be a true relapse, the symptoms need to be experienced outside of having an infection, a fever, or being overheated.

Relapses can last anywhere from a few days to several weeks and will resolve on their own, but sometimes medications are used to speed up the recovery process. Although symptoms such as numbness, tingling or very mild weakness can be frightening and disconcerting, they will generally improve and resolve on their own without medication. Healthcare providers sometimes reserve medication only for those relapses that are significant enough to interfere with your child's functioning at home and at school, like a problem with vision or ability to walk safely.

If medication is used to treat a relapse, it's typically managed with a 3- or 5-day course of intravenous or oral (pill) corticosteroids. This course is sometimes followed by a tapering (gradually decreasing) dose of oral corticosteroids over several days. The goal of corticosteroid therapy is to improve symptoms and hasten recovery time. Corticosteroids do not, however, change the long-term course of MS or have any other long-term benefits. In other words, whether your child's relapse is treated with corticosteroids

will not impact his or her future disability or relapse likelihood.

Maximizing Lifestyle Interventions

A healthy diet, regular exercise, stress management and other wellness strategies can help your child manage his or her overall health and MS.

Your child can feel his or her best by adopting the following preventive health strategies:

- Eat a healthy diet
- Get adequate exercise or physical activity
- Quit cigarette smoking or avoid starting
- Get enough rest
- Utilize effective stress management strategies
- Have regular medical checkups and age appropriate screening tests
- Develop an effective support system
- Build a good social network and have fun with friends
- Pay attention to his or her emotional and spiritual needs

Many parents ask about the use of herbal or naturopathic remedies for their child. In the face of a disease like MS, for which we have no cure, it may be tempting to try products that boast of their ability to cure MS. Discuss the use of any “natural” or alternative therapy with your child’s healthcare provider before trying it. Although there

may be a benefit from some of these remedies, most have never been studied in controlled clinical trials to assess their safety and efficacy. Even natural products can be toxic or have significant side effects, and some may interfere with your child’s other medications.

It is important to be wary of alternative therapies that claim to “boost” the immune system. Because MS is an illness in which the immune system appears to be overactive, in theory, boosting your child’s immune response could worsen their MS.

It is also important to keep in mind that herbal supplements and other over-the-counter products are not regulated in the U.S. in the same way that prescribed medications are. That means that manufacturers can make claims for their products without oversight by the FDA or any other regulatory agency.

Discuss all treatments being considered with your child’s healthcare team.

Managing the Symptoms of MS

MS symptoms can be unpredictable and vary from person to person. It’s important to be familiar with the possible symptoms of MS so that your child can discuss them with his or her healthcare provider. There are medications available to manage the symptoms of MS and many of

the symptoms can be managed with strategies that don't involve the use of medication, like physical therapy, counseling and lifestyle changes. Be sure to discuss all the symptoms your child is experiencing with your child's healthcare team.

Although MS can cause symptoms in many parts of the body, it is not the cause of every symptom that may occur. Your child will still get the same viral illnesses and assorted problems that all children get, and potentially others as well. It is therefore important to maintain regular check-ups with your child's primary care provider.

To learn more about the specific symptoms of MS and their management, visit nationalMSSociety.org/symptoms.

SECTION THREE— RESOURCES AND SUPPORT

The National Multiple Sclerosis Society

We are here to be your supportive partner throughout this journey. Find links to videos, social media and other resources for families and kids.

 [nationalmssociety.org/
pediatricMS](http://nationalmssociety.org/pediatricMS)

Pediatric MS Online Group for Parents


Share concerns and information in a supportive online community. Visit msconnection.org to register and then search "Pediatric MS Group" to get started.

MS Navigator®

Having the right information at the right time can help you make sound decisions. The National MS Society provides answers to questions and access to information on available resources. Our MS Navigators are highly skilled professionals equipped to respond to your individual needs. The National MS Society maintains strict confidentiality policies. Regardless of the types of programs or services you choose to utilize, your privacy will be respected and protected. Contact an MS Navigator to learn more.

 nationalMSSociety.org/navigator

 contactusnmss@nmss.org

 1-800-344-4867

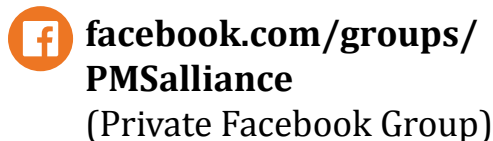
International Pediatric MS Study Group

Their mission is to improve the care of children with multiple sclerosis and acquired demyelinating diseases worldwide, promoting clinical initiatives, education and research.



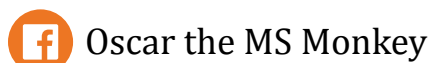
Pediatric MS Alliance

Parents and families whose lives are affected by pediatric MS is what we're about. By sharing information, experiences, knowledge, resources, contacts, and providing educational opportunities, we can better build bridges and better help raise awareness for MS and other neuro-immunologic disorders.



Oscar the Monkey

Supporting kids and families on their journey with MS.



Someonelikeme.ca

For youth and young adults who are living with MS either with a diagnosis of MS or personal connection to MS. The platform features blogs, forums and inspirational stories of young people living with MS and engages youth in a friendly environment that respects and values their opinions and input. There are multiple ways to get informed, to get involved, and to take action.



The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.



**National
Multiple Sclerosis
Society**

nationalMSSociety.org

1-800-344-4867

Partners Pediatric MS Center Tip Sheet:

- Always take your meds – set alarms on your phone so you don't forget!
 - Not taking your meds at the required time points puts you at risk of a relapse or reappearance of symptoms
- Answer your phone! – doctors might be trying to contact you regarding your treatment or condition and it is very important that they can reach you.
 - Make sure that we have your current number and clear out your voicemail for us to be able to contact you and leave a message if needed
- Don't be afraid to call your doctors – if you have questions or concerns or if you are experiencing an emergency feel free to call us at any time!
 - The number for the Center is 617-726-2664.
 - Leave a message if no one is available to take your call.
 - You can also reach out to your doctors through Patient Gateway (<https://patientgateway.partners.org>)

For more information on our Center, Multiple Sclerosis, other demyelinating disorders, and things going on in the community visit our website at <http://pediatricmscenter.partners.org/>