

PEDIATRIC MS FAQs

Q: What is the cause of MS?

While the exact cause is unknown, it is theorized that the MS disease process may be influenced by both environmental factors (such as viral infections, environmental exposure or geographic location) as well as genetics (family members of patients with MS may have an increased risk of MS when compared to the general population).

Q: How common is MS in children?

While the number of children who have MS is low, there is a growing number of diagnoses of pediatric MS and other demyelinating diseases each year. At least 2.5% to 5% of all patients with MS experience their first clinical attack prior to their 16th birthday (Duquette et al., 1987).

Q: What is the difference between adult MS and pediatric MS?

While there are many similarities, the major difference is that there seem to be more atypical cases with pediatric MS. One difference seems to be the impact on learning, particularly for children who have active disease prior to completing their core educational building blocks. A child whose learning process is disrupted prior to learning mathematics or advanced sentence structure will likely develop substantially different deficits as compared to an adult who has already mastered these subjects. The occurrence of a multiple symptom onset may be slightly higher in children than in adults.

Q: Is MS contagious?

No, MS is not contagious and is not directly inherited. However, it is possible that

genetic factors may make certain people more susceptible to the disease.

Q: What is attack/relapse?

Exacerbations cause new symptoms or worsen existing symptoms by causing inflammation and demyelination in the central nervous system.

Q: Is there a cure for MS?

Currently, there is no cure for MS, but treatments do exist. Treatments are directed at modifying the course of the disease. Specifically, the available treatments can prevent or reduce the frequency of attacks and slow the progression of physical disability. The available treatments are injections of *Avonex*, *Betaseron*, *Rebif*, and *Copaxone*.

Q: Will the child with MS eventually need to be home schooled?

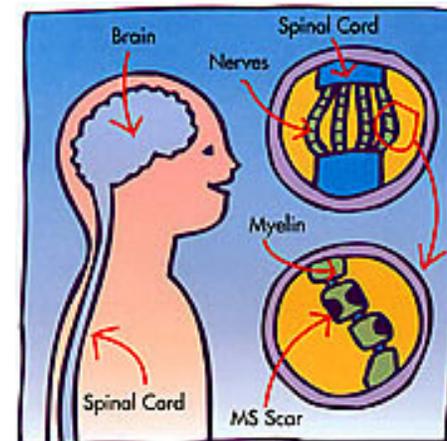
No; while MS is a chronic illness, there are medications that are used to slow down the trajectory of the illness. While each person with MS has unique symptoms, many live a "normal" life, with some modification.

Q: Is MS fatal?

Most people with MS have normal or near normal life expectancy. In extreme cases, MS causes severe symptoms, which could lead to death. While MS is not considered a fatal disease, people with MS often struggle with increasing limitations in their lives.

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Pediatric Multiple Sclerosis



Helpful Information for School Staff

Promoting awareness of the diagnosis and the symptoms of MS in children.

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WHAT IS PEDIATRIC MS?

- ◆ Multiple sclerosis (MS) is a disease that affects the brain and spinal cord (also known as the central nervous system).
- ◆ While we do not know the exact cause(s) of MS, it is believed that the body's immune system sees part of the body as foreign and attacks it; this is called an autoimmune response. This can damage the covering ("myelin") that protects the nerves in the brain and spinal cord ("damage = demyelination").
- ◆ Scars form where myelin is damaged; these scars prevent information (nerve impulses) from getting through. We can see these scars on an MRI of the brain or spine. They are "active" when they light up (enhance) with injection of dye during the MRI.
- ◆ Multiple = many, and Sclerosis = scars, so "multiple sclerosis" = "many scars."

SYMPTOMS OF PEDIATRIC MS

Sensory symptoms:

- ◆ Loss or disturbance in vision, changes in color vision, sometimes pain in the affected eye(s), and double and blurry vision (diplopia).
- ◆ Numbness and tingling (the feeling of "pins and needles"), dizziness, and pain are also common among people with MS.

Cognitive and emotional symptoms:

- ◆ Adults with MS experience varying degrees of change in their ability to think, reason, and remember; this is similar with children/adolescents with MS. While these symptoms remain relatively mild and manageable for most children, they can

significantly impact and limit daily activities for a small percentage of children. Therefore, it is imperative that every effort is made to *recognize* and *address* these problems **before** they have a significant impact on a child's school experience.

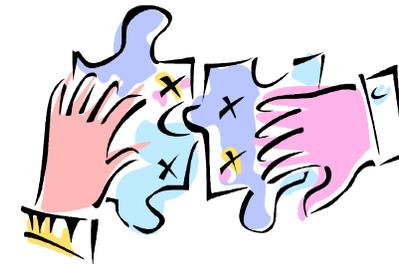
- ◆ While **grief** and **anger** are natural and normal reactions to the diagnosis of a chronic, potentially disabling illness, **depression** and other significant **mood changes** should be brought to the attention of parents to ensure appropriate evaluation and treatment.

Other symptoms:

- ◆ **Fatigue** is one of the most common complaints of people with MS.
- ◆ Bladder and bowel control symptoms, including feelings of urgency and a need to urinate very frequently can result from demyelination in the spinal cord.

HOW DOES MS EFFECT CHILDREN AND ADOLESCENTS IN SCHOOL?

- ◆ Symptoms can wax and wane from week to week.
- ◆ There may be weeks, months, or even years between attacks; we cannot predict when attacks will happen.
- ◆ Learning & Memory: MS can affect a person's cognitive functioning; therefore, their reasoning, processing, attention, and other thinking abilities may be impacted.
- ◆ Writing/hand writing: Acute attacks or residual symptoms can produce numbness or weakness, which can affect the mechanics of handwriting.



WORKING TOGETHER TO ENSURE SUCCESS IN OUR CHILDREN

- ◆ It is important that the student receives appropriate educational services at all times and not only during a relapse. Following are some suggestions regarding accommodation:
 - General educational intervention.
 - Development of an Individualized Education Plan (IEP) to ensure success in learning at school.
 - Students may qualify for Other Health Impaired (OHI) special education services.
 - A section 504 Plan might be needed.
 - Individual Health Plan (IHP) might be needed.
 - Early Individual Transitional Plan (ITP) for those students who are about to start High School and definitely for those who are already in High School.
- ◆ The UCSF Regional Pediatric MS Center team includes a school psychologist and neuropsychologist who can help determine appropriate accommodations and modifications. They can also help educate school personnel about Pediatric MS (with an appropriate parental authorization, this information can be communicated directly to the school).
Staff Neuropsychologist: Laura Julian, PhD