

Family Education Sheet

A School's Guide to Supporting Students With Multiple Sclerosis



Boston Children's Hospital

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What is multiple sclerosis (MS)?

- MS is a kind of autoimmune disease. These are diseases that cause the body's immune system to react against itself and attack its own healthy cells and tissue.
- With MS, the immune system reacts against the central nervous system (CNS). The CNS is made up of the brain, spinal cord and optic nerves in the eyes. The immune system reacts most strongly against myelin, the protective coating around nerve cells.
- Myelin is like padding around an electrical wire. It helps nerve cells send information within the CNS.
- The immune system's attack on myelin causes inflammation and scars in the CNS. The scars can slow or cut off the flow of information along nerve cells. This is what causes symptoms of MS.

Who does MS affect?

- About 5–10% of people with MS first have symptoms before they are 18.
- The average age that MS affects children is 11–14 years old.
- About 90–95% of children with MS have “relapsing-remitting” disease. This means that symptoms may come and go.

What are the symptoms?

Children and teenagers with MS may struggle with physical, cognitive and emotional symptoms. Some may be invisible to others, but are very real to the student. Children and teenagers with MS often try hard to hide their symptoms.

Physical symptoms

- Fatigue: made worse by warm weather
- Vision problems: blurred and double vision
- Sensation changes: numbness and tingling
- Weakness and balance problems
- Dizziness
- Bowel and bladder problems
- Difficulty with moving locations due to physical challenges

Cognitive symptoms

When people think about MS, they often think about the physical symptoms. However, cognitive symptoms are also common. Children with MS may be vulnerable to cognitive impairment because their myelin (the target of the immune system's attacks) is not fully formed. Studies show that at least 35% of children with MS have cognitive impairment.

Someone can have cognitive symptoms without any visible physical symptoms. This is especially common in pediatric MS. Common cognitive impairments may lead to academic struggles in particular areas (see below). A student with MS should be assessed to determine strengths and weaknesses.

- **Verbal learning and memory:** The student may struggle to recall information previously learned. It can help to give prompts and cues. Children diagnosed at an early age may have particular problems with verbal memory or listening learning.
- **Processing speed:** The student may take longer to process information. This may be evident when the student tries to copy or scan visual information quickly, take notes, copy from the board, complete worksheets or think fast—especially on unfamiliar tasks. Having the disease for longer may cause slower information processing and responding.
- **Executive functioning (cognitive flexibility):** The student may struggle to shift gears flexibly, or shift attention between tasks or activities quickly.
- **Attention span:** The “chunk” of information the student may attend to or process at 1 time may be more limited than other students.
- **Spatial processing and visual-motor integration:** copying or writing.
- **Reading:** especially reading quickly (fluency) and comprehension.
- **Naming:** finding the right word.
- **Receptive language** (listening comprehension): The student may need information clarified, repeated or broken down.

Emotional symptoms

- As many as 50% of children with MS develop depression, anxiety and/or panic attacks.
- Depression may be associated with more severe levels of the disease.
- Depressed patients may have more deficits in memory and executive function than those who are not depressed.
- Depression can lead to poor treatment adherence. This can bring on cognitive deficits faster and make them more severe.

Are relapses common?

Many children with MS have a relapsing-remitting disease, so symptoms can come and go. Relapses can be unpredictable, disruptive and unnerving. Sometimes kids do not recognize they are having a relapse (or do not want to talk about it for fear of being hospitalized).

What medications treat MS?

Disease-modifying medications: These medications help prevent new attacks and reduce their severity. They can also slow the progression of the disease.

Will a student with MS miss much school?

- The relapsing-remitting nature of MS means that the student may have unpredictable school attendance. The student may miss school due to symptoms associated with relapses and for many scheduled medical visits and treatments.
- School absences may range from 0-225 days a year (the average is 25 days). It may be necessary to make-up instruction when the child is feeling better.
- Support for a student with MS should be provided through a 504 Plan or an Individualized Education Program (IEP) to help the student continue to be successful at school.

Who is on the student's hospital care team?

At Boston Children's Hospital, most children with MS are seen in the Pediatric MS and Related Disorders Program, which is part of the Neurology Department.

Children are followed by a pediatric neurologist, can be evaluated by a pediatric neuropsychologist and may be seen by these other members of the multidisciplinary team: bostonchildrens.org/neuroimmunology

Contact us

Integrated, coordinated care is essential to support a student with MS and their families. In addition to medical care, children with MS need support from their home, school, peers and the community.

We encourage open communication between parents, the school and the MS clinic team. If necessary, a release of information can be made available.

We appreciate your support for your student. If you have questions, please contact Kitty Petty, our Educational Consultant, at 617-877-8896 or catherine.petty@childrens.harvard.edu.