



# Students with MS: A GUIDE FOR PARENTS AND SCHOOLS

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# SECTION ONE—INTRODUCTION AND OVERVIEW

## 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 (messages) between the brain and other parts of the body. When myelin or nerve MS (called demyelination), messages within the CNS are altered, slowed or stopped completely.

## Who gets MS?

MS is most often diagnosed between the ages of 20 and 50 but can also be diagnosed in children and older adults. Nearly one million people in the United States are living with MS and it's estimated that less than 5,000 are children and teens. 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 Whites of northern European it is equally or possibly more common in African and Black Americans, particularly African and Black American women.

## 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 and there are likely triggers all play a role in making someone with the right genetic make-up more likely to develop MS.

## What are the types of MS?

Children with MS almost 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

more rapid recovery than adults. Other types of MS that occur rarely in children

## What are the Symptoms of MS?

Symptoms from MS result from damage to the central nervous system (CNS). Since demyelination can occur anywhere in the CNS, a person can experience a range of symptoms that can vary from person to person and from day to day. Children and adolescents may experience physical symptoms of MS, cognitive symptoms, or both.

Symptoms can occur as part of a relapse or they can be chronic and happen on a daily or almost daily basis. Fortunately, most people develop only a few chronic

symptoms, and most can manage their symptoms quite effectively.

Some symptoms can affect a student's participation and performance in school activities and could require accommodations. Below is a list of a few of these symptoms and suggested accommodations. MS can affect cognition and memory, which can have a significant impact on school performance.

We address cognition and provide suggestions for accommodations in greater detail in a separate section following this chart. For a complete list of possible MS symptoms, visit [nationalMSSociety.org/symptoms](http://nationalMSSociety.org/symptoms).

Symptom	Description	Accommodation
<p><b>Fatigue</b></p>	<p>One of the most common symptoms experienced by students with MS is fatigue. It is more common than non-MS fatigue. It is often described as a heavy, tired feeling that is not always relieved with sleep/can be experienced in the morning, even after a good night of rest.</p>	<ul style="list-style-type: none"> <li>• Assign student to classrooms in same area of building, if possible</li> <li>• Allow student frequent breaks to the restroom</li> <li>• Allow student to use the elevator</li> <li>• Offer alternative classes on alternate days, alternative classes</li> <li>• Alert bus driver of any special needs</li> <li>• Provide a second set of books to be kept at home</li> <li>• Allow frequent rest breaks</li> <li>• Seat student near window or air conditioner to combat fatigue on hot days</li> <li>• Shorten assignments to reduce work expectations, break work down into smaller segments</li> <li>• Extend time on tests and assignments</li> <li>• Give frequent short quizzes, not long exams</li> <li>• Provide evaluations, consultations and services in physical and occupational therapy (PT/OT), and speech</li> </ul>
<p><b>Pain, Numbness, and Spasticity</b></p>	<p>Neuropathic pain-stabbing, burning, aching, electrical shock numbness-pins and needles spasticity-muscle tightness</p>	<ul style="list-style-type: none"> <li>• Offer breaks to stretch or walk around the classroom</li> <li>• Offer shorter distances between classes or more time to change classes</li> <li>• Offer space and support in the nurse's office or relaxation strategies to manage pain</li> </ul>

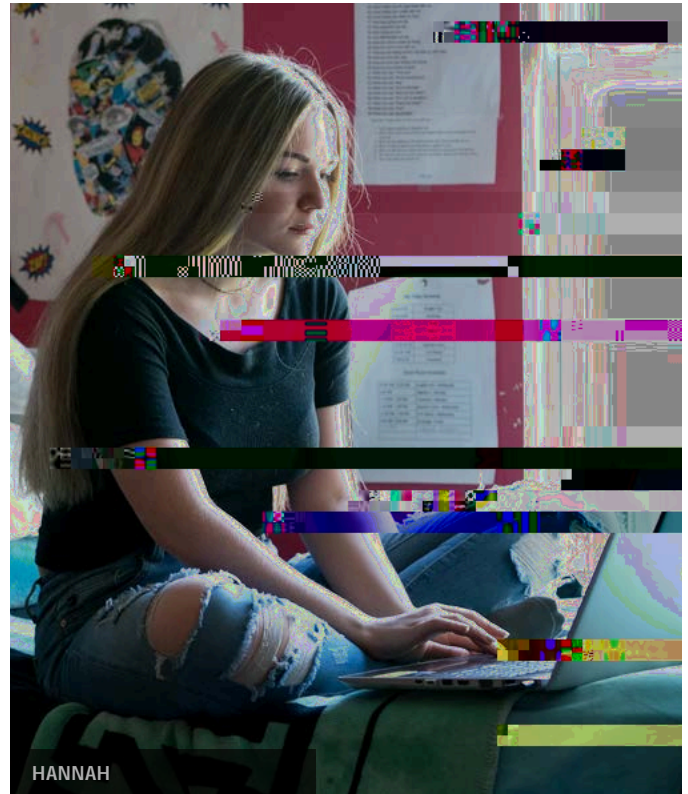
Symptom	Description	Accommodation
<b>Visual disturbances</b>	Blurred, double, pain with eye movement	<ul style="list-style-type: none"> <li>• Enlarge written material and notes</li> <li>• Enlarge print books or ebook</li> <li>• Provide recorded versions of written material to assist student</li> <li>• Provide peer note taker or provide a scribe</li> <li>• Use assistive technology, e.g., computer-assisted instruction</li> <li>• Seat student near the board</li> <li>• Outline or copy of teacher's notes</li> <li>• Read test items to student</li> <li>• Allow use of dictation software</li> </ul>
<b>Bladder/ bowel</b>	Increased frequency, urgency and incontinence	<ul style="list-style-type: none"> <li>• Allow unrestricted use of bathroom</li> <li>• Allow student to have water at desk</li> </ul>
<b>Temperature sensitivity</b>	Exposure to extreme temperatures or increase in body temperature from heat/humidity can cause a temporary symptoms	<ul style="list-style-type: none"> <li>• Seat student near window or air conditioner</li> <li>• Allow student to carry water bottle</li> <li>• Fan in the classroom near student's seat</li> <li>• Provide indoor exercise options</li> <li>• Allow student to wear a cooling device</li> <li>• Store extra sweater or jacket in classroom</li> </ul>

## Cognition

Education disruptions from MS symptoms can have long-term consequences. As compared to their peers, individuals diagnosed with pediatric MS may attain lower educational levels and have diminished lifetime earnings. A common symptom of MS is changes in cognition. Since cognitive changes can have a significant impact on learning in school, we will provide more details on how cognition is affected by MS and offer suggested accommodations.

Approximately one-third of children and teens with MS develop cognitive symptoms that may impact their success in the school setting. Memory, attention and speed of information processing are the most frequently impaired functions. Reasoning, planning and visual perception can also be impaired. There is no clear relationship between level of physical disability and level of cognitive impairment. Some individuals with MS have physical symptoms without cognitive symptoms, while someone with little or no physical impairment can have cognitive symptoms. Individuals with MS may also become easily fatigued when performing physical and cognitive tasks, which may exacerbate cognitive problems.

Cognitive changes often progress slowly and may not be obvious to observe in casual interactions,



and may be challenging to detect. Baseline neuropsychological testing is recommended after diagnosis, regardless of the severity of symptoms. A testing report can be used to formally request accommodations and supports for a student with MS in school. Repeat testing should be performed at least every two years or when there is a report of cognitive or academic decline to ensure that changes are not missed and that appropriate accommodations are in place. Parents should work with the MS healthcare provider to ensure neuropsychological testing is completed as recommended.

Changes in thinking and physical abilities may lead to feelings of inadequacy,



frustration or a sense of not being able to keep up with peers. Additionally, social isolation and fatigue have been associated with reductions in quality of life. This can result in changes in mood which should be brought to the attention of the student's family, school counselor or healthcare provider for appropriate evaluation and treatment.

## Attention/Information Processing

Attentional problems may not be observable in a child with MS who

they can't produce it. Children with these  
 incorrect word in place of the target  
 word (e.g., "sister" rather than "brother"),  
 or "talk around" the word, using  
 unnecessarily indirect and wordy speech  
 to explain something that could be stated

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## Cognition Accommodations

### General

- Use self-monitoring strategies and devices
- Use assistive technology (e.g., for audio books, dictation and enlarging print)
- Provide recorded versions of written material to assist student with visual dysfunction, short-term memory loss or poor comprehension
- Have student review key points orally
- Provide student with a school map highlighted to show areas they need to get to
- Provide extra time to complete tasks
- Keep classroom rules simple and clear
- Provide a structured routine in written form
- Provides written course outline or agenda for the week, month, semester to help student plan

## **During Instruction**

- Provide study skills training/learning strategies
- Give notes before class
- Make sure directions are understood, repeat instructions, provide additional directions if needed
- Use visual cues such as writing key points on the board or other visual aids
- Teach through multi-sensory modes
- Seat student near the teacher
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