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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 that insulates nerve fibers 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, 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 ancestry, but recent findings suggest that 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 that haven't yet been identified, but they 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 include clinically isolated syndrome, primary progressive MS and secondary progressive MS.

What are 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. If medication is used to treat a relapse, it's typically managed with a 3- or 5-day course of intravenous (infused into a vein) or oral (pill) corticosteroids.

How is MS managed?

Although a cure for MS has not yet been discovered, several medications have been approved by the U.S. Food and Drug Administration (FDA) over the past 25 years. These medications modify the disease course by reducing the number of MS relapses and slowing the progression of the disease. Research is also teaching us that lifestyle choices can be beneficial in managing MS. Combining a disease modifying medication with a healthy lifestyle is the optimal management strategy for MS. Additionally, many symptoms of MS can be effectively managed using medication and non-medication strategies. Some medications need to be administered in a healthcare setting so children and teens might need to miss school to receive them. They can also cause side effects, such as fatigue, fever-like feeling and body aches, that might affect how the student feels the day of or after it's administered.



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SECTION TWO-SYMPTOMS AND SCHOOL ACCOMMODATIONS

What are the Symptoms of MS?

Symptoms from MS result from damage to myelin and nerve fibers in the 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 in several ways and 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.

Some common symptoms include:

Symptom	Description	Accommodation
Walking (gait), balance & coordination problems	Difficulty walking; usually caused by muscle weakness, spasticity (muscle tightness) and muscle fatigue	<ul style="list-style-type: none">• Seat student near door to allow easy exit• Allow student to leave classroom early to have extra time to get to next classroom• Assign student to classrooms in same area of building, if possible• Allow student to use the elevator• Consider gym modifications• Allow student's bus to park closest to the door• Provide evaluations, consultations and services in physical and occupational therapy (PT/OT), and speech

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

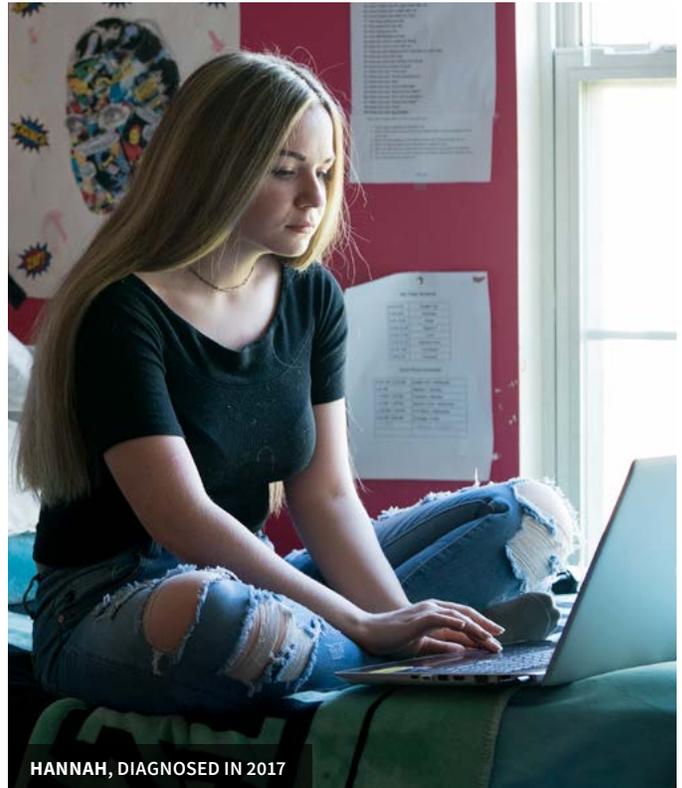
Symptom	Description	Accommodation
Visual disturbances	Blurred, double, poor color vision; pain with eye movement	<ul style="list-style-type: none"> • Enlarge written material and notes • Enlarge print books or ebook • Provide recorded versions of written material to assist student • Provide peer note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

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 a student's success 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 disability. A person can have significant physical symptoms without cognitive symptoms, while someone with little or no physical impairment can have significant cognitive problems. Children with MS may also become easily fatigued when performing physical and cognitive tasks, which may exacerbate cognitive problems.

Cognitive changes often progress gradually over time, are difficult to observe in casual interactions,



and may be challenging to detect. Baseline neuropsychological testing is recommended after diagnosis, regardless of whether cognitive deficits are evident. 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 is speaking with someone in a quiet environment. However, difficulty arises as tasks become more complex, especially when divided attention is required.

Children with MS may also have trouble with working memory — the ability to hold onto information while working with it. This ability is necessary when performing mathematical computations, or other more complex operations. Additionally, the speed at which information is processed may be reduced, requiring more time to respond or to complete tasks and assignments.

Memory

Memory problems are perhaps the most common cognitive complaint in children. For example, children may have difficulty recalling conversations, keeping track of

assignments or remembering teachers' lectures. Children who have difficulty paying attention will encode and store less information, therefore reporting poor "memory" for that information. While the student's outward behavior may seem to indicate lack of motivation to learn, the actual problem is inability to learn.

Children and adolescents with memory problems may have difficulty learning information, may easily forget information, or be unable to report information without cueing or prompting. Children may have difficulty with memory for verbal information (information they hear), as well as visual information (information they see). Children with deficits in visual memory may have difficulty remembering where they put their schoolbooks or keys, or may get lost easily, especially when in unfamiliar neighborhoods or buildings.

Language

Language deficits in children and adolescents with MS tend to be subtle. They are generally related to the speed of information processing and usually involve a reduction in fluency (the speed with which language is produced). As a result, these children may speak more slowly than before. They may also exhibit "naming" deficits (also referred to as "word finding" problems) in which the word is "on the tip of their tongue" but

they can't produce it. Children with these kinds of deficits may say a related but incorrect word in place of the target word (e.g., "sister" rather than "brother"), or "talk around" the word, using unnecessarily indirect and wordy speech to explain something that could be stated with one or two words. Difficulties with language fluency can impact a student's ability to quickly and efficiently answer questions verbally or in writing.

Visual-Perceptual Functions

The term "visual-perceptual functions" refers to how the brain interprets and works with visual information. These functions may include the ability to judge angles and distances, and to comprehend how objects relate to one another or are put together. Deficits in these areas can cause trouble with geometry, reading maps, writing, drawing, sequencing, and building things. The deficits are not correctable with eyeglasses.

Cognition Accommodations

General

- Consider a modified school day, half-days, alternative classes
- 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
- Stand near the student when giving directions or presenting lessons
- Avoid distracting stimuli (high traffic area, etc.)
- Provide peer assistance with organizational skills and as note taker or scribe
- Provide cues to help retrieve information or stay on task
- Allow student to record lessons

During Exams

- Do not time exams/allow extra time
- Give take-home tests
- Allow open book exams
- Give frequent short quizzes, not long exams
- Allow student to complete tests and other assignments orally
- Use more objective items, multiple choice quizzes and exams, and fewer essay responses

Homework

- Email assignments
- Provide student with a homework assignment notebook to be checked by parents and teachers daily
- Shorten assignments, break work down into smaller segments
- Provide short breaks during assignments
- Reduce the reading level of assignments
- Provide additional tutoring and 1:1 instruction as needed

About the National Multiple Sclerosis Society

The National MS Society, founded in 1946, funds cutting-edge research, drives change through advocacy, and provides programs and services to help people affected by MS live their best lives.

Connect to learn more and get involved: nationalMSSociety.org, Facebook, Twitter, Instagram, YouTube or 1-800-344-4867.



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