



Students with MS & the Academic Setting: A Handbook for School Personnel

Acknowledgements

The National Multiple Sclerosis Society wishes to thank the contributing authors:

Sarah Helm, ABD

Mary Karpinski, LMSW

Maria Milazzo, RN, CPNP, MSCN

Eva Rodriguez, OTR-L

Cynthia Shaffer, BA, M.Ed.

Laurie-Lou Smith, Ed.S., NCSP

Gretchen L. Timmel, M.Ed. Licensed Educational Psychologist, Certified Teacher

Editors:

Kimberly Koch, MPA

Deborah Hertz, MPH

National Multiple Sclerosis Society

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Center for Pediatric Onset Demyelinating Disease
University of Alabama at Birmingham

Mayo Clinic Pediatric MS Center
Mayo Clinic Rochester

National Pediatric MS Center
Stony Brook University Medical Center

Partners Pediatric Multiple Sclerosis Center
Massachusetts General Hospital for Children

Pediatric MS Center of Excellence
Jacobs Neurological Institute, SUNY University at Buffalo

Regional Pediatric Multiple Sclerosis Center
University of California — San Francisco

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Why We Created This Handbook

While schools are familiar with various pediatric illnesses and disabilities, pediatric multiple sclerosis (MS) presents some particular challenges due to the fluctuating nature of the disease, the changing needs of the child, and the disease's relative rarity among children. These factors can come together to create an environment of isolation and uncertainty for children with MS and their families.

Parents of children with MS typically gather a vast amount of information about the disease, including how it is affecting their child now and accommodations that others have had success with outside of school. They may not, however, have a realistic understanding of how the family/school partnership can temper their concerns for their child's future. This guide should assist you in providing that information as well.

The National Multiple Sclerosis Society created this handbook for school staff as a quick reference about children living with MS. It will help you create academic accommodations and communicate with the students' families.

It is organized into the following sections:

- Issues that Children & Teens with MS May Face
- Visible & Invisible MS Symptoms
- Cognitive Symptoms in Children & Teens with MS
- Accommodations & Modifications in the School Setting
- Transition Issues: The World After High School
 - Transition to College
 - Transition to Vocational Avenues
- Appendix: Overview of Multiple Sclerosis
- Resources & Publications

While this guide presents general information and suggestions, please be aware that each child and family experiences MS differently. For more information, please contact the National Multiple Sclerosis Society at 1-800-344-4867 (800-FIGHT MS), or on the Web at www.nationalMSSociety.org.

Issues that Children & Teens with MS May Face

Introduction

While everyone's experience of multiple sclerosis (MS) is unique, this section strives to give school officials insight into the most common psychosocial issues that children and teens with MS face, so they may help families meet the students' best interests.

WHAT IS MULTIPLE SCLEROSIS?

Multiple sclerosis is thought to be an autoimmune disease that affects the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. When a person has MS the immune system, which usually works to protect the body from disease-producing organisms, mistakenly attacks the body's own tissue. The primary target of this attack is myelin, the protective coating around the nerve cells in the CNS that facilitates nerve conduction. The nerve cells themselves can also be damaged. The attacks on myelin produce scarring at multiple sites in the CNS, and it is these scars that give the disease its name. The scars, in turn, begin to slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS.

Psychosocial Environment

Multiple sclerosis is characterized by unpredictable symptoms that come and go. Many students and parents report anxiety and uncertainty over the course of the disease. Planning vacations, proms and college entrance exams may be difficult, as the next relapse always seems to loom. "I never know what to expect from one day to the next," one mother said of her teen with MS.

The treatment regimen can be stressful. There is only one medication approved by the U.S. Food and Drug Administration (FDA) to treat children age 10 and older with relapsing MS. This medication is given by mouth but may not be the right medication for each person. Other medications used are injectable, given daily to weekly. Each of the medications has side effects that may be unpleasant. Long-term studies are underway but data on the long-term effects of these therapies on children and adolescents is limited. Encouraging compliance is difficult but important. It may never be clear whether the medication has averted a relapse or if the relapses ceased naturally. Adolescents, with their "magical thinking," find it particularly hard to believe that medication is important.

Children and teens with MS may face the reality that they are unable to continue with all the activities they enjoy. An athlete, for example, may not be able to keep up with teammates due to visual disturbances, weakness, or time away from practices due to a relapse. It is important to encourage the student to continue to do activities that he enjoys, with modifications if necessary. For example, a soccer player who has difficulty functioning in the heat may have success switching to a sport that is played indoors in a cooler setting.

Plans and dreams for the future may also require modification. The student with her heart set on attending a military academy may need to re-evaluate her goals and develop a Plan B. Providing choices is important to help the student seek options instead of focusing on that one broken path or dream.

Many students report that the most difficult part of living with MS is lack of understanding from peers and teachers about invisible symptoms such as fatigue. “You look so good... you can’t be sick!” is a common reaction. It’s important to understand these invisible symptoms and support the student at her current level of comfort.

THERE ARE VERY SPECIFIC PHYSICAL & EMOTIONAL STRESSORS THAT STUDENTS WITH MS MAY EXPERIENCE IN SCHOOL. THEY INCLUDE:

- Bladder symptoms requiring frequent, urgent trips to the bathroom
- Difficulty navigating stairs due to weakness, fatigue or poor balance
- A change in academic placement due to cognitive changes
- Visual changes that, unknown to others, may come and go, and interfere with classroom functioning
- Depression or mood disorder
- Inconsistent level of empathy and support from school staff
- Isolation

As with any chronic illness, there is the stress of missing school and getting behind in schoolwork and activities. Students may even feel pressured by field trips and “pull-outs,” as they take time away from required work. The educational team should strive for a balance that allows time for the special activities that help develop well-rounded students.

Relationships

Deciding when and to whom to disclose the diagnosis is a personal matter to be made after careful consideration with family and the child’s health care team. Attitudes about disclosure will vary and must be respected. The student and family may have concerns about being treated differently because of the diagnosis, however experience suggests young people with MS do not view themselves as different from their peers. Many children with MS find that peers respond supportively to learning of the diagnosis. However, others do share the experience of “finding out who my real friends are.” Most of the teens we have worked with say they have grown more compassionate, strong and mature as a result of their experience with MS.

The effect of the diagnosis on the family is powerful. In some cases relationships become closer, and in some the families become overprotective. It may become even more difficult for parents to “let go” as their child undergoes the normal adolescent rites of passage. On the other hand, some children or teens may try to protect their parents by hiding or down playing symptoms.

Being a Teen with MS

Being an adolescent can be difficult enough. Being an adolescent with a chronic illness is even harder. Self-esteem issues, for an individual who feels he may not be able to trust his own body, are complex. Teens with MS may find it embarrassing to talk about some of their more difficult symptoms, only adding to a sense of isolation.

It is important to note that risk-taking behaviors in teens with a chronic illness have been documented, highlighting the need to screen for them. Alcohol and other substances may have an increased risk for a teen with MS, as they may further interfere with balance and cognition, and also may be harmful in combination with medications. Sexual activity must be considered. While there is no contraindication for birth control use, the disease-modifying therapies are contraindicated in pregnancy.

Working with the Families & Others

Parents of a child with MS may feel isolated because pediatric MS is uncommon and poorly understood. They may not know anyone else with a child who has MS. Many families have been told by friends, educators, and health care providers that “she can’t have MS — she is only a kid.” For a family in stress already, it is very difficult to defend the diagnosis and treatment plan against others’ lack of awareness.

Given the variable nature of MS, different people in the child’s life may develop conflicting opinions about how to approach the situation. Flexibility in accommodating the student will be necessary. Understanding and communication can help a parent shift from aggressive to assertive. Being supportive of the child and family while assisting them in navigating the educational system will yield the best possible outcome for the family.

Visible & Invisible MS Symptoms

Introduction

One of the greatest challenges posed by MS is the unpredictability and variability of its symptoms. Changes in function and sensation can occur in virtually any part of the body, and symptoms may come and go with no apparent rhyme or reason. People with MS often say that they never know how they are going to feel from one day to the next or even from morning to afternoon.

It is important to remember that while MS can cause a variety of physical and sensory changes, most children and adults will experience only a few of them. People with MS may experience visible or invisible symptoms, or both. No two people have exactly the same symptoms, and each person's symptoms can change or fluctuate over time.

Although MS can cause symptoms in many parts of the body, it is not the cause of everything that occurs. Children will still get the same viral illnesses and assorted problems that all children get along the way.

Children may also experience pseudo-exacerbations: a temporary increase in symptoms due to an outside stressor such as heat or a fever that raises the core body temperature. The increase in symptoms disappears shortly after the stressor is removed. For example, a child may see an increase in symptoms during a bout with the flu. As the infection subsides and the child's body temperature returns to normal, the MS symptoms return to baseline.

Visible Symptoms

SYMPTOM	DESCRIPTION
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- Muscle weakness
- Fatigue
- Spasticity
- Loss of balance
- Sensory deficit

SYMPTOM	DESCRIPTION
Spasticity	Spasticity refers to feelings of stiffness and a wide range of involuntary muscle spasms (sustained muscle contractions or sudden movements). It is one of the more common symptoms of MS. Spasticity may be as mild as the feeling of tightness of muscles or may be so severe as to produce painful, uncontrollable spasms of extremities, usually of the legs. Spasticity may also produce feelings of pain or tightness in and around joints, and can cause low back pain. Although spasticity can occur in any limb, it is much more common in the legs.
Tremor	Many people with MS experience some degree of tremor, or uncontrollable shaking. It can occur in various parts of the body.
Speech disorder	Speech disorders are fairly common in MS. Speech patterns are controlled by many areas in the brain, especially the brainstem. Lesions (damaged areas) in different parts of the brain can cause several types of changes in normal speech patterns. They range from mild difficulties to severe problems that make it difficult to speak and be understood.

Invisible Symptoms

SYMPTOM	DESCRIPTION
Fatigue	<p>Fatigue is one of the most common complaints of adults and children with MS. Approximately 30% of children with MS complain of fatigue that is significant enough to limit their daily activities. It is often the most difficult symptom for a child. Fatigue can occur daily, can become worse as the day progresses, can come and go without warning, and interfere with the child's daily routine.</p> <p>The fatigue experienced by people with MS can be caused by a variety of factors:</p> <ul style="list-style-type: none"> ■ There is a primary lassitude or tiredness that is unique to MS, which results from impaired nerve conduction. This lassitude, which is part of everyday life for many people with MS, can come on very suddenly and tends to worsen over the course of the day. It can, however, happen at any time of day, even after a full night's sleep. ■ Emotional upset, bladder symptoms or other uncomfortable physical symptoms can cause sleep disturbances, leading to excessive daytime tiredness. ■ Some of the medications used to treat MS symptoms can cause fatigue as a side effect. ■ The extra effort it takes to accomplish everyday activities can be fatiguing.
Pain	<p>People with MS may experience acute or chronic pain. Acute pain includes stabbing pain in the face, burning, aching or "girdling" around the body, or L'Hermite's Sign (an electrical sensation, produced by bending the neck forward, that runs down the back and into the limbs.)</p> <p>Chronic pain may include <i>burning, aching, prickling or "pins and needles", spasticity-related pain, or back and other musculoskeletal pain.</i></p>

SYMPTOM	DESCRIPTION
Visual disturbances	<p>Visual symptoms are among the most common manifestations of MS. They appear as the first symptom of MS in many people, and affect as many as 80% of people with MS at some point.</p> <p>The three major types of visual symptoms are:</p> <ul style="list-style-type: none"> ■ Optic neuritis — Inflammation of the optic nerve causing temporary loss or disturbance in vision, changes in color vision, and sometimes pain in the affected eye. ■ Double vision (diplopia) — The experience of seeing two of everything is caused by weakening or incoordination of eye muscles. ■ Nystagmus — A rhythmic jerking of the eye(s) that the doctor may detect during the neurologic exam, but which tends not to cause noticeable symptoms.
Cognitive	<p>Approximately 50% of adults with MS experience some degree of change in their ability to think, reason and remember. While these cognitive symptoms remain relatively mild and manageable for most, they can significantly impact daily activities for a small percentage of adults with MS. There is evidence that the same is true for children and teens with MS. Areas that may be impacted include:</p> <ul style="list-style-type: none"> ■ Memory (acquiring, retaining and retrieving new information) ■ Attention and concentration (particularly divided attention) ■ Information processing (dealing with information gathered by the five senses) ■ Executive functions (planning and prioritizing) ■ Visual-spatial functions (visual perception and constructional abilities) ■ Verbal fluency (word-finding)
Depression & mood swings	<p>Depression and other emotional changes are very common in adults with MS, and seem to occur frequently in children with MS as well. The risk of depression is higher in MS than in the general population or other chronic illnesses, suggesting that it is a symptom of the disease itself, as well as a reaction to it.</p> <p>The same seems to be true for mood swings. These problems are most effectively treated with a combination of education, supportive counseling and medication. 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 the student's family or health care provider so that appropriate evaluation and treatment can be recommended.</p>

SYMPTOM	DESCRIPTION
Numbness	Numbness of the face, body, or extremities (arms and legs) is one of the most common symptoms of MS.
Bladder & bowel	<p>Bladder and bowel symptoms are also common in people with MS. The bladder symptoms, involving failure either to store urine properly or empty the bladder completely, can include feelings of urgency, a need to urinate very frequently, hesitancy in starting the flow of urine, or waking several times during the night to urinate.</p> <p>Constipation is a particular concern among people with MS, as is loss of control of the bowels. Diarrhea and other problems of the stomach and bowels also can occur. Bowel dysfunction can cause a great deal of discomfort and humiliation, and could aggravate other MS symptoms such as spasticity or bladder dysfunction.</p> <p>Many children and teens with MS report bladder and bowel disturbances as their most troubling symptom. They need to use the bathroom frequently and may not be able to wait long. They report conflict in the classroom because of frequent bathroom trips.</p>
Difficulty swallowing	Swallowing problems — referred to as dysphagia — result from damage to the nerves controlling the many small muscles in the mouth and throat. When dysphagia occurs, food and liquids can pass into the airway and lungs, causing the person to cough and choke.

People with MS may also have a sensitivity to heat and/or cold. Any exposure to extreme temperature can cause a temporary flare-up of symptoms.

And although not an MS symptom, a child on one of the disease-modifying therapies may experience *flu-like symptoms* and *soreness* at the injection site. Both of these may have an impact on school performance.

Cognitive Symptoms in Children & Teens with MS

Introduction

Approximately 50% of adults with MS experience some degree of change in their ability to think, reason and remember. While these cognitive symptoms remain relatively mild and manageable for most, they can significantly impact daily activities for a small percentage of adults with MS. There is growing evidence that the same is true for children and teens with MS, and every effort must be made to recognize and address these problems before they have a significant impact on a child's school experience.

Sometimes, the changes are subtle enough to escape notice in everyday interactions. Thus people with MS, family members and health care professionals may be slow to recognize them. Memory, attention, speed of information processing, and verbal fluency are the most frequently impaired functions. Reasoning, planning and visual perception are also impaired in some people.

It is important to highlight that not all children and adolescents with MS will demonstrate cognitive problems. While some children and adolescents have no problems, others develop varying degrees of difficulty ranging from mild to severe. Ongoing research efforts will help enhance our understanding of this important aspect of pediatric MS.

There is no clear relationship between level of physical disability and level of cognitive disability. A person can have significant physical symptoms without any cognitive symptoms whatsoever, while someone with little or no physical impairment can have significant cognitive problems.

Attention/Information Processing

Typically, simple tasks that require attention, such as focusing briefly to repeat a phone number, are not a problem for children and adolescents with MS-related cognitive issues. Attentional problems may not be observable in a child with MS who is speaking one-on-one with someone in a quiet environment. However, the potential for difficulty rises as tasks become more complex, especially when divided attention is required.

These children may also have trouble with working memory — the ability to hold onto information while working with it. This ability is necessary, for example, when performing mathematical computations that require carrying numbers, or other more complex operations. Also, the speed at which information is processed can be adversely affected, requiring more time to think about responses in general.

People with MS may become fatigued very easily when performing demanding tasks, either physical or cognitive. This fatigue may exacerbate attentional problems and other cognitive deficits.

Memory

Among children reporting cognitive changes, memory problems are perhaps the most common complaint. This is probably because memory problems are among the most easily observable deficits and the ones with the most immediate negative feedback. For example, these children will have difficulty remembering conversations and forget to do chores, or will be unable to remember teachers' lectures or to keep track of assignments. Attention plays an important role here as well. 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 problem is actually inability to learn. Such a student may require increasing support to keep up with classes.

THREE COMPONENTS OF MEMORY ARE:

- Encoding — the initial learning of the information
- Storage — holding it for a period of time
- Recall — accessing it later

Children and adolescents with memory problems may demonstrate difficulty with one, two, or all three of these steps. Thus, they may have difficulty learning information, have increased rates of forgetting in comparison to other children, 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 verbal memory will have trouble remembering what they are told. Children with deficits in visual memory may have difficulty remembering where they put their school books or their keys, or may get lost more easily, especially when in unfamiliar neighborhoods or buildings. This latter point is an important consideration for teenagers who may soon be getting their driver's license.

Language

Language deficits in children and adolescents with MS, like those seen in adults, tend to be quite subtle. They are generally related to 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. This is often referred to as circumlocution. Such language deficits can cause embarrassment and frustration in social situations, especially when speaking aloud in school.

Visual-Perceptual Functions

The term "visual-perceptual functions" does not refer to visual acuity, which is correctable with eyeglasses, but rather how one's 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 tasks such as reading maps, writing, drawing, sequencing, and/or building things.

Motor Functions

When MS affects the ability to walk, it is quite apparent. More subtle are the problems with fine motor coordination that the disease may cause. When manual dexterity is affected, children may exhibit slowed movements and/or tremors that affect their ability to complete tasks. Handwriting may be adversely affected and hobbies such as building models or competing in sports that require fine motor coordination may become more challenging.

It is important to keep in mind that while a child or teen with MS can experience a change in any or all of these functions, many people experience none of these symptoms and others may experience symptoms in only one or two functional areas. The key to dealing with neurological changes is to recognize them when they develop and find ways to minimize their impact on daily life.

Cognitive Symptoms

Cognitive symptoms, much like sensory and motor functions, may fluctuate along with clinical relapses. Just as sensory and motor functions generally improve following an acute relapse, cognitive skills are likely to as well. Some deficits may remain.

Steroid interventions used during the acute treatment of relapses are known to affect cognition. For example, attentional and memory deficits are common during steroid treatment. Rest assured, however, that these are only temporary medication side effects that will lessen as the child is tapered off of these medications.

Unfortunately, the overall progression of cognitive problems is not entirely understood at this point. Preliminary findings from individual case studies suggest that some people may show a progression of cognitive deficits in as little as a year. In general, progression of symptoms is likely to be related to a number of factors, including the length of time the person has had the disease and the severity of disease activity. Disease severity is indicated by the frequency and number of relapses, the total lesion area as seen on MRI, and the particular areas in which the lesions occur. Therefore, the best way to prevent progression of symptoms, including cognitive changes, is to try and prevent relapses from occurring. Disease-modifying treatments are discussed later in this handbook.

EVEN IF COGNITIVE CHANGES ARE NOT EVIDENT, A NEUROPSYCHOLOGICAL EVALUATION MAY BE HELPFUL FOR SEVERAL REASONS:

- Cognitive changes are often subtle, progressing gradually over time. Therefore, it may be difficult to observe them in casual interactions, and a neuropsychological evaluation may be more sensitive to subtle decline.
- Neuropsychological evaluations rely on normative data to make comparisons regarding how well an individual is performing relative to age-matched peers, so deficits may be difficult to detect in children who are very high functioning. That is to say, for those who once had excellent memory, a performance in the average range may represent a decline. Another function of the neuropsychological evaluation is to establish a baseline level of functioning with which to compare future results, should the child experience cognitive decline in the future. A neuropsychological evaluation may, therefore, be a prudent decision regardless of whether or not cognitive deficits are currently evident.

Merely identifying cognitive decline is not very helpful. However, it serves as the first, important step toward effective interventions. Academic accommodations or modifications may be necessary in school. It is easier to recognize and respond to symptoms that are easy to see and understand (e.g., walking difficulties, balance problems or tremor) than less obvious symptoms like fatigue and cognitive changes.

Accommodations & Modifications in the School Setting

Introduction

Schools often feel there is no need to provide a 504 Plan or IEP because most children with MS do not have visible symptoms. Schools will report that the child is active and appears OK during recess. It is important to remember that every activity the body does utilizes a different area of the brain, so affected activities will depend on where the lesions are located. This may also explain why teachers often state that children with MS appear fine one minute and “not normal” the next. In some cases, students may lose academic skills they once had mastered, leading to learning disabilities and significantly lower scores on cognitive or intelligence tests.

What about Dishonesty — How Do I Know It’s the MS?

This is a very common question. Teachers often worry that a student with MS will use the disease to manipulate people. To the contrary, children and teens with MS do not want to be treated differently and more likely to refuse assistance than to demand extra attention.

What Can I (the Teacher) Do to Help?

Provide appropriate accommodations and modifications to decrease the impact of school stress on exacerbations while maintaining confidentiality. Understand that symptoms may wax and wane from week to week. Work to educate others about the symptoms of MS and what to look for.

REDUCE STRESSFUL SITUATIONS FOR THE STUDENT AS MUCH AS POSSIBLE. CONSIDER THE FOLLOWING:

- Be flexible with homework and/or class work, as work overload can be stressful.
- Work with the student to develop a system to keep track of assignments and expectations.

Recommended Accommodations

MS is an unpredictable and variable disease for which there is no cure. Understanding its symptoms is key to providing an appropriate 504 or IEP plan. Since symptoms can vary over time, accommodations may have to vary as well. A child may not need all the accommodations all the time. The situation may change by the day, week or month.

Because a variety of MS side effects can negatively impact the child's ability to learn, a student with MS may qualify for Other Health Impaired (OHI) special education services. If the MS is adversely affecting the child's learning, it is important to proceed proactively and develop an Individualized Education Plan (IEP) to prepare for new symptoms that may develop overnight.

The following examples can be used to assist children with MS and other related demyelinating conditions in the classroom, depending upon the individual needs of the child. We recognize that not all of these can be accomplished for every child, nor will all be needed.

Physical Environment

- Provide a second set of books to be kept at home; helps reduce fatigue
- Seat student near the teacher
- Stand near the student when giving directions or presenting lessons
- Avoid distracting stimuli (high traffic area, etc.)
- Seat student near door to allow easy exit
- Allow student to leave classroom early to have extra time to get to next classroom
- Seat student near window or air conditioner to combat fatigue on hot days
- Allow student to have water at his/her desk
- Allow student time out of seat to stretch to avoid spasms
- Allow use of bathroom pass if student has bowel or bladder difficulties

Lesson Presentation

- Pair students to check work
- Provide written outline before class
- Use visual cues such as writing key points on the board
- Let student tape record lessons; assists in recall and processing deficits
- Provide peer tutoring
- Have student review key points orally
- Provide visual aids
- Teach through multi-sensory modes
- Provide peer note taker or provide a scribe

- Give notes before class
- Enlarge notes for students with visual problems
- Use assistive technology, e.g. computer-assisted instruction
- Make sure directions are understood, repeat instructions, provide additional directions if needed
- Include a variety of activities during each lesson
- Break longer presentations into shorter segments

Class Assignments

- Provide short breaks during assignments
- Give extra time to complete tasks
- Provide course outline for the week, month, semester to help student plan
- Use self-monitoring devices
- Simplify complex directions
- Modify homework assignments; once a child has mastered the concept, move on to the next area
- E-mail assignments
- Hand worksheets out one at a time
- Don't grade handwriting
- Reduce the reading level of the assignments
- Let student submit tape-recorded work instead of written; assists in recall and processing deficits
- Provide a structured routine in written form
- Provide study skills training/learning strategies
- Shorten assignments, break work down into smaller segments
- Use assistive technology, e.g. a word processor for students who have difficulty writing by hand
- Give frequent positive feedback to ensure the student is on the right track
- Provide study guides, calculator, math charts
- Enlarge written material
- Provide recorded versions of written material to assist students with visual dysfunction, short-term memory loss or poor comprehension

Test Taking

- Allow open book exams
- Allow extra time for exams (if not contraindicated due to fatigue)
- Do not time exams
- Give exams orally
- Give take-home tests
- Use more objective items and fewer essay responses
- Allow student to give test answers on tape recorder
- Give frequent short quizzes, not long exams

Organization

- Provide peer assistance with organizational skills
- Send home frequent progress reports
- Develop a reward system for in-school work and homework completion
- Provide student with a homework assignment notebook to be checked by parents and teachers daily

Behaviors

- Praise specific behaviors
- Use self-monitoring strategies
- Give extra privileges and rewards
- Keep classroom rules simple and clear
- Allow for short breaks between assignments
- Nonverbally cue student to stay on task

Special Considerations

- Alert bus driver of any special needs
- Monitor student closely on field trips
- In-service for school personnel on child's disability
 - All school personnel and transportation providers should be educated about the child's disease
- Provide group or individual counseling
- Provide social skills group experiences
- Develop intervention strategies for transitional periods such as lunch and gym, e.g., allow child to leave five minutes early to get to next class
- Consider gym modifications
- Provide evaluations, consultations and services in physical and occupational therapy (PT/OT), and speech
- Assign student to classrooms in same area of building, if possible
- Have a crisis plan in place
- Allow the student frequent breaks to the nurse's office for rest
- Keep extra clothing in the nurse's office in case of bowel/bladder issues
- Allow the student to use the elevator
- Provide the student with a school map highlighted to show areas s/he needs to get to
- Consider a modified school day, half-days, alternative classes

For the Homebound Student

- A special education/regular education teacher should provide instruction for a homebound student
- Determine the best time of day for the student (e.g., afternoon if fatigue usually occurs in morning) and schedule instruction then
- Set up a webcam in the classroom so the student can have regular contact with classmates
- Encourage e-mail contact with classmates
- Maintain support services that were being provided in school (e.g. PT, OT or speech)

Creativity in developing a plan is the goal. Following are examples to “put it all together:”

SYMPTOM	RECOMMENDATION
Weakness in legs	<ul style="list-style-type: none">■ Top locker access■ Extended time to get to class■ Frequent rest breaks■ Elevator access
Fatigue	<ul style="list-style-type: none">■ Extra set of books at home■ Extended time on tests and assignments■ Frequent rest breaks■ Elevator access■ Flexible class schedule based on best time for student■ Shortened assignments■ Difficult classes distributed evenly throughout the day■ More frequent quizzes rather than longer exams
Low vision	<ul style="list-style-type: none">■ Enlarged print books■ E-books■ Seating near the board■ Outline or copy of teacher’s notes■ Reading test items to student
Motor difficulties	<ul style="list-style-type: none">■ Oral responses■ Allowing for the use of adaptive technology and technology (such as a pencil grip or computer with adaptive software)■ Providing a copy of teacher’s notes■ Not grading handwriting■ PT/OT evaluation, consultation and services

SYMPTOM	RECOMMENDATION
Slowed processing	<ul style="list-style-type: none"> ■ Extended time for tests, quizzes, assignments ■ Allowing student to tape record assignments and homework ■ Providing copy of notes before class
Decreased tolerance to heat	<ul style="list-style-type: none"> ■ Allowing student to carry water bottle ■ Allowing a fan in the classroom near student's seat ■ Providing indoor exercise options ■ Allowing student to wear a cooling device
Sensitivity to cold	<ul style="list-style-type: none"> ■ Storing extra sweater or jacket in classroom
Bowel/bladder weakness	<ul style="list-style-type: none"> ■ Allowing unrestricted bathroom access ■ Keeping change of clothes at school ■ Sitting student near door for easy access to restroom
Verbal fluency difficulties	<ul style="list-style-type: none"> ■ Allowing for written responses ■ Providing extended time to respond
Depression or other emotional difficulties	<ul style="list-style-type: none"> ■ Time with school counselor or referral to outside mental health professional
Information retrieval difficulties	<ul style="list-style-type: none"> ■ Multiple choice quizzes and exams ■ Open book quizzes and exams ■ Providing cues to help retrieve information ■ Allowing visual cues
Attention/concentration problems	<ul style="list-style-type: none"> ■ Cues to stay on task ■ Seating near teacher/board ■ Creating class agenda and course outline ■ Simplifying instructions ■ Providing coaching and counseling

Transition Issues: The World After High School

Introduction

The uncertain future faced by children and teens with MS, including the potential for greater levels of disability, can create more challenges when planning for life after school. With input from family, school and a health care team, the student should create a realistic plan and re-evaluate it over time. The good news is that research indicates many children and teens with MS have the “invincible” attitude typical of youth, and feel positively about their ability to cope with their condition in the present and meet the challenges it will bring in the future.

Teenagers making decisions about future training, education or careers in the face of an unpredictable disease may need more support than usual. The transition to a post-high school environment can be emotionally complex. We know teens may change college plans due to their MS diagnosis. Those who had initially planned to go away to school may instead stay closer to home because of concerns about health, a perceived need to stay close to their health care provider, or a parent’s request. Some college students do not want to disclose their diagnosis, and choose to stay at home rather than have to store their medication in a shared dormitory space.

Transition to Higher Education

IMPORTANT POINTS WHEN PREPARING A STUDENT FOR TRANSITION TO HIGHER EDUCATION:

- Students must meet same admission and classroom requirements.
- Waiving essential requirements of the curriculum is not available as an accommodation.
- Administrators have less contact with parents.
- Students must self-identify to receive accommodations.
- Students must self-monitor their disability.

Admissions Process & Registration with Disability Services

- Encourage student to research various institutions and their disability services office to learn more about the services provided.
- Upon admission, encourage student to register with the disability services office prior to the beginning of the first academic semester. For first-year students, registering during their college or university’s orientation program helps ensure that accommodations will be in place on the first day of the semester.

Documentation of Disability

Unlike in secondary school, it is the students' responsibility to disclose, document and self-monitor a disability. The roles and responsibilities of both students and the disability services office are listed below. Colleges and universities will vary in the services they provide.

Responsibilities of the Student

- Students need to understand their disability and how it may affect their ability to be academically successful.
- Students will be responsible for providing the disability services office with detailed medical documentation about their diagnosis and functional limitations, including their latest 504/IEP plan if applicable. It is very important for students to obtain current medical documentation. The medical documentation will need to be signed by a medical professional who has knowledge of the student's diagnosis and medical history.
- In addition to the disability services staff, students are responsible for disclosing their MS diagnosis to faculty, advisers, and career services staff as they see appropriate.
- Students must self-monitor their disability and inform the disability service staff if their accommodation needs change.

Responsibilities of Disability Services

- Provide access to campus, curriculum and programs
- Determine eligibility for services through review of documentation and recommendations for accommodation and services
- Help students understand their disability in the context of higher education
- Help students inform faculty members of agreed-upon accommodations and work together to determine what is reasonable and appropriate
- Refer students to additional resources on campus and in the community

Sample Accommodations for College

- Extended test time
- Distraction-reduced testing environment
- Permission to record lectures
- Accessible classroom location
- Note-taking services
- Priority registration
- Assistive technology
- Accessible dormitory, with air conditioning and refrigerator

Transition to Vocational Avenues

TRANSITION TIMEFRAME

Transition planning begins for those with a 504 or IEP at age 14. Even those students without a 504 or IEP should begin thinking about what happens after high school. If the workplace or vocational training is the direction in which the student wants to go, initiate discussions about:

- What kind of job do you want?
- How will you get that job?
- Where can you learn the skills to qualify?

YOU CAN HELP WITH:

- Career assessments to identify student's preferences and interests
- Structured exposure to post-secondary education and other lifelong learning opportunities
- Exposure to career opportunities that ultimately lead to a living wage, including information about educational requirements, entry requirements, income and benefits potential, and asset accumulation
- Training designed to improve job-seeking skills and basic workplace skills
- Ensure student is connected to their local state vocational rehabilitation agency. This agency provides vocational support and transition services to students with disabilities.

Key point

Make sure the student and parent understand the diagnosis and symptoms. Stress with the family that accommodations can change over time, whether in the workplace or in school, due to the unpredictability of MS.

Help the student learn to find, formally request and secure appropriate supports and reasonable accommodations in education, training and employment settings. As they transition, this becomes the responsibility of the student/employee, not the parent.

Understanding Workplace Rights & Responsibilities for People with Disabilities

- Understand protections under the Americans with Disabilities Act (ADA) and other federal, state and local laws.
- Disclosure
 - Why, when and how much information the employer needs to know
- Accommodations
 - Responsibility of the student/employee
 - You can only request accommodations if you disclose your illness
 - Students need to learn to communicate their disability-related work support and accommodation needs.
 - Employer does not have to be proactive
 - If an accommodation isn't requested and you don't succeed, your employer can terminate you.
- Resources for the school, student and parents
 - Learn about community services.
 - Be clear about the service program's purposes and what it requires of participants.
 - Ask what information the agency needs to establish eligibility. Speed the process by being prepared with supporting documents.
 - Have a clear idea of what types of services you need and how getting these services will help with achieving transition goals.
- Be aware of local, state and federal employment resources
 - Vocational Rehabilitation
 - Job Accommodation Network
 - One-Stop Employment Centers
 - ADA & Information Technology Centers
 - National MS Society

Appendix: Overview of Multiple Sclerosis

What is Multiple Sclerosis?

Multiple sclerosis (MS) is thought to be an autoimmune disease that affects the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. When a person has MS the immune system, which usually works to protect the body from disease-producing organisms, mistakenly attacks the body's own tissue. The primary target of this attack is myelin, the protective coating around the nerve cells in the CNS that facilitates nerve conduction. The nerve cells themselves can also be damaged. The attacks on myelin produce scarring at multiple sites in the CNS, and it is these scars that give the disease its name. The scars, in turn, begin to slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS.

What causes MS?

We do not yet know. The current thinking is that the disease appears in individuals who have a genetic predisposition to react to some infectious agent in the environment such as a virus or bacterium. There is research to suggest certain genes or combinations of genes make some individuals more susceptible than others to the infectious agent(s). While several different viruses and bacteria have been studied for their possible role in MS, the trigger(s) have not yet been found. We do know, however, that MS is not a contagious disease.

Who gets MS?

An estimated 450,000 people live with MS in the United States and Canada. Although MS is typically diagnosed between the ages of 20 and 50, the disease can appear in young children and people over the age of 65.

We do not know the specific reasons why one person gets MS and another person does not. While it is natural to look for some recent event or trauma or stress to explain the onset of MS, there is no evidence to suggest a direct relationship between specific life events and the onset of MS.

Like most autoimmune diseases, MS is more common in women than in men. MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of Northern European ancestry. The disease is more common in temperate areas of the world, away from the equator, and relatively rare in the tropics. The evidence suggests that the disease occurs most often in people of northern and central European ancestry who may share some common genetic predisposition.

The role of genetics in MS is an area of active research. Experts tell us that the estimates of risk for developing MS tend to be oversimplified and therefore easily misinterpreted. The important point to remember is that the risk is greatest in families in which there are several family members who have the disease, and significantly lower in other families. With that in mind, the average risk for any person in the general population is 1 in 750. The risk for the child of a parent with MS rises to 1 in 40. Although this represents a significant increase, the absolute risk remains fairly low.

Studies indicate that the chances of a person developing MS depend in part on where he or she lived before adolescence. In other words, a child with a certain genetic predisposition comes into contact with some kind of environmental trigger during the early years, but the MS does not become active in most people until adulthood. We still do not know what causes it to become active in some young children and adolescents.

What happens when a person gets MS?

Misguided immune cells enter the CNS, causing inflammation in the brain, spinal cord and/or optic nerves. It is this inflammation that can cause damage to the protective myelin coating around the nerve cells, producing scars (also called plaques, lesions or demyelination) that interfere with nerve transmission. While many of these scars may have no apparent effect, others are responsible for the various symptoms of MS.

Each person's symptoms will vary depending on the particular location(s) of the scars. The possible symptoms of MS include fatigue; changes in vision; stiffness; weakness; imbalance; sensory problems such as numbness, tingling and pain; changes in bladder and/or bowel function; emotional changes; speech difficulties; sexual dysfunction; and problems with thinking and memory.

Is there a cure for MS?

No. Because we do not yet know the underlying cause of the disease, it is very difficult for scientists to develop treatments to prevent or cure it. Most people with MS can expect to live very close to a normal life span, and die of unrelated causes.

Fortunately, scientists are increasing their knowledge of MS at an ever-increasing rate. While no one can promise that a cure is just around the corner, each year brings us closer to answers. In the meantime, we have learned a great deal about slowing progression of the disease and helping people manage symptoms.

What treatments are available?

Although there are no treatments that can prevent MS from occurring or make it go away once it has appeared, there are various strategies to manage symptoms and slow disease progression.

Treating Exacerbations or Attacks

An exacerbation of MS is caused by inflammation in the CNS that causes damage to the myelin and slows or blocks the transmission of nerve impulses. To be a true exacerbation, the attack must last at least 24 hours and be separated from a previous exacerbation by at least 30 days. Most exacerbations last from a few days to several weeks or even months. Exacerbations can be mild or severe enough to interfere with a person's ability to function at home and at work. These attacks may cause new symptoms or aggravate old ones. Many physicians prescribe corticosteroids, either orally or by intravenous infusion, to reduce the inflammation and thus the symptoms.

Managing MS Symptoms

Symptoms of MS are highly variable from person to person and from time to time in the same individual. While symptoms can range from mild to severe, most can be successfully managed with strategies that include medication, self-care techniques, rehabilitation (with a physical or occupation therapist, speech/language pathologist, cognitive remediation specialist, among others), and the use of assistive devices.

Modifying the Disease Course

An exciting new era in MS care was ushered in by the development of disease-modifying medications designed to alter disease activity and slow disease progression. There are currently over a dozen medications approved by the U.S. Food and Drug Administration (FDA) and the Canadian Food and Drugs Act for relapsing forms of MS in adults. One of those medications is also approved by the FDA to treat children with MS age 10 and older. Based on the demonstrated ability of these medications to impact disease activity, the MS Coalition recommend starting treatment with an FDA-approved disease-modifying therapy as soon as possible:

- When a person has been diagnosed with relapsing or primary progressive MS, regardless of age.
- When a person has had a first episode of neurologic symptoms as well as MRI findings consistent with MS, and other possible causes have been ruled out.

The goal of early intervention is to reduce the frequency and severity of exacerbations, thereby reducing the risk of permanent disability.

Resources & Publications

General Information on Multiple Sclerosis

- **National Multiple Sclerosis Society**
nationalMSSociety.org
1-800-344-4867 (1-800 FIGHT MS)

THE NATIONAL MS SOCIETY OFFERS A WIDE RANGE OF PUBLICATIONS INCLUDING:

- Kids Get MS Too: A Handbook for Parents
- Mighty Special Kids — an activity book for children ages 5–12 with MS
also available online at nationalMSSociety.org/mskids
- Knowledge is Power — an at-home educational series for people newly diagnosed with MS and their families

Network of Pediatric MS Centers

The National MS Society supports 12 Network of Pediatric MS Centers that provide multidisciplinary care to young people with MS and related disorders nationwide. A priority of this network is to provide comprehensive care regardless of ability to pay. Each center includes a social worker who can help school personnel implement physicians' recommendations.

- **The Blue Bird Circle Clinic for MS**
Texas Children's Hospital
texaschildrens.org/blue-bird-circle
832-822-5046
- **Center for Pediatric Onset Demyelinating Disease**
University of Alabama at Birmingham
main.uab.edu/Sites/cpodd/
205-996-7633
- **Mayo Pediatric MS Clinic**
Mayo Clinic Rochester
mayoclinic.org/multiple-sclerosis/children.html
1-866-598-4777
- **Mellen Center for Multiple Sclerosis, Cleveland Clinic**
my.clevelandclinic.org/services/neurological_institute/mellen-center-multiple-sclerosis
216-444-5559
- **National Pediatric MS Center**
Stony Brook University Medical Center
pediatricmscenter.org
631-444-7802
info@pediatricmscenter.org
- **Partners Pediatric Multiple Sclerosis Center**
Massachusetts General Hospital for Children
partnersmscenter.org
617-726-2664

- **Pediatric MS and Related Disorders Program**
Boston Children's Hospital
childrenshospital.org/centers-and-services/programs/o-_-z/pediatric-multiple-sclerosis-and-related-disorders-program
617-355-2751
- **Pediatric MS Center of Excellence**
Jacobs Neurological Institute
SUNY University at Buffalo
pedsms.org
716-878-PDMS (716-878-7367) or 877-878-PDMS (877-878-7367)
- **Pediatric MS Center at Loma Linda**
University Children's Hospital
lomalindahealth.org/childrens-hospital/our-services/clinical-services/pediatric-neurology/index.page
909-835-1810
- **Pediatric Multiple Sclerosis Center**
New York University Langone Medical Center
nyulangone.org/locations/pediatric-multiple-sclerosis-center
646-501-7500
- **Regional Pediatric Multiple Sclerosis Center**
University of California — San Francisco
ucsfhealth.org/pedsms
415-353-3939
- **Rocky Mountain MS Center**
University of Colorado at Denver
mscenter.org
720-848-2080
- **Washington University Pediatric MS and other Demyelinating Disease Center**
neuro.wustl.edu/patient-care/pediatric-neurology/pediatric-ms-demyelinating-diseases-center/
314-454-6120

Federal Government

- **U.S. Department of Education Office of Special Education and Rehabilitative Services (OSEP)**
OSEP funds a large information dissemination and technical assistance network.
Plus, there's a customer service specialist for each state.
ed.gov/about/offices/list/osers/index.html?src=mr
- **U.S. Department of Education National Institute on Disability and Rehabilitation Research**
ed.gov/about/offices/list/osers/nidrr/index.html?src=mr
- **U.S. Department of Education Office for Civil Rights**
Technical assistance, pamphlets, complaint information on Section 504 of the Rehabilitation Act.
ed.gov/about/offices/list/ocr/index.html?src=mr
800-421-3481
877-521-2172 TTY
- **U.S. Department of Justice**
Technical assistance, publications, complaint info on Titles II and III of the Americans with Disabilities Act (ADA).
ada.gov
800-514-0301
800-514-0383 TTY

■ **Disability and Business Technical Assistance Center (DBTAC)**

The DBTAC runs 10 regional centers known collectively as the National Network of ADA Centers. Each center provides technical assistance, materials, training and referrals. The information they provide is intended solely as informal guidance and is neither a determination of one's legal rights or responsibilities under the ADA, nor binding on any agency with enforcement responsibility under the Act.

adata.org/network/index.html

800-949-4ADA (800-949-4232)

Children with Disabilities/Chronic Illness

■ **Family Village**

A Web directory of thousands of resources for children and adults with disabilities, their families, and their friends and allies, sponsored by the Waisman Center at the University of Wisconsin-Madison.

familyvillage.wisc.edu/

■ **PACER Center**

A parent training and information center for families of children and youth with all disabilities from birth through 21 years old.

pacer.org

952-838-9000

Education

■ **Band-Aides and Blackboards**

Kid-friendly information about being sick, by nurse and educator Joan Fleitas.

lehman.cuny.edu/faculty/jfleitas/bandaides/contkids.html

■ **Compliance with the Americans with Disabilities Act: A Self-Evaluation Guide for Public Elementary and Secondary Schools, provided by the Southwest Disability and Business Technical Assistance Center**

dlrp.org/html/publications/schools/general/guidcont.html

■ **ADA & Accessible IT Centers**

Technical assistance and publications on all aspects of the ADA and accessible information technology in educational settings.

adata.org

800-949-4232 voice/TTY

■ **Parent Training and Information Centers and Community Parent Resource Centers**

Parent centers in each state provide training and information to help parents participate more effectively with professionals in meeting the educational needs of children with disabilities.

taalliance.org/PTIs.htm

888-248-0822 voice/TTY

■ **Education Law Center**

Advocates on behalf of public school children for access to an equal and adequate education under state and federal laws.

edlawcenter.org/index.htm

973-624-7339

973-624-4618 TTY

■ **National Dissemination Center for Children with Disabilities**

Provides technical assistance and publications on disability issues, focusing on children and youth (birth to age 22) and IDEA.

nichcy.org

800-695-0285 voice/TTY

Transition from High School to Higher Education & the Workforce

- **National MS Society Scholarship Program**
Post-secondary scholarships for high school seniors who have MS or a parent who has MS, or for anyone with MS who has never been to a post-secondary school.
nationalMSsociety.org/get-involved/programs-and-services/scholarship/index.aspx
- **National Center on Secondary Education and Transition**
Coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures.
ncset.org
612-624-2097
- **AHEAD — The Association on Higher Education and Disability®**
Publications, information and training on higher education and students with disabilities.
ahead.org
704-947-7779
- **U.S. Department of Labor Office of Disability Employment Policy Job Accommodation Network (JAN)**
Includes a list of state vocational rehabilitation agencies.
jan.wvu.edu
800-526-7234

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The National Multiple Sclerosis Society is the largest nonprofit organization in the United States supporting research for the treatment, prevention and cure of multiple sclerosis. The Society addresses the challenges of each person affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, collaborating with MS organizations around the world, and providing programs and services designed to help people with MS and their families move their lives forward. To learn more, call 1-800-344-4867 or visit nationalMSSociety.org.



nationalMSsociety.org

For Information:
1 800 344 4867

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