



Managing School- Related Issues

A GUIDE FOR PARENTS WITH A
CHILD OR TEEN LIVING WITH MS

Regional Pediatric MS Center | University of California-San Francisco
350 Parnassus Avenue, Suite 908 | San Francisco, CA 94117

For the Network of Pediatric MS Centers

Authors

REGIONAL PEDIATRIC MS CENTER AT
UNIVERSITY OF CALIFORNIA-SAN FRANCISCO

Sunny Im-Wang, PsyD, SSP

Kimberly Erlich, RN, MSN, MPH, CPNP

Dorothee Chabas, MD, PhD

Mary Crittenden, PhD, NCSP

Marianne Doyle, MSW

Laura Julian, PhD

Jonathan Strober, MD

Emmanuelle Waubant, MD, PhD

THE AUTHORS THANK THE FOLLOWING
PEOPLE FOR CONTRIBUTING TO THIS PUBLICATION

Paula Freitag, MSW, LISW

Mayo Clinic Pediatric MS Center

Mary Karpinski, SPA, LMSW

Pediatric MS Center of Excellence at the

Jacobs Neurological Institute, SUNY University at Buffalo

Maria Milazzo, RN, CPNP, MSCN

National Pediatric MS Center at Stony Brook University Medical Center

Laurie Lou Smith, EdS, NCSP

Center for Pediatric-Onset Demyelinating Disease at the University of Alabama at Birmingham

Gretchen Timmel, MEd, Licensed Educational Psychologist, Certified Teacher

Partners Pediatric MS Center at the Massachusetts General Hospital for Children

National Multiple Sclerosis Society

Deborah Hertz, MPH

Kimberly Koch, MPA

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Foreward

Parents of children with MS often report feeling frustrated, overwhelmed or even helpless about how to help their children. The task of gathering appropriate information to prepare parents to help their children cope and advocate for them at school can seem like a daunting task.

The goal of this handbook is to provide you with the tools and resources to be your child's best advocate. You will learn proactive strategies that you and your child can use to manage MS in school to create a successful learning environment.

The Successful Parent: You as Your Child's Advocate

What is the true definition or “job description” of a parent? We know that parents are legally responsible for their children until they are 18 years old, but what does that mean? How much “common sense” is involved in parenting and how much is learned?

When we think of parenting, we think of meeting a child's basic needs first: food, shelter, clothing and safety. Having a child with a chronic illness can present certain obstacles for children *and* parents. So then, what is “successful” parenting? Can anyone with so many obstacles be a successful parent?

Successful parents are aware of their child's needs and stressors. Parents do not need to solve the child's problems, but provide empathy and tools to help their child along the way. Successful parents are not perfect; they are aware of their own emotions, so that their own emotional state does not adversely impact their relationship with their child.

This kind of awareness can only be achieved by having a strong support network of people and appropriate resources. Good communication with your child is essential. Connecting with your child requires a continuous open dialogue about how your child is doing. However, good communication also means accurate communication.

It is easy to rely on “small talk” within the family, using the shortest dialogue possible, especially with adolescents. You may choose to speak with your child on a regular basis or wait for “the right time” to broach a delicate subject. Whatever you choose, it is important to ask him or her what is the preferred way to communicate, and always keep in mind your child's developmental capacity.

It is important to establish a trusting relationship so your child does not fear approaching you with problems. Your child must feel safe to bring up difficult topics without fear, guilt, or shame.

It is also important for you to know that you are not alone. The National Multiple Sclerosis Society has a network available to support you and your family. You can contact them at childhoodms@nmss.org, or by calling 1-800-344-4867.

You as Your Child's Advocate: Navigating Your Child's School Life

You now also have the job of helping your child's school to understand and respond to your child's needs. One resource you and your child's teachers might find helpful is *Students with MS in the Academic Setting: A Handbook for School Staff*, a publication of the National MS Society. This handbook is a quick reference about children living with MS, and can be used to help your child's academic team create academic accommodations.

It is helpful to keep in mind that teachers and administrators, like most other people, will have an easier time recognizing and responding to symptoms they can easily see and understand (e.g., walking difficulties, balance problems or tremor) as compared with less obvious symptoms like fatigue, cognitive changes or bladder/bowel concerns.

The more you understand the symptoms your child is experiencing, the better prepared you will be to help others understand them. Also, do not hesitate to ask your healthcare team to provide suggestions for interacting with the school.

In order to get and have a full appreciation of your child's MS, consider your child's lifestyle before illness.

- What changed?
- How much has changed?
- What does "change" mean to you, your child, and your family?
- How big of an issue are the new stressors?

Stress Related to Chronic Illness

A variety of factors can influence the stress you may experience:

(Adapted from University of California-San Francisco's Division of Adolescent Medicine Symposium)

- What the illness/diagnosis means to the child/adolescent and family
- Diagnostic and treatment procedures
- Change in physical appearance
- Compliance with the demands of treatment
- Interrupted schooling
- Difficulty planning family outings and holidays
- Financial burden
- Sibling and friend stress
- Social stress

It is also important to evaluate and understand your child's developmental stage and issues that may arise during that stage. *(For more information please see "General Developmental Sequence" and "Aspects of Chronic Illness by Developmental Stage" in Chapter 2.)* This information can be helpful not only for your own personal understanding, but also when explaining to others how MS has impacted your child's life.

Child Development: Ages & Stages

Aspects of Chronic Illness by Developmental Stage

As a parent, it is helpful to understand child development and how it can be affected by MS. Keep in mind that in addition to dealing with MS, developmental issues have a large influence in your child's life. These issues affect how your child may think and feel about socialization, peer acceptance, self-esteem, etc.

Developmental issues may also affect how your child understands MS and how s/he deals with treatments. S/he may want to fit in and not appear different, or may be worried about what peers think. Therefore, your child may choose to not let peers know s/he has MS or may be resistant to using a mobility device such as a wheelchair or scooter.

The following is an overview of the various stages of child development and the potential impact of MS.

Young Children

3–6 YEARS OLD

Multiple sclerosis in children can significantly impact a young child's development, personality, or self-image. This is a complex stage, because it is such an early stage in development. Even minor life events can alter the developmental trajectory.

At this stage, your role is to provide encouragement and reassurance while your child explores the world, while also setting limits, and providing guidance¹. It may be difficult for you to stick to your parental role of disciplinarian and balance it with nurturing your child. It is also challenging to balance protecting a child and letting a child be a "child," and experience a "normal" childhood. These issues exist in all stages of development.

When a child is newly diagnosed at this stage, it is common for parents to struggle with setting limits and boundaries due to the desire to comfort and nurture the child. And while extra nurturing to help your child feel safe and secure is natural and essential, setting boundaries is equally important. Boundaries also allow your child to feel safe and secure, while preserving the parental role (caring for the best interests of your child). Parents need to demonstrate that things are still under control, that the family structure still exists, and that when the child feels good, s/he can do what other children do.

¹ Erikson, E.H. (1959)

School-aged Children

7–10 YEARS OLD

School-aged children begin to seek independence from their parents — while at the same time, still depend on them. They are getting ready to be more independent and become individuals; yet they are unsure and will at times act immature, in other words, act “like a baby.” This can be a clue to parents about their child’s level of confidence. School-aged children need reassurance that their feelings are normal. At times, they may also need re-direction.

For example, “I see that you’re very interested in doing _____. I think you might also like doing _____ as well.”

Dealing with a chronic illness is confusing for children in this age group because the natural developmental instinct is to graduate toward independence. Children with MS in this age group are sometimes in situations where they need to be more dependent on their parents, which conflicts with their natural drive to seek independence.

Adolescents

- Early adolescence: 10–13 years old
- Mid adolescence: 14–17 year old
- Late adolescence: 18–20 years old

In this stage, adolescents are becoming individuals. There is a natural drive to be independent (which can be scary in itself), and facing MS can increase anxiety. A critical component of this stage is the involvement in their own medical care and treatments. This is a component of independence that is important to encourage and support.

In addition, treatment regimens (like giving injections) can conflict with normal developmental challenges such as body image issues. Teens tend to be focused on physical changes occurring in their bodies. They may have fears related to MS and may have concerns, e.g. injection site(s) will be visible and result in embarrassment among their peers. Beginning a transition plan (*see Transitions section in Chapter 5*) would make this stage less mysterious and would be beneficial to both adolescents and parents.

Child Development Stages & Phases All Kids Go Through

Why is it important to understand expected child development?

It is important to understand the normal challenges children face in order to recognize and help your child or adolescent if s/he is having difficulties that extend beyond what is typical².

² Anderson et al., 2001; Drotar et al., 2001

GENERAL DEVELOPMENT SEQUENCE

Infancy to Young Adulthood / Erikson's Psychosocial Stages

STAGES	DEVELOPMENT TASKS
Infancy	<ul style="list-style-type: none">■ Infants depend on their caregivers for food, warmth and affection.■ With parents and caregivers providing for physical and emotional needs, infants will develop a basic sense of trust in their caregivers and the world.
Toddler	<ul style="list-style-type: none">■ Toddlers try to become more independent — walking, talking, using toilets and generally doing things for themselves.■ Self-control and autonomy (self-governance) begin to develop during this stage.■ If encouraged and allowed to explore, experiment, make mistakes and test limits, toddlers will develop autonomy, self-reliance, self-control and confidence. If not, they may begin to doubt their abilities and may feel ashamed of their behavior.
Pre-schooler	<ul style="list-style-type: none">■ Preschoolers become more engaged in social interaction with people around them.■ They will try to find balance in the ability to control impulses and childish fantasies.■ If provided with encouragement to pick and choose their own activities, they will develop a positive view of themselves. If they are not allowed to make some of their own decisions, they may feel timid or even guilty when taking steps toward independence. They may come to believe that it is wrong to be independent, refrain from new activities and allow others to make decisions.
School Age	<ul style="list-style-type: none">■ School-age children make the transition from the world of home to school and peers.■ They learn to make things, use tools and acquire the skills to be productive at school.■ Many kids experience receiving feedback from outsiders about their accomplishments for the first time.■ If they can discover pleasure in learning, being productive and seeking success, they will develop a sense of competence. If they do not, they may develop a sense of inferiority and feelings of inadequacy.

Adolescence	<ul style="list-style-type: none"> ■ At adolescence, children will begin asking, “Who am I? Who do I want to be?” ■ Their task is to explore, test limits, become autonomous from parents and commit to an identity or sense of self. ■ One can only establish an identity after trying out various roles, behaviors and ideologies. ■ Failure to achieve a sense of identity results in confusion about one’s role and effectiveness in life.
Youth (Young Adults)	<ul style="list-style-type: none"> ■ During this stage, the young adult must learn how to form intimate relationships, both in friendship and love. ■ It may be difficult to establish intimacy if one has not developed a basic sense of trust or a sense of identity. ■ The alternative to developing those intimate relationships results in alienation, isolation, a fear of commitment and an inability to depend on others.

ACADEMIC & SOCIAL DEMANDS ALL CHILDREN FACE

(M. Crittenden, Ph.D. and N. White, Ph.D.)

LEVEL	ACADEMIC	SOCIAL
Pre-school	<ul style="list-style-type: none"> ■ Readiness Skills 	<ul style="list-style-type: none"> ■ Taking turns
Primary Grades (K–2nd ±)	<ul style="list-style-type: none"> ■ “Decoding” Skills & Numerical Skills 	<ul style="list-style-type: none"> ■ One to one, small group sharing
Intermediate (3rd ± to 6th ±)	<ul style="list-style-type: none"> ■ Subject content mastery: for example, “I know all of my 50 states.” ■ Application (<i>homework</i>) ■ Competition (<i>tests</i>) 	<ul style="list-style-type: none"> ■ Formal Groups (<i>Scouts</i>) ■ Gangs (<i>Us vs. Them</i>)

<p>Middle School/Junior High (6th ± to 9th ±)</p>	<ul style="list-style-type: none"> ■ Study/organizational skills ■ Time management ■ Early abstract thinking 	<ul style="list-style-type: none"> ■ Peer influences ■ Dependency & independency conflicts ■ Egocentrism surges (tendency to think everything evolves around them)
<p>High School (9th± to 12th)</p>	<ul style="list-style-type: none"> ■ Advanced cognitive skills, e.g. critical thinking ■ Past/present/future links 	<ul style="list-style-type: none"> ■ Understanding their place & involvement in the community (sociocentrism) surges ■ Larger community horizons
<p>Post High School (Grade 12 and on)</p>	<ul style="list-style-type: none"> ■ All of the above ■ Functional vocational skills 	<ul style="list-style-type: none"> ■ Responsibility for self ■ Responsibility for others

MS & It's Potential Impact on School Life

Multiple sclerosis is an unpredictable disease. Symptoms can come and go without apparent reason or warning, and no two people experience symptoms in exactly the same way.

Likewise, some symptoms are clearly visible (like weakness causing walking problems) or less visible (like fatigue or cognitive concerns). It is not possible to predict when symptoms will occur or what parts of the body will be affected. Your child may require special accommodations in the school setting to support his/her educational needs. For more information, see *Chapter 4: Working with the School System to Get Services for Your Child — Examples of General Accommodation and Formal Interventions*.

Examples of how MS can affect children and adolescents in school:

- Symptoms such as fatigue or bowel/bladder problems can decrease a child's interest in socializing. Children may also feel embarrassed or have difficulties with their mood and/or self-esteem, which directly impact socialization.
- Blurry or double vision may impact reading, writing and/or attention.
- MS can affect a broad range of thinking skills. Thus, reasoning, processing, attention span, information processing, learning and memory may be impacted.³ See *Chapter 4* for more information.
- Acute attacks or residual symptoms can cause numbness, weakness, fatigue, poor posture or coordination difficulties, all of which can affect handwriting and typing.

MS symptoms can change from week to week. It is essential to recognize what symptoms your child experiences in order to prevent ongoing problems in school. Likewise, school personnel need to understand that symptoms come and go without warning, so accommodations need to be in place, even when symptoms seem to diminish for a time.

While most MS symptoms remain relatively mild and manageable for most children, they can significantly impact and limit daily activities for some children. It is critical that every effort is made to *recognize* and *address* these problems *before* they have a significant impact on a child's school experience. Therefore, it is essential that children with MS and their parents know what signs may indicate emerging difficulties in school life.

³ MacAllister, W.S., Belman, A.L., Milazzo, M. (2005)

Diagnosis of MS in the pediatric population can have a unique impact on children's cognitive abilities and school performance. This is particularly true for younger children who have an active disease before mastering their core educational building blocks⁴. A child whose learning process is disrupted prior to learning specific skills like mathematics or sentence structure might develop deficits when compared with those who have mastered these subjects⁵.

Whether your child is having difficulty with vision, motor skills or memory, you should focus on how s/he can cope with his/her symptom(s). Specifically, the focus should be on helping your child come up with strategies to get challenging tasks done.

For example: My child has _____ symptom(s).

- Have I seen him/her using a different way to get a task done? (e.g., using the opposite leg to kick a ball, counting on fingers when s/he didn't usually use this method, etc.)
- When I teach my child a new way to get a task done, can s/he produce better?
- Once my child learns a task (even if it takes a while), can s/he reproduce the task alone? If s/he can't do it by him/herself, can s/he do it with assistance? How much help is needed?
- Does this mean s/he will need more structure in the classroom?

School Work

Learning & Memory

MS can affect cognitive functioning. Reasoning, processing, attention span, information processing, information retrieval and other thinking abilities may be impacted.

The following table includes a selected list of cognitive abilities as they relate to schoolwork. Becoming familiar with these may help you to better understand or interpret psycho-educational or neuropsychological reports from your child's school.

⁴ Banwell, B.L., (2004) Boston Cure Project. November

⁵ Kalb, R.C., DiLorenzo, T.A., LaRocca, N.A., et al. (1999)

COGNITIVE ABILITIES AS THEY RELATE TO SCHOOL WORK

(Select List)

Fluid Reasoning	Learning ability that can influence the speed and amount that someone learns, and ability to manipulate and use information in a reasoning process. This is important for reading, solving problems and generating solutions.
Crystallized (learned) Knowledge Short-Term Memory	Learned and stored knowledge and experience (e.g., vocabulary, spelling, ability to read, social studies). The ability to hold information a short period of time, like remembering a locker combination in the first 20 minutes after it is assigned.
Long-Term Associative Storage and Retrieval	The ability to store information for a long period of time <i>and</i> the ability to recall that information when it is needed. This ability is important in school where students are constantly required to recall information that they were taught days, weeks and months before.
Visual Processing	The ability to process information that is seen. This involves visual recognition and memory for visual information. This ability would be necessary in such tasks as copying notes from the chalkboard, processing slides, video, etc.
Auditory Processing	The ability to process information that is received orally. This involves sound recognition and memory for recall important in understanding classroom instructions, following directions, etc.
Information Processing Speed	The speed at which mental processes occur. This can impact a range of other thinking skills and is heavily related to test taking skills and rapid comprehension (e.g., grasping concepts quickly in the classroom) — an important part of school.

Life at School

Children spend a large part of time at school. School can be seen as their workplace. They go to school every day to learn new academic material. However, school life is not just about books, pop quizzes and homework. It is not just about academic performance and standard tests. School is also where much of socialization occurs; kids learn about social skills and interpersonal functioning through interaction with their peers.

Socialization

Developmentally speaking, no matter which stage we focus on, developing social skills is critical⁶, and school is where the majority of this development happens. What happens during the school day carries over into time at home, which can dictate children's behavior there.

While little is known about the specific effects of MS on socialization, we do know that overall, children with chronic illness are at a greater risk for difficulties with socialization than healthy children. It has been found that among children with chronic illness, those with more obvious physical limitations or disabilities have more difficulty with socialization due to feeling isolated and different from their peers.

For many children and adolescents with MS, school life as it relates to socialization can become difficult for various reasons such as:

- Changes in cognitive functioning can lead to feelings of inadequacy and a sense of not being able to “keep up with” peers, feeling different than peers, or even experiencing teasing from peers.
- Frustration or embarrassment because school personnel often don't understand MS symptoms (such as fatigue, decreased vision, and frequent bathroom use.)
- Low self-esteem and/or embarrassment, causing a low desire to socialize due to physical limitations (if any) and/or other symptoms.
- Compromised drive towards independence, because the nature of the disease can require increased dependence on parents, caregivers and teachers.
- Anxiety, which can be emotionally internalized (withdrawal) or externalized (acting out), because of the uncertainty that comes with MS.

It is important to remember, that while chronic conditions leave a child more vulnerable to social problems, the presence of a condition does not invariably lead to social problems. It is also important to understand that healthy peer relationships may actually be protective to the well-being of children/teens with chronic conditions, and therefore should be encouraged and supported by parents and caregivers.

⁶ Erikson (1959)

Emotional Impact

Having a chronic illness, such as MS, can impact children and adolescents' emotions in various ways (*see Chapter 2, Aspects of Chronic Illness by Developmental Stage*). Differences in cognitive abilities may cause changes in the ability to do every day tasks, such as recalling a locker combination, completing homework or doing a classroom assignment. Even changes in school schedule, transportation requirements and changes in how a child gets around school, can impact his/her emotions.

It is possible that children with MS who have changes in cognitive functioning have a greater emotional impact from the disease. This may be due to children often feeling left behind or not feeling "as good" as other children due to difficulties in academics and this may affect self-esteem and self-view. Without intervention, this can result in a greater gap between a child's actual level of functioning in school and where s/he should be, based on chronological age. There may be other emotional hardships that may originate from social situations that are unique to schools and other places where children socialize.

Teasing

Teasing and/or bullying in schools has become an increasing problem and has garnered more attention in communities nationwide. Children with chronic illness are an at-risk group for teasing and bullying. The following is some general information about teasing that will help you to prepare your child for possible encounters with bullies at school.⁷

Why Children Tease

- Attention — teasing is an effective way of getting negative attention.
- Imitation — some children mimic or model what is happening to them at home by acting the same way to others at school.
- Feeling of superiority or power over others.
- Peer acceptance.
- Lack of understanding normal differences among people.

Teasers want to provoke anger, frustration or make their victims feel weak or inadequate, often with the subconscious goal of making themselves feel powerful.

⁷ Judy Freedman (2002), *Easing the Teasing: Helping your child cope with name-calling, ridicule and verbal bullying*.

Strategies Parents Can Teach Children about Teasing

These strategies can be used alone or in combination. Role-play with your child and have him/her come up with examples and scenarios.

- **Self-Talk**

Encourage children to come up with phrases that they can say to themselves when they are in a teasing situation (e.g., “Even though I don’t like this teasing, I can handle it.”).

- **Ignore**

Displays of anger or tears often invite more teasing. It is more effective for children to ignore the teaser.

- **Visualize**

Especially for young children, visualizing words “bouncing off” of them helps them imagine not having to accept what is said.

- **Reframe**

Change your child’s perception about the negative comment. For example, “Four eyes, four eyes, you have four eyes.” The child being teased could respond, “Thanks for noticing my glasses.”

Working with the School System to Get Services for Your Child: Interventions Adaptations, Accommodations & Consultation

Each school system establishes, maintains and implements a general education intervention procedure. Interventions are implemented on school premises for students whose classroom performance is adversely affecting educational outcomes. In other words, because a child's school performance is suffering, the child would not meet educational milestones.

When school personnel, a parent (or guardian) or the student has concerns regarding his/her academic performance and/or social/behavioral adjustment, the procedure usually looks like this:

- The school principal, principal's designee, or the classroom teacher is contacted and referral is made to a designated school-based team. This team would create general educational accommodations.
- Soon after the referral is made, the school-based team meets to plan strategies for resolving the problem or concern.
- A general educational accommodation plan (informal) is developed and implemented.
- Parents get a copy of this plan.
- There is a follow-up meeting to determine the success and/or progress of the accommodation.

At the follow up meeting:

- The general educational accommodation plan may be re-designed and/or the duration can be extended to see whether the existing plan will continue to work.

AND/OR

- A 504 Plan conference can be scheduled (in addition to revising the general educational accommodation plan).

AND/OR

- The group will discuss and initiate a psychoeducational evaluation. If the group decides that an evaluation is necessary, a copy of the general educational accommodation plan should accompany the psychoeducational evaluation referral when it is sent to the Special Education Office.

Your Child's Educational History

Be prepared to give your child's educational history to the school psychologist and neuropsychologist:

- Was your child tested for educational assessment (psychoeducational testing) before being diagnosed with MS?
- Have you or anyone who knows your child (e.g., teacher) had concerns about his/her learning?
- Has your child received, or does your child currently receive, any educational services (formal or informal) at school?
- What are your child's current complaints at school?
- What symptoms get in the way of your child's schoolwork and life at school? Have specific examples ready.

Accommodations & Interventions

Informal Accommodations

This is something you can discuss and negotiate with your child's teacher(s). It is usually very informal and is made at the classroom level. Formal testing is not involved, and your child does not have to be "eligible" or meet specific criteria.

Formal Interventions

504 PLAN

This is the next level and involves school administration (such as the principal). You need a medical provider's documentation to qualify. Parents are strongly encouraged to discuss this plan with school personnel (such as guidance counselors) at the beginning of each school year.

FACTS ABOUT SECTION 504

This is a civil rights law.

The intent is to prohibit discrimination based on disability, and to ensure that people with disabilities are provided an equal opportunity for education.

It is implemented and enforced by the Office for Civil Rights within the U.S. Department of Education.

Section 504 protects any individual with a disability (students, parents, teachers, guests and the public).

Under Section 504, an individual with a disability is any individual who:

- Has a physical or mental impairment, which substantially limits one or more major life activities
- Has a record of such an impairment
- Is regarded as having such an impairment

A child can be eligible under IDEA (*see below*) and meet the Section 504 definition of disability.

It also protects those children who are not eligible for IDEA services. For example, a child with MS who does not need special education (because he or she is not having academic or behavioral problems) is still covered by Section 504 if s/he needs aids and/or services within the regular educational setting.

Educational/Supplemental Plans

Special Education: Individuals with Disabilities Education Act (IDEA) and Individualized Education Program (IEP)

This is very formal, involves formal testing, group meetings, and children need be “*eligible*” to get intervention under Special Education. Depending on the school system, these services may be provided either in or outside of the school. IEPs are evaluated every three years.

FACTS ABOUT IDEA

- The IDEA is a federal law.
- Requires school districts to provide special education and related services to eligible children with disabilities.
- The office of Special Education Programs within the U.S. Department of Education administers the IDEA regulations.
- Each state’s Department of Education is required to ensure that public school districts comply with IDEA.
- Special education means an educational plan is designed for each child’s unique needs, so it makes sense to call the plan an “Individualized Educational Program” (IEP).

- To qualify for services under IDEA, a child must fall into one of the following categories:
 1. Deafness
 2. Hearing impairment including deafness
 3. Deaf-blindness
 4. Speech or language impairment
 5. Visual impairment, including blindness
 6. Serious emotional disturbance
 7. Orthopedic impairment
 8. Autism
 9. Traumatic brain injury
 10. Other health impairment
 11. Specific learning disability
 12. Multiple disabilities
 13. Cognitive impairment

Individualized Education Program (IEP)

This plan should be tailored to your child's academic and medical needs in school. When you are thinking about types of accommodations, think of what would help your child function better at school physically (if they have motor function symptoms) and/or academically (if they have cognitive symptoms).

For children and adolescents moving on to another school, an Individual Transitional Plan (ITP) should be in place, which is part of an IEP plan. Students about to start high school and already in high school, should have an ITP as well.

Individual Health Plan (IHP)

The Individual Health Plan (IHP) provides your child or adolescent with specific care in the event of any medical problems that may occur at school. The IHP contains the history and medical issues of the student, as well as contact information for parents, relatives, pediatricians, neurologists, other healthcare providers and anyone else who might need to be contacted. (If a 504 Plan is in place, this information may be included into that plan). For students with medical issues, the IHP is a vital part of the student record.

Parents could write an IHP, but they do need to be mindful of school resources and policies. If there is a school nurse, that person needs to be involved with the process, as s/he may have to be trained for some of the procedures.

Examples of General Accommodations & Formal Interventions

Keep in mind that accommodations are *individualized* for each student's needs. Therefore, it is impossible to provide a comprehensive list of all possible accommodations because each student is different and has unique learning and/or medical needs at school.

GENERAL ACCOMMODATIONS (INFORMAL)

- A multiple-choice test (if your child has trouble remembering and/or recalling information)
- Provide a second set of books to be kept at home (if your child experiences significant fatigue or other motor limitations)
- Preferential class seating (if your child's symptoms include visual problems, attention deficit, or bladder/bowel problems)
- Bathroom pass and/or extended bathroom time (if your child's symptoms include bladder and/or bowel control problems)
- Frequent breaks (if your child's symptoms include fatigue or difficulty concentrating)
- Modify homework assignments (helpful for children who experience extreme fatigue and have problems with writing)
- Portable air conditioner to be carried from class to class (if the school does not have air conditioning)
- Step stool for bus access
- Slant board to prop up books/binders/papers for better vision
- Clear colored ruler to highlight sentences in books
- Lockers to be opened with keys rather than combinations

504 ACCOMMODATIONS (FORMAL) *(See Appendix II for sample plan)*

- Extended test-taking time (This is extremely useful during standardized tests (e.g., PSAT, SAT and ACT). These accommodations typically include "stop the clock" breaks for bathroom visits or for taking breaks when extreme fatigue occurs. Testing organizations may require that students have a 504 plan on file before providing this accommodation.
- Relocation of classrooms (for children with fatigue and/or physical disabilities that affect gross motor skills).
- Aid for students with visual impairments (e.g., a reader).
- Laptop computer for taking notes and tests (use of software such as *Dragon Naturally Speaking* Computer Software — a voice activated software that types what you speak).
- Speech and language therapy
- Psychological services
- Physical and occupational therapy
- School health services

SPECIAL EDUCATION INTERVENTION (FORMAL)

- Occupational therapy for those with fine motor and/or visual needs
- Speech/language therapy and audiology services
- Psychological services
- Physical therapy
- Therapeutic recreation/adaptive physical education
- Mobility services and/or medical services for *diagnostic or evaluation purposes only*
- School health services by a school nurse or other qualified personnel
- Social work services
- Parent counseling and training

Americans with Disabilities Act (ADA)

Facts about the ADA

The ADA is a broad civil rights law.

Prohibits discrimination on the basis of disability and requires an equal opportunity.

The ADA uses the same definition of disability as the Section 504, and also applies to students, parents, teachers, guests and the public.

Provides the same protections for students with disabilities in public schools as Section 504.

For additional recommended accommodations please see, *Students with MS in the Academic Setting: A Handbook for School Staff*, a publication of the National MS Society.

Coping Skills & Strategies

Learning coping skills and strategies to overcome troublesome symptoms can be empowering and beneficial when facing challenges in the school setting. Both parents and children can benefit from learning these skills.

Parents benefit because they feel that they're helping their child. Children benefit because they feel that something can be done about what they often feel they have no control over.

Talking about an exacerbation/attack with a child can be anxiety provoking and difficult for parents. Keep in mind, however, that talking about these issues, as challenging as they are, makes it less scary for your child.

Have open discussions and encourage talking about ways to reduce, or cope with the effects of the disease and its related disabilities. Involve your child or adolescent when developing coping strategies.

Talk to your child or adolescent about anticipated physical effects of MS and how they are treated.

For younger children and early school-aged children, create “what if” plans and talk about different scenarios that could occur for your child when you are not around. If certain symptoms have occurred previously and then went away, talk about how s/he would handle this symptom if it occurred again in school.

Older children and adolescents should be encouraged to generate some coping strategies on their own; often this increases the chances that they will use the strategy when necessary.

For some adolescents and older school-aged children, the effects of having a chronic illness conflicts with the natural desire to be independent. This is sometimes described as a feeling that “someone else” or “something else” is “controlling” their life.

A chronic illness such as MS can sometimes interfere with time spent with peers at school, which is a child's primary social environment. Self-esteem issues related to acceptance and concerns about being accepted by others are intensified by chronic illness and related treatment needs.

Additional support such as support groups and/or therapy/counseling can help parents, the child and his/her sibling(s) cope with MS.

SOMETIMES IT HELPS TO ROLE PLAY WITH YOUR CHILD

“Let’s say you’re in school during lunch in the cafeteria, and all of a sudden you notice your vision became blurry just like it did a few months ago. What would you do?”

- Keep in mind that you’re not quizzing your child.
- Play out different types of scenarios for your child in order to help him/her to feel less anxious.
- Help prepare your child to cope with the symptoms on his/her own.

HERE ARE SOME WAYS TO HELP YOUR CHILD FEEL MORE INDEPENDENT

- Involve him/her in health-related discussions (such as concerns about MS or treatment choices).
- Teach him/her self-care skills.
- Encourage him/her to monitor and manage his or her treatment needs as much as possible.
- Encourage and support the development of coping skills to address problems or concerns related to MS that might arise.

HERE ARE SOME WAYS TO HELP YOUR CHILD FEEL MORE SAFE & PREPARED TO SOCIALIZE

- Encourage spending time with friends.
- Discuss concerns about disclosure — what to share, and what not to share with friends.
- Help your child find ways to respond if teased by peers.
- Encourage humor.
- Encourage and assist friends in being supportive.

Transitions

Youth with chronic illness face a number of important transitions:

- A developmental transition (from childhood to adolescence to adulthood)
- A situational transition (changing schools or educational services)
- A transition from relative health to living with a chronic disease (depending on the progression)

What Will Happen to Me?

The fear of an unknown future has been found to be one of the most challenging stressors that children and adolescents as well as parents face. Living with a chronic illness further complicates this normal stressor. Children find it very difficult to understand that illness or life outcomes cannot be predicted — it is virtually impossible to tell a child exactly what impact MS may have on each aspect of his/her life.

Even though MS is unpredictable, talking about the future with your child can help to alleviate some of the fear of the unknown. If a transition plan already exists through your child's IEP, you can also modify it to add in personal/social life issues or make the transition plan longer — say for 10 years instead of 5.

Transitional plan simply means being prepared for anticipated change(s) that will occur (e.g., changing schools from elementary to middle school, moving, etc.) Each child is unique in his/her future needs, and parents together with the child are often the best authors of transition plans. It may be comforting for your child to know that an adult is thinking ahead with them.

Goal of a Transition Plan

THE GOAL OF A TRANSITION PLAN SHOULD BE

- To provide educational and healthcare services that are uninterrupted, coordinated, developmentally and psychologically appropriate. This needs to be in place prior to, and throughout transitioning into, a different school and/or developmental stage.
- Planned and facilitated with involvement of the child or adolescent, in order to equip him/her with the knowledge and skills to face each new stage in his/her life.

Transition Planning Checklist — First Stage

(PRESCHOOLER TO KINDERGARTEN THROUGH THIRD GRADE)

The child is being introduced to the world. The child begins to take part in group social activities and is preparing to attend school.

Self-advocacy

- Support your child to be as independent as he or she is ready to be (e.g., washing hands, getting dressed, etc.).
- Help your child verbalize what s/he wants or needs by “using your words.”
- Have a list of names and, if possible, pictures of your child’s healthcare providers for him or her to look at, to promote familiarity. Talk about when you and your child saw them last and when you will see them next.
- Encourage your child to ask questions during each healthcare visit. If a child is too shy or scared during the visit, ask him/her to whisper questions in your ear, which you can then relay to the provider on his/her behalf.
- Discuss MS and treatments your child needs (discuss with your child’s healthcare team first). Have pictures available and use developmentally appropriate examples to explain concepts. You can ask your healthcare provider(s) for examples if needed.
- Discuss and demonstrate (by role playing) how to seek help from others.

Psychosocial support

- Provide your child opportunities to take part in social activities, peer involvement and structured play to resemble the school setting.
- Start talking about supportive relationships (e.g., teacher, family members, counselor, etc).

Educational planning

- Identify schools that may be appropriate for your child. Ask yourselves, what kind of school fits our overall values, religion, educational beliefs, and my child’s needs?
- Discuss restrictions that may (or may not) interfere with your child’s educational or recreational activities.

Health and lifestyle

- Create a binder or a large folder to keep all medical records, and use a separate one for your child’s school records.
- Have discussions with family members about how MS might impact each of you.
- Make sure that you, as a parent, have adequate social support with whom you can talk about your feelings and concerns about the future.

Transition Planning Checklist — Early Stage

(8–12 YEARS/GRADES 4–7)

At this stage the child can begin to participate in his/her own care. Skills are supported and practiced at home with the family.

Self-advocacy

- Educate your child by describing MS, its symptoms and treatments in basic terms.
- Review findings, news and new information with your child.
- Encourage your child to ask questions during each office visit to support development of independence.
- Discuss the medications and treatments your child needs, including side effects (discuss and consult with your child's healthcare team first).
- Discuss how to seek help from others. Have your child discuss when, how and from whom to seek emergency and medical help.

Sexual Health

- Discuss the change of puberty, differences and similarities in comparison to peers, and any impact of puberty on the child's health condition.
- Talk to your healthcare team about where children and parents can obtain information about sex education.

Psychosocial support

- Support your child's drive for independence. Supporting independence should be balanced with appropriate structure.
- Talk to your child about social activities, peer involvement and supportive relationships.

Educational planning

- Talk about your child's responsibilities at home (e.g., chores) and at school (e.g., homework, clubs, etc.)
- Discuss restrictions (real and hypothetical) on your child's educational or recreational activities.

Health and lifestyle

- Ask your child or pre-teen about smoking, use of alcohol and street drugs.
- Discuss impact of smoking, street drugs and alcohol on health, treatments and general well-being.
- Make sure you, as a parent, have access to supportive persons to discuss your feelings and concerns about the future.

Transition Planning Checklist — Middle Stage

(13–15 YEARS/GRADES 8–10)

Here you and your adolescent will gain an understanding of the transition to and expectations of adulthood. The younger adolescent practices skills, gathers information and sets goals for participating in his/her care.

Self-advocacy

- Discuss strategies to access accurate information about health conditions and treatments with your child's healthcare team (e.g., support groups, Internet, library, condition-specific health associations).
- Discuss with your adolescent, appointment times and dates, and let them help make decisions about scheduling appointments.
- Encourage your adolescent to check-in at the front desk for his or her own healthcare appointments.
- Encourage your adolescent to learn about medication and practice having a prescription refilled.

Sexual Health

- Provide your adolescent time to meet alone with their healthcare providers to discuss any questions or concerns about sexuality-related issues. Parents can meet with the provider separately to raise any additional concerns.
- Discuss importance of using contraception.

Psychosocial support

- Prompt your adolescent to create and verbalize positive goals for self and health.
- Encourage your adolescent to join a club at school, a community or peer support group, or to attend camp.

Educational and vocational planning

- Focus on school, favorite subjects, plans for high school and even college or trade school, and ideas for careers.
- Have your adolescent visit school counselors to talk about career prep courses or volunteering in the community.

Health and lifestyle

- Discuss plans for driving; identify any restrictions with your adolescent's healthcare team.
- Discuss issues of body image, importance of exercise, concerns regarding dieting, weight gain or weight loss.
- Encourage and help find support outside of the family to enhance your child's support system, to include peer-to-peer support with other teens living with MS. If professional help for mental health concerns is appropriate, ideally, the adolescent should choose who they would like to see such as a psychologist, social worker, counselor, etc.

Transition Planning Checklist — Late Stage

(16–18 YEARS/GRADES 11–12)

The older adolescent uses independent behaviors (as much as possible) to move into the adult world.

Self-advocacy

- Discuss choices for medical care and community services (e.g., going away to college, summer program, etc.)
- Encourage your teenager to maintain a personal health record book for medical/dental appointments, health information, treatments, and health care providers (including names and telephone numbers).
- Parents and teens meet with the healthcare team separately to discuss concerns.

Sexual Health

- Discuss sexual capabilities, fertility and sexual vulnerability with your adolescent.
- Give opportunities for the adolescent to address sexual issues privately with the healthcare provider.
- Discuss importance of using contraception.

Psychosocial support

- Identify needs related to living away from family (e.g., going away to college).

Educational and vocational planning

- Discuss employment options and plans for healthcare benefits.
- If choosing college, discuss medical care coverage, educational services (should be discussed in the very last IEP the adolescent had while still in high school), transportation, living arrangements and impact on health condition.

Health and lifestyle

- Discuss impact of smoking, street drugs and alcohol on health, treatments, and general well-being.
- Discuss issues of body image, concerns regarding dieting, weight gain or weight loss and the importance of exercise.
- Provide opportunities for older teens to discuss emotional topics. Listen for clues suggesting emotional problems, depression, thoughts that life is not worth living or urges to hurt oneself.
- Encourage and help find additional support outside of the family for extra support, to include peer-to-peer support with other teens living with MS. If professional help for mental health concerns is appropriate, ideally, the adolescent should choose who they would like to see, such as a psychologist, social worker, counselor, etc.

Sample Letter Requesting Special Education Process and Assessment

(Today's date)

TO: Mrs. Joan Smith (school principal's name)
123 Main Street (school's address)
Anywhere, US 12345

RE: Ellen Jones (student's name), a student in the 5th grade class taught by
Ms. Camryn Graves (teacher's name)

I am writing to you because Ellen was recently diagnosed with multiple sclerosis. I am formally requesting that the school begin its special education process, including initial assessment for eligibility.

Thank you very much for your attention and kind assistance.

Sincerely,

Robert Jones (parent or guardian of student)

Contact Information:

987 Any Street (parent or guardian's address)
Anyplace, US 54321

(123) 456-7890 (parent or guardian's phone number)
email@address.com (parent or guardian's e-mail address)

Sample 504 Plans

A thorough 504 plan contains

1. Concrete information about the child's disability;
2. Specified actions for teachers to take that will impact their attitudes, knowledge and behaviors;
3. Strategies for promoting the child's self-concept and minimizing possibly embarrassing situations;
4. Ways to support the child's autonomy and decision-making regarding his/her healthcare needs.

Sample 504 Plan #1

Accommodations that are necessary for (child's name):

1. Provide (child's name) Reading and English teacher information on pediatric MS.
2. Provide (child's name) the book titles necessary for reading in advance, so there is ample time to order them on tape and work through the assignment.
3. Only call on (child's name) in class (to read aloud, or offer an answer) if she is raising her hand.
4. Permit written assignments to be done with dictation software and submitted in a typed format.
5. Give extended time for, or shortened assignments in, reading, spelling and written expression.
6. Avoid classmate checking in English and Reading so not to embarrass her with peers.
7. When possible, provide written notes or worksheets to minimize the amount of material that needs to be copied.
8. During tests, be available to read words, sentences, or to paraphrase questions as needed.

Signatures and Indication of Agreement

Parent or Guardian Signature

Date

School Principal Signature

Date

School Teacher Signature

Date

Emergency Contacts

MOTHER'S CONTACT INFORMATION

Name: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

FATHER'S CONTACT INFORMATION

Name: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

CHILD'S PRIMARY CARE PROVIDER

Name: _____

Work Phone #: _____

Pager #: _____

CHILD'S OTHER HEALTH CARE PROVIDER

Name: _____

Work Phone #: _____

Pager #: _____

OTHER

Name: _____

Relationship: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

Sample 504 Plan #2

Accommodations that are necessary for (child's name):

1. (Child's name) shall be permitted to use the bathroom without restriction.
2. An extra set of clothes is allowed to be stored on the school premises.
3. (Child's name) will be permitted to participate in all field trips and extracurricular activities (such as sports, clubs, and enrichment programs) without restriction and with all of the accommodations and modifications set out in this plan.
4. If (child's name) is affected by fatigue or exacerbated symptoms at the time of regular or standardized testing, he will be permitted to take the test at another time without penalty. If John needs to take breaks to use the bathroom during a test or a classroom assignment, he will be given extra time to finish the test or assignment without penalty.
5. (Child's name) will not be penalized for absences or tardiness required for medical appointments, illness, visits to the office or time necessary to manage his symptoms.
6. (Child's name) will be granted a laminated "Nurse Pass" that he can use at any time and place during school activities in order to get the care he needs on an immediate basis.
7. The school nurse/designee will be trained to administer (child's name) injection/medication.
8. Each teacher will receive a packet of information about pediatric multiple sclerosis.

Signatures and Indication of Agreement

Parent or Guardian Signature

Date

School Principal Signature

Date

School Teacher Signature

Date

Emergency Contacts

MOTHER'S CONTACT INFORMATION

Name: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

FATHER'S CONTACT INFORMATION

Name: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

CHILD'S PRIMARY CARE PROVIDER

Name: _____

Work Phone #: _____

Pager #: _____

CHILD'S OTHER HEALTH CARE PROVIDER

Name: _____

Work Phone #: _____

Pager #: _____

OTHER

Name: _____

Relationship: _____

Home Phone #: _____

Cell Phone #: _____

E-Mail Address: _____

Resources

In school

- School psychologist
- School nurse (if your child's school has one)
- Principal
- Resource Specialist Professional (RSP) teacher
- School counselor
- Your child's classroom teacher

Parent Resources

THE FAMILY VILLAGE

Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705-2280

familyvillage@waisman.wisc.edu
www.familyvillage.wisc.edu

The Family Village is a web site for children and adults with disabilities, their families, friends and allies. Family Village brings together thousands of online resources in an organized, easy-to-use directory. The centerpiece of Family Village is the library, where visitors can find information on over 300 diagnoses. Visitors can also learn about assistive technology, legal rights and legislation, special education, leisure activities and much more.

NATIONAL MULTIPLE SCLEROSIS SOCIETY

1-800-344-4867 (voice)
childhoodms@nmss.org
www.nationalMSSociety.org

The National MS Society helps each person address the challenges of living with MS through our 50-state network of chapters. *Children and Teens with MS: A Network for Families* offers educational and psychosocial support for families living with MS. The Society also offers resources for school personnel.

OFFICE OF SPECIAL EDUCATION PROGRAMS (OSEP)
AT THE U.S. DEPARTMENT OF EDUCATION

202-245-7459

www2.ed.gov/about/offices/list/osep/index.html?src=mr

OSEP funds a large information dissemination and technical assistance network, and there's a customer service specialist for each state.

OFFICE FOR CIVIL RIGHTS AT THE
U.S. DEPARTMENT OF EDUCATION

800-421-3481 (voice)

877-521-2172 (TTY)

www2.ed.gov/about/offices/list/ocr/index.html

Technical assistance, pamphlets, complaint information on Section 504 of the Rehabilitation Act.

U.S. DEPARTMENT OF JUSTICE

800-514-0301 (voice)

800-514-0383 (TTY)

www.ada.gov

Technical assistance, publications, complaint info on Titles II and III of the ADA

ADA & ACCESSIBLE IT CENTERS

800-949-4232 (voice/TTY)

www.adata.org

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

PARENT TRAINING AND INFORMATION CENTERS AND COMMUNITY PARENT RESOURCE CENTERS

888-248-0822 (voice/TTY)

www.taalliance.org

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. They can help parents to:

- Understand special education laws, rights, and responsibilities
- Understand their child's disabilities
- Provide follow-up support for the educational programs
- Communicate effectively with special and regular educators, administrators, related services personnel and other relevant professionals
- Participate fully in education decision-making processes, including the development of the Individualized Education Program (IEP) for a child with disabilities
- Obtain information about the range of options, programs, services, and resources available to children with disabilities and their families

NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH DISABILITIES (NICHCY)

800-695-0285 (Voice/TTY)

www.nichcy.org

Provides technical assistance and publications on disability issues — focus is children and youth (birth to age 22) and IDEA.

ASSOCIATION ON HIGHER EDUCATION AND DISABILITY (AHEAD)

704-947-7779

www.ahead.org

Publications, information and training on higher education and students with disabilities.

MS Resources & Links

NATIONAL MULTIPLE SCLEROSIS SOCIETY

www.nationalMSSociety.org

The National MS Society helps each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

NATIONAL INSTITUTES OF HEALTH

www.nlm.nih.gov/medlineplus/multiplesclerosis.html

MS Information Page

NETWORK OF PEDIATRIC MS CENTERS OF EXCELLENCE

In 2006, the National MS Society established a nationwide network of Pediatric MS Centers of Excellence to provide comprehensive evaluation and care to children and teens (up to age 18) with MS, and other related central nervous system (CNS) demyelinating disorders. Each center includes staff who can help school personnel implement physicians' recommendations.

CENTER FOR PEDIATRIC ONSET DEMYELINATING DISEASE

■ **University of Alabama at Birmingham**

205-996-7633

main.uab.edu/sites/cpodd/

■ **Mayo Pediatric MS Center**

Mayo Clinic Rochester

507-293-0378

www.mayoclinic.org/multiple-sclerosis/children.html

■ **National Pediatric MS Center**

Stony Brook University Medical Center

631-444-7802

www.pediatricmscenter.org

■ **Partners Pediatric Multiple Sclerosis Center**

Massachusetts General Hospital for Children

617-726-2664

www.partnersmscenter.org (then navigate to Pediatric MS Center)

■ **Pediatric MS Center of Excellence**

Jacobs Neurological Institute

SUNY University at Buffalo

716-878-7367 or toll free 877-878-7367

www.pedsms.org

■ **Regional Pediatric Multiple Sclerosis Center**

University of California-San Francisco

415-353-3939

www.ucsfhealth.org/pedsms

Cognitive/Neuropsychological Evaluation

A cognitive/neuropsychological evaluation may be a part of your child's treatment plan. A baseline evaluation is highly recommended with testing repeated bi-annually to monitor progress. These evaluations are very helpful for all parties involved.

- For children and adolescents, this testing provides an opportunity to understand how their brain works — which tasks are easy for them and which are hard. This can help to develop strategies and ways to get around cognitive symptoms that may occur.
- For parents, this testing provides an opportunity to understand how MS affects their child's behavior and thinking. This can help parents learn how to better communicate with their children and advocate for school accommodation if needed.
- For healthcare providers, this testing will serve to evaluate a child's cognitive status, and changes over time, and is a part of the process of monitoring disease evolution—it is used in conjunction with the neurological exam and/or the MRI. It tells the health care provider if intervention is needed.
- For schools, this test can aid in providing overall cognitive function of the child if formal psycho-educational testing at school have not been done.

Types of Tests Given & What They Evaluate

COGNITIVE/NEUROPSYCHOLOGICAL TESTS

When people hear “cognitive testing,” they immediately think of IQ/Intelligence tests. This is only true in part. Cognitive testing measures the ability to succeed in school. Neuropsychological testing evaluates different parts of listening, visual and motor skills, as well as attention, different kinds of memory, speed of responses and use of strategies. These abilities are dictated by different parts of our brain. So, by finding out *how* our brains work, we can also find out which area in our brain is affected by MS.

The most important part of this test is understanding *how* your child solves problems. This is often more important than the end result of the test because it is more helpful to understand how someone comes up with their answers than what their score was on a particular test. Cognitive testing should be repeated over time. In a nutshell, neuropsychology provides a way to understand how MS might impact behavior and learning and how this might affect your child at school.

Behavioral Assessments

Some of these assessments evaluate purposeful, goal-directed and problem-solving behaviors. These are used to estimate how a child will do in a classroom or social setting. This type of assessment has components that seek input from the child, teachers and parents. Other assessments examine the psychological functioning of the child.

Developmental/Psychosocial Assessments

Developmental and psychosocial assessments evaluate *levels of functioning* out in the world — in their own environment on a daily basis. These assessments are usually done through in-depth parent interviews. Typically, a child’s capabilities in *communication* (what s/he understands and what s/he says), *daily living skills* (what s/he can do to take care of her/himself), *socialization* (how s/he gets along with others and how s/he plays), and *motor skills* (how s/he gets around physically) are examined.

Frequently Asked Questions about Cognitive/Neuropsychological Testing

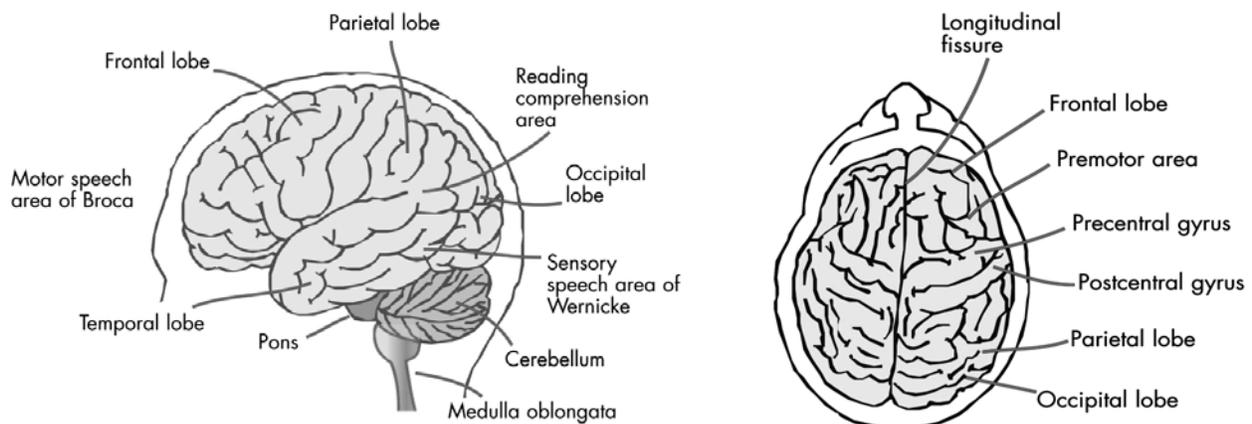
WHAT IS INVOLVED IN PREPARATION FOR THE TEST?

There is no advanced preparation for cognitive testing. Neuropsychological evaluations can range in length from a “screening” measure (less than 1 hour) to an “intermediate” assessment (1 to 3 hours) to a “comprehensive” assessment (4 or more hours). The most accurate results are obtained if the child is well rested and is not hungry. If a child becomes too tired, the neuropsychologist may recommend that the tests be given during several short appointments, instead of one long session.

Cognitive testing should be conducted when the child is *not* on a steroid treatment, as it may interfere with neuropsychological status.

WHAT DO THE TEST RESULTS MEAN?

The test results show how a person performs when given different tasks that examine different facets of cognitive ability. This correlates with success in school. The result can be most useful when used as a tool to evaluate a child’s cognitive ability to inform parents and kids about their range of abilities. The results can emphasize areas in which children can do well, ones that are more difficult, and those that may require supportive help. Nobody has a perfect brain! These results can be used to formulate school-based interventions to make any difficulties more manageable.



Glossary of School-related Terms

Accommodations — interventions and/or modifications in the school setting designed to help the student compensate for any difficulties in learning.

Achievement Tests — measures of learned knowledge in academic skills (such as reading, writing, math and science).

Assessment (or psychoeducational assessment) — process of identifying needs to assist in educational planning, which includes classroom observation, record review, interviews (including parents, teachers, and others as needed), and tests.

Assistive Technology (AT) — A piece of equipment or system that helps kids with disabilities compensate for their disability.

Cognition — High level functions carried out by the brain including comprehension and use of speech; visual perception and construction; calculation ability; attention (information processing); memory; and executive functions such as planning, problem-solving and self-monitoring.

Cognitive impairment — Changes in cognitive function caused by trauma or disease process. Some degree of cognitive impairment occurs in approximately 50-60 percent of people with MS, with memory, information processing and executive functions being the most commonly affected functions. *See Cognition.*

Cognitive rehabilitation — Techniques designed to improve the functioning of individuals whose cognition is impaired because of physical trauma or disease. Rehabilitation strategies are designed to improve the impaired function via repetitive drills or practice, or to compensate for impaired functions that are not likely to improve. Cognitive rehabilitation is provided by psychologists, neuropsychologists, speech/language pathologists and occupational therapists. While these types of specialists use different assessment tools and treatment strategies, they share the common goal of improving the individual's ability to function as independently and safely as possible in the home, school and/or work environment.

Designated Instruction and Services (DIS) — Also called specialized instructional, and/or support services identified through an assessment and written on an Individualized Education Program (IEP) as necessary for a child to benefit from special education (i.e., speech therapy, etc).

Disability — As defined by the World Health Organization: a disability (resulting from an impairment) is a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being.

Discrepancy — Difference between two abilities (usually indicated by tests that are designed to measure different abilities).

Due process — Procedural safeguards to protect the rights of the parent/guardian and the child under federal and state laws and regulations for special education (includes voluntary mediation or a due process hearing to resolve differences with the school).

Free Appropriate Public Education (FAPE) — Entitles a public school child with a disability to an educational program and related services to meet his/her unique educational needs at no cost to the parents; based on IEP.

Individuals with Disabilities Education Act (IDEA) — Federal law that provides for special education and related services to eligible children with disabilities.

Individualized Education Program (IEP) — Also known as Individualized Education Plan, this plan is individualized for eligible child's needs — a direct result of an IDEA.

Informed Consent — Agreement in writing from parents that they have been informed and understand procedures and potential outcomes (*permission is voluntary*).

Least Restrictive Environment (LRE) — Educational instruction in place that encourages maximum interaction between children with disabilities and children without disabilities.

Modification (as term used in school) — Changes in the delivery, content, and/or instructional level of a subject or test.

Neuropsychologist — A psychologist with specialized training in the evaluation of cognitive functions. Neuropsychologists use a battery of standardized tests to assess specific cognitive functions and identify areas of cognitive impairment. They also provide remediation for individuals with MS-related cognitive impairment.

Occupational therapist (OT) — Occupational therapists assess functioning in activities of everyday living including dressing, bathing, grooming, meal preparation, writing and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coordination, (3) adaptations to the home and work environment, including both structural changes and specialized equipment for particular activities, and (4) compensatory strategies for impairments in thinking, sensation, or vision.

Referral — Written request for assessment to see if the child meets eligibility criteria for special education and related services to benefit from his/her general education program.

Resource Specialist Program (RSP) — under IEP a student may have extra academic assistance outside of the regular classroom taught by a credentialed resource specialist.

School Psychologist — a psychologist employed by the school district who is specialized in evaluating a student's learning potential, identifying learning disabilities, and recommending appropriate interventions and/or accommodations at school.

Special Day Class (SDC) — Students in SDC are assigned to these classes by their IEP eligibility and receive support from the Special Day Class teacher and the support staff. Other students in SDC typically also have eligibility under IDEA.

Special Education — Specifically designed instruction to meet the needs of eligible kids whose educational needs cannot be met through modification of the regular instructional program; provides for a range of options for services available to kids enrolled in public schools.

Speech/language pathologist (SLP) — Speech/language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a SLP for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

Notes

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For Information:
1 800 FIGHT MS (1 800 344 4867)