# **Moving Forward**

A Guide to College and Other Life Choices for Teens with Multiple Sclerosis

By the U.S. Network of

Pediatric Multiple Sclerosis Centers of Excellence

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### I. INTRODUCTION

#### A. Overview (Tanuja Chitnis M.D.)

In 2006, with the support of the National Multiple Sclerosis Society (NMSS), six Pediatric MS Centers of Excellence have been developed in the U.S. These six sites are located in Boston, MA; Stony Brook, NY; Buffalo, NY; Birmingham, AL; Rochester, MI and San Francisco, CA. In collaboration with each other, these sites have written a guide for high school students about college and other options for them to consider upon graduation. In addition to the doctors, psychologists and other specialists who work for these pediatric MS centers, current college students living with MS have provided a "student's perspective" to enrich this guide.

As teenagers living with MS, you are most likely engrossed in many different transitions in your lives as you struggle to find your own independence, strive to understand who you are as individuals and think about your lives after high school. Up until this point, you have likely been told that you must attend school and what is expected of you at home, in school and among friends. Now that you are nearing the end of high school, you are probably beginning to think about your next big transition: life after high school. Because every teenager has different interests, strengths, and skills there are many options that you can pursue after high school. This guide is intended to help you discover for yourself in what direction you wish to take your life. Many of you will decide that you want to attend a two or four year college; others may decide that you would rather enroll in several undergraduate courses before matriculating at a longer-term institution. Some of you may decide that you want to attend a vocational program while others may choose to seek full-time employment after high school. In this guide you will find helpful information about the myriad of options open to you after high school. Section III is designed specifically for those of you who are applying to college and are seeking advice about the college process, arriving at school and managing academics. This section is written largely by a college student who has MS, and who has successfully navigated the college selection process, as well as lived at college with MS. The other sections include information applicable to all teenage students who are making the transition from high school to young adulthood.

#### **B.** Multiple Sclerosis in Kids and Teens

#### 1. Definition of Multiple Sclerosis (Tanuja Chitnis, M.D.)

Multiple Sclerosis (MS) is thought to be an autoimmune disease that affects the brain and spinal cord. Together the brain and spinal cord make up the central nervous system.

White blood cells, which are part of the body's immune system normally fight infection. In MS, these white blood cells become mis-programmed and attack the brain and spinal cord. These white blood cells damage the nerves (neurons) and their myelin coating. Therefore MS is often referred to as a demyelinating disease. Damage to the nerves and their myelin coating causes the neurological symptoms that affect children and teens with MS. MS affects each person differently. Most patients experience a relapsing-remitting course in which neurological relapses or attacks appear and then go away. Others experience a more progressive disease course, in which neurological symptoms progressively worsen. In most patients, a progressive course can follow a relapsing-remitting course by 10-20 years, and this is called "secondary progressive MS". A few patients experience progression from the start of the disease, and this is called "primary progressive MS". The actual nature of MS attacks or symptoms also varies greatly between patients. The types of attacks can sometimes appear to be quite random, and patients often experience different combinations of problems. Below is a list of common symptoms associated with MS. These may appear as "attacks" or relapses, or may appear over several weeks, and may progressively get worse.

#### 2. Symptoms Associated with Multiple Sclerosis (Carrie Bryant B.A., Catherine Becker R.N., Tanuja Chitnis M.D.)

MS can cause a variety of symptoms. Some symptoms may fluctuate while others may be constant. Symptoms may include any of the following:

- Weakness
- Numbness or tingling
- Blurred or double vision
- Dizziness
- Balance problems
- Fatigue
- Cognitive changes
- Bladder and bowel issues
- Sexual dysfunction

MS symptoms may also be triggered by hot weather, fever, or infection. These exacerbations are sometimes called "pseudoexacerbations" and often improve when the underlying cause resolves.

#### 3. Managing Symptoms at College

**Weakness:** Weakness in your extremities is a common symptom of MS. Weakness may affect your arms, hands or legs. If you are having trouble getting around school, contact your public safety/school security office. These offices often provide transportation services for students who demonstrate a medical need. In addition, you may want to stock up on cereal, snacks, etc. in your room for the times you feel weak and do not want to exert yourself by trekking to the dining halls. Be sure to stay in close contact with your doctor, especially if you feel that your weakness is getting worse, changing, etc.

**Numbness and Tingling:** Once again, numbness and tingling are common symptoms of MS. If you are experiencing new numbness or tingling in any part of your body, contact your physician immediately for symptom relief suggestions. Allow yourself ample time to walk to class or other commitments if your feet/legs feel numb. Don't be shy about asking for rides or assistance!!

**Blurred or Double Vision:** It is not uncommon for pediatric MS patients to experience visual changes and disturbances. The three major types of visual symptoms are optic neuritis, double vision (diplopia) and nystagmus.

Optic neuritis is an inflammation of the optic nerve, which can cause temporary loss or disturbance in vision, changes in color vision, and sometimes pain in the affected eye. Although episodes of optic neuritis typically get better on their own, treatment with high-dose intravenous corticosteroids may be required. If you have had a history of optic neuritis, be vigilant of your eye symptoms. The moment you notice that your vision has changed, contact your doctor about the best treatment option.

Double vision is the experience of seeing two of everything and is caused by weakening or incoordination of eye muscles. Double vision can be treated with a short course of corticosteroids. Your doctor may recommend patching one eye for brief periods of time to prevent the double image. However, it is not recommended that you patch one eye for extended periods of time because patching prevents the brain from accommodating to the weakness on its own in order to create a single image. You should talk to your doctor about recommended management of double vision.

Finally, nystagmus is a rhythmic jerking of the eye(s) that your doctor may detect during the neurologic exam, but which tends not to cause noticeable symptoms. If you develop nystagmus and you notice that it is causing you significant visual disturbance or discomfort, ask your doctor about medications available to help control the jerking.

You may want to contact the ADA Coordinator at your school and your professors about accommodations they would be able to make for you while you are experiencing visual disturbances. You may find that sitting up close in the classroom is helpful. Also consider asking your professor for a copy of his/her lecture notes especially if you feel that your vision is affecting your own ability to take notes. If you are having a difficult time reading, ask your ADA Coordinator about getting your textbooks on tape. This is a common accommodation made for students with visual disturbances. Finally, keep all of your professors updated about your eye condition; they will help you out as much as they can and will likely provide other suggestions on how to keep up with their classes while you are battling visual problems!!

**Dizziness:** Many students with MS experience some form of dizziness. Dizziness or the sensation of the room spinning can be due to a problem in the base of the brain or in the inner ear. This type of dizziness can be due to MS, and there are medications available to reduce this. Sometimes people describe feeling "light-headed" as dizziness, however this may be due to other causes such as being dehydrated and lack of sleep. Since you are on

your own while you are at school, it is very easy to slip into poor sleeping and eating habits. You may discover that an extra hour of sleep per night and well-balanced meals make you feel much less dizzy. Contact your doctor if your dizziness is unmanageable because he/she may be able to offer some management advice and may prescribe medication to help. If your dizziness is impacting your academic performance after you have made these adjustments to your daily routine, contact your ADA Coordinator and professors about extensions on assignments.

**Balance Issues:** Balance problems can be the result of weakness, numbness, dizziness, or problems with the "balance center" of the brain. Sometimes a combination of these problems contributes to being "off balance." It is important that you tell your doctor if you are having problems with your balance. Physical therapy is often helpful for managing balance problems. You should do your best to minimize things that can throw your balance off such as carrying heavy loads of books and wearing high heels. Some strategies to minimize carrying heavy loads of books are: using a pull-bag, leaving the heavy textbooks at home, and borrowing a copy of a textbook at the library while you are there instead of bringing your own.

**Fatigue:** Fatigue associated with MS is a real symptom that can affect your school performance. It is often made worse by warm weather. MS related fatigue can come on very suddenly, be severe, and affect your daily life. For a diagnosis of MS-induced fatigue to be made, your doctor should make sure that there are no other obvious causes for being chronically tired such as getting less than 8 hours of sleep at night and other medical conditions. Good sleep hygiene, stress reduction, time management, and avoiding warm weather can help improve MS-induced fatigue in some people. If you continue to have fatigue despite getting enough sleep, contact your doctor, since there are some medications that can help with these symptoms.

If you are having a difficult time keeping up with your schoolwork because of fatigue, talk to the ADA Coordinator at your school. The ADA Coordinator can help you manage your workload, contact your professors, and request extensions on your behalf. If you do not feel comfortable discussing your medical condition with your professors, that is fine. However, it is important that you or an advocate, such as the ADA coordinator, are in touch with your professors and that you are proactive about your assignments. Be sure to attend extra-help sessions, meet with peer tutors and schedule a meeting with your professor during his/her office hours to get extra help. You want to show your professor that you are trying your best to keep up with your work; taking advantage of all the on-campus academic resources will help show your professor that you are dedicated to your work and are trying your hardest.

**Cognitive Changes:** MS can occasionally affect your ability to concentrate, remember or think for prolonged periods of time. These tasks are particularly important for college, so it is important that you report any such symptoms to your doctor. It is very helpful for you to undergo a testing session called "neuropsychological testing" in which all of these items are tested in detail. The results of this testing can help your doctor make recommendations for academic "accommodations" (see Accommodations section).

**Bladder and Bowel Issues:** Most students, understandably, do not like to talk about bladder and bowel issues but they are common in MS. The most common bladder symptom is a feeling of urgency or inability to "hold it". Other less common symptoms are the inability to empty your bladder completely, or occasional incontinence. MS can sometimes affect the bowels similarly, by causing difficulty in retention or constipation. If these issues are a concern to you, you may want to contact the housing coordinator about getting a room near a bathroom. Since many colleges and universities have co-ed bathroom options, think about whether you would prefer to live on a residential hall where the bathrooms are single sex. If you do, be sure to contact the housing coordinator and make your request. A change in diet to include bran cereals, flax seed and fruit juices can often help constipation. There are treatment options available to help control bladder and bowel symptoms so talk to your doctor and don't be shy about speaking up!! These symptoms are common and your doctor will have some suggestions to help you be more comfortable.

**Sexual Dysfunction:** MS can occasionally affect the ability to perform or to fully enjoy sexual contact. It can be different for men and for women. Sometimes men with MS have difficulty achieving an erection or achieving ejaculation. Women with MS sometimes report difficulty in getting aroused or in achieving orgasm. Even though this is a difficult topic to broach, you should feel comfortable talking to your doctor about these issues, particularly since there are strategies and medications that can help.

#### 4. Treatment Options for Students with Multiple Sclerosis (Catherine Becker R.N., Tanuja Chitnis M.D.)

It is important for you to know that there are several different FDA (Food and Drug Administration) approved treatments for MS, which are generally called disease-modifying treatments.

There are two major categories of medications available for the treatment of relapsingremitting MS. These drugs help to prevent the long-term effects of MS. The first category is called Beta-interferon. Beta-interferons are cytokines that are normally produced by the body. They have been found to have protective effects on the immune system. There are three commercially available Beta-interferon drugs:

- 1. Avonex (Beta interferon 1a); given once a week by intramuscular injection
- 2. Rebif (Beta interferon-1a); given 3 times a week by subcutaneous injection
- 3. Betaseron (Beta interferon-1b); given every other day by subcutaneous injection

The second category of drug for the treatment of relapsing-remitting MS is called glatiramer acetate (Copaxone). This is a synthetic drug that is designed to look like the myelin coating in the brain and acts to make the white blood cells more benign. This medication is given by subcutaneous injection every day.

There are additional drugs that may be used if the above drugs do not work or are not tolerated, and these may include Tysabri (natalizumab), Cellcept (mycophenolate

mofetil), Novantrone (mitoxantrone), Cytoxan (cyclophosphamide). If you have an acute attack or relapse, intravenous steroids will help with recovery. More information about treatments for MS is available on the NMSS website (<u>www.nmss.org</u>).

Symptomatic medications: In addition to a disease-modifying medication, you may be taking medications for certain symptoms (called symptomatic medications) such as fatigue, and bladder or bowel symptoms.

BELOW ARE A FEW TIPS FOR CREATING A TREATMENT PLAN WHILE YOU ARE AT SCHOOL:

- If you are planning to move away from home after high school, make sure you discuss your treatment plan with your current doctor and ask for a referral to a doctor near your school or new home.
- You may decide that you want to stay with your current doctor even though you have chosen to live in a different area or attend school in another region. Many students choose to stay with their current doctor while they are away at school. You should discuss with your doctor whether it is a good idea to have another physician near your college helping to manage your care.
- Because your daily schedules change when you go off to college, you may decide that you want to reevaluate your treatment plan with your doctor. Remember, if you are having a difficult time away from home managing your medications you should contact your doctor immediately to discuss treatment alternatives.
- You want to be as happy and comfortable as possible in your new environment. To ensure this, you may want to discuss other options to best treat and manage your MS. What worked for you at home may not be the best treatment for you now that you are away at school and more independent.

#### 5. Research Being Done in Pediatric Multiple Sclerosis (Tanuja Chitnis M.D.)

Over the past five years large national and international efforts have been initiated to study MS in children and teenagers. Some of the questions that researchers in the field are studying are listed below:

- Is the course of MS in children and teenagers different from that in adults?
- How does MS impact physical development and function?
- How does MS affect school performance and cognition?
- What are the best and safest treatments for children and teens with MS?
- Are there certain genes that predispose children and teens to develop MS?
- Why is the immune system overactive in MS patients?
- Can neuroimaging help us understand what is happening in MS?
- Is there an oral medication that is safe for children and teens with MS?

You may have been asked to participate in a research study related to MS. It is important to know that participation in a research study is confidential, and your name will never be made public. Since MS in children and teens is rare, researchers from all over the country, and all over the world, are collaborating to bring together information. The hope is that this research will help find better treatments for kids and teens with MS.

## 6. U.S. Network of Pediatric MS Centers of Excellence (<u>www.nationalmssociety.org</u>)

In 2006, the National MS Society established a nationwide network of six 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. The centers were selected (through a peer review process) on the basis of having multidisciplinary teams of adult and child specialists; ties to an adult MS center; staff to evaluate and address school and other psycho-social issues; support for families; and the ability to work collaboratively with other institutions in the network.

The centers are working together to:

- 1. Improve evaluation and management strategies to enhance diagnosis and care of children with MS and other related disorders
- 2. Develop resources for families, health care professionals and the public
- 3. Collect data that will enable large scale research initiatives

#### The Centers:

Center for Pediatric-Onset Demyelinating Disease at the Children's Hospital of Alabama

CHB 314K 1600 7th Ave South Birmingham, AL 35233 Center director: Jayne Ness, MD, PhD Contact person: Sarah M. Dowdy, MPH Phone: (205) 996-7633 Web: www.uab.edu/cpodd/

UCSF Regional Pediatric MS Center

350 Parnassus Avenue, Suite 908 San Francisco, CA 94117 Project director: Emmanuelle Waubant, MD, PhD Contact person: Janace Hart Phone: (415) 353-3939 Web: www.ucsfhealth.org/pedsms

#### Partners Pediatric MS Center at the Massachusetts General Hospital for Children

Yawkey Center for Outpatient Care, Suite 6B 55 Fruit St. Massachusetts General Hospital Boston, MA 02114 Center director: Tanuja Chitnis, MD Contact person: Rose Fratarcangeli Phone: (617) 726-2664 Web: partnersmscenter.org/index.php?id=62&mn=12

#### Mayo Clinic Pediatric MS Center

200 1st St. SW Rochester, MN 55905 Center directors: Nancy L. Kuntz, MD & Moses Rodriguez, MD Contacts: Paula Freitag, MSW Phone: (507) 538-2555 or (507) 284-2111 Web: www.mayoclinic.org/pediatric-center

#### Pediatric MS Center of the Jacobs Neurological Institute

219 Bryan St. Buffalo, NY 14222 Center director: Bianca Weinstock-Guttman, MD Contact person: Mary Karpinksi, MSW Phone: (877) 878-7367 Email: PedMS@thejni.org Web: www.pedms.com

#### National Pediatric MS Center at Stony Brook University Hospital

Department of Neurology, HSC-T12-020 Stony Brook University Stony Brook, NY 11794-8121 Center director: Lauren Krupp, MD Contact person: Maria Milazzo, MS,CPNP Phone: (631) 444-7802 Email: info@pediatricmscenter@stonybrook.edu Web: www.pediatricmscenter.org/

Families now have Society-supported resources for evaluation, diagnosis, medical care and support. A child does not need to have a definite diagnosis of MS to be evaluated at one of these sites. Children with symptoms suggestive of any CNS demyelinating disorder will be seen. A priority of this network is to provide comprehensive care to children with central nervous system demyelinating conditions, regardless of ability to pay. Financial assistance is also available for travel and accommodation according to need.

### II. POST HIGH SCHOOL STUDY AND CAREER OPTIONS

(Gretchen Timmel M.Sc., Carrie Bryant B.A.)

#### A. What's After High School?

#### 1. How Multiple Sclerosis Affects your Post High School Choices

It is important to recognize that you should base your college choices on many factors, many of which will reflect your individual personality. Just as your career ambitions factor into your college choices, your experience with MS should be considered when selecting a school. As is the case with college choice in general, there are many options and combinations of factors that exist for a variety of reasons, including medical condition.

#### 2. Exploring College Options Informally

For some students a work practicum geared to provide exposure to a chosen career or occupation constitutes post college education. Often, more "formal" aspects of learning in the form of English, Science, and Math classes accompany the applied practicum. Job Corps is an example of this type of program as are some technical schools. This "informal" experience can be used as a "springboard" to either Junior or four-year College at a later date.

Some students are not certain what college they want to attend or what to study. Therefore, they select a college; usually a state school, and take several introductory level courses and then decide if they want to apply to that college, matriculate in, or go elsewhere. If the general focus of the area of study is known, this choice can be most productive. If, as a student, you have struggled to complete high school due to effects of MS, this option may be helpful because it continues education at a reduced course load, allows for exploration as to content of subjects, and affords the viewing of what actual college life would be like with respect to medical support, logistics etc. A college within commuting distance is recommended.

#### 3. Junior College

A somewhat more formal approach to starting a college career exists in the form of attending a Junior College. This choice often has the advantage of a flexible course schedule, in that a modified course load is more common than at a four-year college. You would have the "college life" experience, establish the medical contacts that you might

need, and anchor supports, if needed, in the community. After completion of the Junior College requirements you would also, most likely, be granted an Associate's Degree that is an important degree in and of itself, and could also be applied to a four-year curriculum at a four-year school. It may be possible to work part-time while going on to complete four years of college work or stagger the course load to accommodate for fatigue, etc. Thus, balancing education and medical experience may be easier to negotiate.

#### 4. Four-Year College

Many of you will want to go directly to a four-year college. The key "take home" message is that of flexibility. Do not be afraid to ask for accommodations if you need them or discuss with your advisor your wish for a modified course load. You have the right to a tailored college program at a four-year college, as does everyone else; your medical needs may be at the core of the tailoring whereas another student's attention deficit or dyslexia may be at the core of their tailored plan. The goal is to obtain a meaningful education in a setting that supports you as an individual. Carefully consider what you need and ask for it; if you encounter difficulty expressing your needs or being responded to appropriately, ask for help; admissions personnel, counselors, and curriculum support staff (tutors) can be quite helpful. The Dean's office or counseling center may be a good place to start because they will be able to direct you to the appropriate people on campus.

As one could expect, your experience with MS is one important factor to incorporate into your higher education plans. Many other factors can and should be considered as well.

#### 5. Finding the Right Job for You

You may have decided not to attend college and, instead, to look for full-time employment. You may also be planning to attend school and know you will need a parttime job to help support yourself. When searching and applying for a job, it will be important to consider your need for medical accommodations and to think carefully about whether and how to tell potential employers about your medical condition. Unlike school, where the general advice is to inform your professors and administration about your medical condition and needs as soon as possible, there is no right answer as to whether or not you should disclose your medical status to a potential employer. Knowing that you have a diagnosis of MS should not affect an employer's decision to hire you or not to hire you. Nor should it affect their evaluation of your performance on a job. But the reality is that it might.

The best advice is to consider both the kind of job you are interested in and the kind of job that you are best suited for – both because of your personal strengths and weaknesses and in light of your current health. Depending on the job and your own needs, you may decide to disclose more or less about your health and medical history. In general, it may be best to take the approach of telling potential employers what they need to know so that you can do a job well. The Americans with Disabilities Act protects anyone who has a physical impairment that "substantially limits one or more major life activities" from unfair discrimination in hiring and employment and requires employers to provide reasonable accommodations to allow people with disabilities to perform a job. Examples

of reasonable accommodations for a person with MS might be a modified work schedule, use of a dictation system if fine motor difficulties limit the ability to type, or wheelchair access. You are not required under ADA to provide specific details about your medical condition to any employer. You only need to tell them what they need to know in order to justify any accommodations that you might ask for. Keep in mind that employers are not required to make an accommodation if it would impose an "undue hardship" on the operations of the employer's business. This is why it is so important for you to consider whether or not a particular job is right for you in light of your current health.

Your doctor can help you to decide if a job you are interested in is a realistic one given your current health and can provide a letter, if needed, specifying that you have a neurological impairment and the ways in which your condition limits your activities. The "career crossroads" section on the National Multiple Sclerosis Society website, <u>http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/index.aspx</u>, provides some useful tools for deciding whether or not to tell an employer about your MS and how much to disclose. Particularly if you have decided not to attend college and are looking for full-time employment, it may be helpful to pursue vocational counseling. Vocational counseling is available through most high schools and privately and might include a vocational assessment to help you determine the best career path for you.

#### 6. The Armed Forces (Ellen O'Donnell Ph.D.)

It is especially important to consult with your doctor if you are considering a career path where your MS could significantly interfere with your ability to do your job. Examples would include applying to be a firefighter, police officer, or a member of the military. While your medical condition may not be permanently disqualifying, it would definitely be considered a red flag for any of these careers. In applying for any of these kinds of jobs, your health will be a key consideration in the process of applying and these are situations where it is best to be up front from the beginning about your MS. In fact, in the case of the military, if you do not inform your recruiter of your MS and your condition is discovered after you have enlisted, you will most likely be dishonorably discharged for fraudulent enlistment. It is possible to get an official waiver in order to enlist even if you have a diagnosis of MS. The most important thing to do if you are considering the military or a physically demanding career is to consult with your doctor about whether or not it is a realistic path for you. While it may be very difficult to adjust your goals and aspirations, try to be open to other ideas if your doctor advises against applying to the military, police force, etc. Consider other positions within those organizations or similar ones that might be open to you. Examples might be applying to be a 911 operator or fire department dispatcher. Again, a high school guidance counselor or vocational counselor may be able to help you brainstorm ideas for how to pursue your interests in light of your medical condition.

## 7. Gap Year: Ways to Spend a Year After High School Before Enrolling in College (Ellen O'Donnell Ph.D.)

An increasing number of young adults are choosing to delay going to college for a variety of reasons. College is expensive and it may not make sense to attend before discerning

what you want to study and which college experience is going to be the best fit for you. Not everyone has this figured out by the end of high school! You may need to work for a year to save money to cover expenses. If you have MS, you may also have missed out on key courses and experiences in high school because of hospitalizations or absences and decide to take a year, or even more, to "catch up." Whatever the reason that you choose to take a "gap year," it does not mean that you have to feel stuck. One of the most popular ways to spend a gap year is volunteering for an organization that will provide you with a stipend or scholarship money to save for college. These experiences can also look great on a college application. Some of the more popular programs are City Year (www.cityyear.org/) and AmeriCorps (www.americorps.gov/). If it is realistic for you in light of your current health, you might choose to leave home to participate in one of these programs. Just as in applying to college, though, it will be important to consider your own personal needs (including medical status) when deciding where and how to spend a year volunteering. This is a situation where it will probably be helpful to disclose your medical status early in the application process. Organizations like City Year and AmeriCorps have hundreds of programs around the country and can place you close to home if needed.

If you decide that volunteering full-time for a year is not right for you, consider piecing together your own experience for a gap year. You might decide to work part-time, volunteer part-time and/ or take a few courses at a local community college to fill in gaps in your education. You might decide to travel for a year. If you do, consider planning shorter trips that will allow you to return home and rest and check in with your medical team in between traveling. Again, talk to your doctor, parents, or another trusted adult about what kind of experience is going to be right for you. And be sure to leave some time to think about and plan for the next year – whether that means applying to college or choosing to take additional time before deciding on the right path for you.

#### **B.** Accommodations Offered in College

If you have benefited from accommodations made by your high school and would like to find a school that would offer you similar services, you may want you consult the K&W Guide to Colleges for Students with Learning Disabilities or Attention Deficit Disorder. In addition to offering information on specific programs at schools located all around the country, the K&W Guide categorizes the services offered at each school so that you know what type of services and accommodations are offered. The following information is taken directly from the K&W Guide and breaks down the services offered by colleges for students with learning disabilities into three categories: Structured Programs, Coordinated Services and Services. Remember, every college is different so use this information only as a starting point from where you can expand your search. Note that not every college uses the same language so it is best to get a general sense of the resources out there and then decide what type would benefit you most. After deciding on the type of program, investigate individual programs. Once you have this basic information, contact each school to which you are considering and inquire about the specific services that it offers.

You can find the following information on pages 34-35 of the *K*&*W Guide* as well as information on individual programs.

#### 1. Structured Programs (SP)

Colleges with Structured Programs offer the most comprehensive services for students with learning disabilities. The director and/or staff are certified in learning disabilities or related areas. The director is actively involved in the admissions decision and, often, the criteria for admission may be more flexible than general admission requirements. Services are highly structured and students are involved in developing plans to meet their particular learning styles and needs. Often students in Structured Programs sign a contract agreeing to actively participate in the program. There is usually an additional fee for the enhanced services. Students who have participated in a Structured Program or Structured Services in high school such as Learning Disabilities Resource Program, individualized or modified coursework, tutorial assistance, academic monitoring, note-takers, test accommodations, or skill classes might benefit from exploring colleges with Structured Programs.

#### 2. Coordinated Services (CS)

Coordinated Services differ from Structured Programs in that the services are not as comprehensive. These services are provided by at least one certified learning disability specialist. The staff is knowledgeable and trained to provide assistance to students to develop strategies for their individual needs. The director of the program or services may be involved in the admission decision, or be in a position to offer recommendations to the admissions office on the potential success of the applicant, or to assist the students with an appeal if denied admission to the college. Receiving these services generally requires specific documentation of the learning disability- students are encouraged to self-identify prior to entry. Students voluntarily request accommodations of services in the Coordinated Services category, and there may be specific skills courses or remedial classes available or required for students with learning disabilities who are admitted conditionally. High school students who may have enrolled in some modified or remedial courses, utilized test accommodations, required tutorial assistance, but who typically requested services only as needed, might benefit from exploring colleges with Coordinated Services.

#### 3. Services (S)

"Services" is the least comprehensive of the three categories. Colleges offering Services generally are complying with the federal mandate requiring reasonable accommodations to all students with appropriate and current documentation. These colleges routinely require documentation of the disability in order for the students with LD/ADHD to receive accommodations. Staff and faculty actively support the students by providing basic services to meet the needs of the students. Services are requested on a voluntary basis, and there may be some limitations as to what is reasonable and the degree of service available. Sometimes, just the small size of the student body allows for the necessary personal attention to help students with learning disabilities succeed in college. High school students who require minimum accommodations but would find comfort in

knowing: that services are available, who the contact person is, and that this person is sensitive to students with learning disabilities; might benefit from exploring colleges providing Services.

There are many different programs and services available at colleges and universities of all different sizes and in all different places. Once you have thought about where you want to attend college and the ideal size of the school, start investigating the various services offered at each school. Don't be shy about articulating what services would be most beneficial to you and what services have worked well for you in high school. You want your college experience to be positive and successful. The best way to ensure your individual success is to find a program that matches your wants and needs!!

#### III. COLLEGE (Carrie Bryant B.A.)

#### A. Applying for College

#### 1. General Timelines of the College Process

The following checklist is a general guide and overview for the college admissions process, and should be consulted as a general reference. Many schools and guidance counselors advise their students using a different timeline. You may find it helpful to use this timeline as a starting point especially if you want to begin the college process earlier than some of your peers, but do use the resources and advice of the guidance office at your high school in addition to this guide.

#### Sophomore Year (It's NEVER too early to start planning)

- ✓ Start exploring your options and gathering material. This may mean gathering information about the various support services and programs (as discussed above) that would offer you the most helpful accommodations at a given school.
- ✓ Meet with your guidance counselor and case manager about potential schools.
- ✓ Set realistic goals for yourself and ask for the input of your parents, doctors, neurologist, and guidance counselor.
- ✓ Find out what documents are needed for standardized test accommodations and come up with a game plan to make sure you get all the necessary materials in on time.
- ✓ Contact the DSS office or ADA office on campuses to which you may potentially apply and gather information about the services they offer.
- ✓ Try to analyze your learning style, addressing both your strengths and weaknesses. If you understand how you learn best now, you can implement aids during your junior and senior years to hone in on your learning skills.
- ✓ Understand your MS and think objectively about its impact on your life. By being honest with yourself, you can find a postsecondary program that plays to your strengths.

#### Junior Year

- ✓ Consider taking the PSAT and request appropriate testing accommodations. This is a good test run to make sure that all of the proper documentation is in place so that you receive the necessary accommodations on all subsequent standardized tests.
- ✓ Review your course registration for senior year. Students considering four-year college/universities should be enrolled in as many mainstreamed college preparatory courses as possible but remember that nothing is set in stone!! You can always adjust your coursework/course load when necessary. Therefore, don't panic about your course selection. The best thing to do is find a course load that is stimulating, rewarding and challenging to you.

- ✓ Review the services, which have been helpful to you in high school and identify the level of services you think you will need in college. This will help you narrow down potential schools to a less overwhelming number!!
- ✓ Be able to talk about your disability. Although this is difficult for many students, it is important to find several people with whom you are comfortable talking about your medical condition because these people can help you narrow down your college options, discuss an appropriate "game plan", and offer you guidance. These people may include a high school guidance counselor, a favorite teacher, an education consultant, and a team of doctors including a neurologist.
- ✓ Be comfortable asking for support and accommodations. This will probably be hard for you at first, especially if your parents have been instrumental in helping you get the necessary services in high school. Start small-perhaps by approaching a high school guidance counselor yourself- and begin to ask for accommodations yourself. This will help you become more independent and will make the transition to college and the separation from your parents easier when the time comes. One way to do this is to participate in the IEP process and be actively involved in your IEP meeting.
- ✓ Start visiting schools, and try to meet with current students.
- ✓ Register for the necessary tests, standardized or non-standardized, including the ACT and SAT.

#### Senior Year

- ✓ Submit general applications with all supplementary materials including the letter discussed in the College Essay Section if you chose to write one.
- ✓ Submit special applications (if required).
- ✓ Schedule interviews (if appropriate).
- ✓ Disclose your disability to the school you are planning to attend if you wish to receive accommodations once you enroll. In order to receive accommodations, you will have to release your current neuropsychological testing materials and proper documentation of other health-related disabilities (talk to your neurologist about the paper work). Be sure that the documentation includes a description of your disability and the recommended accommodations.
- ✓ Make sure you get copies of your ENTIRE special education file including testing assessments and IEP or 504 summaries to have in your personal files after your high school graduation. Bring a copy to college with you when you arrive for new student orientation!!

\*\*This timeline has been modeled after the timeline found on pages 22-23 of *The K&W* Guide to Colleges for Students with Learning Disabilities or Attention Deficit/Hyperactivity Disorder (ADHD), 9<sup>th</sup> Edition and has been adapted to make it more relevant for students with MS.

#### 2. Narrowing Down Your Options / College Choice

Everyone will have, and should have somewhat different aims and interests in choosing a college, and will therefore be using different criteria to make the college selection that best suits his/her own goals and aspirations. Listed below are some criteria, which may play a role in choosing the college that is right for you. The list is in alphabetical order and NOT in order of criteria importance. However, a star indicates particularly important considerations for students who have MS.

Academic atmosphere

- \*Accessibility (See ADA Section for more on campus accessibility, services offered, transportation and accommodations)
- Admissions criteria (tests, grades, class rank, teacher/personal recommendations, interest)
- Background of enrolled students
- Calendar schedule (quarter, trimester, semester, term breaks, independent study opportunities)
- Cars (Are first year students allowed to have cars, how many students have cars, are there good alternatives to having a personal car)

Career Services

- Cost (tuition, room and board, books, fees, transportation, financial aid)
- Computer friendly (technologically savvy campus/on the cutting edge of computer technology)
- \*Counseling services available on campus or have an affiliation with a group nearby

Course offerings

Dining options (meal plans, off campus food options, dietary restrictions, dining hall accommodations, food choice)

Distance from home

Distribution requirements/CORE curriculum

Diversity (race, religion, national, international, age, sexual orientation)

\*Dormitory requirements and/or facilities (on-off campus, coed, single sex, special interest, size of room, roommates, single room options, suite style living) (see Housing section for more details and things to consider)

Early Decision/Early Action options

- Extra-curricular offerings (sports, entertainment, culture, religious, educational, internships, co-op programs, community service)
- Facilities (buildings, architecture, libraries, student center, classrooms, lecture halls, labs, recreation/athletic offerings, stores, laundry)

Field of study programs

Financial aid availability/Merit Scholarships

\*Geographic location (region, state, distance from home, terrain- is the campus hilly or flat, compact or spread out etc.)

\*Health Services (See Health Service section for more details and things to consider)

Honors system

Independent study options/Undergraduate Independent Research opportunities

Intercollegiate athletics or intramural sports

Inter-disciplinary major/Option to design one's own major

Internship/Externship opportunities

January Plan

- Job opportunities
- Library facilities

Location

Male/Female ratio

Methods of instruction (Lecture style courses, Discussion based courses, all courses taught by full professors, courses taught by teacher's assistants (TA's))

Off-campus experience

On-campus living requirements

Pass/Fail options, and course flexibility

Percentage of seniors going to graduate school

Placement services offered

Pre-professional programs (Pre-law, Pre-medicine, Pre-architecture)

Religious affiliation and facilities

School/town relationship

Selectivity (very difficult, difficult, moderately difficult, open enrollment)

Size of college or university (small, medium, large, very large)

Size of first-year class

Size of teaching classes (Student/Faculty ratio)

\*Specialized Programs (programs and services for students who are learning disabled, physically disabled or have English as a second language) (See Academic section for more information)

Student involvement in school government

\*Transportation options (getting around campus and the surrounding area without a car)

Type of student body: male, female, coed, coordinate

Type of School: liberal arts, education, business, fine arts, vocational college or university, engineering, two or four year

Urban/rural/suburban setting

Weather

\*Indicates an IMPORTANT consideration for students with MS

#### 3. College Admissions Policies

The most common admissions policies students may encounter are explained below. If you have any questions regarding the various procedures and deadlines, talk to your guidance counselor or college advisor. Some schools may have policies that differ slightly from those listed below. Check with the individual schools to which you are applying about their admissions procedures and policies.

#### **Regular Application Deadline and Candidate's Reply Date**

Many colleges have an application deadline by which all applications MUST be received such as January 1, January 15, or February 1. All students are then notified of the college's decisions at a uniform response date, typically on or before April 1<sup>st</sup>. Be sure to check with each college to which you are applying about its application deadline. Since the dates may vary, make sure you know when each application is due. Many schools will not consider applications received after the application deadline. At most colleges, May 1 is the date by which accepted applicants must indicate their intention to enroll.

#### **Early Decision**

Many colleges offer this plan to applicants who have clearly identified their first choice college. Traditionally, the deadline for early decision applications has been November 1 or 15. Colleges then render a decision by mid-December. Some colleges also have a second round of early decision (usually in January or February). These later plans have the advantage of giving students more time to think through their decision.

\*\*If you are accepted under this plan, you are under a strong ethical obligation to attend the college (assuming they can provide a reasonable financial aid package) and to withdraw or forego applications to all other colleges. A disadvantage to early decision is that you are not able to compare the financial aid packages of several schools to which you have been accepted, as you would be able to do under the regular admissions policy since you must withdraw all other applications once you have been accepted under an early decision plan.

Some colleges have recently done away with their early decision option. Be sure to check with each college to which you are applying about their admissions policies and whether the school still has its early decision option.

#### **Early Action**

This program is similar to early decision except that, if admitted, you are NOT ethically obligated to withdraw other applications and you have until May 1<sup>st</sup> to decide whether you want to attend the school or not.

#### **Rolling Admission**

Under this program a college considers your application as soon as all the required credentials have been received. You will be notified of your acceptance or rejection as soon as the admissions decision is made. Colleges that follow this practice may make their admissions decisions continuously over several months. If you are applying to a school that has a rolling admissions policy, it is advisable to get in all of your materials as

soon as you can (without compromising the quality of your application) because once the school has accepted its incoming class, it will stop accepting applications.

#### 4. Writing the College Essay

If you are like most students, you see the college essay as yet another obstacle to overcome on your way to being accepted to the college of your choice. It may seem like a daunting task to write a 500-word essay on a topic of your choice, which must appear insightful, witty and endearing to the college admissions office while also conveying the right message about yourself to your readers. While most students find themselves staring endlessly at a blank Word document pondering what they should write about themselves in 500 words or less, you don't have to be one of them. Try not to think of the college essay as a hurdle that you must jump over in order to be admitted to your dream school. Rather, think of the essay as an opportunity for you to "talk" directly to the college's admissions committee in an attempt to help them see you as the whole person that you are. Since you are not just a composite of impersonal statistics including SAT scores, grades, teacher recommendations and extra-curricular activities, the essay is your chance to complete the package and convey to the committee the essence of who you are. Therefore, try to enjoy the writing process as you find yourself learning more about who you are as a person, and who you see yourself becoming.

**\*\***Although you should highlight your strengths and draw attention to your assets, do not entirely neglect the discrepancies in your transcript, especially if they have resulted from circumstances out of your control (like an MS flare or other medical exacerbations during an exam period).

#### **Purpose of the Essay**

The purpose of the college essay is twofold. It affords the college admissions office the opportunity to assess your communication skills, the clarity of your thought process, and your ability to convey your thoughts in a cohesive piece of writing. In addition, the essay enables the admissions office to learn more about you as a person, beyond what your grades, standardized test scores, extra-curricular activities and teacher recommendations can convey. It allows the committee to hear directly from you, the applicant and a potential member of the school's community. A well-written and well thought out essay can speak volumes about your attitudes, feelings, experiences, personal attributes and creativity. Finally, for the admissions staff, the essay adds another important piece to your application because it distinguishes you as an individual, a person with your own experiences, trials and triumphs all of which separate you from every other applicant.

Except for the interview (which is not required at some institutions and is not even offered at others), the essay is your only chance to share your own personal thoughts, insights and opinions, all of which you have acquired and honed over the past 17 or 18 years. The essay is your time to shine; show the admissions committee the person you are and the person whom you hope to become. Remember, the essay is one of the only parts of your application over which you have complete control; use the opportunity to your advantage and have fun writing your personal statement.

#### **Choosing a Topic**

Choosing a topic for your essay is often not an issue because many colleges and universities will either give you a topic to write about or present several rather specific topics from which you must choose. Other colleges may suggest broad general topics or give you total freedom to write about something that intrigues or concerns you. This is especially true with the Common Application, which is accepted by 346 institutions, and gives you the following six essay topic choices:

- 1. Evaluate a significant experience, achievement, risk you have taken, or ethical dilemma you have faced and its impact on you.
- 2. Discuss some issue of personal, local, national, or international concern and its importance to you.
- 3. Indicate a person who has had a significant influence on you, and describe that influence.
- 4. Describe a character in fiction, a historical figure, or a creative work (as in art, music, science, etc.) that has had an influence on you, and explain that influence.
- 5. A range of academic interests, personal perspectives, and life experiences adds much to the educational mix. Given your personal background, describe an experience that illustrates what you would bring to the diversity in a college community, or an encounter that demonstrated the importance of diversity to you.
- 6. Topic of your choice.

Regardless of whether you must respond to a provided topic or write on a topic of your choosing, here are a few general hints about the most effective way to approach your topic:

- 1. Keep your topic narrow and focused. Be as specific as possible and show your attributes by reflecting on personal experiences rather than simply stating your attributes. Show rather than tell!!
- 2. The best way to show rather than tell is to use the active voice. By giving examples and illustrating your topic through descriptive verbs, you help bring it to life. Your reader should be able to imagine himself/herself in your shoes or should be experiencing your topic as he/she is reading your essay. You want your reader to "feel" the essence of your essay; by experiencing what you have experienced and are now reflecting upon, your reader is more likely to empathize with you and feel a connection to you. This connection will only enhance your chances of being admitted!!
- 3. Be brief. Stay away from flowery prose and pretentious language. Say what you want to say and conclude.
- 4. Pay attention to grammar and spelling. Egregious grammatical errors and spelling mistakes will detract from your message and your voice. Don't distract the reader with unnecessary and avoidable mistakes. PROOFREAD!!! You may want to have a friend or teacher read your essay to look only for grammatical mistakes and typos.
- 5. Your essay must prove a single point or have ONE thesis statement. It is essential that your reader be able to follow your main idea throughout the essay.

- 6. Show the admissions committee who you are rather than what you have done.
- Find your voice. Write in a style that is comfortable to you and true to you. Your writing style can reveal as much to the admissions office as the words themselves. "As an applicant you must not only 'know yourself,' you need to 'be yourself'" (Hayden, 1999: 109).
- 8. Don't try and get into the mind of the admissions committee by writing what you think they want to hear. Write about yourself and something that is important to you. They much prefer reading about something that profoundly concerns you rather than a trite essay about your attempt at saving the world.
- 9. Not surprisingly, the easiest topic to write about is yourself. After all, you know yourself better than anyone else. Since one of the purposes of the essay is for the admissions committee to learn more about you as a person, don't be shy or modest. However, do not exaggerate your accomplishments or write with the intent to impress! Admissions officers have a knack for knowing the truth and they will find out if you have not been truthful in your essay. Exaggerating the truth does not reflect highly upon you in the long run! In a similar vein, remember that little incidents and seemingly insignificant experiences at the time often reveal the most about your character and your outlook.
- 10. Do not be afraid to write about something you think is a little different. A unique topic or approach is often refreshing to a college admissions officer who has been reading applications all day, everyday for weeks on end. Furthermore, an unusual essay is an excellent way to show your creativity, wittiness and sense of humor.

#### How to Address your MS in your Application if you are Comfortable Doing So

Since you have MS, chances are that your high school experience has been vastly different from that of your classmates and peers. You may decide that you want to write about your experience as a high school student living with MS. You may have had to miss several weeks of school, may have had to drop a course or two, may have watched your grades dip during a particularly difficult flare or you may have had to quit an extra-curricular activity unexpectedly and against your wishes. Although you have done your best to maintain a sense of normalcy throughout high school and were probably able to participate fully in most facets of high school life, your experience has been different. If you suffered a particularly difficult flare during your high school tenure and your grades/activities were affected by your health, the college essay may just be the best forum to explain your experiences.

Don't be afraid to draw attention to the semester that your grades dropped or the season that you had to quit your athletic team because you were battling a flare. Sharing your experience (even the hard ones) will help admissions committees better understand the discrepancies in your transcript or your extra-curricular activities sheet. They want to get a sense of who you are; if they understand what you have been through, what you have overcome, and the resolve you have developed at such a young age, they are more likely to see you as the strong, determined individual rather than the student who had a dip in motivation and suffered the consequences. Explain to the committee that MS is unpredictable and, as a result, hard to manage especially when flares occur at the most inconvenient times (think exam weeks, tournament weekends, the days prior to your big musical recital, spring break, etc.) Remember, the committee readers cannot read your mind. Be proud of what you have accomplished and illustrate to them that you have been successful even in the face of adversity.

#### **Supplementary Letter**

If you prefer writing your essay about something completely unrelated to your MS or your ongoing medical issues, you may want to consider writing a supplementary letter to the admissions committee about your experiences living with a chronic illness. This letter will help them better understand what you have been through and what you have learned about yourself in the process. Remember, the committee cannot read your mind. A supplementary letter could be the perfect forum to explain why you had to stop playing your favorite sport unexpectedly or why your grades spiraled down during a particularly difficult flare. Just as it is important to use the active voice in your essay (regardless of the topic you choose) so that your reader will feel/experience your retelling of an experience, it is equally as important to take the initiative and explain why you have discrepancies in your transcript or your extra-curricular activities. When asked if it is okay to send additional material that will support a given application. Nadine K. Maxwell, coordinator of guidance services for Fairfax County Public Schools in Fairfax, VA, answered, "It depends on what you want to send. Most colleges and universities read hundreds or maybe thousands of applications, and they expect to find the information that they need to make an admission decision about you in their specific application form. It is okay to send an additional letter of information to explain something that cannot be explained on the application forms, but other items that students sometimes send are not helpful and may be viewed as trying to distract the admission staff from the actual application" (www.collegeboard.com). If you are still unsure of how you want to address the health component or whether you want to address it at all, talk to your guidance counselor or college advisor about your concerns. Thomas C. Hayden, author of The Insider's Guide to College Admissions, goes as far as to say, "If you feel you have something special to say to a college, something that does not fit on the application or in it, then you SHOULD write a SPECIAL letter to your admissions officer or to the Dean of Admissions" (Hayden, 1999: 129). Just remember that the more information the admissions office has about you, the more informed they will be about you when they are considering you for admission. Don't be ashamed of your MS; rather, be proud of what you have accomplished and consider writing an additional letter to schools about your unique experience.

#### Disclosure

In no way at all should you feel obligated to disclose your medical issues. In fact, "college admissions applications are generally prohibited from asking students if they have a disability; however, whether to disclose the existence of a disability is a personal decision that should be considered carefully" (Kravets and Wax, 2007: 9). For example, if you have overcome significant odds and have shined in the face of adversity, disclosing your MS in your personal statement or in a supplementary letter will highlight your record of accomplishment and could enhance your application. If you do elect to disclose information about your MS, remember that your goal is to highlight your strengths, not your weaknesses. What you have learned about yourself and the perspective you have

gained from having to deal with adversity are two valuable attributes which you will carry with you to college. Admissions officers are always looking for candidates who bring a unique perspective to the community. You have a lot to offer your classmates; don't sell yourself short!

#### For helpful tips on how to write your college essay, see <u>www.collegeboard.com</u>.

#### 5. Admissions Interview

Some schools do not require and do not offer college interviews. For schools that do offer interviews and recommend that their applicants schedule one, the interview will be an opportunity for you to supplement impressions created by your application, and to clarify for yourself information about the school. The best way to prepare for your interview is to READ THE COLLEGE CATALOGUE CAREFULLY before your interview. At your interview, do not ask questions that have been answered in the college catalogue or online. Instead, feel free to ask for more information on anything discussed in the college literature. Don't be afraid to write down questions you have for the admissions officer in advance. Chances are you will be a little nervous in the beginning of the interview. Having some questions in hand when you begin the interview will make you feel more confident and will help you remember everything you want to ask about the school. Questions can demonstrate your depth of interest and knowledge of the school. If you come prepared, the interviewer will appreciate your diligence and your enthusiasm about the school. In addition to familiarizing yourself with the college catalogue, review what you have written on your application and be prepared to expand on any of the points you have made (if you have already submitted your application). Like it or not, people remember first impressions. Therefore, dress neatly!! When preparing for your interview, know that a typical interview lasts between twenty and forty minutes. Try not to be afraid of the interview. While it is normal to be nervous, try and remember that the interview is a conversation, not a confrontation.

The following is a list of potential questions for you to think about before your interview. It is not an exhaustive list and should only be used as a guide to help you think about your interview. Sometimes an admissions officer will ask you a creative question or a question that puzzles you a bit. The most important thing to remember is to be honest with yourself and the interviewer.

- 1. Why do you want to go to college?
- 2. Why are you interested in our school?
- 3. What are your favorite courses of study?
- 4. What do you do in your free time?
- 5. How do you spend your summers?

6. Is there a certain current event you are following? Why is this event important to you?

7. During your high school years what was your single largest setback and how did you deal with it?8. What are some of the most important aspects about yourself that you hope I [interviewer] would bring to the attention of our admissions committee?

9. What fears do you have about college? What are you excited about?

\*\*If questions 7-9 make you think about your diagnosis or a specific aspect of your MS, you may want to consider sharing your experiences with the admissions officer. If you are uncomfortable discussing your medical condition in an interview, you do not have to share anything about your health. However, if you would like to share information about your medical condition, it is important that you think ahead of time about how and in what context you want to address your health issues and/or your diagnosis in your interview. Ask your parents, doctors, and college advisors for advice about how to best approach/address these topics. Since some people are uncomfortable talking about medical issues be sure to discuss your experiences and situation in a way that is factual, non-confrontational and informative about your character/growth. Remember, be yourself in the interview and be honest because interviewers respect honesty.

#### 6. Teacher Recommendations

Most colleges and universities ask for two letters of recommendation from your teachers. Before soliciting your teachers for letters, try to think objectively about how they see you as a student and as a member of your school's community. Talk to your teachers BEFORE you ask them to write on your behalf and start an open dialogue with them. Out of courtesy to your teachers, you should try to give them at LEAST two weeks to write the letter. The more time they have to write the letter, the more thought they can put into writing something that stands out to the admissions committee.

In addition, the better your teachers know you, the more personal and insightful letters they will be able to write. Therefore, it is to your benefit to start a dialogue with a potential reference early and to keep in touch with teachers from your earlier high school years with whom you have fostered a positive relationship. Whenever possible, choose two teachers who know you best and for whom you have performed well. However, if you have developed a close relationship with a teacher and you believe that he/she will write a favorable recommendation even if you struggled in his/her particular class, consider asking him/her to write on your behalf. Some of the best teacher recommendations are not from teachers in whose class you received a straight 'A'. This may be particularly true if you had a difficult time in a class because your MS flared and you were forced to miss a substantial amount of school. A teacher whom you have gotten to know well, who has gotten to know you well and who has been especially supportive, compassionate and empathetic during a difficult flare may be the best person to write on your behalf. He or she can offer insight into your character and your ability to overcome adversity. This teacher can draw attention to your dedication in his/her class exemplified through extra help sessions if you fell behind and can articulate your ability to take the initiative, especially if you tried hard to stay on top of the material while you were out of school. You may not have received the highest grade on your transcript from this teacher (especially if you struggled in the class) but the teacher may be the best person to talk about your personal attributes and academic zeal, which you were able to exemplify in the face of adversity. These qualities speak much greater volumes about you as a person and about your potential to positively impact the college's community than your highest letter grade!

It is also perfectly understandable if you do NOT want your teacher to address your health issues in his/her letter. Be sure to tell your teacher that you do not wish for them to address your health even when accounting for missed school or poor academic performance because they may not have realized that they included confidential or sensitive information especially if they are providing an explanation for your absences or missed assignments.

Finally, if you feel that a coach, mentor, or doctor could offer a unique perspective that a teacher would be unable to provide, consider getting an additional letter of recommendation. This supplementary letter does NOT replace the two required teacher recommendations and should only be used if you feel that your application would be incomplete without the added insight of the given reference. If you are unsure about adding information to your application (like a supplementary letter written by you discussed earlier in the writing the essay section) and about including more than two letters of recommendations, consult your guidance counselor or college advisor for specific advice.

#### **Proper Procedure for Filling out Teacher Recommendation Forms**

- 1. Before approaching your teachers about writing a letter of recommendation on your behalf, FINALIZE the list of colleges to which you will be applying.
- 2. Collect teacher recommendation forms for EACH college to which you are applying. Although most schools require TWO letters of recommendations, some colleges may only require one teacher recommendation, others may not require any while others may require more than two. Since you have finalized your college list, you should know how many recommendations are required for each school. For the schools that do not give you a specific form for your teacher, just complete an envelope for the teacher and he/she will send a letter without a provided form.
- 3. Fill in the required information at the TOP of each teacher recommendation form. If you are using the Common Application form (See section on the Common Application), AFTER you fill in the top section, you may run the form through a copy machine for each college on your list which requires that form (you only need to copy the FRONT side of the form).
- 4. CIRCLE the NAME of the college you want the form to be sent to on the list at the top masthead. Only circle ONE college on each form. The circled name indicates the school you wish the letter to be sent. If a particular college does not require any letters of recommendation, it is still advisable that you have two teachers write letters on your behalf. Your teachers can add a unique perspective and can enhance your application. Remember, the more information that a school has about you, the more informed the admissions committee will be when it has to make an acceptance decision!!
- 5. Provide EACH recommending teacher with an envelope addressed to each college ADMISSIONS OFFICE and a domestic postage first class stamp on the UPPER RIGHT HAND CORNER. The teacher's LAST NAME and your SCHOOL'S ADDRESS should be written on the UPPER LEFT CORNER (return address).

- 6. Note each application deadline for your teacher by CIRCLING the DATE on the FORM or PROVIDING the date on the BACK 'V' FLAP of the envelope. The deadlines vary from school to school so make sure you check the deadlines and indicate the dates for your teachers. \*\*If you are applying Early Decision (ED)/Early Action (EA), write ED or EA and the DEADLINE on the envelope. Be sure to tell your teachers that you are applying early decision or early action to a given school so that they know that the letters must be written in a timely fashion. Be sure to keep your teachers apprised of your admissions status. Indicate to them in December whether the other recommendations should be mailed (if you are deferred or denied).
- 7. Fold the teacher recommendation form in thirds and put it in the corresponding envelope.
- 8. Hand each teacher the COMPLETED FORM inside the UNSEALED envelope for each college and thank them for supporting you in your college search process.
- 9. Check with your teachers TWO (2) WEEKS after the application deadline to ensure your recommendations were sent. Their recommendations do not have to arrive at the deadline; however, YOUR part of the application and your fee/fee waiver MUST be postmarked by the deadline for your application to be considered for admission.

\*Consider preparing your application forms as early as possible and do not leave them to the last minute. As you may have already experienced, MS flares can occur at the most busy and inconvenient times. Therefore, you don't want to jeopardize your application because of an unpredictable medical situation. If, however, you find yourself falling behind and know that you will have a difficult time meeting the application deadlines because you are experiencing a MS flare, don't panic. Talk to you college advisor or your guidance counselor about the best way to handle the situation. In all likelihood, you will need to call the college admissions office and explain to them your situation. Ask your guidance counselor if he/she thinks that a doctor's note to the admissions office explaining the current medical situation would be beneficial. It is best to avoid these stress-inducing situations by planning ahead!!!

#### 7. Common Application

Over 345 colleges and universities accept the Common Application in place of their own individual applications. The Common Application can be a real time saver because you only have to fill it out once before submitting copies of it to all the schools to which you are applying. The schools that are members of the Common Application have agreed that they will not look less favorably upon an applicant who decides to use the Common Application in lieu of the individual institution's applications. Conversely, schools will not look more favorably upon an applicant for choosing to use the individual school's application in lieu of the Common Application. Thus, there is absolutely NO advantage/disadvantage to using the Common Application in terms of admission. If you do choose to use the Common Application, make sure you consult the admission requirements for each school to which you are applying. Many of the institutions that accept the Common Application REQUIRE supplementary materials (additional essays, letters etc.). Your application is INCOMPLETE and will NOT be considered for admission without the school's supplementary materials. For more information about the Common Application and for a downloadable version of the application, visit the Common Application website at <u>www.commonapp.org</u>.

## See the <u>Appendix</u> for a list of Colleges and Universities, which currently accept the Common Application

#### 8. SAT and Standardized Tests

In this section, you will find general information about the SAT, reporting of scores, and test accommodations. To find out more about testing accommodations visit the College Board's website at <u>www.collegeboard.com</u>, talk to your school counselor, college advisor, neurologist and general physician. This guide is intended to provide general information about testing policies and accommodations. For more specific concerns and information, consult with your doctors and school counselors.

Most schools, but not all, require you to submit standardized test scores of some kind. Check with each school to which you are applying about their testing policy. Some may require that you send a quantitative (Math, science) test score, a qualitative (English, history, humanities) test score and a test score of your choice. Others may require the SAT or ACT and additional subject based test scores while others may make submitting any standardized test scores optional. Be sure you know about the testing requirements for each school to which you are submitting an application so that you can plan accordingly and take the necessary tests.

#### For more information on the SAT, visit <u>www.thecollegeboard.com</u>

#### SAT Subject Tests (Formerly called SAT II)

In addition to the general SAT, students may wish to take the SAT Subject Tests, which were formerly known as the SAT II: Subject Tests. These tests differ from the general reasoning SAT in that they are designed to test a student's knowledge in a particular subject. Many colleges allow prospective students to choose which subject tests they wish to take, allowing them to demonstrate their knowledge in their best subjects. Students can take tests in English, history, mathematics, science, and language.

Some colleges specify the Subject Tests they require for admission or placement; others allow applicants to choose which tests to take. Because each school has different testing requirements, make sure you check with each school to which you are applying about the tests they require or recommend that you take.

#### ACT

The ACT is another standardized test option, which many high school students opt to take as part of their college application. Although most colleges and universities accept the ACT often in lieu of the SAT, be sure to check with the schools to which you are applying about the specific tests they prefer. For specific information about the ACT please visit the official website of the ACT at www.act.org. You can find practice test

questions, general information and frequently asked questions about the ACT on this website. The website may be particularly helpful for students who are applying to schools in the mid-west which REQUIRE the ACT.

#### 9. Accommodations and Test Options for Students with Disabilities

#### Knowing your Rights as a Student with a Disability

As a student with MS, you should know your rights and responsibilities under the Americans with Disabilities Act of 1990 as well as the responsibilities that colleges and universities have toward you

The Americans with Disabilities Act protects students of all ages from discrimination. However, several of the conditions that protect students through high school are different from the conditions that apply beyond high school. For example, Section 504 requires that a school district provide a "free appropriate public education" (FAPE) to each student with a disability. Whatever the disability, the school district must identify a student's education needs and provide any regular and all special education/services necessary to meet those needs.

Unlike high schools, colleges and other institutions of higher learning are not required to provide FAPE. Instead, these institutions must provide appropriate academic accommodations to their students to ensure that the student is not discriminated against on the basis of disability. Also note that if a college or university provides housing to non-disabled students, it must provide comparable and accessible housing to students with disabilities at the same cost. For more information on the Americans with Disability Act of 1990, see www.ada.gov.

#### Taking the Tests Necessary for Admission

Because the College Board (Administrators of the PSAT, SAT, SAT Subject Tests, AP Exams) and the ACT have slightly different procedures for obtaining test accommodations, this packet explains the procedures necessary for obtaining accommodations for the tests administered by the College Board and follows with the procedure for acquiring accommodations on the ACT.

#### Accommodations Procedure for the College Board Tests

"Students with a documented disability are permitted to take an SAT I or SAT II (subject tests) test with accommodations appropriate to that disability. Those students need to procure a copy of SAT Services for Students with Disabilities by writing to P.O. Box 6226, Princeton, New Jersey 08541, or by asking their counselor to call for one. In addition to filing the regular application for a particular test, students with disabilities are asked to file a supplementary form that comes with the pamphlet. They also need to ask their school counselor to write on their behalf and request the particular accommodations they need. Those might include a wheelchair-accessible desk, photo-enlarged test book, the opportunity to take necessary medication, a large-block answer sheet, or audio equipment so that they can hear oral instructions" (Hayden, 1999: 87).

#### **Eligibility for Standardized Test Accommodations**

In order to receive testing accommodations from the College Board, students with a documented disability must complete The Student Eligibility Form. For instructions on how to fill out this form properly, please download the *Instructions for Completing the Student Eligibility Form* at:

www.collegeboard.com/prod.../ssd/eligibility\_form\_instructions.pdf

This procedural packet explains how the *Student Eligibility Form* is to be completed. This form MUST be completed in order to receive testing accommodations from the College Board (Administrators of the PSAT, SAT, SAT Subject Tests, Advanced Placement Exams (AP's)). If you are unsure about any of the procedural information, talk to your neurologist and the educational liaison or counselor at your MS Center. In addition, a guidance counselor or college advisor at your high school will be a good resource.

#### What are the College Board's eligibility requirements?

If you have a documented disability you may be eligible for accommodations on College Board tests. If you are seeking accommodations on a College Board test, you must complete a *Student Eligibility Form*.

#### To be eligible, you must:

- 1. Have a disability that necessitates testing accommodations.
- 2. Have documentation on file at your school that supports the need for requested accommodations and meets the *Guidelines for Documentation*.
- 3.Receive and use the requested accommodations, due to the disability, for schoolbased tests.

If any of these requirements are not met, you may still be eligible. You may send your disability documentation with the *Student Eligibility Form* to the College Board for review and determination. The disability documentation must adhere to the *Guidelines for Documentation* on page 1 of the *Instructions*.

#### What disabilities make you eligible for accommodations?

There are many disabilities that impact a student's academic functioning. Here are a few examples:

- Blindness/Vision Impairment
- AD/HD (formerly known as A.D.D. /A.D.H.D.)
- Learning Disabilities
- Deafness/Hearing Impairment
- Certain Medical Conditions
- Certain Physical Disabilities
- Certain Psychiatric Conditions

#### How do I know if I am eligible?

- Do I have a diagnosed disability that makes it difficult for me to learn and take tests in the traditional manner?
- Do I have documentation on file at school showing that I have a disability that requires testing accommodations and addresses each of the information categories in the *Guidelines for Documentation*?
- Have I received accommodations for tests I took in school?

\*\*If the answer is **yes** to these questions, and you wish to take College Board tests, accommodations may be appropriate for you.

#### What types of accommodations are available on College Board tests?

The College Board's procedures for determining appropriate accommodations on its tests provide for considerable flexibility or customization to accommodate your special needs (for greater detail, visit the Accommodations section on the College Board's website, <u>www.collegeboard.com</u>). There are four major categories for testing accommodations:

- Presentation
- Responding
- Timing/scheduling
- Setting

#### Accommodations Provided by the College Board (Administrators of the SAT)

The College Board is responsible for providing the appropriate accommodations on its tests if you have a diagnosed disability. Because each student's need for accommodations is individual, accommodations among students cannot be compared. The laws that protect the rights of students with disabilities ensure that a determination is based on each student's individual needs. Accommodations are to 'level the playing field' so that students with disabilities have the same opportunities as students who do not have a disability to demonstrate on tests what they have learned and how they can use what they have learned.

Appropriate accommodations are identified based on your disability documentation, whether as verified by your school, or as determined by the College Board's review of the documentation. The College Board's process for determining appropriate accommodations provides for considerable flexibility or customization to accommodate each student's special needs. For the four major categories of testing accommodations, the following are examples of accommodations the College Board provides to ensure that eligible students get the accommodations they need:

#### Presentation

- Large print (14 pt; 20 pt)
- Fewer items on each page
- Reader
- Colored paper

- Use of a highlighter
- Sign/orally present instructions
- Visual magnification (magnifier or magnifying machine)
- Auditory amplification
- Audiocassette
- Colored overlays
- Braille
- Braille graphs
- Braille device for written responses
- Plastic covered pages of the test booklet

#### Responding

- Verbal; dictated to scribe
- Tape recorder
- Computer without spell check/grammar/cut & paste features
- Record answers in test booklet
- Large block answer sheet

#### **Timing/Scheduling**

- Frequent breaks
- Extended time
- Multiple day (may/may not include extra time)
- Specified time of day

#### Setting

- Small group setting
- Private room
- Screens to block out distractions
- Special lighting
- Special acoustics
- Adaptive/special furniture/tools
- Alternative test site (with proctor present)
- Preferential seating

\*\* Talk to your neurologist, physician, educational liaison, guidance counselor, or college advisor about other more specific accommodations you may need when taking standardized tests. They will help provide the necessary documentation to the testing agencies. REMEMBER: PLAN EARLY. It can take several weeks for the necessary approval to come through and for you to be on file with the testing agency to receive the necessary accommodations.

#### **Required Documentation**

What disability documentation is needed to support the requested testing accommodations?

The following *Guidelines for Documentation* (also found on page 1 of the *Instructions for Completing the 2008-2009 Student Eligibility Form* - A copy of this form can be found on the College Board's website, <u>www.collegeboard.com</u>) list the information that the College Board considers fundamental in determining eligibility for testing accommodations, and what accommodations appropriately meet a student's individual needs on their tests.

Please note that when the documentation that is part of your high school-generated plan/program (e.g., IEP; 504; formal educational plan) aligns with the College Board's *Guidelines*, and your school verifies this, the College Board accepts what your high school verifies.

Often, plans/programs developed at schools to meet local needs do not align with the College Board *Guidelines*. If this is the case, students have two options: to work with your school officials (guidance counselors, college advisors etc.) to ensure that your disability documentation includes all the information identified in the *Guidelines*, or to submit your disability documentation with the *Student Eligibility Form* and have the College Board review it to determine the appropriate accommodations.

The following are the seven categories that make up the *Guidelines*:

- 1. State the specific disability, as diagnosed.
- 2. **Be current** (In most cases, the evaluation and diagnostic testing should have taken place within 5 years of the request for accommodations. (Since it is important to have up-to-date neuropsychological-testing information, be sure that your documentation current. If you have any questions about the necessary documentation, ask your doctor or neuropsychologist)).
- 3. Provide relevant educational, developmental, and medical history.
- 4. **Describe the comprehensive testing and techniques** used to arrive at the diagnosis (including test results with subtest scores [standard or scaled scores] for all tests).
- 5. **Describe the functional limitations** (i.e., the limitations to learning impacted due to the diagnosed disability).
- 6. **Describe the specific accommodations** being requested on College Board tests.
- 7. Establish the professional credentials of the evaluator (e.g., licensure; certification; area of specialization).

Your neurologist or physician, along with your school guidance counselor or college advisor can help you acquire the necessary documentation and explain to you the proper steps for obtaining this documentation.

# Commonly Asked Questions about Testing after you have been approved for Accommodations (This information can also be found at <u>www.collegeboard.com</u>)

#### What happens after I am approved for accommodations?

Each year in August, your school will receive a roster of all students at your high school who are eligible to receive accommodations on College Board tests. Your school also will receive copies of their *Services for Students with Disabilities (SSD) Eligibility Letters*. The roster and the SSD *Eligibility Letters* will indicate your approved accommodations.

When your school receives the roster, your school will check the roster to ensure that all students who have submitted an *Eligibility Form* are listed. *Eligibility Forms* that have been submitted recently will be listed as "pending." Your school will also receive weekly updated rosters while there is activity from your school.

#### Once I am approved, will I ever have to go through this process again?

As long as you remain within your school's district, you will not have to go through the applications process again as long as your school annually verifies that you continue to receive the accommodations previously approved. Should you transfer to another school district after having been approved for accommodations, you will need to complete another *SSD Student Eligibility Form* verifying that the accommodations received at your previous school will continue or identifying what accommodations will be received at the new school.

# What is the "Renewal Roster"? And what is included in the Annual Roster of Student Eligibility?

A *Renewal Roster* is sent to a school's SSD Coordinator each spring. It lists the school's students and their accommodations. If you are eligible for accommodations, please check with your school to ensure that you are included on the roster.

This year-end roster can be used to modify or update your status (if necessary), for example, if you have graduated or have transferred to another school. This is also a good time to submit requests for any changes in your accommodations if you continue to attend your school.

Your school will receive an *Annual Roster of Student Eligibility* in August each year, just before the new school year begins. It will reflect the information on the *Renewal Roster* namely, if you are approved for testing accommodations, or if your eligibility is pending. Also listed will be your unique SSD Eligibility Code to be used when communicating with the College Board, and your specific accommodations for College Board tests.

# Can I choose to test without accommodations even after receiving College Board approval for accommodations?

Yes. Once the College Board has approved your for testing accommodations you may still choose to test without the accommodations in the future. For the PSAT/NMSQT or AP Exams, which are school-based tests, you can ask the SSD Coordinator to be removed from the testing roster if you are not planning to use your approved accommodations and, instead, are planning to test under standard conditions.

For any SAT test, you may register either by mail or online and not include your SSD code.

If you have taken an SAT previously you may register by telephone by calling the SAT registration line. If you choose to register by telephone for standard testing, you should not give the representative your SSD Code. Be sure to indicate that you will NOT be using your approved accommodations.

# What should I do if I was previously approved for accommodations and I transfer to another school?

If you are transferring within the same school district (e.g. from middle school to high school, from one high school to another in the same school district), you do not need to repeat the eligibility process for accommodations on College Board tests if the receiving high school verifies that you continue to receive the same accommodations on school based testing as in your previous school. The receiving high school can send a note on school letterhead informing the College Board that you have transferred.

If you transfer to a different school district or independent school, you will need to submit a new Student Eligibility Form for testing accommodations on College Board tests.

#### I am graduating this year. Will I continue to receive accommodations after graduation?

On the *Renewal Roster*, the SSD coordinator of your school can verify that you still meet the College Board's *Eligibility Guidelines*. If you do, you will continue to receive accommodations for one year after graduation.

#### Accommodations Procedure for the ACT

Like the SAT, the ACT is committed to serving students with disabilities by providing reasonable accommodations appropriate to the student's disability. ACT has established policies regarding documentation of an applicant's disability and the process for requesting accommodations. For details, see ACT Policy for Documentation to Support Requests for Test Accommodations on the ACT website, at <u>www.ACT.org</u>.

If you currently receive accommodations in school due to a professionally diagnosed and documented disability, you may provide documentation to support a request for one of the following:

- <u>Center Testing #1</u>: Standard Time National Testing with Accommodations
- <u>Center Testing #2</u>: Extended Time National Testing (50% more time). If approved, you will be allowed up to 5 hours total to work on all four multiple-choice tests at your own pace, including breaks between tests. If you are taking the ACT Plus Writing, you will be allowed up to 5 hours and 45 minutes total.
- <u>Special Testing</u>: Testing at school with extended time and alternate formats available—not as part of national or international testing at a test center.

The basic fees for all forms of testing are the same. Read the information about each to determine which **one** to choose and follow that application process carefully. You may find the comparison chart helpful to review the requirements and features of Extended Time National Testing and Special Testing. If you have already been approved for Extended Time National Testing, you may request a test date change or re-register.

The information you provide to ACT about your disability will be treated as confidential and will be used solely to determine your eligibility for accommodations. Details about your test accommodations will be shared only with the testing staff and will not be released to anyone else.

#### **Center Testing #1: Standard Time National Testing with Accommodations**

Request this **only** if you can test at a regularly scheduled national test center under *standard time limits* and use *either* a regular type (10-pt.) or large type (18-pt.) test booklet, but your disability requires accommodations at the center. All scores achieved through National Testing are reported as "National." No details about the accommodations provided are reported.

Examples include assignment to a wheelchair-accessible room, large type test booklet, marking answers in the test booklet, permission for diabetics to eat snacks, etc. Examples of accommodations for students with hearing impairments include: seating near the front of the room to lip-read spoken instructions; a sign language interpreter (*not* a relative) to sign spoken instructions (not test items); a printed copy of Spoken Instructions with visual notification from testing staff of start, time remaining, and stop times.

To request this form of testing *for the first time*, include **all** of the following information in a written request **with** your paper registration folder **postmarked by the registration deadline**:

- Your name, mailing address, and phone number.
- The test date (month and year) and test option (ACT or ACT Plus Writing) you marked in Block M on your registration folder.
- The name, city, state, and 6-digit code for each of the test center choices you marked in Block N on your registration folder.
- Explain your disability and clearly state the accommodations you are requesting with enough detail so we can make arrangements.

- Enclose written documentation from your school describing in detail the accommodations you normally receive in school.
- The name and phone number of a school official familiar with your current test accommodations.

If you are requesting this form of testing *for the first time*, you must **register by paper folder** (*not* on the Web), so that you can provide your current documentation.

The paper folder and your written request for accommodations must be mailed together and be **postmarked by the registration deadline**. If you do not submit your request with your registration folder postmarked by that deadline, the test center will not be required to provide accommodations for you on test day.

If you are re-registering and want to test again with the same previously approved accommodations, you may re-register through your student Web account or by calling (319) 337-1270.

Because advance arrangements are necessary, students requiring accommodations at the test center cannot test as standbys.

If necessary, ACT will contact you or your high school for additional information. If accommodations are approved, ACT will then make arrangements for you. In order to provide the approved accommodations, ACT may not be able to assign you to your preferred test center.

#### Center Testing #2: Extended Time National Testing (50% more time)

If approved, you will be allowed up to five hours total (including breaks between tests) for the multiple-choice tests. If you are taking the ACT Plus Writing, you will be allowed 5 hours and 45 minutes total to complete all five tests (including breaks between tests). Students approved for extended time national testing pace themselves through each test in order to complete all tests within the time allowed.

To apply for this type of testing *for the first time*, you and a school official must complete and sign the *Application for ACT Extended Time National Testing*. The application explains the eligibility criteria, documentation requirements, and how to request a test date change or re-registration after you have been approved.

Your completed *Application for ACT Extended Time National Testing* and required documentation must be returned **with** your paper registration folder **postmarked by the registration deadline**. If you are approved for extended time national testing, you will be notified on your admission ticket and assigned to an extended time room (usually with 10 or fewer examinees). If you are not approved, you will be notified in writing and assigned to a room with standard time limits.

If you are applying for this form of testing *for the first time*, you must **register by paper folder** (*not* on the Web), so that you can provide your current documentation.

#### Special Testing: Extended Time and Alternate Test Formats Available

Special Testing is the appropriate option for students who:

- Normally use **more** than time-and-a-half for tests (or use extra time only on writing tests) in school, *or*
- Require testing over multiple days due to the nature of the disability, or
- Normally use alternate test formats such as Braille, audiocassettes or audio DVDs, a reader, or aides such as a computer or scribe for essays, and/or alternate response modes, *or*
- Are participating in testing at an international test center and cannot use a regular type (10-point) booklet or need any accommodations your test center cannot provide.

If you can test with time-and-a-half and paper formats, you should apply for Center Testing #2 (see above) instead.

NOTE: If ACT approves you for accommodations that can be provided at a national test center, the application will be transferred from Special Testing to National Testing. You will receive notification of the transfer and an admission ticket for the next available national test date at the nearest national test center with a seat and materials available for your test option that can provide the approved accommodations.

To request Special Testing, do **not** complete a registration folder or register on the Web. Instead, you must ask your counselor or qualified school official to complete and submit the *Request for ACT Special Testing* for you.

The *Request for ACT Special Testing* explains the eligibility criteria, documentation requirements, schedules, deadlines, and retest restrictions.

NOTE: ACT Plus Writing is available through Special Testing only during designated two-week testing windows.

#### **ACT Policy for Documentation**

#### **Procedures for Implementation**

Information on ACT's procedures for requesting test accommodations and its review and implementation process is provided to prospective testing applicants in test registration materials. For the ACT (No Writing) and ACT Plus Writing, information is provided on ACT's website (www.actstudent.org) and in the registration booklet. In addition, two brochures are published annually—one for extended time testing on national test dates and the second for other requests for accommodated (special) testing. These brochures explain what options are available, eligibility requirements, guidelines for documentation to be submitted to support the request, other important details about the process, and a printed request form to be completed and submitted to ACT for review.

Requests for accommodations are initially reviewed by trained ACT staff who look for specific information on the request form and in the accompanying documentation. If a

staff member determines that some or all of the documentation is missing or inadequate, ACT will request the additional information. The ACT request form asks the applicant (and the student's parent or guardian, if the student is under 18) to sign a statement authorizing release to ACT of diagnostic information by school officials. On the basis of this release and in an effort to ensure timely processing, ACT frequently contacts the school official who completed the initial request form to request missing information, rather than the applicant.

If the initial reviewer determines that the request appears complete, it is submitted to a staff specialist for the next level of review. The specialist might:

- Approve the request and send it on for processing.
- Submit the request to an expert reviewer with specific training in an appropriate clinical area.
- Determine that documentation is missing or otherwise insufficient.

Expert reviewers might be consulted to review documentation regarding cognitive or learning disabilities, for sight and hearing impairments, and for other physical conditions. If either the ACT specialist or the expert reviewer determines that documentation is lacking, the applicant is notified, usually by mail, and given the opportunity to submit additional documentation. If time does not allow for resolution prior to the requested test date, the applicant's request will be considered for a later test date.

If the only accommodation requested and approved for national testing is extended time, the examinee is notified on the admission ticket, and the test center is notified on a separate roster. If other accommodations are approved for national testing, ACT staff contact the test supervisor at the requested test center to determine whether the center will be able to provide the approved accommodations. If the requested test center is unable to provide all the approved accommodations, another test center (usually the applicant's indicated second choice) is contacted. Once the test center is assigned, a confirmation letter is sent to the test supervisor, identifying the examinee and confirming the reporting time, the reporting location, and the precise accommodations to be provided. The examinee is sent a copy of the confirmation letter.

#### **Documentation Requirements**

#### **Qualified Diagnosticians**

The administration of diagnostic assessments, determination of specific diagnoses, and recommendation of appropriate accommodations must be made by a qualified professional whose credentials are appropriate to the disability. The name, title, and professional credentials (e.g., degrees, areas of specialization, license or certification, employment) must be clearly stated in the documentation. For physical disabilities, a qualified physician must provide documentation.

#### **Currency of Submitted Documentation**

To best assess the current impact of an examinee's disability or functional limitations as they apply to the test-taking process, the documentation must be sufficiently current and appropriate to the particular disabling condition. For the ACT, the disability must have been diagnosed or reconfirmed by a qualified professional within the three academic years prior to the date of the request.

Students applying for accommodations on the ACT who have current reconfirmation of a diagnosis originally made early in the student's educational life and a history of accommodation on the basis of that diagnosis normally need not submit full documentation. Instead, ACT usually accepts the school's verification of appropriate documentation on file at the school. However, ACT reserves the right to request copies of documentation from the school to verify compliance. In cases where the initial diagnosis was made or the school accommodations plan was first effective less than 3 years prior to the request for accommodations, full documentation must be submitted with the request.

In addition to the diagnostic documentation, applicants are asked to submit information regarding whether accommodations have previously been provided in an academic setting or on other standardized tests due to the disability. For the ACT, documentation of prior accommodations often takes the form of a current Individual Education Plan (IEP) or Section 504 Plan. If the applicant has not had prior accommodations, full documentation must be submitted with the request.

#### Substantiation of Diagnosis

Documentation must provide a comprehensive evaluation with objective evidence of a substantial functional limitation. The information needed for each general category of disability is provided below.

- *Learning Disabilities:* The applicant must provide the results of age-appropriate diagnostic testing performed by a qualified professional. Documentation, including all standard scores and percentiles (including subtests) which are reliable, valid, and standardized measures, must address the following:
  - 1. Description of the presenting problem(s) and its (their) developmental history, including relevant educational and medical history.
  - 2. Neuropsychological or psychoeducational evaluation which includes results of an aptitude assessment using a complete and comprehensive battery.
  - 3. Results of a complete achievement battery.
  - 4. Results of an assessment of information processing.
  - 5. Other appropriate assessments for consideration of differential diagnosis from co-existing neurological or psychiatric disorders.
  - 6. Specific diagnosis and evidence that alternative explanations were ruled out.
  - 7. Description of the functional limitations supported by the test results and a rationale for the recommended accommodations specific to those functional limitations.

- *Attention Deficit/Hyperactivity Disorder:* ACT has adopted documentation guidelines consistent with those developed by the ADHD Consortium (see Appendix). The applicant must provide diagnostic results from an evaluation by a qualified professional. Documentation must address the following:
  - 1. Evidence of early impairment which, by definition in the *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed.) (DSM-IV), is first exhibited in childhood and manifests itself in more than one setting
  - 2. Evidence of current impairment including:
    - a. Statement of presenting problem
    - b. Diagnostic interview
  - 3. A ruling out of alternative diagnoses and explanations.
  - 4. Relevant testing using reliable, valid, standardized, and age-appropriate assessments.
  - 5. Number of applicable DSM-IV criteria and description of how they impair the individual.
  - 6. Specific diagnosis.
  - 7. Interpretive summary including a discussion of how the effects of ADHD are mediated by the recommended accommodation(s).
- *Visual Impairment:* The applicant must provide diagnostic results from a complete ocular examination performed by an optometrist or ophthalmologist. Documentation must address the following:
  - 1. Chief complaint and history of impairment.
  - 2. Test results, including visual acuity, complete ocular motility exam (versions, tropias, phorias, stereopsis), slit lamp exam, visual field, pupil exam, optic nerve, and retina.
  - 3. Specific ocular diagnosis.
  - 4. Description of functional limitation and supporting evidence that the abnormality impedes functioning in settings such as standardized testing.
  - 5. Discussion of the extent to which the limitation has been addressed through glasses, contact lenses, or other treatment or devices.
  - 6. Specific recommendation for accommodation(s) and accompanying rationale.
- *Hearing Impairment:* The applicant must provide diagnostic results from a full hearing test performed by a qualified professional. Documentation must also address the following:
  - 1. Relevant medical history, including date of hearing loss.
  - 2. Related educational development, especially effect on reading ability and processing speed.
  - 3. Specific diagnosis.
  - 4. Description of functional limitation (with and without any hearing aids or other assistive devices or treatments).
  - 5. Specific recommendation for accommodation(s) and accompanying rationale.

• *Other Physical Disorders:* The applicant must provide diagnostic results from an appropriate medical examination that documents the relevant medical history, provides a description of functional limitation, and states a specific recommendation for accommodation(s) and accompanying rationale.

Each request for accommodation is evaluated on a case-by-case basis using the information described above. If a particular element of documentation is not provided, the diagnostician must explain why it is not included in the submission.

#### **Recommendation for Accommodations**

Requests for accommodations must specifically address the functional limitation of the disability. The diagnostic report must include specific recommendations for accommodations as well as an explanation of why each accommodation is recommended and how it alleviates the impact of the impairment when taking a standardized test. The diagnostic information provided must be age-appropriate for the population of examinees taking the test. The evaluator(s) must describe the impact, if any, that the diagnosed disability has on a specific major life activity as well as the degree of significance of this impact on the individual in a testing situation. The evaluator must support recommendations consistent with specific functional limitations as determined by objective data substantiating a history of functional impairment, appropriate test results, clinical observations, and a comprehensive diagnostic interview.

It is important to recognize that accommodation needs can change over time and are not always identified through the initial diagnostic process. Conversely, a prior history of accommodation does not, in and of itself, and without supporting documentation of a current need, warrant the provision of a similar accommodation. If no prior accommodations have been provided, the evaluator(s) and/or qualified school officials must include a detailed explanation of why no accommodations were used in the past and why accommodations are needed at this time.

If recommended accommodations are not clearly identified or supported in a diagnostic report, ACT will seek clarification and, if necessary, more information. ACT will make the final determination regarding appropriate and reasonable testing accommodations on the ACT (No Writing) or ACT Plus Writing for individuals with documented disabilities.

#### **Confidentiality**

All documentation submitted to ACT is kept confidential, and is used solely to determine the applicant's eligibility for accommodations. Test supervisors are also instructed to treat as confidential all information they receive relative to the examinee's disability and accommodations. ACT Score Reports do not include any specifics about the disability or accommodations provided.

Please visit <u>www.ACT.org</u> for more information on testing accommodations and procedures.

#### **10.** College Visits

Once you have narrowed down your college list and feel good about the schools to which you will be applying, you should definitely consider visiting the schools BEFORE you send in your application. If it is unrealistic to visit all of the schools on your list, try to make arrangements to see the schools on the top of your list. Visiting campuses will enable you to ask questions of real people (professors as well as currently enrolled students) so that you don't have to rely on websites, databases and directories for all of your information. Furthermore, you may find it helpful to set up a meeting with the disability support staff at each school to discuss your medical concerns and possible accommodations. It is a good idea to meet the people with whom you will be working once you arrive as an enrolled student to make sure that you would feel comfortable working with them. Meeting the ADA coordinator, the staff of the learning center, the dean of students, and other professors who teach a subject of particular interest to you, will allow you to interact with the people who may become your closest academic allies. Since it is not always possible to visit your top choice schools before you apply, consider calling members of the faculty, the ADA coordinator, member of the tutoring staff, and the dean of students to see how responsive they are and whether you feel that you could comfortably work with them.

\*\*When you arrive on campus for your visit, drive around the boundaries of the school and make note of the landscape. Are the buildings close together? Is the campus spread out? Is there an academic quad where most of the academic buildings are located? Are the dorms spread out or in a concentrated area? Are the dorms located near the academic quad? Where are the dining halls located? Is the campus hilly? Noting where places are located is essential especially since you have MS. If fatigue and mobility are issues for you, pay close attention to the proximity of the buildings, which you anticipate using the most. If the campus is extremely spread out and is situated in a particularly hilly place, you may want to think about how that will affect your fatigue. You want to be happy at the school you enroll in; if you would feel limited because of mobility issues and would have a difficult time trekking up a large hill everyday, a mountainous terrain may not be the best place for you. You don't want to always be thinking about conserving energy; if the dorms are far from the academic buildings and dining facilities, this school may not be ideal for you either.

#### **Campus Tour**

Once you have done a general sweep of the college and have surveyed the layout, plan to take a campus tour. The tour guide is usually a current student and can often offer keen insight into student life and academics from a student perspective. If mobility and fatigue are concerns for you, consider telling the admissions office about these limitations and they will likely provide you with an individual tour guide.

#### Things to Ask your Tour Guide

Use the tour as an opportunity to ask your guide about dorm living including the various living options (single sex halls, coed halls, suite style living, singles, doubles, roommates etc.), whether all students are allowed to have refrigerators (important especially if you are on a medication that requires refrigeration), whether the dorms are air-conditioned (if

heat exacerbates your symptoms). Ask him or her about the social life, whether there are sororities and fraternities, whether there are alternatives to large parties, whether drinking is a problem/is prevalent on campus, ask what he/she tends to do on a typical Friday night. Find out whether most students have cars and whether the majority of the campus clears out on weekends. If you will not have a car on campus, ask if there are rides/bus services into town or the city. Ask about the academics, whether the professors are approachable, are willing to offer help outside of class, whether their office doors tend to be open and inviting, whether the work is overwhelming. Ask how much time your tour guide spends on homework each night. Ask how he or she got involved in campus activities. Ask about the campus activities and clubs including sports teams and intramural sports. Finally, ask your guide why he/she chose the school and what he/she likes most and least about the school. Knowing some of the criticisms will help you decide whether the same things will bother you and to what extent they would bother you. The more information you can get from your guide, the better you will know the school. After all, familiarizing yourself with the school is the main objective of the tour and campus visit. You may also consider setting up a meeting with the ADA coordinator and a member of the tutoring services/learning center staff to discuss what services they offer and how you could benefit from them the most.

#### Meet with the ADA Coordinator and/or Learning Center

\*\* Since you may be working closely with the ADA coordinator and the learning center staff, make sure you set up appointments to meet with these people BEFORE you arrive on campus for your visit and tour. When you meet with the ADA coordinator or the Director of Support Services (DSS), be prepared to answer questions about when you were diagnosed, what accommodations you have received in high school, and how your MS has affected your ability to learn. Be honest about your MS and explain to the ADA coordinator exactly what has helped you in high school. If you can provide the ADA coordinator with specific accommodations that have helped you in high school, the coordinator will be better able to inform you whether those same accommodations could be offered in college. Use this opportunity to ask the ADA coordinator about the admission requirements, about additional fees for special programs or services including tutoring, about remedial or developmental courses offered at the school, about the coordinator's experience working with students with MS, about his/her willingness to learn more about MS, and about the number of students receiving services. Also find out how long the learning center, tutoring services and other accommodating programs have existed on the campus. Finally, make sure that you will be able to access services throughout your college tenure as long as the necessary documentation is complete and up-to-date.

Remember that your conversation with the ADA coordinator or learning center staff will be confidential unless you give permission for the coordinator or DSS to speak with others regarding your health condition. Knowing that the content of the meeting will remain confidential should make you feel more comfortable about discussing your medical history. You may feel more comfortable having a parent or other supportive friend join you in this meeting. You can also request that the ADA coordinator or learning support staff discuss your concerns and their services with your high school guidance counselor so that everyone is in sync regarding your needs and available accommodations.

# **B.** Pre-Arrival Information

#### 1. Connect with the ADA Coordinator or Learning Center Staff

One of the biggest differences between high school and college is the level of responsibility that the student must take regarding his/her MS and the accommodations he/she may wish to have in college. In high school, accommodations are often automatically put in place by the school district after it has identified a student as having a disability. In post-secondary education, it is the responsibility of the student to come forward with a disability and request accommodations. Students must take the lead, and for some students this is a hard adjustment to make. At many colleges and universities, the student must contact the ADA coordinator or learning center for professor notification each semester. The ADA coordinator may ask the student whether he/she would like the ADA office to contact the individual's professors about his/her accommodations or if he/she wants to initiate that conversation with professors instead. Once the ADA office has helped the student make the initial contact with the student's professors, it is often up to the student to work out the specific details of their exams and other assignments with their professors. When things get confusing or overwhelming, the ADA coordinator is there to offer help and support but students must be involved with their own accommodations.

The summer before you arrive on campus, you should consider contacting the ADA coordinator or other academic support staff at your college or university to discuss appropriate accommodations. As mentioned above, the responsibility falls heavily on the student to make sure that he/she receives the necessary accommodations. Don't think that accommodations DON'T exist!! They DO; you just need to take the initiative and seek out the support services yourself.

Because you may feel a heightened, yet completely normal, sense of anxiety over your first few weeks on campus as you adjust to being away from home (especially if you have not been away before and are now gone for the first time), the new routines, course work, extra-curricular activities, etc., you should definitely try to make contact with the ADA coordinator BEFORE you arrive on campus for new student orientation. If you do not receive information in the mail from the ADA office about the general services it offers and the procedures it requires its students to complete before they are eligible for accommodations, contact the office at least two weeks prior to the first day of new student orientation. To find the ADA office's contact information, search the college's website for the ADA office/learning support staff or call the college's main switchboard and ask to be transferred to the ADA coordinator. Once you have obtained the office's contact information, you may initially feel more comfortable emailing the coordinator. However, you may be able to get the ball rolling more quickly if you call the coordinator directly.

Regardless of whether you choose to email or call the ADA coordinator, DON'T be shy about disclosing your medical condition to the ADA office and be SPECIFIC as to what accommodations you are looking to receive. The more specific you are, the more helpful the office can be in providing you with the most comprehensive services to best suit your needs. There are confidentiality laws that the ADA office must adhere to when you disclose your medical condition to the coordinator and you are protected by law. Therefore, if you prefer to keep your medical issues private, you can be assured that the ADA coordinator or learning support staff member will NOT disclose your condition to any outside party without your consent.

# Role of the ADA Office/ADA Committee, ADA Coordinator, Faculty, and Student Requesting Accommodations

Although the role of the ADA office/ADA Committee, the ADA coordinator and student requesting accommodations differs from college to college, the following is a guide to help you navigate what role each of the various agencies plays to ensure the success of the student. Remember that the names of the offices and committees that provide services and accommodations to their students vary from campus to campus. If you find that there is not an "ADA office", "ADA coordinator" or "ADA Committee" at your school, they are probably under a different name. Contact the Dean of Students or Dean of Freshman if you are having trouble finding the proper office, committee and person to contact. These people will be able to tell you the proper names of the offices and committees at your specific school and will be able to connect you directly with the person in charge of handling ADA related issues.

#### ADA Office and Committee

At many schools there is an ADA office comprised of a committee of faculty and staff members that certifies eligibility for accommodation under the American with Disabilities Act of 1990 (ADA) for students presenting documented evidence of qualifying disabilities, and reviews and acts upon all student requests for reasonable accommodations. The ADA Committee also facilitates the implementation of accommodations that have been deemed reasonable and appropriate for the student requesting the accommodations. Furthermore, the ADA Committee serves as a resource to students and faculty on issues of accommodation. This is the committee that students are often told to consult in the unlikely event that their professors are not complying with or sensitive to the accommodations to which the student is entitled by law.

#### **ADA Coordinator**

Depending on your institution, the ADA coordinator may play a large, personal role in helping you acquire necessary accommodations or may help you navigate your way through various offices, each of which is responsible for an individual accommodation, if you are requesting multiple accommodations. The ADA Coordinator is often one of the student's greatest allies and can provide emotional and academic support to students as they settle into their daily routines each semester. If the ADA coordinator plays a comprehensive role on campus, expect him or her to have the following responsibilities: coordinates and administers ADA-related note-taking, reader, scribe, and interpreter services and ADA equipment services (e.g. textbooks on tape, Brail conversion software,

etc.). On many campuses, the ADA Coordinator also serves as a liaison between students, faculty, staff, Facilities Management, Residential Life, Health Services, Counseling Office, Career Services and Media Services (to name a few). Ask the ADA coordinator at your school about his/her role on campus and what he/she can provide to you.

#### **Role of the Faculty**

The ADA essentially REQUIRES that ALL students are provided with equal access to the essential course content, and that the impact of a documented disability on the student's learning and academic performance is mitigated without compromising course or program integrity. Accommodations may involve modifications of the ways in which material is presented or learning is evaluated; however, accommodations that compromise the essential integrity of a course are NOT required of faculty members.

Professors are encouraged to communicate with the ADA coordinator concerning any accommodation request. The ADA coordinator is allowed to communicate with faculty within the limitations of privacy laws. The faculty can in no way challenge the fact, nature, and/or extent of a disability that has been certified by the ADA Committee. Furthermore, the faculty is not authorized to review the underlying documentation of a disability without WRITTEN CONSENT of the student. As a student, you are in complete control over the extent to which you disclose your medical issues to your professors. Once you have been granted accommodations, your professors must adhere to and provide you with the approved accommodations. You are under NO obligation to disclose medical information to your professors if you do not feel comfortable doing so. If you feel that your professors are treating you differently, not providing you with accommodations to which you are ENTITLED or are making you feel uncomfortable in their class, contact the ADA coordinator or Dean of Students to see how best to handle the situation. You may be asked to submit a written complaint to the Dean of Faculty or another governing body. Your ADA coordinator can provide you with the proper procedure concerning filing a complaint and will likely help you write the letter if you wish.

Faculty members have the right to receive a status report of a student accommodation request and clarification of recommended accommodations. If your professor approaches you for clarification of your requested accommodations and you do not feel comfortable discussing the matter directly with him/her, politely request that your professor speak to the ADA coordinator. The ADA coordinator or learning support staff will gladly clarify any uncertainty he/she may have regarding the services he/she must provide to you.

You will find that some faculty members are more supportive and responsive than others. Don't be discouraged if a professor asks for clarification regarding your accommodations. He/she is NOT questioning the validity of your disability or your personal integrity. Rather, he/she is finding out how best to help you. Try not to get defensive if your professor asks for clarification. Look at this as a learning opportunity. You could be providing your professor with helpful information regarding the latest accommodations, which will certainly help students in the future!!

Your professors may suggest alternative accommodations they think would be more appropriate in light of the nature of their course. Alternative accommodations MUST be as appropriate and as effective in mitigating the effects of a disability as those initially recommended by the ADA Committee.

\*\*Accommodations normally should be implemented as soon as reasonably possible after the faculty member has received the accommodation recommendation in writing from the ADA coordinator. Undue delays in the implementation of accommodations may be construed as a form of discrimination.

#### **Role of the Student**

It can not be stressed enough that you, as the student, are responsible for requesting your own accommodations, contacting the ADA service offices, and providing the necessary medical documentation to the ADA office so that you can receive the requested accommodations. Colleges and universities neither impose accommodations on their students nor pre-empt their responsibilities, as legal and social adults, to identify their individual special needs and to ensure that these needs are being met. If you do not speak up, you will not receive the accommodations that you wish to receive and are entitled to receive!! It is the student's responsibility to initiate the certification process for receiving accommodations by contacting his/her college's ADA coordinator and following the necessary procedures as laid out by each college.

\*\*It is imperative that you find out the process you need to complete in order to receive accommodations BEFORE you arrive on campus. Your school may require that your documentation and neuropsychological testing be up-to-date. Make sure that if your college requires you to have recent testing results on file, you check to see when your last evaluation took place. If you notice that you have not had an evaluation done within the designated period of time, contact the ADA Office IMMEDIATELY and ask whether you have to undergo another, more recent, set of tests. Explain to the coordinator that you have an ongoing chronic illness. It may be enough that the ADA Committee sees your most recent test results (even if they have 'expired' under the guidelines of your school's policy), and subsequent recommendation for accommodations if this information is accompanied by a note from your neurologist detailing your condition and explaining that further testing is unnecessary at this time (since your condition is chronic). Knowing exactly what you need in hand when you arrive on campus will save you hours of unnecessary angst!!

You must also remember that it may take the ADA Committee several weeks to process your request for accommodations, especially if you are attending a large school. If you want to be sure that your accommodations are in place during your first week of classes, you MUST contact the ADA office and coordinator before you arrive for orientation. However, if you forget to submit all the necessary forms before you get to campus, DON'T panic. The first few weeks of classes consist of an overview of the course, ironing out logistical matters and learning new material. You don't need to worry about having your testing accommodations in place when you have your first class meeting. Look at the syllabus to evaluate when your first major assignments are due and when your first test is scheduled. You should have completed the ADA certification for accommodations before your first scheduled test to ensure that you receive accommodations on that test. The sooner you get the information to the ADA office, the sooner your accommodations will be put in place!!

#### Documentation

Again, remember that this information is general. Check with your college about the specific documentation you need to provide so that there are no surprises when you arrive on campus as a new student. Examples of suitable documentation include recent medical notes from your neurologist and neuropsychological testing reports that may have been done at a hospital or at your school. A letter from your physical therapist or rehabilitation specialists may also be helpful.

Talk to your neurologist as well about how he/she can be helpful as you transition to college life. Having a letter from your doctor/neurologist on file at school detailing your diagnosis, treatment protocol, medications and recommended accommodations (including housing accommodations, course load adjustments, the need for air-conditioning and a refrigerator etc.) is an EXTREMELY good idea even if your college does not require it. Give copies to the ADA coordinator, Health Center, Counseling Services and keep one in a safe place for yourself; these offices can then share necessary information with other agencies on campus if the need arises. Remember, you must give your consent to have your medical information released. Thus, you are ALWAYS in control as to who knows about your condition and who does not. A general letter on file from your neurologist explaining your medical condition, your limitations, necessary accommodations, and your current treatment protocol could come in handy if you ever need to be seen by the school doctor or another doctor near your college. You would be spared from having to explain everything yourself. Plus, doctors like "doctor-speak". A letter from your neurologist could make you feel less anxious about being treated by someone else and would provide all the information necessary to contact your 'go to' neurologist in a timely fashion.

#### Generally, documentation verifying a disability MUST:

- 1. Be prepared by an objective professional qualified in the diagnoses of such conditions.
- 2. Include information regarding the testing procedures followed, the instruments used to assess the disability, the test results, and a written interpretation of these results as they pertain to an educational environment and/or participation in the college's programs.
- 3. Reflect the individual's present level of functioning in the areas related to the particular accommodations being sought.
- 4. Be appropriately recent. NOTE: if your condition is chronic, you may only be required to submit your most recent testing results along with a letter from your neurologist verifying the chronic nature of your condition. This way, you would not have to undergo the same tests repeatedly.

When a student seeks accommodation for a learning disability, the student must provide professional testing and evaluation results, which reflect the student's present level of processing information and present achievement level.

Documentation Verifying the Learning Disability MUST:

- 1. Be prepared by an objective professional qualified to diagnose a learning disability, including but not limited to a licensed physician, learning disability specialist, or psychologist.
- 2. Include the testing procedures followed, the instruments used to assess the disability, the test results, and a written interpretation of the test results by the professional.
- 3. Reflect the individual's present level of functioning in the achievement areas of reading comprehension, reading rate, written expression, writing mechanics and vocabulary, writing, grammar, and spelling.
- 4. Be appropriately recent.

#### Services

The following are examples of accommodations, which, in appropriate cases, would preserve essential academic program requirements while minimizing the effect of a certified disability upon a student's performance.

- 1. Classroom Access: The school is responsible for ensuring that programs and activities are accessible. If a classroom is inaccessible to a student and prohibits him/her from attending class, the college is responsible for relocating the class. Problems with access include: classes located in buildings without ramps or elevators; classes held in locations temporarily inaccessible due to construction; classes held in locations too distant for the student to reach class in the time available; and classes held in locations with inadequate acoustics or lighting, or where other aspects of the physical environment would deny substantial access to students with a qualifying disability.
- 2. Interpreter Services: **\*\***Documentation of need for such services (American Sign Language, Signed English, or Oral Interpreting services) must be made well in advance of the beginning of classes. Some schools require a month or more advanced notice. If you require interpreter services, be sure to contact the ADA coordinator as soon as possible!!
- 3. Note Taker/Scribe Services: Note-takers from among other students enrolled in a course may be asked to assist students with motor, hearing, processing or other disabilities.
- 4. Reader Services: Reader services will be provided for students with reading, visual, visual processing or other disabilities when the proper documentation supports this service. Textbooks on tape, when available, will also be supplied to eligible students.
- 5. Tutoring Services: Many colleges do NOT provide individual tutorial assistance tailored to the special needs of students with learning disabilities or other disabilities. However, you should ask the ADA coordinator or the Learning

Center about tutoring services available through the school or from an outside agency. Some schools provide peer tutors for the benefit of all students, without discrimination on the basis of disability, for no extra cost. Be sure to ask about additional costs for tutoring services whether through your school or an outside consultant so that you are not surprised when you meet with the tutor.

6. Time Extensions: Accommodations may include time extensions on timed exams and/or other assignments. If you are seeking an extension on a long-term assignment (e.g. term paper, or final exam) because you feel it is within your accommodation rights, contact the ADA office and your professor well before the due date of the given assignment to make special arrangements.

#### 2. Housing Issues

You MUST contact the Housing Coordinator or person in charge of making residential decisions as soon as possible if you are seeking special housing accommodations. Many residential life decisions are made well in advance of your arrival on campus. In fact, it is not a bad idea to contact the Housing Coordinator immediately after you have decided to matriculate at a given institution during the spring of your senior year in high school. Most residential life decisions are made gradually over the summer and you want to be sure that you articulate your requests before the Housing Coordinator has assigned you a roommate, and a dorm so that your school can be as accommodating as possible. Remember, if you want your school to be as helpful as possible, you should be as helpful to them as possible. If you contact the Housing Coordinator before he/she has started to make housing assignments and can articulate EXACTLY what accommodations you would find helpful, he/she is much more likely to welcome your requests.

At many colleges and universities, the ADA Committee works in collaboration with the residential life personnel to arrange reasonable accommodations for students with special needs living in the residential halls. While the ADA office and residential life personnel are willing to make all the necessary accommodations for their students, it is vital that you contact both the ADA Coordinator and Housing Coordinator about your specific housing requests as soon as you know the exact nature of the accommodations you will be requesting.

#### 3. Pre-arrival Timeline: Preparing Yourself to Go

- a. Once you are accepted and have decided to enroll (three months before matriculating):
  - Contact the ADA coordinator at your school and start an open dialogue about the accommodations you will be requesting when you arrive on campus.
  - Obtain a letter from your neurologist stating your diagnosis and outlining any accommodations you may need.
  - Have a physical exam done and ask for a copy of all your immunizations. Be sure to keep a record of your immunizations for yourself and be prepared to submit one to your school's health services office (most

schools require all entering students to have a physical exam and be up to date on immunizations before they start)

- Contact your Housing Coordinator and request any accommodations you may need in your dorm. Things to consider: getting a refrigerator in your dorm room, delivery of your medications, air-conditioning in your room, a room on the entry level, a single room, a room near a bathroom, etc.
- Contact the Student Health Center and create a plan for what you will do in the case of a relapse. Find out who should be your main contact person and who else should be involved (i.e. dean of students, advisor etc.).
- Create a plan for administering your medication. Ask the Health Center if the staff is familiar with your medications and whether they would help with injections. Provide them with information about the medication, which you can obtain from your doctor.
- b. Academics (One month before matriculating):
  - Find out when you can register for classes.
  - Discuss an appropriate course load with your neurologist, parents, student advisor, etc. before you register for classes. Map out a tentative long-term academic plan keeping in mind all requirements you must fulfill before graduation.
- c. Other Helpful Information (One month before matriculating):
  - Read up on your school's public safety/security office and inquire about the transportation services they offer.
  - Contact your roommate (if you are assigned one) and think about how you want to address your health issues with him/her. It is perfectly normal to wait to discuss your health issues until you know your roommate better and feel comfortable talking about personal issues. However, you should think about how you would answer questions relating to your symptoms or medication in case your roommate asks. Having a "prepared" response can ease the anxiety about telling him or her. Furthermore, you and your roommate are probably feeling normal anxiety about starting a new phase in your lives; talking about the fears and excitement can help alleviate the anticipatory angst you are feeling. You are not alone!!
- d. Two weeks before matriculating
  - If you anticipate having your medications sent to your school address, contact your mail order pharmacy with your new address. Ask the mail order pharmacy if they anticipate any delivery problems. Remember that some delivery companies will not deliver to a P.O. Box and will ONLY deliver to a street address. Find out what the street address is for the mail center on campus and provide the mail order pharmacy with BOTH your P.O. Box number and the correct street address.

EXAMPLE: Joe Smith College Name P.O. Box 3456 15 College St. City, State zip code

You may decide to have your medications sent directly to the school's health center. This way, the health center can refrigerate your medications for you until you pick them up and you would not have to worry about them sitting in your student mailbox for a long time.

- Check that you have all the medical supplies you need for the first month of school (including Sharps container, alcohol wipes, auto-inject if you use one, etc.).
- Contact the ADA Office or the school's learning support service office to make sure that your academic accommodations are in place. There will be an opportunity to do this when you arrive on campus but you may feel less anxious knowing that everything is properly in order before you arrive.

# C. Upon Arrival on Campus

#### 1. 504 and IEP Programs to College

One of the first things to do when registering for classes is to meet with learning support staff regarding the transfer of your 504-accommodation plan to your new college setting. It is important to meet with an academic advisor to review the accommodations, perhaps adding ones tailored specifically to the college setting, such as arrangement of classes in a confined area to minimize physical fatigue or adjustments to your testing accommodations. Next, determine how the 504 accommodations will be conveyed to professors. It will be important to establish a "working relationship" with your academic advisor so that communication is facilitated with the professors throughout the year. If you are entering college without a 504 plan, establishing an initial meeting with the administrator, reviewing medial documents and prior evaluations could lead to the writing of a 504 accommodations plan. Remember that the plan is only as good as it serves you so make sure that it meets all of your needs.

If you are entering college with a high school IEP in place, the accommodations listed on the IEP will need to be transferred to a 504-accommodation plan. Follow through with the above process and list your accommodations. It may be necessary to obtain some updated testing to continue to support your need for accommodations. Generally evaluations are updated every three to four years.

#### 2. College Orientation

Most colleges have an orientation program for their new students before the start of the academic year. This time is a great opportunity for you to meet your fellow classmates, your hall mates (if you will be living in a dorm on campus), and other people who will be

able to offer you advice and guidance as you settle into your new college routine. If you are living on campus, you will most likely have a residential advisor (RA), who is often an upperclassman, living on the same hall with you. This student has gone through training and can offer you advice about transitioning smoothly into college life. The RA will also be able to tell you where you can find other support services on campus.

Although it may be tempting to overexert yourself during orientation because you will be exposed to new people, new activities and a new environment, try your best to pace yourself. You will have many opportunities to try new things, join new clubs, and hang out with new people, so don't feel that you have to experience everything that your school has to offer in the first few days. If you are having trouble managing fatigue, stress or anxiety, contact your doctor or visit the school's health center.

## 3. Health Services/Counseling Center

All colleges have a Health Center. The Health Center generally functions as a mini health clinic, staffed by nurses, physician assistants, and / or physicians. Soon after arrival, make an appointment with the Health Center to introduce yourself, to give the Center copies of relevant medical records, and to alert them to your specific medical needs. Some students have received a good deal of support from their college health centers, sometimes in the form of help with injections, a quick check-in if they are not feeling well, and consultation about how to handle a variety of situations including stress, anxiety, and homesickness.

College health centers also feature counseling centers. The beginning of college is a time of transition, and counseling can be very helpful during transitions. Since most college students are facing their first time away from their homes, their parents, siblings, and friends, it is natural to feel homesick, anxious, worried, and uncertain. When you add a chronic illness to the mix, the counseling center could be a good support for a successful adjustment to more independent life. There is a large range of issues for which you might choose to work with a counselor. You might be experiencing uncertainty about how to disclose your MS to new friends and roommates. You might need support in reassuring your parents that you are doing a great job of caring for yourself, and staying on your medication. And you might use counseling as a way of making sense of some of the new experiences that you observe and in which you participate.

#### 4. Dealing with Stress

Many new college students experience stress, anxiety, uncertainty, and homesickness during their first year in college. Much of this uncertainty will pass when you have established new friendships and when you have identified supportive people (these might include faculty members, nurses, dorm advisors, upperclassmen, and counselors). It might help to make a point of finding supportive people, and sticking to the friends you make in the beginning. In the meantime, remember that you are experiencing a normal adjustment process, which will pass within days, weeks, or several months at the longest.

#### 5. Campus Activities Fair

During the first few weeks of the semester, your college will likely hold an activities fair, which will introduce you to the many extra-curricular activities offered on campus. This fair will introduce you to the various sports, clubs, and other activities in which you can participate. Before you sign up for any strenuous or physical activity, check with your doctor about participating. Use the fair as an opportunity to meet new people, try new activities, and learn about potential new interests. Again, be conscious of overexerting yourself. Be sure to talk to your doctor about your limits regarding fatigue, stress and physical activity. You may decide that the best way to try all the new things that interest you is to sign up for a handful of activities the first semester, and a handful of new activities at the beginning of the second semester. If you sign up to do activities or clubs outside of your courses, make sure that you have planned time for homework and academic meetings.

# **D.** Academics

Before the academic year officially begins, you will likely be required to meet your academic advisor to discuss your course selection. The school will likely assign an academic advisor (often times a professor who teaches first year students) to you before your allotted registration time. This person will be able to provide you with advice about balancing your schedule and taking on a manageable course load. You may want to consider some of the following when you are deciding what courses to take: balance your schedule with courses that are heavy in reading and writing with those that are more quantitative; balance your daily schedule (avoid taking four courses that all meet on the same day); if you are a morning person, schedule your courses for the morning blocks; if you prefer afternoons, try to schedule your courses for the afternoon blocks; balance courses with familiar material with courses that you know little about.

At most colleges, there is a "grace" period (often called an add/drop period) during which you are allowed to withdraw from (i.e. drop) a course without it appearing on your transcript. Use this grace period to decide whether you have chosen a balanced schedule. If you feel that you need to make adjustments to your schedule, talk to your academic advisor about adding a different course and dropping one in which you are already enrolled. A good way to gage a balanced schedule is to gather the individual syllabi from each of your courses and visually "map out" the required work on a large academic calendar. This exercise will enable you to see when major assignments are due, and how much reading and writing is expected.

#### 1. Time Management

Time management is crucial to success in college, and it is important not to leave longterm assignments to the last minute. Therefore, try your best to plan ahead!! Look at the syllabi for each course at the beginning of the semester so that you can plan for long-term projects and plan ahead in anticipation of stressful weeks and due dates. If the professor does not provide a long-term syllabus within the first few days of class, ask for one!! Chances are that other students in the class will want one as well. When you know that you have a project or an essay due several weeks in the future, plan it out so that you do a little bit each night and stick to your schedule. You will be pleasantly surprised that your assignment all of a sudden does not feel so daunting and overwhelming after you have broken it down into more manageable pieces.

If you know about an exam that is coming up, start studying at least a week in advance. You may find that it is helpful to make a study schedule: plan out your studying times and how you are going to use that time (i.e. one night you might make flashcards, another night you may outline your notes, and another night you may answer practice test questions). Study your notes each night and get to know the material each day so that when you study it is more like reviewing and not learning the material for the first time. If you know you have an exam, make sure you get all of your other projects and assignments done in advance so that you can devote the evening prior to the exam to studying for it. This will ensure that you do not have multiple assignments to complete at the same time and will enable you to get to bed at a decent hour so that you are alert and well rested for the exam.

Most colleges have resources on campus to help students with time management issues. If you are having trouble budgeting your time, or planning your own schedule, talk to your academic advisor about time management strategies. He or she will also be able to direct you to the appropriate resources on campus, which may include tutoring services, time management workshops, or a peer-to-peer academic program.

## 2. Extensions for Assignments

Although it is not always possible to anticipate a situation that would merit an extension for an assignment, try your best to map out your assignments at the beginning of the semester (see section on time management above). If you anticipate needing an extension after looking at your course syllabus, ask for one well in advance of the due date. You will find that professors are often more accommodating and understanding if you take the initiative in advance. Sometimes medical issues arise without warning and a last minute extension may be necessary. Don't panic if this occurs. Instead, explain the circumstances to the extent that you are comfortable and have a plan in mind for when you anticipate completing the assignment. Your plan will show the professor that you have taken the initiative, have thought about how you are going to make up the assignment, and are working towards completing the task.

## 3. Managing Fatigue on a Campus when there is so Much to Do

Fatigue is both a challenge and a mystery. No one really understands why fatigue occurs in MS, but we do know something about how to handle it. Managing your fatigue can be a challenge on a college campus. First of all, lack of sufficient sleep can worsen fatigue. We know that many college students stay up late at night, and skimp on their sleep. You might have to go to sleep earlier than your roommates and friends, sometimes negotiating to obtain sufficient quiet. Second, although it may sound counterintuitive, exercise is one of the best ways to combat fatigue. If you find that exercise helps combat your fatigue and boost your stamina, you may decide to pay a visit to the athletics center to meet with a trainer to help you set up a regular, moderate exercise program. It is then up to you to stick to it! Thirdly, there are medications that can reduce fatigue. If you are experiencing more fatigue and you find that it is inhibiting your daily activities, you should consider contacting your neurologist to discuss adding medication to reduce your fatigue. Lastly, depression can cause fatigue, or perhaps add to MS fatigue. If you find that your mood is low, you should let your neurologist know, and pay a visit to the counseling center.

# IV. NEGOTIATING THE MEDICAL SYSTEM

#### A. Taking Responsibility for your Own Medical Issues (David Rintell Ed.D.)

Many parents are very protective of their children, teens, and young adults. Parents of a young adult with MS are usually very involved in the daily life of their children, particularly about health issues. A beginning college student, in contrast, often enjoys the new feeling of independence and self-reliance. As you might imagine, the intersection of involvement/protectiveness and independent self-reliance can sometimes be a bit rough, and at times can create conflict.

Here's an example. A mother and daughter were discussing the daughter's upcoming trip to college. The mom expressed that she has always been the one to monitor the daughter's health, checking to see how she was feeling, whether her daughter was taking her medication, and whether the daughter needed to slow down a bit to prevent her from overdoing it. The mom had the idea that she would continue to monitor her daughter's health through frequent cell phone check-ins. Her daughter, however, felt that she was capable of looking after her own health needs, monitoring her activity level, and taking her medication on her own. It became clear that it would be difficult for the mom to back off and let her daughter take more responsibility. And it was probably not that easy for the daughter to really take on all the responsibility for herself. They decided on a compromise. The mom promised not to hover and call all the time, and told her daughter that she had confidence in her ability to care for herself. The daughter agreed to keep her mom posted about her health and her care.

This anecdote highlights the importance of communication especially between you and your parents as you transition into young adulthood and begin to take on more responsibilities for yourself. Before you leave for college, try to have a conversation with your parents about how you are going to manage your health while you are away at school. Although your parents may have different expectations about how active they are going to be in managing your health care, it is important to address these issues before you leave for college so that you and your parents are comfortable with the role that they and you will be playing in your health care. You may find establishing a set of ground rules helpful. This way, both you and your parents will be thinking along the same lines about your health. You can always adjust the rules as you settle into a routine away from home and become more familiar with your new independence and responsibilities.

# **B.** Negotiating the Medical System (Catherine Becker R.N.)

As you enter adulthood it is important that you begin to take responsibility for your own health. For teenagers with a chronic disease like MS, this is especially important. Navigating today's medical system can be scary for anyone, but there are many resources available to help you.

#### 1. Heath Insurance

As a person living with MS, you should make sure that you have health insurance at all times. As you turn 19, enter college, or start your first full-time job, it is important to make sure that you will continue to have adequate health insurance. The National MS Society has many resources to help answer your insurance questions. You can find basic insurance information on their website at <a href="http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/index.aspx">http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/index.aspx</a>. You doctor's office can also help answer your questions so don't be afraid to ask for help.

Teenagers entering full-time college after high school often qualify to remain on their parent's private insurance until age 26. Ask your parent to check their individual health care plan. Many schools also offer a health insurance plan that you can enroll in. These insurance options are detailed on pages (74-75) of this booklet

If you have received your health insurance though a **State Child Health Insurance Program**, remember that these health plans only cover children until their 19<sup>th</sup> birthday. Talk to a social worker about other options for your insurance several months before your 19<sup>th</sup> birthday. They can help you find out if you will qualify for another public health insurance program such as Medicaid. These programs vary greatly from state to state.

For those young adults starting a full-time job, it is important to find out if your job offers health insurance to its employees. Before accepting a job, ask what, if any, health insurance plans are offered. Ask for written materials on the health plans that you can review with your parents. Remember to pay attention to what services are and are not covered through the insurance plan.

## 2. Prior Authorizations

When reading information about your new insurance plan, make sure to find out if you will need prior authorizations for appointments or medications. You will want to know if you need a referral to go to a specialist, such as your neurologist. You can also check your insurance companies "drug formulary" to find out if your current medications are covered. If you find that your medication is not listed in your insurance company's drug formulary, then talk to your doctor. Your doctor can help you get authorization for the medication, or in some cases may have to think about using a different medication instead. If your insurance company requires you to get a prior authorization for your MS medications every year, be sure to ask your doctor for a prescription renewal at least 3 WEEKS PRIOR TO THE EXPIRATION OF YOUR CURRENT PRESCRIPTION IN ORDER TO AVOID ANY DELAYS IN YOUR MEDICATION DELIVERY.

# 3. Selecting your Health Care Team

Depending on how far you will be moving away from home and how often you plan to visit home, you will need to decide if you will be keeping your current doctors or will be choosing a new medical team. If you want to continue seeing your pediatrician or pediatric neurologist, find out if their offices will continue to see you after you turn eighteen. If you decide you would like to change doctors, ask your neurologist or pediatrician for recommendations of adult practices.

For students who are moving far away from home, but are planning to stay with their current neurologist, it is important to come up with a plan for what you will do if you have a relapse while at school. This plan should include a specific hospital or health care center that you would visit in the event of a relapse and a physician to oversee your care during a flare. Some people develop a relationship with a local neurologist who can see them urgently during a relapse. Similarly, you may want to be familiar with a local health center for urgent primary care issues. All schools have a health services office, but you may also want to be familiar with local hospitals, and physicians on staff there.

#### 4. Shots and other Medications

As you enter young adulthood, it is important that you continue to take your medications as prescribed. This may be the first time that you will be responsible for ordering your own medications or administering your own shots (injections). As mentioned in the College section of the booklet, getting your medication and storing it can also be a bit tricky if you are in a dorm or living with roommates. However, if you plan ahead, these logistical matters should not be a significant problem.

Before you leave your parents' house make sure to find out where your medication will be delivered at your new address. If you are in a dorm at college you may need to ask your residential advisor where medications should be delivered. Also make sure that you have a safe refrigerator to keep your medications in.

If you have not been giving your shots to yourself at home, taking your shots on your own can be scary. Many teenagers also rely on their parents to remind them to take their medication. In the months before you leave home begin taking full responsibility for your own shots. Call to order your medication on your own. Keep track of your own shots on a calendar, or set an alarm on your cell phone or watch to remind you to take your medication. If you have never given your own shots, you can ask an MS nurse to train you at home or in your doctor's office. If you strongly prefer to have someone else continue to give you your medication, identify who that person will be before you leave home. Some college students have had their student health center or a reliable friend give their medication.

Once you begin your new life, think about the best way to fit your shots into your new routine. It may be that your weekly shot would now be better given on a different day, or that it's easier to take your shot in the morning than at night. If you are on a weekly injection, talk to your neurologist or prescribing physician about how best to change the day on which you take your medication. You may be advised to transition gradually to a different day so be sure to discuss changing your medication routine with your doctor before you change your current routine.

#### 5. Keeping Track of your Medical Records

Keeping track of your own medical records is important for everyone, but it is especially important when you are away from your home and from your regular physicians who have copies of your medical records at their offices. If you are changing doctors, make sure to give the new doctors a copy of all of your records.

For yourself, it is a good idea to keep a card with emergency contact numbers, physicians' names, and current medications on you at all times. You can also keep a copy of your full records in your new home, dorm room or apartment. Many people find a three ring binder or folder helpful so that they can keep all of their records organized and in one place. Your last neurologist's visit note, copies of your most recent MRI (including a CD copy), and a list of current medications along with prescribing physicians is particularly important information. This information can be very helpful if you ever need to be seen by a doctor away from home or in an emergency room. On page 84 of this booklet you will find a "Medical Contacts and Medical Information" form that can help you organize your medical records.

#### 6. Scheduling Routine Appointments

Young adults can often be so busy with day-to-day life that they forget to have regular appointments with their doctors. As a teenager with MS, it is very important that you continue to see your neurologist and other doctors regularly. If your primary neurologist is far from your new school, plan ahead and schedule your appointments for school vacation times. Winter break, spring break, or summer vacation can be great times to have your routine appointments or MRIs.

# V. ENTERING ADULT LIFE (David Rintell Ed.D.)

# A. Your Responsibilities as a Young Adult

In addition to taking more responsibility for your own health and medical care, you are also about to take more responsibility for many other things that your parents have probably taken care of until now. You may be responsible for paying rent and bills, for buying and cooking your own meals, and for unexpected things like getting your car repaired. You will be responsible for managing your time so that you can balance school, work with taking care of yourself. The list of responsibilities involved in taking care of your health probably seems like enough on its own. Combine those with the responsibilities of being an independent young adult - job, school, managing your money, making decisions on your own - and it might seem overwhelming. It doesn't have to be.

Becoming more independent and self-reliant is exciting, and it definitely comes with more responsibilities than you have probably ever had, but it doesn't mean having to *do everything* for yourself. A responsible adult knows how to ask for help and support when he or she needs it and takes steps to organize his or her life so that things run smoothly and get done well without being overwhelming. Here are some ideas for ways you can be more responsible without letting yourself get overwhelmed.

- Try coming up with a list of your responsibilities and then breaking it down into things you can do on your own and things for which you can ask for help. For example, it is your responsibility to monitor when you are running low on medications, but you can ask your parents to call in a prescription refill for you. This leaves you time to focus on other responsibilities, like finishing a paper due that week or studying for an upcoming exam.
- Cross anything off the list that is not *actually* a responsibility. Watch out for "shoulds" those things you tell yourself that you should do but that are not really a responsibility or a priority. For example, telling yourself that you "should" work out five days a week is not a responsibility and may not be realistic. Exercise is important, but be sure to set realistic goals for yourself, and prioritize your list by focusing on completing the most important tasks first.
- Organize the list from top to bottom by priority and adjust your expectations for yourself where needed. Maybe you want to set a goal of working out three times a week and put it on your list. But be sure that goal is below the responsibility of completing assignments on time. And, again, remember to ask for help when you need it. There may be times, for example, when you need to ask for an extension on one assignment to allow you time to get enough rest and to study for an exam date that can't be changed.
- Make as many of your responsibilities automatic or routine as you can so that you don't have to constantly remember to take care of essential tasks on time. For example, set up an online billing service for your car and credit card payments.

Use your phone or PDA to remind you to pay your rent on time and to keep a running list of things you need at the store.

• If you didn't start keeping an agenda or personal calendar in high school, now is the time to do it. Figure out a system that works for *you*. Some people do best with a wall calendar, others with a paper and pencil agenda, and others with an iPhone, Blackberry, or PDA calendar.

# **B.** Managing your Emotions

As stated above, when you are at college, you begin to be more responsible for yourself, and for your health. Part of this responsibility is to maintain an awareness of your mental health. At times of transition and separation, most people become more vulnerable to depression. Since depression is more common among people who have MS than others, it is particularly important to pay attention to the signs of depression. Depression can be very disabling, can interfere with your studies and your relationships with others, and, in its most extreme form, can be life-threatening.

#### What are the signs of depression?

- Depressed mood (feeling sad, tearful)
- Irritability
- Decreased interest in activities
- Decreased pleasure from activities
- Negative thinking
- Change in appetite, weight loss or gain
- Trouble sleeping, or sleeping too much
- Fatigue, low energy
- Feeling worthless, hopeless
- Difficulty concentrating

As you can see, there is overlap between some MS symptoms and depression. Depression can contribute to fatigue, and can interfere with one's ability to pay attention and concentrate.

### What do I do if I think I'm depressed?

Tell someone! It would be appropriate to talk to your parents about feeling depressed. You could also go to the Counseling Center or Health Center at your school. And, you might want to contact your neurologist. Since it is believed that depression can be a symptom of MS, it can help your neurologist provide the best care if she or he knows how you are feeling.

#### How is depression treated?

Generally, depression is a very treatable condition. The "gold standard" for treatment is the combination of counseling and medication. Anti-depressants are now very commonly used, very safe, and have few side effects. In addition to counseling and anti-depressant medication, the following is a list of other activities, which have been proven to help depression:

- Exercise
- Helping Others
- Spending time with friends

# C. Friends / Roommates / Asking for Help / What to Tell Friends

#### Telling your new friends about your Multiple Sclerosis

Disclosing that you have MS is a very personal decision. Some people prefer to keep their health status private, and choose not to reveal to others that they have a chronic illness. Others feel like their MS is one of their important characteristics, and tell just about everyone. Of course, there are plenty of people who are somehow in between, or tell some people but not others. For those of you who choose not to tell others, you might find that keeping your MS private is taking more and more energy, and perhaps it is not worth it. For those who talk about their MS, you might be upset that some people respond with pity, ignorance, or misunderstanding.

If you want to tell a new person that you have MS, here is one way that has worked for some people. Think ahead, and plan a sentence which includes talking about MS, and instructing the person how you would like them to respond. Here's an example:

"I have MS, which is a chronic illness; I'm doing well and it's not keeping me from enjoying life, but I thought you might want to know."

There is no single right or wrong way to tell others about your MS. It's OK to keep it private, and it's OK to share your experience with others.

## **D.** Sports Participation with Multiple Sclerosis (Carrie Bryant B.A. and Natalie Baruch B.Sc.)

When choosing a sport to participate in, make sure you will not be pushing yourself too hard but don't underestimate yourself either. As long as you take care of yourself properly and pay attention to your body, MS should not hold you back from participating in something you want to do. You should talk to your doctor about your plans to participate in regular sports activities. He or she will provide recommendations about what is safe for you to do.

#### **Time Management and Sports**

It is important for any athlete to manage his/her time well so that he/she can maintain a healthy and productive lifestyle. It is especially important for an athlete with MS to manage his/her time well so that he/she can accomplish all of his/her daily tasks and

ensure that he/she gets enough sleep each night. Since fatigue is such a common symptom for MS patients, try to get plenty of sleep at night and pace yourself during the day so that you are able to participate fully in and enjoy your chosen sport. Also be aware of your physical limits and do your best to listen to your body. If the sport involves waking up very early in the morning and you know that you have a lot of work to do at night or you have an evening class, you may want to see if there is a way to practice later in the morning. This could mean joining another team, setting up an individual practice schedule or suggesting that the team change its practice time. If changing the team practice time is not possible, see if several members of the team would be willing to train with you at a later time on the days that an early morning practice is scheduled. You could also suggest staggering the practice times so that you do not have to wake up really early every morning.

#### **Medication and Athletics**

Make sure that you always take your medications as prescribed (daily, weekly, monthly, etc.) before participating in sports. Also, check with your doctor to make sure that you will be okay to participate in sports after taking certain medications. For example, intravenous or oral steroids may increase your blood pressure and heart rate and may make it harder for you to participate in practice. If there have been any recent changes in your medications or your medical status, you should talk to your doctor about your participation in sports.

#### **Disclosing to Coaches**

If you are comfortable disclosing your medical condition to your coach, you may find that your coach can help you manage your symptoms and remind you to stay hydrated. Make sure that your coach understands what it means to have MS. For example, the signs and symptoms (especially fatigue and sensitivity to heat as well as possible attacks that may affect the legs, eyes, and other body parts), the medications you are taking and the possible side effects are all valuable pieces of information for your coach to know. If you wish, your doctor can provide a letter to your coach explaining how MS may impact your athletic performance, and any limitations that he or she has recommended.

#### Symptom Management and Sports

If you are going to be participating in strenuous exercise, remember to stay hydrated and avoid overheating because heat can cause your MS symptoms to temporarily worsen. This is called Uhtoff's phenomenon. Here are several things to consider about managing your symptoms while you are participating in strenuous exercise: be mindful of the duration that you are exposed to heat. If your sport permits, you may find that practicing indoors where there is air-conditioning or a fan helps combat heat related symptoms; stay well-hydrated. Drinking a lot of water and electrolyte enhanced beverages will help fight the heat and keep you hydrated. Pace yourself during practice (this may mean taking a break and sitting down to cool off); Visual impairments associated with MS sometimes make it difficult to participate in fast moving sports, such as ball games or racquet sports. If you are experiencing visual disturbances, be sure to talk to your doctor and coach about your sports participation. Decreased joint and muscle movement may also prevent someone with MS from participating in fast moving sports like those that involve a lot of

running or a great deal of muscle coordination and joint movement. If you are experiencing these symptoms, talk to your doctor and coach about your participation. Remember, you can be a vital member of a sports team without being on the field. If your symptoms are preventing you from participating fully, consider taking on a leadership role either through assisting the coach or acting as a role model to your teammates.

## *E. Dating and Sex* (Paula Freitag ?, David Rintell Ed.D. and Tanuja Chitnis M.D.)

#### Do you tell someone you are dating that you have Multiple Sclerosis? If so, when?

Once again, this is a personal decision. Most people feel that a dating relationship is a bit different from other relationships. We are accustomed to holding some information about ourselves back, until we know our dating partner better. This doesn't only apply to health and illness. Let's say your date had to drop out for a semester for financial reasons. He or she might not tell you that until you have established a certain amount of trust in each other. It's the same with health issues – you might wait until you get to know your date, and he or she gets to know you, before discussing your MS. If you talk about your MS too soon, the information might be unexpected and misunderstood. If you wait until you have been going out together for a long time, your date might feel that she or he has been misled because you haven't been honest. It might be wise to talk about MS in the context of a romantic relationship, somewhere in the middle – when you have gotten to know each other better, and you feel that the relationship might go somewhere.

#### Sexuality

College is a time of life when many people have a variety of new experiences with intimacy and sexuality. This is as true for people who have MS as for people who don't. MS ought not to interfere with intimate relationships or sexuality.

College students with MS, in the same way as their peers, should exercise good judgment. Alcohol and drug use can cause disinhibition and you might find yourself in situations that make you feel unsafe or uncomfortable.

There are a couple of special considerations about sexuality for college students with MS. The first is unplanned pregnancy. It is very important that females with MS who are taking disease-modifying treatments (Avonex, Betaseron, Copaxone, Rebif, Tysabri, etc.) do not become pregnant while taking the medication. The effects of these medications on a fetus are unknown, and for now they are considered to be unsafe during pregnancy. Unplanned pregnancy can be easily prevented, through the use of birth control pills or IUD's. Every woman with MS who is sexually active should be using birth control.

The second special consideration for college students with MS involves STD's (sexually transmitted diseases), including HIV. STD's are, of course, a concern for everyone. But for people with MS who are on a medication which alters the functioning of the immune system, some STD's can be much more problematic. For example, genital herpes can be more difficult to control for people taking medications for MS. STD's can be prevented

by the use of condoms. Condoms should always be used when you have sex. Since it is not always possible for your partner to know if he or she is carrying an STD, one should always use a condom during sexual intercourse.

Close and intimate relationships can be hard for everyone, whether you have MS or not. Be sure to stay in control of what is happening to you when dating and trust your instincts. If you have concerns about a potential date, get to know the person before going out or go out with a group. Be cautious with the use of drugs or alcohol that may decrease your ability to make good decisions about your safety. If you are in an abusive relationship, seek support through the National Domestic Violence Hotline: 1-800-799-SAFE (7233) or 800-787-3224(TTY).

If you are sexually active or thinking about it, you may want to consider the risks. The main risks of becoming sexually active include facing an unplanned pregnancy, acquiring a sexually transmitted disease (STD), and experiencing emotional consequences. Be sure to take the time you need to make this important decision. Talk with your partner about your relationship and about your commitment to one another. You may want to discuss abstinence, birth control, and what you would do if it failed. Find out about your partner's sexual history, including exposure to STD's. If you are unable to talk about these topics with your partner, reconsider whether you should begin a sexual relationship with that person.

#### F. Alcohol and Drugs (Ellen O'Donnell Ph.D.)

Chances are that you have already had to make some decisions about alcohol and drugs. You may already have decided whether or not you are willing to take the risks associated with drinking and/or using drugs. Even if you think you know where you stand on the decision of whether or not to drink or use drugs and how often, you may find yourself reevaluating that decision in the next few years. Especially if you are attending college away from home, you are likely to be presented with many more opportunities to drink or use drugs. Whether or not you choose to do so is a personal decision that only you can make and many factors will affect that decision. Ask yourself:

- Do I want to drink?
  - If so, how much and how often do I want to drink?
- Do I want to use drugs?
  - If so, which ones?
  - How much and how often?

It is important to notice that each of these is a separate question and that you can change your mind about where you stand on alcohol and drug use at any time. Being thoughtful about these questions and the issues associated with them is part of your responsibility as a young adult. Many factors will influence your decisions. Things like family history of substance abuse and dependence, your willingness to take the legal risks of underage drinking or illegal drug use, and your friends' attitudes toward drinking and drugs will probably play a role. While it may not be an obvious factor to consider, you should consider your diagnosis of MS and the treatments that you are taking when answering the above questions.

Some people with MS feel that they are more vulnerable to the effects of alcohol than people with healthy neurological systems. Alcohol may interact with the medications that you are taking for your MS, and/or other conditions, such as depression. Alcohol could have adverse effects on your liver or blood counts. Keep in mind that alcohol is one of the few substances that have a direct effect on the brain. You may find that you experience symptoms of intoxication well before your friends do and by drinking significantly less than your friends. If you are currently experiencing symptoms of MS, like dizziness, difficulties with balance, or fine motor impairments, alcohol and certain drug use will make these symptoms much worse.

If you are currently on medications, these can interact with alcohol and drugs and increase the possibility of you experiencing negative side effects. For this reason, it is important that you are honest with your doctor about your alcohol and drug use so that they are fully informed of any possible influences on your medical status and so that they can help you think through these issues to make the best decisions for you about alcohol and drug use.

Finally, keep in mind that if you are experiencing symptoms of depression (not at all uncommon among both people with MS and other college students) alcohol and drugs can significantly worsen those symptoms and interfere with the effectiveness of anti-depressant medications. Also, be aware of the signs and symptoms of alcohol abuse and dependence. If you are experiencing any of the following, it may be time to ask for help from a trusted friend or adult:

- ✓ Drinking or using drugs is interfering with your normal activities (completing school work, doing things you used to enjoy doing).
- $\checkmark$  You've been drunk or repeatedly hung over at work or in class.
- ✓ You plan most of your social activities around drinking or using drugs.
- ✓ Being drunk or high has put you in a dangerous situation or made you a danger to others (for example driving when drunk or high).
- ✓ You have repeatedly gotten sick or hurt because of drinking or using drugs.
- $\checkmark$  Your moods shift dramatically when you drink or use drugs.
- ✓ Using drugs or alcohol has caused conflict in your relationships with friends, family, or significant others.
- ✓ You have tried to stop or cut back on your use of alcohol or drugs but find that you can't.

Remember that no decision about drinking or using drugs is an "all or none" decision. It is up to you to decide whether or not to drink or use drugs, how often, how much, in what situations and with whom. You can change your mind about any of these decisions at any time! A useful website for thinking through the issues related to alcohol and drugs in college is <u>www.factsontap.org</u>.

### G. Stress Management (Sunny Wang Psy.D/UCSF)

Entering adulthood can be exciting and a long awaited freedom; however, it can also be a source of increased stress. This is a very natural reaction to newfound freedom. Often, once the reality of your independence sets in, you realize that new responsibilities come with independence, and this realization can lead to anxiety. Managing your own stress is yet another responsibility, and an acquired skill that often takes practice. The first step to healthy stress management is to prioritize your well-being and make relaxation part of your daily routine.

- ✓ Learn ways to manage and decrease stress and increase positive well-being.
- ✓ Learn your relaxation basics:
  - **Breathing**: Yes, we all know how to do this. However, you'd be surprised how often we do not use this basic skill to our advantage. Deep breathing while paying close attention to your body will help both your body AND mind settle. In many activities that are listed below, breathing will be an important component in relaxing your mind and body successfully.
  - Be in the right frame of mind: This will not be easy to do. However, the fact that you're reading this list is a good sign. Even if you don't believe in relaxation techniques or your ability to relax, have an open mind and be willing to try with a sincere effort.
  - Understand the connection between mind and body: At times, it is virtually impossible to quiet down your mind, your busy thoughts and worries. This is especially true during stressful times. Ironically, these are the most important times to use the ability to quiet down your thoughts and relax your mind. You can do this by practicing relaxation, but how do you do this when you're stressed out?
    - First, pay attention to your body. Have you ever noticed when you're emotionally anxious and/or tense that your body feels tense and stiff too? This is because the body affects the mind and vice versa. While it is often difficult to quiet down your mind, you can identify tension in your body more easily than your thoughts. Use this to your advantage. Work on relaxing your body: first, by deep breathing and stretching, then by working on being mindful. Practicing mindfulness is being aware of your present moment, a practice derived from meditation.
    - Another way to shift your mind is to externalize your thoughts, which will help your busy mind focus on something other than the source of your stress. Ways to do this are to 'observe' an object, use visualization, and/or meditate. For example, observe a leaf or a small rock (an example of being mindful—being in the moment). You can

focus on the little details of an object you're observing. In the meantime, you're paying attention to your breathing and relaxation of your body. This is a great strategy that can be used easily.

- For example, let's say you're going to observe a leaf: Sit comfortably in your chair. Make sure your feet are touching the floor and your arms are relaxed. Shake them to make sure you're not tense. Begin to breathe nice and slowly—try to get into a regular rhythm that feels comfortable to you. Feel the floor against your feet. Begin to notice the leaf in front of you. Notice its color, texture, shape, the shadow it makes, etc.
- ✓ Activities can also help reduce stress by relaxing you, distracting you, and introducing you to new positive behaviors. See below for some ways to relax your mind and body. These activities may take 10 to 20 minutes (more if you prefer and time permits):
  - Exercise
  - Read a book
  - Meditate
  - Write/type a letter to a friend
  - Write poetry
  - Keep a photo journal: take pictures
  - See a movie
  - Window shop
  - Have fun with a pet (if you have one)
  - Go to the park
  - Nap for 10 minutes
  - Plan your dream vacation
  - Sit under a shady tree
  - Watch a sunrise or sunset
  - Do deep breathing exercises
  - Take a bath or a long shower
  - Listen to your favorite song
  - Play an instrument
  - Go for a walk
  - Draw or paint a picture
  - Begin a new hobby or craft
  - Attend a free concert
  - Have a good laugh
  - Swim or splash in the water

- ✓ To learn more about mindfulness here are some recommended readings:
  - Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness (1990) By Jon Kabat-Zinn
  - Wherever You Go There You Are: Mindfulness Meditation for Everyday Life (1994) By Jon Kabat-Zinn

# H. Money Management (Mary Karpinski SPA, LMSW)

### **Start Budgeting**

Establishing a budget and sticking to it isn't easy, but it's the best way to be in control of your finances and make sure your money is going toward the expenses that matter most to you.

Follow the steps below as you set up your own personalized budget:

- 1. Make a list of your values & prioritize them.
- 2. Set & write out your goals.
- 3. Determine your income.
  - a. Take home (employment, work-study, etc...)
- 4. Determine your expenses.
  - a. "Fixed expenses," such as a rent, auto, insurance, etc...
  - b. "Flexible expenses," such as food, utilities, schoolbooks, entertainment, vary from month to month.
    - 1. Be economical in your expenses: Comparison shopping, buying generic, garage sales, used books, public transportation, and eating in. Take advantage of the free and cheap activities on and around campus & the community, etc...
- 5. Create your budget.
  - a. Think of your budget as a "spending plan", a way to be aware of how much money you have, where it needs to go, and how much, if any, is left over.
  - b. Meet your "needs" first, then the "wants" that you can afford.
  - c. Your expenses should be less than or equal to your total income.
  - d. If your income is not enough to cover your expenses, change your spending habits.
- 6. Pay yourself first
  - a. <u>Saving</u> is a very important part of protecting yourself financially.
  - b. Save as much as you can every month. Small amounts can make a big difference if you keep it up. (Even \$5 a week can add up).

- c. A great goal is to establish an emergency savings fund large enough to cover three to six months of your living expenses.
- 7. Be careful with credit cards use them only when necessary and maintain only a small credit line.
- 8. Review your budget often.

#### Learn to Balance your Checkbook

Benefits of keeping your checkbook balanced:

- Helps you keep track of your money.
- Verifies that the information you have tracked is accurate.
- Catches any mistakes your bank might make.

#### To balance your checkbook:

- 1. Ensure you have entered all automatic transactions (e.g. ATM withdrawals, electronic transfer of funds, online bill payments, debt card transactions) into your check register.
- 2. Review your statement.
- 3. Compare your statement with your check register and mark off all items that match.
- 4. Add to your register any deposits or additions from your statement, including interest payments and ATM or electronic deposits.
- 5. Subtract from your register any account deductions, including fees and ATM or electronic deductions that are not already entered.
- 6. Update your statement information.

### Credit Card Wisdom

Think before getting your first credit card. It's easy to get a credit card but managing a credit card well isn't as easy. Every time you use a credit card, you are borrowing money. If you don't pay off your balance each month, interest will be added to the total amount you owe.

Some other options to think about:

- 1. Consider getting a debit card. A debit card withdraws from your checking or savings account rather than borrowing money for each transaction.
- 2. Consider sharing a card with your parents and asking them to help you stay on track.
- 3. Consider waiting. Just put off the decision for six months or a year and see how well you might do without a credit card.

### If you need to get a credit card here are some tips:

1. Choose wisely. Shop around for the best deal. Compare different cards based on your own situation. Look for the following:

- a. A low annual percentage rate (APR). The lower the rate, the less interest you have to pay. Watch out for low introductory rates that are raised after a year or less.
- b. Low or no annual fees.
- c. All other charges (i.e. late payment fees, transaction fees, over the limit fees, etc.).
- d. A grace period. Some credit cards charge interest from the day that the charges appear on your account. Other cards offer a grace period for you to pay off your balance before interest charges begin to accrue.
- e. The credit limit. Keep your credit limit low (think about \$500 or less) to make sure you don't get in over your head.
- f. Wide acceptance. A major credit card is convenient, and easier to manage.
- g. Services and features, such as cash rebates, frequent flyer miles, extended warrantees, etc.
- h. Limit the number of cards you get.
- i. Track your spending.
- j. Check your account online frequently, save receipts, and pay your bills on time.
- k. Keep a record of the following in case your card is lost or stolen (account number, issuer's name, phone number).

### **Understanding your Credit Report**

- 1. Your credit report is a collection of information about you and your credit history, and can have a major impact on your life. The three credit reporting agencies are Equifax, Trans Union, and Experian.
- 2. Know whether you have a credit report. If you have ever applied for any of the following, you have a credit report:
  - a. Credit card
  - b. Student loan
  - c. Auto loan
  - d. Mortgage
- 3. Understand who looks at your credit report. Your credit report may be looked at by all of the following:
  - a. Potential creditors
  - b. Landlords
  - c. Potential and current employers
  - d. Government licensing agencies (Student Loan)
  - e. Insurance underwriters
- 4. Know what these entities are asking.
  - a. How promptly do you pay your bills?
  - b. How many credit cards do you hold?

- c. What is the total amount of credit extended to you?
- d. How much do you owe on all of your accounts?
- 5. Be aware of the consequences of credit mistakes. Any negative information found on your credit report (late payments, bankruptcies, too much debt) can have a serious impact on your ability to do the following:
  - a. Get credit
  - b. Get a new job
  - c. Advance in your current job
  - d. Rent or buy a home
- 6. Know what is on your credit report.
  - a. Personal identifying information Name, Social Security number, date of birth, current and previous addresses, and employers
  - b. Credit account information date opened, credit limit, balance, monthly payment, and payment history
  - c. Public record information bankruptcy, tax and other liens, judgments, and, in some states, overdue child support
  - d. Inquiries names of companies that requested your credit report
  - e. <u>Your credit score</u>, depending on the type of report
- 7. Know what is NOT on your credit report.
  - a. Checking or savings account information
  - b. Medical history
  - c. Race
  - d. Gender
  - e. Religion
  - f. National origin
  - g. Political preference
  - h. Criminal record
- 8. Be aware of how long information stays on your credit report.
  - a. Positive information indefinitely
  - b. Inquiries 6 months to 2 years
  - c. Most negative information 7 years
  - d. Some bankruptcies 10 years
- 9. Check your credit report at least once a year to make sure your information is accurate to prevent and detect identity theft (Equifax, Trans Union, and Experian)
- 10. Report inaccurate information (Fair Credit Reporting Act)

#### **Prevent and Detect Identity Theft**

Identity theft is when someone uses another person's personal identifying information to commit fraud. This can include someone borrowing money in someone else's name, leaving victims of identity theft with debt and credit problems.

#### Keep your Information Safe!

- 1. Shred financial documents and paperwork with personal information before you discard them.
- 2. Protect your Social Security number. Don't carry your Social Security card in your wallet or write your Social Security number on a check. Give it out only if absolutely necessary (you can always ask to use another identifier).
- 3. Don't give out personal information on the phone, through the mail, or over the Internet unless you know whom you are dealing with.
- 4. Never click on links sent in unsolicited e-mail messages. Instead, type in a web address you know.
- 5. Use firewalls, anti-spy ware, and anti-virus software to protect your home computer--and keep them up-to-date. Visit <u>OnGuardOnline.gov</u> for more information.
- 6. Don't use an obvious password like your birth date, your mother's maiden name, or the last four digits of your Social Security number.
- 7. Keep your personal information in a secure place at home, especially if you have roommates, employ outside help, or are having work done in your house.

Regularly monitor your financial information. Review your various financial accounts and statements. Also, <u>request a free copy of your credit report</u> every year and review it. Be alert to things that require immediate attention:

- 1. Purchases you did not make
- 2. Bills that do not arrive as expected
- 3. Unexpected credit cards or account statements
- 4. Denials of credit for no apparent reason
- 5. Calls or letters about purchases you did not make

Act quickly when you suspect identity theft. Review the <u>Federal Trade Commission's</u> (<u>FTC</u>) victim recovery guide. Understand identity theft in relation to student loans. A federal student loan may be cancelled if it was falsely certified as a result of a crime of identity theft. <u>See the loan cancellation, forgiveness, and discharge chart</u> for more information.

### I. Insurance

(http://www.naic.org)

#### Health Insurance

Check individual insurance policies/benefits as most will cover full time students who are enrolled in a college program at least 12 credit hours per semester (6 or 9 credits in the summer) until age 23 or older.

#### Know your Policy

- 1. Take a copy of the relevant insurance cards, copy of the handbook, and know about obtaining referrals and approvals (if needed) before seeking treatment.
- 2. Familiarize yourself with the local campus medical community, a local physician, and hospital.
- 3. Make sure you have your own neurologist/medical information on hand to provide in case of an emergency. Consider telling a roommate or close friend where your medical information is in the event that you need someone to retrieve it for you.
- 4. If you are insured by a health maintenance organization (HMO), check to see if you will be outside the HMO service area while you are away at school. If this occurs, you will likely have coverage for emergency care, but might have to travel to a physician or hospital within the HMO service area for routine care.
- 5. If your insurer is part of a preferred provider organization (PPO), your insurer may pay benefits at out-of-network levels if you are outside your network.
- 6. Check your plan provisions or speak with your insurer to find out what levels of benefits are provided by your policy.

### **Student Health Insurance Plans**

- 1. If your healthcare coverage is limited by the network service area, another option is a student health insurance plan.
- 2. These plans are sold by an insurer that has contracted with a college to offer coverage to its students.
- 3. These plans have more limited benefits and more exclusions than traditional health insurance plans.
- 4. Contact the college you will attend to find out about the additional coverage.
- 5. If you need additional insurance assistance in the state in which you will attend college, visit the local state insurance department website at <a href="http://www.naic.org/state\_web\_map.htm">http://www.naic.org/state\_web\_map.htm</a> or log on to <a href="http://www.insureUonline.org">www.insureUonline.org</a>

### **Renter's Home Insurance**

- 1. On or Off Campus Find out if your parent's homeowners insurance will cover you if not, you may want to consider purchasing a plan in the event that your personal property is damaged, destroyed or stolen.
- 2. Make a comprehensive list of your possessions including purchase prices, model numbers and serial numbers.
- 3. Make sure to take photos or video of the possessions, and store the inventory in a secure, off-site location.
- 4. To download an easy-to-use home inventory checklist and get more tips about disaster preparedness, visit <u>www.naic.org/index\_disaster\_section.htm</u>.

# J. Financial Aid

(https://studentaid.ed.gov)

### Applying for Financial Aid

- 1. Eligibility for federal student aid is based on financial need and on several other factors. The financial aid administrator at the college or career school you plan to attend will determine your eligibility.
- 2. The Free Application for Federal Student Aid (FAFSA) is the form used by virtually all two and four-year colleges, universities and career schools for the awarding of federal student aid and most state and college aid. http://www.fafsa.ed.gov/

### Types of Aid

### • Grants and Scholarships

- 1. Grants & Scholarships, unlike loans, do not have to be repaid.
- 2. Your school has lists of local community, state, & federal resources that fund grants & scholarships that you can apply for. For example the National MS Society (www.nationalmssociety.org).
- 3. Eligibility is based upon the different types of grants & scholarships, for example, academics, sports, achievement, leadership, etc...
- 4. Each one has to be applied to individually.

### • College Based Financial Aid (Administered by Financial Aid Offices by the College – NOT all Participate)

- 1. How much aid you receive from each of these programs depends on your financial need, on the amount of other aid you receive, and on the availability of funds at your college or career school.
- 2. Provide a certain amount of funds for each participating school to administer each year.
- 3. When the money for a program is gone, no more awards can be made from that program for that year.
- 4. Apply for federal student aid as early as you can.
- 5. Each school sets its own deadlines for campus-based funds:
  - a. The Federal Supplemental Educational Opportunity Grant (FSEOG)
    - 1. Exceptional Financial Need
    - 2. Doesn't have to be paid back
  - b. Federal Work-Study (FWS)
    - 1. Employer will usually be a private nonprofit organization or a public agency
    - 2. The work performed must be in the public interest.
  - c. Federal Perkins Loan

- 1. Interest (5 percent) loan
- 2. Repay this loan to your school nine months after you graduate, leave school, or drop below half-time status.

### • Loans

- 1. Federal Family Education Loan (FFEL) & William D. Ford Federal Direct Loan (Direct Loan)
  - a. Considered Stafford Loans (for students) and PLUS Loans (for parents).
- 2. Schools generally participate in either the FFEL or Direct Loan program but sometimes participate in both.
- 3. Under the Direct Loan Program, the funds for your loan come directly from the federal government. Funds for your FFEL will come from a bank, credit union, or other lender that participates in the program.
- 4. Eligibility rules and loan amounts are identical under both programs, but repayment plans differ somewhat.
- 5. For either type of loan, you must fill out a FAFSA. After your FAFSA is processed, your school will review the results and will inform you about your loan eligibility.
- 6. You will have to sign a promissory note, a binding legal document that lists the conditions under which you're borrowing and the terms under which you agree to repay your loan.
- 7. You'll need to choose a lender if you obtain a FFEL Stafford Loan. (i.e. Stafford Loan the U.S. Department of Education—is your lender.) Schools that participate in the FFEL Program will usually have a list of preferred lenders. Student loan borrowers may choose a lender from that list, or choose a different lender they prefer (i.e., a credit union).
- 8. How much you borrow depends on your year in school and whether you have a subsidized or unsubsidized Direct or FFEL Stafford Loan.
  - a. A subsidized loan is awarded on the basis of financial need. If you're eligible for a subsidized loan, the government will pay (subsidize) the interest on your loan while you're in school, for the first six months after you leave school, and if you qualify to have your payments deferred.
  - b. In that case, you'd receive an unsubsidized loan. Unlike a subsidized loan, you are responsible for the interest from the time the unsubsidized loan is disbursed until it's paid in full. You can choose to pay the interest or allow it to accrue (accumulate) and be capitalized (that is, added to the principal amount of your loan). Capitalizing the interest will increase the amount you have to repay.
  - c. You can receive a subsidized loan and an unsubsidized loan for the same enrollment period as long as you don't exceed the annual loan limits.

- 9. Repayment begins 6 months after you graduate, leave school, or drop below half-time enrollment. This is called a "grace period." You will receive information.
- 10. You can place your loan into deferment or forbearance, as long as it is not in default or failure to pay on the loan. During a deferment, no payments are required. No interest for a subsidized FFEL or Direct Stafford loan will be charged. If you have an unsubsidized Stafford Loan, you are responsible for the interest during deferment.
- 11. If you're temporarily unable to meet your repayment schedule (for example due to poor health or other unforeseen personal problems), but you're not eligible for a deferment, your lender might grant you forbearance for a limited and specified period.
- 12. PLUS Loans (Parent Loans)
  - a. Parents can borrow a PLUS Loan to help pay your education expenses if you are a <u>dependent</u> undergraduate student enrolled at least half time in an eligible program at an eligible school.
    - 1. Federal Family Education Loan (FFEL) Program or William D. Ford Federal Direct Loan (Direct Loan) Program.

# VI. PARENTS' PERSPECTIVE (David Rintell Ed.D.)

# To the Students:

While beginning the college experience is a very exciting time for you, a student who has MS, it can be a time full of anxiety for your parents. Parents tend to become more involved with your life when you are diagnosed with a chronic illness. Sometimes it can feel that your family has taken a number of steps back to a time when you had less independence, when you were younger.

When you begin college, parents have the difficult task of beginning to let go. In many ways, you (the student) can influence how this goes. If you keep your parents in the dark about how you are feeling, how you are managing your medication, and if you've had any exacerbations, it is likely that your parents will be calling you multiple times a day to check how you are doing. If you keep them posted, and allow them to develop a feeling of confidence that they will be informed if a problem with MS does occur, they will back off and let you manage. They might even re-focus their attention on your siblings, their interests, etc. The key here is to come to a comfortable middle ground in communication with your parents.

# To the Parents:

When you have a young adult with a chronic illness like MS, you might never feel that your job is done – there is always more to do, to monitor, to educate, and to care for. But let's face it, by the time your young adult enters college, he or she has already learned from you how to take care of him or herself. You've likely done all you can do to prepare your young adult for a new level of independence.

As you help your young adult pack for college, you might reflect on any preparation which has not yet taken place. Does your young adult have a list of contact numbers entered into her/his cell phone, including physicians, neurologists, emergency contacts etc? Has she or he understood the process of renewing prescriptions for medications? Have you discussed sexuality and birth control?

A great resource in preparing your young adult can be other parents of a young adult with MS, who has already entered college. They can advise you on what preparations to make, and guide you through the process of letting your young adult begin to take charge of her own life, medical care, and education.

# VII. HELPFUL RESOURCES (David Rintell Ed.D.)

# 1. College Chat (MS World)

There is nothing better than chatting with other college students who are also living with MS. They are the ones most likely to understand the challenges you face, the solutions you've found, and what it's like to be a college student with MS. It is most likely that there are no other young adults with MS on your campus. Fortunately, there is Facebook page for college students with MS.

### 2. Support Groups in the Area (David Rintell Ed.D. and MS Society)

As stated above, it can be great to have the opportunity to talk with other young adults who are living with MS. One of the best ways to do so is to join a support group. Support groups are generally organized by the local chapters of the National MS Society. You can locate the chapter nearest you by calling 1-800-344-4867, or by accessing the National Multiple Sclerosis Society (NMSS) website at: <u>http://www.nationalmssociety.org</u>.

Support groups are sometimes initiated by other organizations, such as the <u>Multiple</u> <u>Sclerosis Association</u>, the <u>Multiple Sclerosis Foundation</u> and the <u>Accelerated Cure</u> <u>Project</u>. We advise college students to seek out support groups that are designated for college students or young adults, rather than to join a general MS support group. As with other areas of life, the concerns of college students with MS tend to be different from adults living with MS.

### 3. Finding a Doctor Near School while Maintaining Relationships with the "Team" at Home (Tanuja Chitnis M.D.)

While it is very helpful to maintain your relationship with your neurologist and doctors in your hometown especially if you are comfortable interacting with them, it is important to establish a relationship with doctors in the area of your college in case you have any urgent medical needs. Speak to your "hometown" doctors about this issue before you leave for college, and ask them to refer you to a doctor that they may know in the area of your college. The National MS Society can also help you find a doctor close to your college. You can refer to their website (www.nmss.org) or call your local chapter. You should transfer a copy of your medical records to your "college" doctor before you leave for college. Your "college" doctor may also be helpful in organizing infusions or other treatments that you may need while you are away at school. Your College Student Health services should also be aware of your medical condition, and you should contact them prior to starting college. They may also help you find a neurologist and other resources on campus or close to school. You can still continue to see your "primary" or

"hometown" neurologist throughout your time at college. Many students visit their doctors in the winter and summer breaks, thus not interfering with schoolwork.

### 4. Books

- Braaten, Ellen, PhD and Felopulos, Gretchen, PhD. Straight Talk about Psychological Testing for Kids. New York, New York: Guilford Press, 2004.
- Cribb, T. Kenneth Jr., President of the Intercollegiate Studies Institute. *Choosing the Right College 2008-2009*. Wilmington, Delaware: ISI Books, 2007.
- Hayden, Thomas C. *The Insider's Guide to College Admissions*. Princeton, New Jersey: Peterson's Educational Center, 1999.
- Kravets, Marybeth, MA and Wax, Imy F., MS. *The K&W Guide to Colleges for Students with Learning Disabilities or Attention Deficit/Hyperactivity Disorder (ADHD)*, 9<sup>th</sup> Edition. New York, New York: The Princeton Review, Inc., 2007.

### 5. Websites

www.act.org

www.collegeboard.com

www.commonapp.org

# VIII. CHECKLIST FOR MULTIPLE SCLEROSIS MEDICATION (Catherine Becker R.N.)

## A. Tips for Travel

Multiple Sclerosis should not interfere with your ability to travel. However, it is important that you continue to take your medication throughout your trip. To do this, it is important to think ahead and pack plenty of supplies. When possible, pack enough supplies for an extra day or two. This will be helpful should your trip be unexpectedly extended.

### What to Pack for your Trip

- Contact information for your doctors
- Copy of your current medications
- Copy of your health insurance card
- Puncture resistant container
- □ Medication!
- □ Autoinjector (If applicable)
- □ Alcohol wipes
- Gauze pads
- □ Heading pads / Ice packs (If part of your medication routine)
- □ Tylenol or Advil
- **□** Emla cream (If part of your medication routine)
- □ Insulated storage container to keep your medication cold if you are on Avonex, Copaxone, or Rebif

**NOTE:** Many MS drug companies offer free insulated storage containers for travel. To obtain these travel kits simply call your respective drug company's hot line and request a travel kit.

### **Special Considerations for Flying**

When flying with your MS medications, it is important to keep your medication and supplies with you at all times in your carry-on luggage. Try to keep all of your syringes and needles together in an easily accessible container so that they are accessible for security inspection. It is also recommended that you bring a current prescription label with you to verify your need for medical supplies to airline officials.

# **B.** Packing for College

As you pack your personal items for college, remember to take some time to think about your MS medications and medical records.

You will want to talk with your resident advisor or ADA counselor several weeks before moving to school. Make sure to ask them where your medications need to be mailed. You will then need to change your mailing address with your pharmacy. You will also need to ask about refrigerators. Ask if your dorm room comes with a refrigerator and, if not, how you can get a refrigerator in your room.

When packing, make sure to pack enough supplies for at least one month. Many insurance companies will allow you to receive 60 to 90 day supplies of medication at a time. Make sure to check with your insurance.

### What to Pack:

### **D** Puncture Resistant Container

- **Refrigerator** (Make sure that it is large enough to hold at least a 1 month supply of your medication remember some dorms may already have refrigerators, or have a specific company that you have to order them through)
- □ **Medication** (1-3 months supply, check with your insurance company to see what your insurance will allow)
- **Autoinjector** (If applicable)
- Alcohol Wipes
- **Gauze Pads**
- **Heating Pad / Ice Packs** (If part of your medication routine)
- **Tylenol or Advil**
- **Emla cream** (If part of your medication routine)
- □ **Insulated Storage Container** to keep your medication cold when traveling if you are on Avonex, Copaxone, or Rebif
- **Copy of Medical Records**
- List of current MDs and contact information

# C. Medical Contacts and Medication Information

Name:		Birth Date:	
Emergency Contact 1:			
	Name	Phone Number	
Emergency Contact 2:			
	Name	Phone Number	
Allergies:			
Diagnosis:			

# **Current Physicians**

Physician	Specialty	Phone Number	Fax Number	Email

# **Current Medications**

Medication	Dose	Prescribing Provider	Start Date	End Date	

## **Hospitalizations & Surgeries**

Date	Reason for Hospitalization	Physician	Hospital	Comments

## **Pharmacy and Medical Supplies**

Medication / Medical Supply	Company	Contact number	Comments

**Diet or Nutritional Restrictions:** 

### **Comments:**

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# **IX. APPENDIX**

# Schools Using the Common Application Form:

- 1. Adelphi University
- 2. Agnes Scott College
- 3. Albion College
- 4. Albright College
- 5. Alfred University
- 6. Allegheny College
- 7. American University
- 8. Amherst College
- 9. Arcadia University
- 10. Assumption College
- 11. Augsburg College
- 12. Augustana College (IL)
- 13. Augustana College (SD)
- 14. Austin College
- 15. Babson College
- 16. Baldwin-Wallace College
- 17. Bard College
- 18. Barnard College
- 19. Bates College
- 20. Belmont University
- 21. Beloit College
- 22. Bennington College
- 23. Bentley College
- 24. Berry College
- 25. Binghamton University (SUNY) \*
- 26. Birmingham-Southern College
- 27. Boston College
- 28. Boston University
- 29. Bowdoin College

- 30. Bradley University
- 31. Brandeis University
- 32. Brown University
- 33. Bryant University
- 34. Bryn Mawr College
- 35. Bucknell University
- 36. Burlington College
- 37. Butler University
- 38. California Lutheran University
- 39. Caltech (California Institute of Technology)
- 40. Canisius College
- 41. Carleton College
- 42. Carnegie Mellon University
- 43. Carroll College
- 44. Case Western Reserve University
- 45. Catholic University of America
- 46. Cazenovia College
- 47. Centenary College of Louisiana
- 48. Centre College
- 49. Chaminade University of Honolulu
- 50. Champlain College
- 51. Chapman University
- 52. Chatham University
- 53. Claremont McKenna College
- 54. Clark University
- 55. Clarkson University
- 56. Coe College
- 57. Colby College
- 58. Colby-Sawyer College
- 59. Colgate University
- 60. College of Idaho
- 61. College of Mount Saint Vincent
- 62. College of New Jersey

- 63. College of Santa Fe
- 64. College of St. Benedict/St. John's University
- 65. College of the Atlantic
- 66. College of the Holy Cross
- 67. College of William and Mary \*
- 68. Colorado College
- 69. Colorado State University \*
- 70. Concordia College New York
- 71. Connecticut College
- 72. Converse College
- 73. Cornell College (IA)
- 74. Cornell University
- 75. Creighton University
- 76. Culver-Stockton College
- 77. Curry College
- 78. Dartmouth College
- 79. Davidson College
- 80. Denison University
- 81. DePauw University
- 82. Dickinson College
- 83. Dominican University of California
- 84. Drew University
- 85. Drexel University
- 86. Duke University
- 87. Earlham College
- 88. Eckerd College
- 89. Elizabethtown College
- 90. Elmira College
- 91. Emerson College
- 92. Emmanuel College
- 93. Emory University
- 94. Erskine College
- 95. Eugene Lang College of New School University

- 96. Fairfield University
- 97. Fisk University
- 98. Florida Southern College
- 99. Fordham University
- 100. Franklin and Marshall College
- 101. Franklin Pierce University
- 102. Furman University
- 103. Geneseo College (SUNY) \*
- 104. George Fox University
- 105. George Washington University
- 106. Gettysburg College
- 107. Gonzaga University
- 108. Goucher College
- 109. Green Mountain College
- 110. Grinnell College
- 111. Guilford College
- 112. Gustavus Adolphus College
- 113. Hamilton College
- 114. Hamline University (MN)
- 115. Hampden-Sydney College
- 116. Hampshire College
- 117. Hanover College
- 118. Hartwick College
- 119. Harvard College
- 120. Harvey Mudd College
- 121. Haverford College
- 122. Hendrix College
- 123. Hillsdale College
- 124. Hiram College
- 125. Hobart and William Smith Colleges
- 126. Hofstra University
- 127. Hollins University
- 128. Hood College

- 129. Illinois College
- 130. Illinois Institute of Technology
- 131. Illinois Wesleyan University
- 132. Immaculata University
- 133. Iona College
- 134. Ithaca College
- 135. John Carroll University
- 136. Johns Hopkins University
- 137. Juniata College
- 138. Kalamazoo College
- 139. Kenyon College
- 140. Keystone College
- 141. Knox College
- 142. La Roche College
- 143. Lafayette College
- 144. Lake Forest College
- 145. La Salle University
- 146. Lasell College
- 147. Lawrence Technological University
- 148. Lawrence University
- 149. Le Moyne College
- 150. Lees-McRae College
- 151. Lehigh University
- 152. Lesley College
- 153. Lewis & Clark College
- 154. Linfield College
- 155. List College, The Jewish Theological Seminary
- 156. Loyola College in Maryland
- 157. Loyola Marymount University
- 158. Loyola University New Orleans
- 159. Luther College
- 160. Lycoming College
- 161. Lynn University

- 162. Macalester College
- 163. Manhattan College
- 164. Manhattanville College
- 165. Marietta College
- 166. Marist College
- 167. Marlboro College
- 168. Marquette University
- 169. Massachusetts College of Pharmacy and Health Sciences
- 170. McDaniel College
- 171. Meredith College
- 172. Merrimack College
- 173. Miami University (OH) \*
- 174. Middlebury College
- 175. Mills College
- 176. Millsaps Moravian College
- 177. Moravian College
- 178. Morehouse College
- 179. Mount Holyoke College
- 180. Muhlenberg College
- 181. Naropa University
- 182. Nazareth College
- 183. New College of Florida \*
- 184. New England College
- 185. New York University
- 186. Nichols College
- 187. Northeastern University
- 188. Northland College
- 189. Northwestern University
- 190. Notre Dame de Namur University
- 191. Oberlin College
- 192. Occidental College
- 193. Oglethorpe University
- 194. Ohio Wesleyan University

- 195. Pace University
- 196. Pacific University
- 197. Pitzer College
- 198. Pomona College
- 199. Presbyterian College
- 200. Prescott College
- 201. Princeton University
- 202. Providence College
- 203. Quinnipiac University
- 204. Randolph College
- 205. Randolph-Macon College
- 206. Reed College
- 207. Regis College
- 208. Regis University
- 209. Rensselaer Polytechnic Institute
- 210. Rhodes College
- 211. Rice University
- 212. Richard Stockton College of New Jersey \*
- 213. Rider University
- 214. Ripon College
- 215. Rochester Institute of Technology
- 216. Roger Williams University
- 217. Rollins College
- 218. Russell Sage College
- 219. Sacred Heart University
- 220. Sage College of Albany
- 221. Saint Anselm College
- 222. Saint Joseph's College of Maine
- 223. Saint Joseph's University
- 224. Saint Leo University
- 225. Saint Louis University
- 226. Saint Mary's College (IN)
- 227. Saint Mary's College of California

- 228. Saint Michael's College
- 229. Saint Peter's College
- 230. Saint Vincent College
- 231. Salem College
- 232. Salve Regina University
- 233. Santa Clara University
- 234. Sarah Lawrence College
- 235. Scripps College
- 236. Seattle University
- 237. Seton Hall University
- 238. Seton Hill University
- 239. Sewanee (University of the South)
- 240. Siena College
- 241. Simmons College
- 242. Skidmore College
- 243. Smith College
- 244. Southern Methodist University
- 245. Southern New Hampshire University
- 246. Southwestern University
- 247. Spelman College
- 248. Spring Hill College
- 249. St. John Fisher College
- 250. St. Lawrence University
- 251. St. Norbert College
- 252. St. Olaf College
- 253. Stanford University
- 254. Stetson University
- 255. Stevens Institute of Technology
- 256. Stonehill College
- 257. Stony Brook University \*
- 258. Suffolk University
- 259. SUNY College at Oneonta \*
- 260. SUNY Cortland \*

- 261. SUNY Fredonia \*
- 262. SUNY New Paltz \*
- 263. SUNY Oswego \*
- 264. Susquehanna University
- 265. Swarthmore College
- 266. Sweet Briar College
- 267. Syracuse University
- 268. TCU (Texas Christian University)
- 269. Thiel College
- 270. Thomas College
- 271. Transylvania University
- 272. Trinity College (CT)
- 273. Trinity University (TX)
- 274. Tufts University
- 275. Tulane University
- 276. Union College
- 277. University at Albany (SUNY) \*
- 278. University at Buffalo (SUNY) \*
- 279. University of Chicago
- 280. University of Dallas
- 281. University of Dayton
- 282. University of Delaware \*
- 283. University of Denver
- 284. University of Findlay
- 285. University of La Verne
- 286. University of Maine \*
- 287. University of Maine at Farmington\*
- 288. University of Maine at Machias \*
- 289. University of Mary Washington \*
- 290. University of Massachusetts Amherst \*
- 291. University of Massachusetts Boston\*
- 292. University of Miami
- 293. University of New England

- 294. University of New Hampshire \*
- 295. University of New Haven
- 296. University of Notre Dame
- 297. University of Pennsylvania
- 298. University of Portland
- 299. University of Puget Sound
- 300. University of Redlands
- 301. University of Richmond
- 302. University of Rochester
- 303. University of San Diego
- 304. University of San Francisco
- 305. University of Scranton
- 306. University of Southern Maine \*
- 307. University of Tampa
- 308. University of the Pacific
- 309. University of Tulsa
- 310. University of Vermont \*
- 311. University of Virginia \*
- 312. Ursinus College
- 313. Utica College
- 314. Valparaiso University
- 315. Vanderbilt University
- 316. Vassar College
- 317. Villanova University
- 318. Wabash College
- 319. Wagner College
- 320. Wake Forest University
- 321. Washington & Jefferson College
- 322. Washington and Lee University
- 323. Washington College (MD)
- 324. Washington University in St. Louis
- 325. Webster University
- 326. Wellesley College

- 327. Wells College
- 328. Wentworth Institute of Technology
- 329. Wesleyan University
- 330. Westminster College (MO)
- 331. Westminster College (PA)
- 332. Westminster College (UT)
- 333. Wheaton College (MA)
- 334. Wheelock College
- 335. Whitman College
- 336. Whittier College
- 337. Willamette University
- 338. William Jewell College
- 339. Williams College
- 340. Wilson College
- 341. Wittenberg University
- 342. Wofford College
- 343. Wooster, The College of
- 344. WPI (Worcester Polytechnic Institute)
- 345. Xavier University
- 346. Yale University