National Multiple Sclerosis Society

Experience Ability: Multiple Sclerosis (MS) Awareness

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Learning objectives

- To become more familiar with multiple sclerosis (MS)
- Define employment issues experienced by individuals with MS
- Recognize and understand characteristics of adult-onset physical disabilities, hidden disabilities, and the implications they may have in the workplace
- Expand knowledge of resources available when working with employees with MS

What is MS?

- MS is thought to be an autoimmune disease that affects the central nervous system (brain, spinal cord, and optic nerves)
- Its name is derived from the *scarring* caused by inflammatory attacks in *multiple* sites in the central nervous system
- Myelin sheath is what gets affected
- Is not fatal, contagious, directly inherited, or always severely disabling

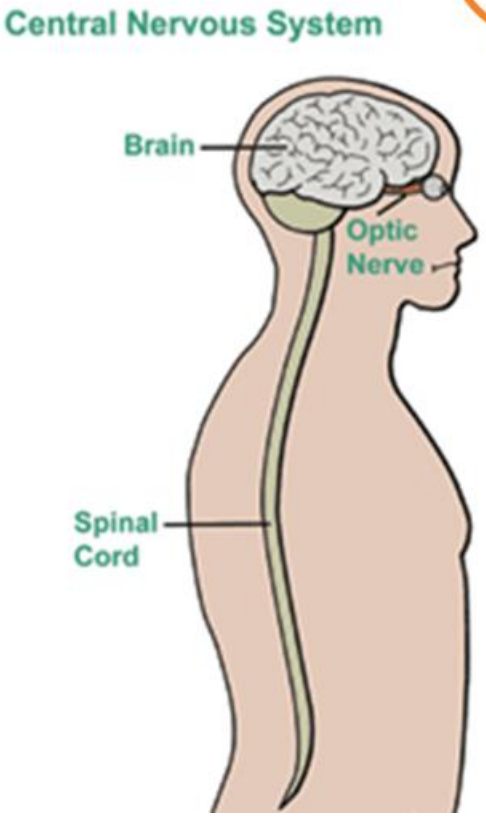
What is MS?

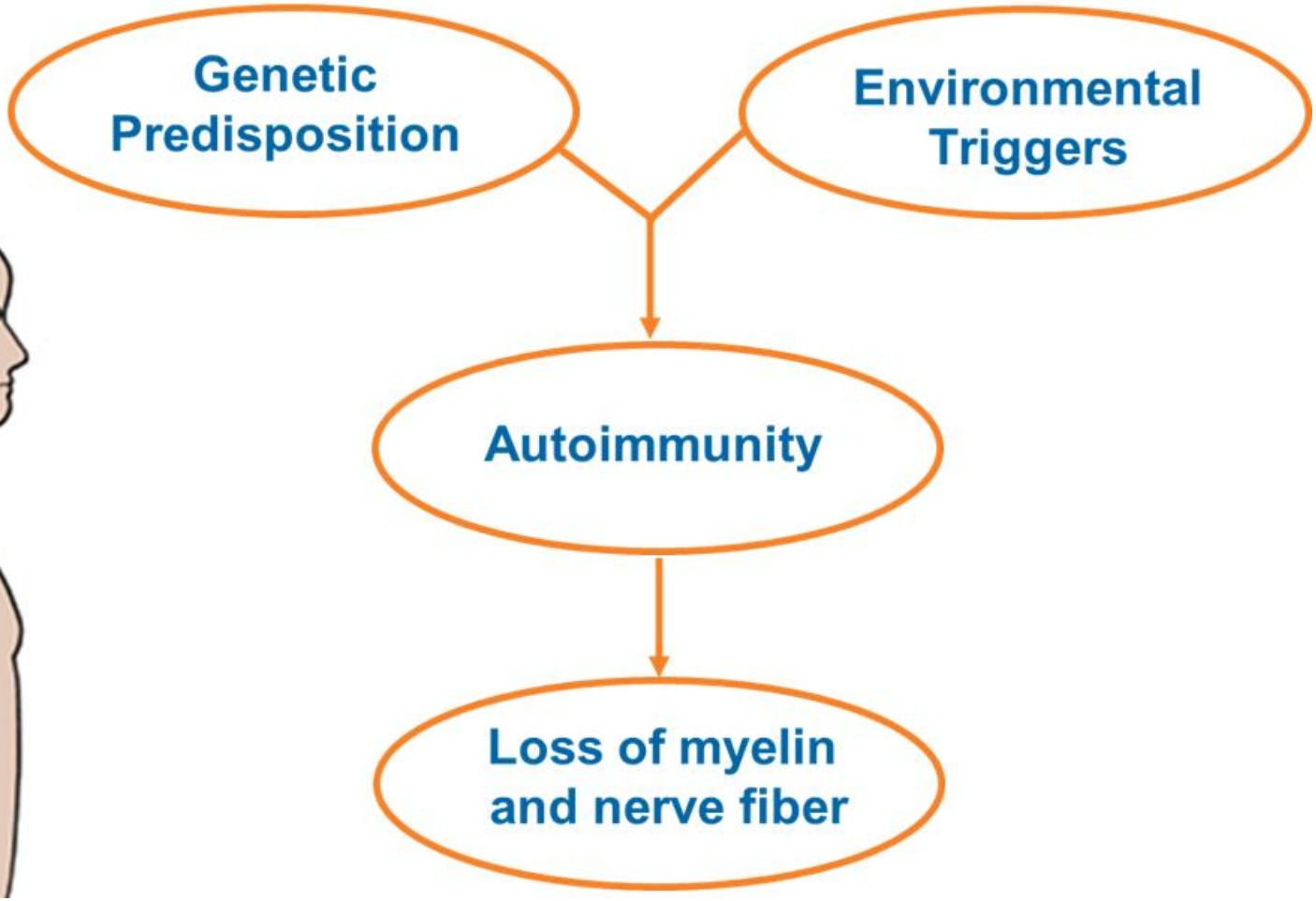
- Autoimmune = body "attacks" itself
- Immune response (inflammation and damage) mounted against myelin (nerve fiber insulation)
- Other autoimmune disorders include rheumatoid arthritis, lupus

What causes MS?

- We do not yet have the answer to this question
- Current hypothesis:
  - Genetic predisposition to respond to an environmental trigger
  - As-yet-unidentified environmental trigger
    - Virus(es)?
    - Bacterium(ia)?

What causes MS?





Who gets MS?

- Usually diagnosed between 20 and 50
  - Occasionally diagnosed in young children and older adults
  - In the midst of a person's career
- More common in women than men (2-3:1)
- More common in those of Northern European ancestry
  - More common in Caucasians than Hispanics or African Americans; rare among Asians
- More common in temperate climates of the world
- Approximately 400,000 people with MS in the US, 2.3 million worldwide
- Every week about 200 people are diagnosed

How is MS diagnosed?

- MS is a clinical diagnosis
  - Medical history
  - Symptoms and signs
- Requires evidence of scarring (plaques) in at least 2 areas of the CNS as seen on a MRI
- Requires evidence that the plaques occurred at different points in time
- There must be no other explanation

Diagnostic tests commonly used

- Magnetic resonance imaging (MRI)
- Evoked potentials
  - Visual evoked potentials (VEP)
  - Somatosensory evoked potentials (SEP)
- Lumbar puncture (spinal tap)

What is the prognosis?

- Hallmarks of MS is its unpredictability and variability
- Approximately one-third will have a very mild course
- Approximately one-third will have a moderate course
- Approximately one-third will become more disabled

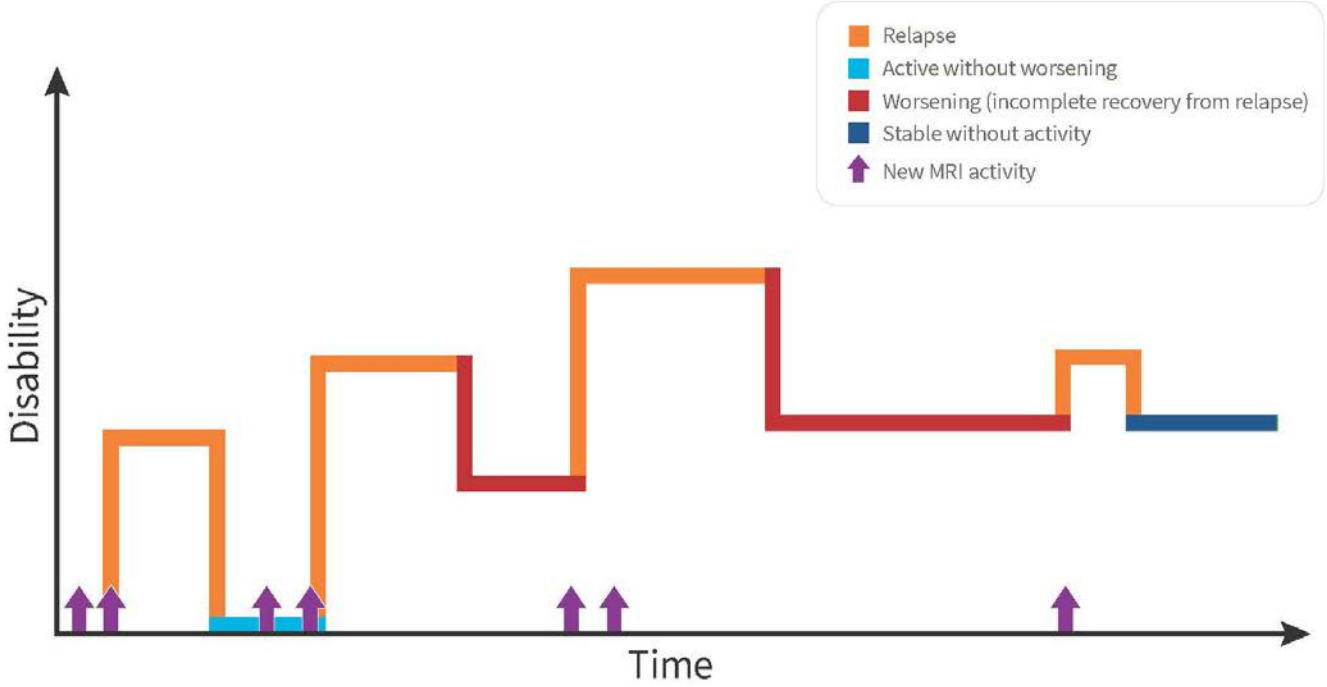
Four General Patterns/Types

- Clinically Isolated Syndrome
- Relapsing Remitting MS
- Primary Progressive MS
- Secondary Progressive MS

What are the different patterns of MS?

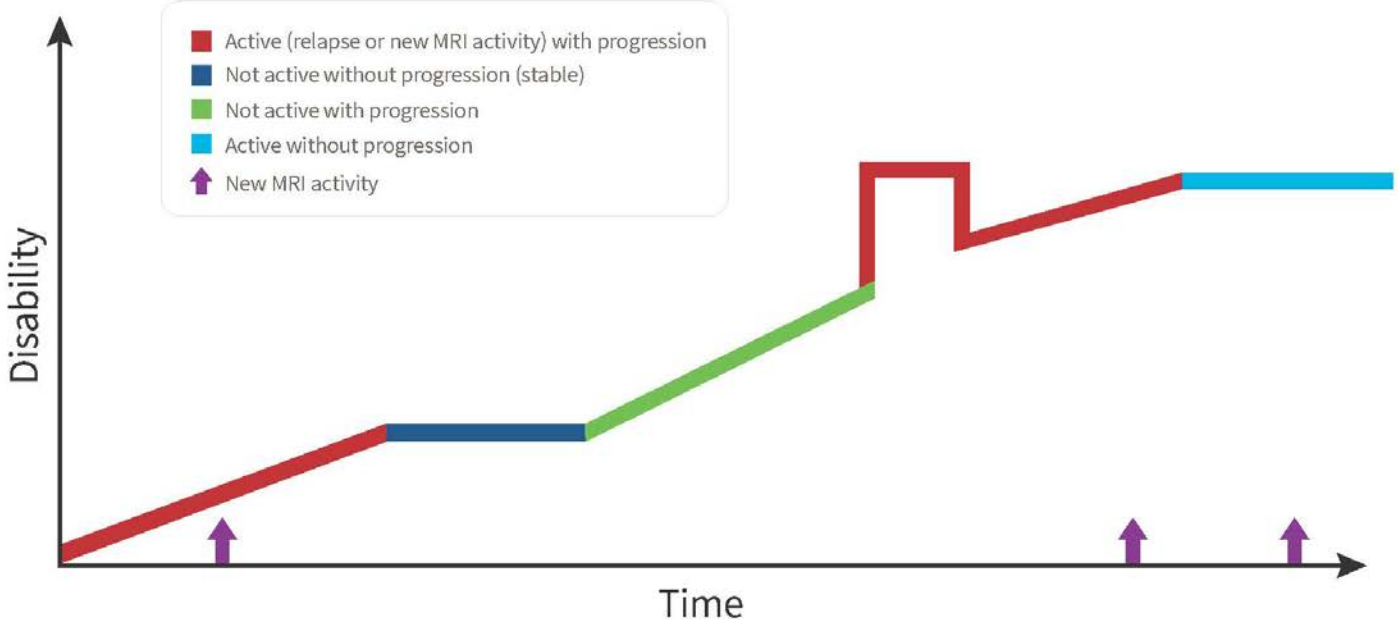
- **Clinically Isolated Syndrome (CIS)**: First episode of inflammatory demyelination in the CNS that could become MS if additional activity occurs.
- **Relapsing-Remitting MS (RRMS)**: Attacks (relapses) followed by recovery (remission) — most common form. No apparent progression during remission.
- **Primary-Progressive MS (PPMS)**: A small percentage of people experience progression from onset, without initial relapses or remissions.
- **Secondary-Progressive MS (SPMS)**: Following a RRMS course in most individuals, the disease becomes more steadily progressive, with or without relapses.

RRMS



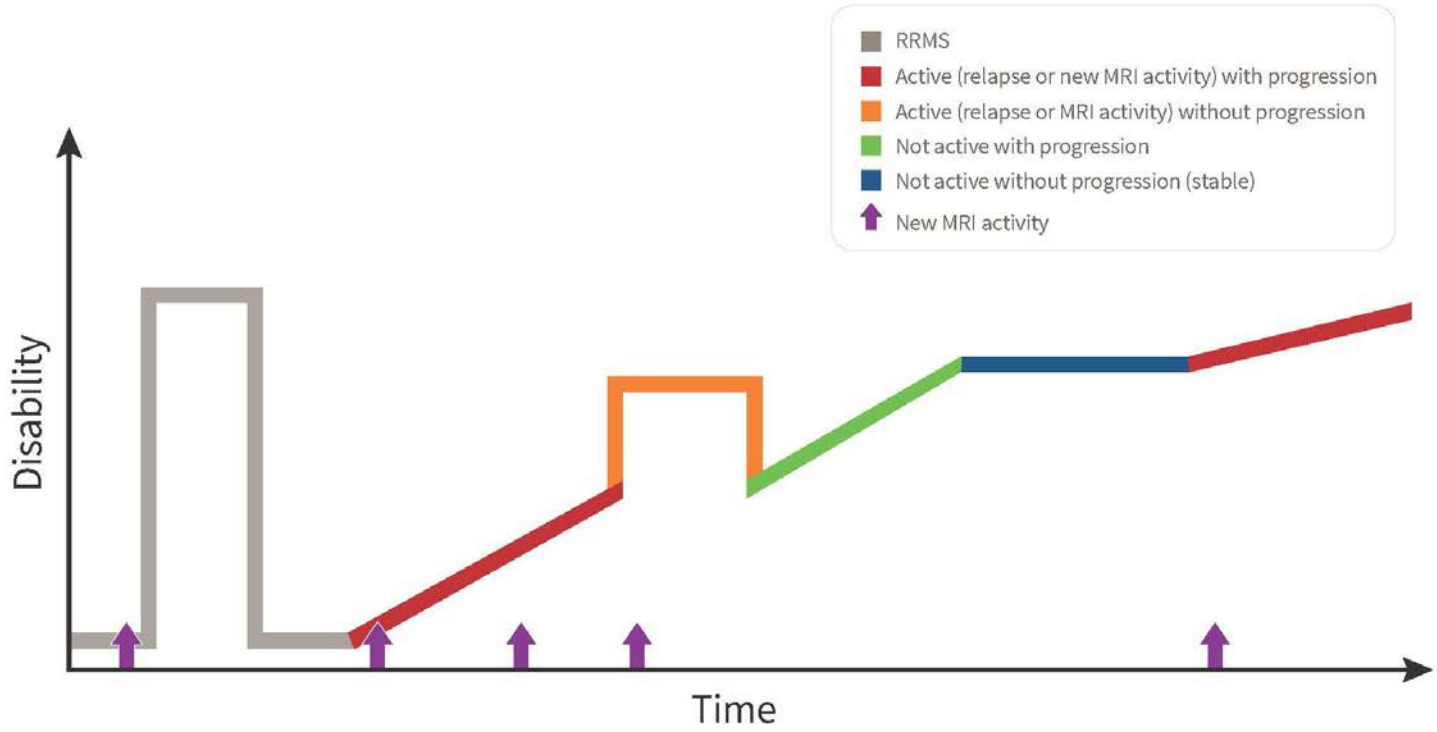
Source: Lublin et al., 2014.

PPMS



Source: Lublin et al., 2014.

SPMS



Source: Lublin et al., 2014.

What are the *possible* symptoms?

- Fatigue (most common)
- Vision problems
- Stiffness (spasticity)
- Cognitive changes (memory, attention, processing)
- Walking difficulties (weakness, imbalance)
- Emotional changes (depression, mood swings)
- Bladder/bowel dysfunction
- Sexual problems
- Sensory problems (tingling/numbness)
- Heat sensitivity
- Speech/swallowing difficulties
- Pain
- Tremor

How is MS treated?

- While we continue to look for the cure, the focus of MS care is:
  - Treating exacerbations (flare-ups or attacks)
  - Slowing disease progression
  - Managing symptoms
  - Maintaining/improving function
  - Enhancing quality of life

How are exacerbations treated?

- Exacerbations (flare-ups of new symptoms or aggravation of old ones, lasting at least 24 hours) may be treated with corticosteroids to reduce inflammation
  - Short course of intravenous, high-dose methylprednisolone followed by a taper of oral prednisone; oral steroids
  - Not all exacerbations require treatment

How is the disease course treated?

Thirteen FDA-approved disease modifying therapies

- Target inflammation process and decrease lesions
- All reduce attack frequency/severity, reduce scarring on MRI, and probably slow disease progression/level of disability
- Are not a cure for MS
- Do not prevent recurring symptoms
- Early treatment is important

FDA-Approved Disease-Modifying Agents

- Aubagio (teriflunomide), oral, 2012
- Avonex (interferon beta-1a), intramuscular injection, 1996
- Betaseron (interferon beta-1b), subcutaneous injection, 1993
- Copaxone (glatiramer acetate), subcutaneous injection, 1996
- Extavia (interferon beta-1b), subcutaneous injection, 2009
- Gilenya (fingolimod), oral, 2010
- Glatopa (glatiramer acetate), subcutaneous injection, 2015 [generic equivalent of Copaxone 20mg]
- Lemtrada (alemtuzumab), IV infusion, 2014
- Novantrone (mitoxantrone), IV infusion, 2000
- Plegridy (pegylated interferon beta-1a), subcutaneous injection, 2014
- Rebif (interferon beta-1a), subcutaneous injection, 2002
- Tecfidera (dimethyl fumarate), oral, 2013
- Tysabri (natalizumab), IV infusion, 2006

How are MS symptoms treated?

- Symptoms caused by inflammation are likely to disappear as the inflammatory attack subsides
- Symptoms caused by scarring and damage to the nerve cells themselves are likely to remain
- There are a variety of medications and management strategies available to manage the many types of symptoms that can occur
- Rehabilitation may prove useful as well – PT, OT, SLP, wellness and exercise programs, etc. to manage symptoms as well as improve overall quality of life

Impact of MS on employment

- 90% of people with MS have work experience
- Approximately 60% are working at the time of diagnosis
- Several years down the road, the percentage remaining in the workplace drops to around 40%
- Diagnosis often occurs in the midst of a person's career; oftentimes have completed advanced training/degrees
- Have a wealth of experience and been working in chosen field for a considerable amount of time and moving up the "career ladder"
- Importance of recognizing implications of adult-onset condition

Employment issues and reasons for leaving the workplace

- People might leave prematurely and voluntarily
- People might not tap into legal protections designed to assist individuals with disabilities retain employment
- People might not know of appropriate accommodation strategies
- Concerns involving disclosure
- Particular challenges – variability of symptoms, condition changing over time
- Significant others in person's life tell person to stop working – say work is "too stressful"
- They may erroneously believe that working will make their MS worse
- Don't know of appropriate resources
- Transportation issues

Characteristics of adult-onset physical disabilities

- Since diagnosed later in life, may have completed advanced training/degrees
- May have been working in their chosen field for a considerable amount of time (wealth of experience)
- Been working and moving up the career ladder
- May be in high level positions but finding it more difficult to maintain that level of work
- The probability of a white-collar worker becoming disabled for 90 days or longer between the ages of 35 and 65 is 27% for men and 31% for women*
- Anyone can experience a disability at any time so think about how you would want to be treated if you incurred an adult-onset disability
- Other adult-onset conditions can include lupus, rheumatoid arthritis, diabetes, spinal cord injury, fibromyalgia, etc.

*(Source: "The Real Risk of Disability in the United States," Life and Health Insurance Foundation for Education, May 2007)

Implications of hidden/invisible symptoms or non-apparent disability

- “But you look so good” mentality by others prevents others from “accepting” hidden disabilities as real
- May be even more stressful for that employee – don’t want to be seen as different or getting preferential treatment so hesitant to ask for needed accommodations
- According to ADA individuals don’t need to disclose unless requesting accommodations but may feel the stress of not telling others (am I being dishonest?)
- Reality is that hidden symptoms cause just as many limitations as visible ones
- Hidden disabilities not limited to MS – examples may include epilepsy/seizure disorder, arthritis, diabetes, learning disabilities, psychiatric illness

Common Hidden Symptoms of MS

- Fatigue
- Tingling/numbness
- Cognitive symptoms
- Vision problems
- Bladder/bowel problems
- Pain
- Heat sensitivity
- Emotional changes/depression

Common legal protections person might tap into

- Americans with Disabilities Act (ADA)/Rehabilitation Act of 1973 (section 504)
  - Issues including disclosure and reasonable accommodations
  - Offers equal opportunity and anti-discrimination
  - Key components of the ADAAA (ADA Amendments Act of 2008) apply to conditions like MS
- Family and Medical Leave Act (FMLA)
  - Job-protected leave without pay and maintenance of benefits
- Consolidated Omnibus Budget Reconciliation Act (COBRA)
  - Allows for continuation of health insurance coverage

Employment issues and MS - Disclosure

- Relationship to accommodations
- Personal decision to make
- Can be a stressful experience/decision, especially with "invisible symptoms"
- Employee may ultimately decide not to disclose
- Timing, how much information, who is appropriate person?
  - Before interview? At interview? Once receive offer? Once start job? Never?
- May be beneficial depending on type of employer (e.g., Section 503 re: Federal Government contractors, Schedule A for Federal Government agencies)

The disclosure dilemma: Advantages and disadvantages

ADVANTAGES

- Reduces stress
- Educate others about MS and adult-onset disabilities
- Allows individual the opportunity to ask for accommodations now or in the future
- May be freer to examine health insurance and other benefits
- May simply feel more comfortable

DISADVANTAGES

- Fear of rejection…ultimate fear of losing job
- May fear being pigeon-holed at work
- Don’t want to be seen as different or weak by others
- Might want to maintain privacy

Tips on disclosing

- Think about it….script it…practice it
- Stay away from medical terminology and don't give complete medical history
- Use "sound bites" and easy to understand language
- Determine WHO appropriate person is…WHEN is the correct time…WHAT to say…WHY disclose?
- Four general components of disclosure script
  - Disclosing the condition (actual medical diagnosis or not?)
  - Relating it to individual's symptoms
  - Requesting appropriate accommodations
  - Finishing on a positive note
- Employee plays major role and has bulk of responsibility; ultimately needs to be interactive process

Job Accommodations

- Many people living with MS want to work and continue to work despite their symptoms
- Many symptoms can be managed on the job with accommodations
- Computer technology, other forms of assistive technology, and proper ergonomic work station set-up
- Arrangement of workspace by task frequency and priority
- Flexible work schedule – telecommuting, altered hours
- Elimination of distractions/clutter that might impair attention and other cognitive functioning
- Type of and need for accommodations may change over time as symptoms change or when person experiences an exacerbation or when job situation changes

Accommodations for common MS symptoms

Symptoms	Accommodations
• Fatigue	• Flexible work hours • Combining breaks • Rest period • Telecommuting
• Cognitive symptoms	• Eliminate distractions • Calendar/day planner • Organize work area • Project focused
• Heat sensitivity	• A/C or fan • Cooling vest

Accommodations for common MS symptoms

Symptoms	Accommodations
• Fine motor impairment	• Provide alternate computer and telephone access • Writing and grip aids
• Gross motor impairment	• Ensure work-site and work-station are accessible • Adjust desk height for wheelchair • Parking close to work-site
• Vision difficulty	• Increase font size and use accessibility computer features • Install proper lighting • Glare screen

Employer best practices

- Disclosure may be even more stressful – create an environment of openness and support
- Be supportive if employee discloses for disclosure sake but no need for accommodations at present time
- Variability of symptoms may require accommodations to change from time to time
- Importance of confidentiality from managers/ supervisors as well as coworkers
- Be open to questions about employer-sponsored benefits including FMLA and disability
- Employee resource groups

Real life success stories

- Practical accommodation strategies to manage cognitive symptoms
- Career change utilizing transferrable skills
- Federal government positions – utilizing Schedule A for hiring

Don’t do it alone - resources

- National MS Society employment-related publications/ brochures
  - The Win-Win Approach to Reasonable Accommodations
  - ADA and People with MS
  - Focus on Employment
  - A Place in the Workplace
  - Should I Work? Information for Employees
  - Information for Employers
- National MS Society website – www.nationalMSsociety.org
- National MS Society information regarding employment – www.nationalMSsociety.org/employment
- National MS Society interactive disclosure tool – www.nationalMSsociety.org/Resources-Support/Employment/Disclosure-Decisions
- National MS Society telephone number – 1-800-344-4867

Don’t do it alone - resources

- *MS in the Workplace: A Guide for Employers* DVD available from National MS Society (also available online)
- *Employment Matters: Managing MS in the Workplace* available from National MS Society (DVD and toolkit, available online)
- *Career Crossroads: Employment and MS* available from National MS Society (DVD and workbook, available online)
- Job Accommodation Network (JAN) – http://askjan.org, 1-800-526-7234
- JAN’s information on MS – http://askjan.org/media/mult.htm
- ADA National Network – http://www.adata.org, 1-800-949-4232
- AbleData - http://www.abledata.com/, 1-800-227-0216

National Multiple Sclerosis Society

Chapters serve every state. To find your local chapter go to
http://www.nationalmssociety.org/chapters

- Information and referral
- Support/self-help groups
- Educational workshops and teleconferences
- Physical wellness/exercise programs
- Financial assistance
- Advocacy efforts
- Newly diagnosed education and information
- Benefits, employment, and health insurance assistance services
- Brochures/publications, *MS Connection* newsletter, *Momentum* magazine
- Online community – www.msconnection.org
- Together We are Stronger - www.WeAreStongerThanMS.org
- Fundraising events – WalkMS, BikeMS, Challenge WalkMS, RunMS, MuckFestMS

Key points to remember

- MS is an unpredictable, variable and progressive disease
- MS is different for every individual
- People living with MS often have considerable professional experience and education
- Many symptoms of MS may not be apparent
- Employers should be aware of and sensitive to disclosure issues
- Accommodations are key
- Success is possible

Thank you!

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www.nationalMSsociety.org

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