Overview of Multiple Sclerosis for Vocational Counselors

Presented by Gloria Hou, MD

April 6, 2016

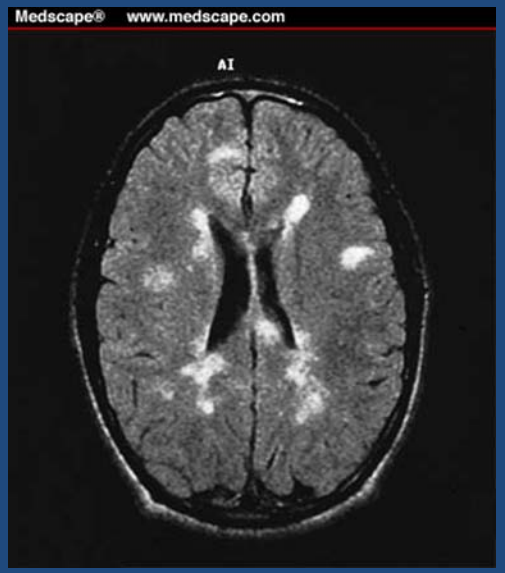
Outline

- MS overview, epidemiology, natural history
- Symptoms and symptom management
- Employment and MS
- Patient Examples

What is MS?

- At least 2 neurologic deficits separated in time and space, not explained by other etiology

- Immune attack on the central nervous system
  - Affects white and gray matter
  - Affects myelin and axons



Mahad and Ransohoff 2013

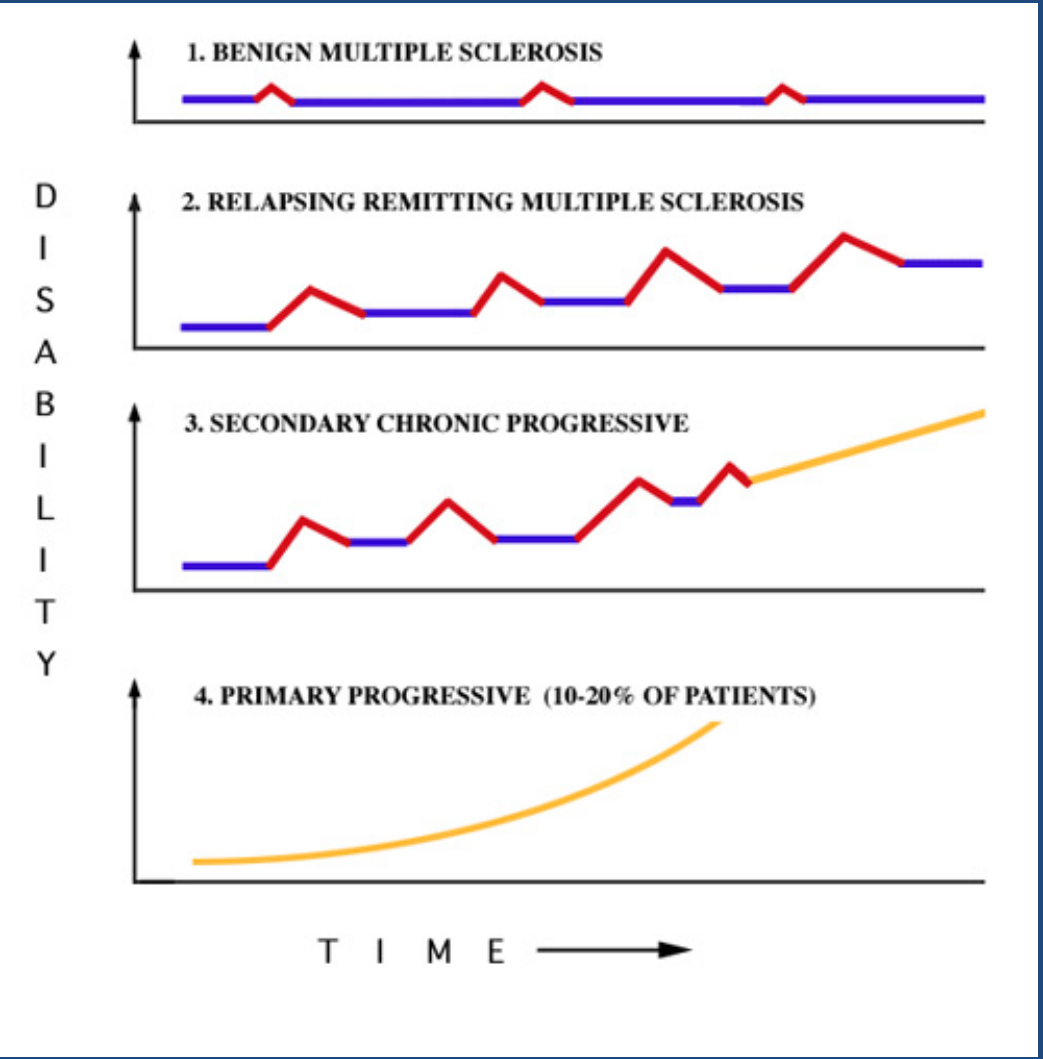
Epidemiology and Natural History

Epidemiology

- Affects 1 in 1000 people
- More common further from the equator
  1 in 400 in Canada, 1 in 5000 in Brazil
  - Risk: low Vitamin D
- More common in those with European ancestry
- Rare in those with African ancestry, but disease is more aggressive
- Smoking: faster brain atrophy

Koch 2013.

Multiple Sclerosis Subtypes



http://library.med.utah.edu/kw/ms/mml/ms_class.html

Multiple Sclerosis Subtypes

- 80-90% start off relapsing remitting
  - Median age of onset: 30
  - Female: Male 2:1
- 10% primary progressive
  - Median age of onset: 40
  - Female: Male 1:1
- Conversion to secondary progressive
  - Median age of onset: 40
- "Benign MS"—among those with milder disease (EDSS 3) after 10 years, 80% did not need a cane at 20 years

Koch 2013

Natural History

- Lifespan: ~6 years shorter than general population
- RRMS, progression to cane use:
  - Median 30 years
- PPMS, progression to cane use:
  - Median 15 years
  - 8 years fastest quartile vs. 25 years in slowest quartile

Relapse

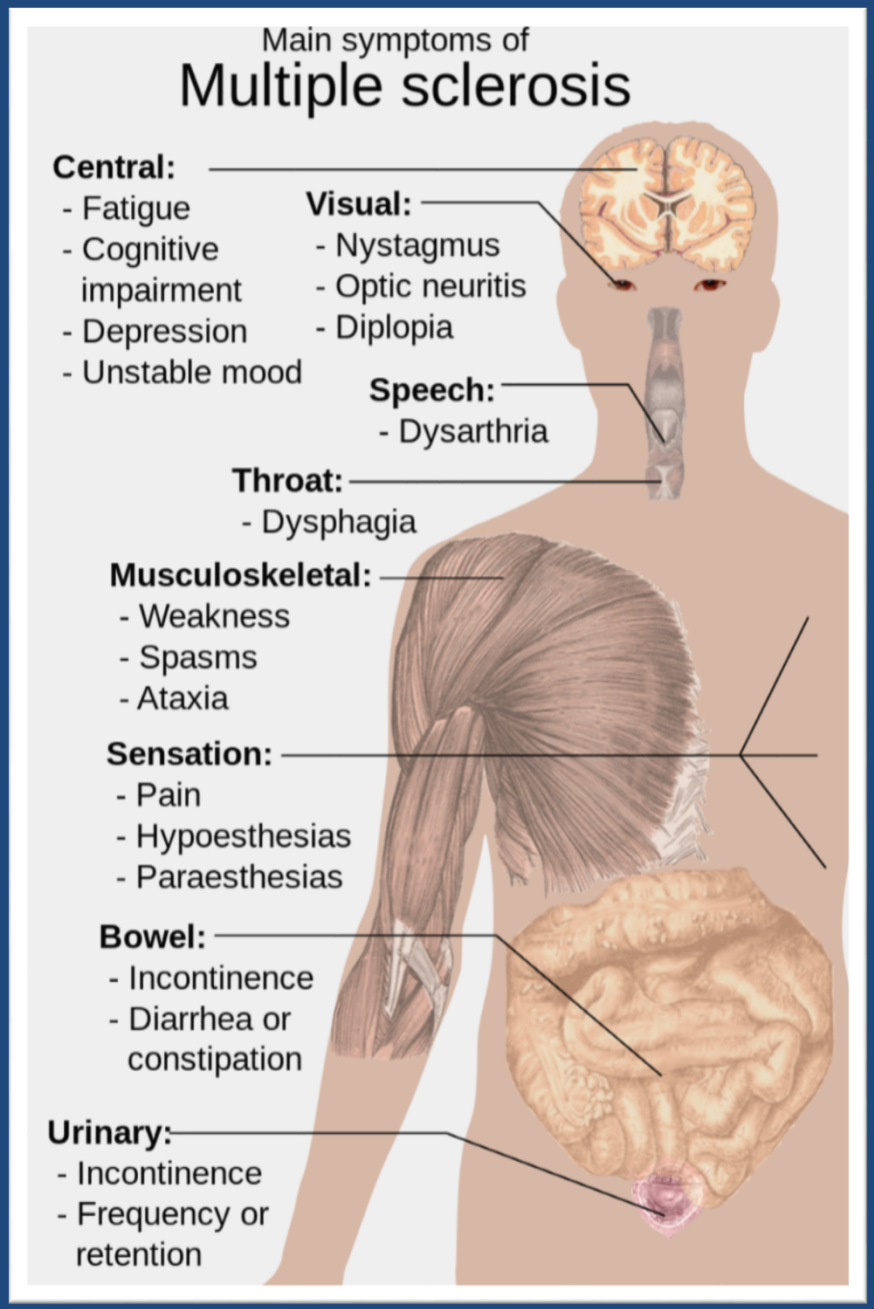
- New or worsening MS symptoms
- Must rule out pseudorelapse (secondary to infection or other cause)
  - Ddx:
    - Urine infecton
    - Pneumonia
    - Skin ulcers
    - Sleep deprivation
    - Stress/depression

Fox 2013

Relapse

- Onset typically over days to weeks.
- IV steroids for 3-5 days may hasten recovery
- Recovery typically takes weeks to months
- Most relapses leave minimal residual effects

Fox 2013



Wikipedia

Symptoms

And

Symptom Management

Symptoms

- Fatigue
- Sleep disorders
- Depression/anxiety
- Cognitive Impairment
- Weakness (ADLs/exercise/ambulation)
- Pain
- Spasticity
- Bowel/bladder dysfunction
- Visual disturbance

Fatigue

- Affects 80% of persons with MS
- Different from fatigue in persons without MS:
  - Daily
  - May be independent of sleep
  - Worse with heat
  - Worse later in the day
  - May interfere with daily responsibilities

National MS Society Website

Fatigue

- Many causes:
  - Sleep disorders
  - Anemia
  - Thyroid dysfunction
  - Deconditioning
  - Heat
  - Depression
  - Pain

Fatigue: Medications

- Amantadine
- Modafanil
- Methylphenidate
- Others…

Fatigue: Rehab Interventions

- Rehabilitation interventions bigger effect size than medication (Asano and Finlayson 2014)

- Mindfulness Based Interventions (Mindful breathing/tai chi/yoga) decreased fatigue at 6 month follow up (Simpson et al. 2014)

Fatigue: Energy Conservation Management

- "Managing Fatigue" course—systematic best use of limited energy
  - Balance work and rest
  - Delegate
  - Prioritize
  - Organize work spaces
  - Communicate needs to others
  - Use assistive technologies
  - →learn self management

- Meta-analysis shows ECM helpful in short term (Blikman et al., 2013):
  - Reduces impact of fatigue
  - Helps physical function
  - Helps social function
  - Helps mental health

Conservation of Energy: Key Concept

- Occupational therapists can help
- Efficiency = Less Fatigue
- Examples:
  - sit for meals/dressing/grooming
  - shower at night instead of before work
  - Place frequently used objects at front of fridge/cabinet

Heat Sensitivity: Contributes to Fatigue

- Air conditioner
- Cool beverage
- Cooling collars/vests/headbands

Sleep disorders

- Treatment may help fatigue.

- Half pwMS poor sleep
  - Pain
  - Restless legs
  - Leg spasms
  - Nighttime urination
  - Depression/anxiety

Veauthier and Friedemann 2014

Mood

- Depression and anxiety are common (46%, 17%)
- Untreated pwMS tend to become more depressed
- Loss of social roles may contribute more than loss of physical functioning

Simpson et al. 2014; DeLuca and Nocentini 2011

Cognitive Impairment

- Cognitive impairments in 50-60% pwMS
  - Correlates with width of 3rd ventricle > brain atrophy > lesion load

- Affects:
  - Attention
  - Memory formation and retrieval
  - Processing speed
  - Executive function

Pepping M, Brunings J, Goldberg M 2013

Cognitive Impairment

- Neuropsychologists, speech therapists can help.

- Cochrane Review (Rosti-Otajarvi and Hamalainen 2014)
  - Positive low level evidence (18 out of 20 studies)
  - Helps:
    - Memory span
    - Working memory
    - Immediate verbal memory
    - Delayed memory
    - Attention

Cognitive Strategies

- Memory and new learning:
  - Summarize key points
  - Take notes in single location, review notes
- Decreased processing speed:
  - Ask for written summary of verbal information
- Attention:
  - Minimize distraction
  - Earplugs, reduced clutter, avoidance of crowded places
  - To do list
  - Avoid phone/email alerts
- Time management:
  - Daily time to plan the day
  - Schedule breaks
- Strategies for Task Completion:
  - Plan timeline to complete steps in project
  - Allot extra time

Pepping M, Brunings J, Goldberg M 2013

Gait Difficulty

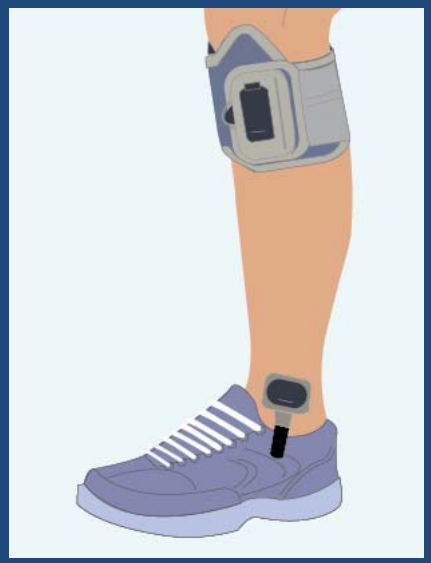
- Foot drop
- Weakness
- Decreased endurance
- Loss of range of motion

Treatment of Gait Impairment

- Referral to physical therapy
- Exercise
  - Reduces fatigue
  - Improves mobility
  - Improves strength
  - May enhance health-related quality of life
- Medication
  - Dalfampridine

Latimer-Cheung et al., 2013

Gait Impairment



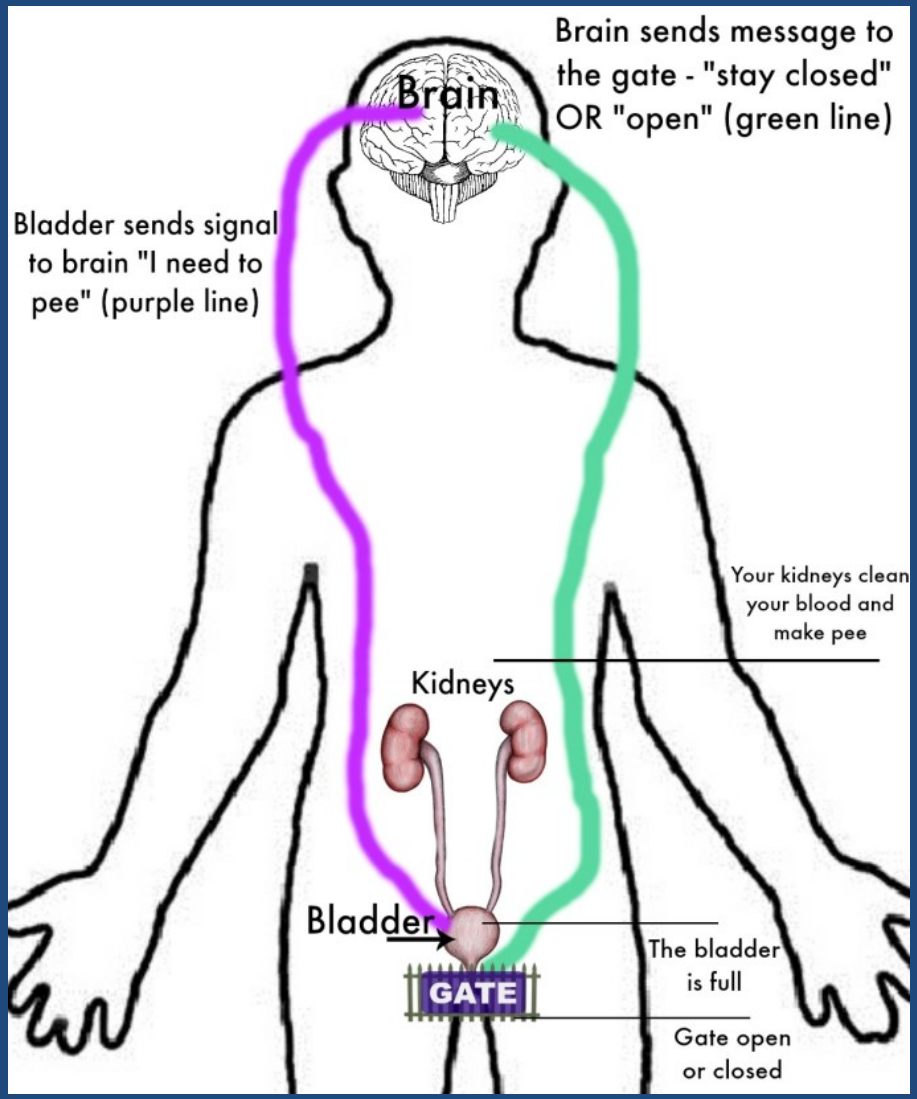
Pain

- Musculoskeletal→ Physical/occupational therapy
- Neuropathic→Meds such as gabapentin, pregabalin, duloxetine, carbamazepine
- Concomitant depression/anxiety/stress→ Psychology referral

Spasticity, Spasms

- Velocity-dependent increase in tone
- Medications: baclofen, tizanidine, diazepam
- Stretching/Physical Therapy
- Rule out urine infection.

Bladder Urgency and Incontinence



- Most commonly small, frequent, urgent voids
- Sometimes urinary retention
- Correlates with gait dysfunction

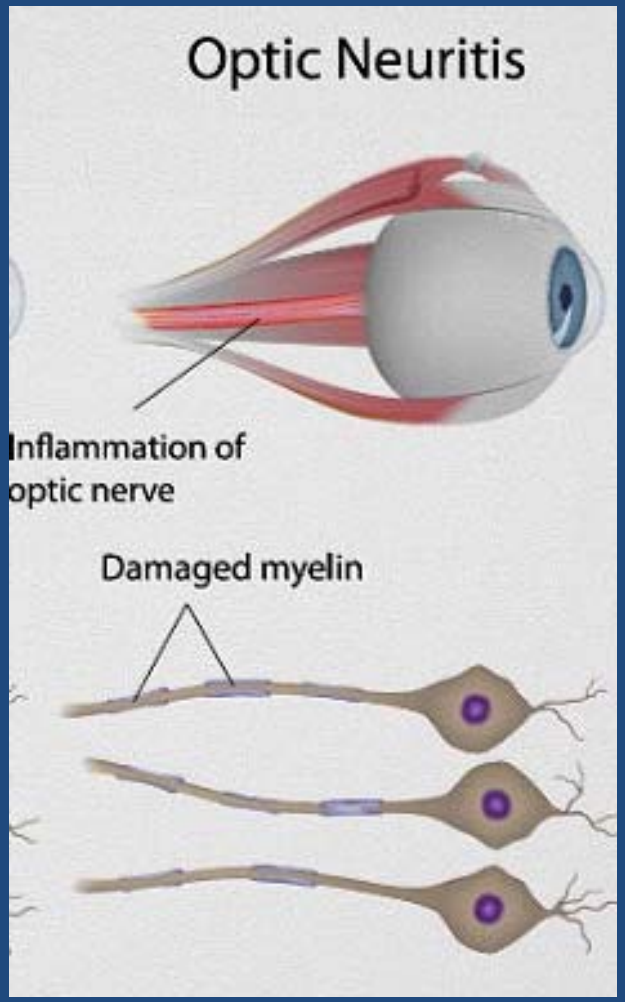
Denys et al. 2014

Bladder Treatments

- Behavioral: Timed void, fluid restriction, pelvic floor therapy
- Condom catheters, incontinence pads
- Meds: Anticholinergics/tricyclic antidepressants medications/desmopressin
- Bladder Botulinum Toxin
- In dwelling catheters, Intermittent catheters

Yang 2013

Optic Neuritis



-Patients feel as if they are going blind

-LUCKILY, most resolve with few residual deficits

Employment and MS

Work and MS

- At diagnosis
  - Most people are working or in school
  - 90% have a work history

Doogan and Playford 2014

Why Work?

- Financial security
- Structure to the day
- Social interaction
- Self esteem

Doogan and Playford 2014

Loss of Work and MS

- Loss of work especially rapid in first 3 years after diagnosis
- 10 years post diagnosis, 25% still working
- Often move to lower demand jobs
- Hard to be promoted, hard to change jobs, hard to be rehired

Doogan and Playford 2014

Trying Times

- Time of diagnosis
- Relapse
  - Graded return to work often helps
- Progression
  - Financial planning
  - Part time work?

Doogan and Playford 2014

Challenges to Working

- Unpredictable relapses
- Invisible symptoms: fatigue, mood, cognition
- Visible symptoms: mobility, dexterity, vision, urinary frequency

Doogan and Playford 2014

pwMS Reasons for Quitting

- 64% left their job for one of these reasons:
  - Mobility
  - Decreased arm/hand use
  - Fatigue
  - Cognition

Doogan and Playford 2014

What help is desired?

- Disclosure, talking with employers
- Information about anti-discrimination laws, FMLA (>50 employees)
- Information about reasonable accommodations
- Referral to support sources
- Supporting work performance
- Symptom management

Patients' Reasons for Quitting

- 1/3 felt that they were too stressed to work or weren't doing a good enough job
- 1/3 advised to quit by health professional
- By comparison, only 18% were fired or asked to leave

Doogan and Playford 2014

Improving Performance

- Fatigue management
- PT to manage tone or mobility difficulties
- Cognitive rehabilitation/retraining
- Psychological adjustment to diagnosis
- Psychology for anxiety and depression
- Psychology for self-esteem, self-efficacy and confidence

Doogan and Playford 2014

Compensatory Techniques

- Ensuring toilet access
- Minimizing distractions
- Making “to do” lists
- Using voice-activated software
- Taking agreed upon regular rest breaks
- Using memory aids e.g. diary, calendar, mobile/computer apps

Doogan and Playford 2014

Modifying Demands

- Working from home
- Working part time
- Exploring alternate work roles

Doogan and Playford 2014

Patient Cases

Case #1

- Flight controller getting more and more fatigued and stressed, feels unable to meet deadlines. Has back pain, getting weaker.

→Works from home 2 days a week

→Took FMLA to start exercising and feeling better

→Moved to more administrative role with fewer deadlines

→Sit to stand desk to decrease back pain

→Bigger office to accommodate her rollator

Case #2

- 40 yo Male with sensation of urinary urgency multiple times an hours with associated anxiety and decreased concentration.

→urology referral
→Condom catheter
→Medication to decrease urgency
→Considering bladder botulinum toxin
→Speech/Psychology referrals

Case #3

- Health professional with severe fatigue, dizziness, falls.

→Medication for fatigue

→Timing tasks needing more concentration for times of day with less fatigue

→Avoiding sedating medications

→Referral to physical therapy

→Cane use

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