Multiple Sclerosis: What You Need to Know

For People Who are Newly Diagnosed
Today is a Starting Point

- For learning basic information about MS:
  - What *it is* and what *it is not*
  - How it is diagnosed
  - How it is treated
- For learning some basic guidelines for living with MS
  - Dealing with common feelings and concerns
  - Accessing available resources
MS-related central nervous system pathology—Jean Cruveilhier, c 1841

Jean-Martin Charcot (1825–1893) described features of MS
What MS Is:

- MS is thought to be a disease of the immune system—probably *autoimmune*.
- Its name comes from the *scarring* caused by inflammatory attacks at *multiple* sites in the central nervous system.
What MS *Is Not:* 

- **MS is not:**
  - Contagious
  - Directly inherited
  - Always severely disabling
  - Fatal—except in fairly rare instances

- **Being diagnosed with MS is not a reason to:**
  - Stop working
  - Stop doing things that one enjoys
  - Not have children
What Causes MS?

- Genetic Predisposition
- Environmental Trigger
- Autoimmunity
- Loss of myelin & nerve fiber
What happens in MS?

“Activated” T cells...

cross the blood-brain barrier...

activate other immune cells and launch attack on myelin & nerve fibers...

to obstruct nerve signals.
Cross-section of a Nerve Fiber

Myelin

Nerve Fiber
What happens to the myelin and nerve fibers?
Who gets MS?

- Usually diagnosed between 20 and 50
  - Occasionally diagnosed in young children and older adults
- More common in women than men (2-3:1)
- Most common in those of Northern European ancestry
  - More common in Caucasians than Hispanics or African Americans; rare among Asians
- More common in temperate areas (further from the equator)
Why did I get MS?

• We do not know why one person gets MS and another does not

• We do not know of anything:
  ▪ You did to cause MS
  ▪ You could have done to prevent it

• We do not know any way to predict who will get it and who will not
What is the genetic factor?

- The risk of getting MS is approximately:
  - 1/750 for the general population
  - 1/40 for person with a close relative with MS
  - 1/4 for an identical twin
- 20% of people with MS have a blood relative with MS

The risk is higher in any family in which there are several family members with the disease (aka multiplex families)
How is MS diagnosed?

• MS is a *clinical diagnosis*:
  - Medical history
  - *Symptoms and signs*
  - Laboratory tests (for confirmation only)

• Requires evidence of *dissemination in time and space*:
  - Space: Evidence of scarring (*plaques*) in at least two separate areas of the central nervous system
  - Time: Evidence that the plaques occurred at different points in time

• *There must be no other explanation.*
What tests may be used to confirm the diagnosis?

- Magnetic resonance imaging (MRI)
- Evoked potentials – most commonly visual evoked potentials (VEPs)
- Lumbar puncture (spinal tap)
What are possible symptoms?

- **Fatigue (most common)**
- Bladder/bowel dysfunction
- Sensory problems (numbness, tingling)
- Emotional changes (depression, mood swings)
- Walking difficulties
- Thinking/memory problems
- Vision problems
- Stiffness (spasticity)
- Pain (neurogenic)
- Sexual problems
- Speech/swallowing problems
- Tremor
- Breathing difficulties
- Impaired temperature control
What is the prognosis?

- One hallmark of MS is its *unpredictability*.
  - Approximately one-third 1/3 will have a very mild course
  - Approximately one-third will have a moderate course
  - Approximately one-third will become more disabled
What are the patterns (courses) of MS?

- Relapsing-Remitting MS (RRMS)
- Secondary-Progressive MS (SPMS)
- Primary-Progressive MS (PPMS)
- Relapsing-Progressive MS (RPMS)
Relapsing-Remitting MS

The majority of people (about 85%) initially experience attacks (*relapses*) followed by periods of full/partial recovery (*remissions*), with no progression of disability between attacks.
Relapsing-Remitting MS

Increasing disability

time
Of those who are diagnosed with a relapsing-remitting disease course, many will transition to a secondary-progressive course in which the disease begins to progress between attacks.
Secondary-Progressive MS

Increasing disability vs. time
A small percentage of people experience progression from onset, with no attacks along the way.
Primary-Progressive MS

Increasing disability

Time
Progressive-Relapsing MS

In the rarest pattern of MS, people experience progression from onset, with some relapses along the way.
Progressive-Relapsing MS

Increasing disability vs. time
Is there a cure for MS?

• Unfortunately no—not at the present time
• Without knowing the underlying cause of MS, it is very difficult identify the cure
• The Society and other agencies are funding research to stop disease progression, repair damage to the nervous system, and—ultimately—to prevent the disease from happening in the first place
So what do we do in the meantime?

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

• Exacerbations (flare-ups of new symptoms or worsening of old ones, lasting at least 24 hrs.) may be treated with corticosteroids to reduce inflammation.
  - Short course of intravenous, high-dose methylprednisolone, sometimes followed by an oral taper

Not all exacerbations require treatment
Is it possible to alter the course of MS?

Ten disease-modifying therapies are FDA-approved to treat MS:

- Aubagio® (teriflunomide) - oral
- Avonex® (interferon beta-1a) – injection
- Betaseron® (interferon beta-1b) – injection
- Copaxone® (glatiramer acetate) - injection
- Extavia® (interferon beta-1b) – injection
- Gilenya® (fingolimod) – oral medication
- Novantrone® (mitoxantrone) - infusion
- Rebif® (Interferon beta-1a) – injection
- Tecfidera™ (dimethyl fumarate — formerly called BG-12) - oral
- Tysabri® (natalizumab) - infusion

All reduce attack frequency and scarring on MRI, and may slow disease progression.
Will a disease-modifying drug make me feel better?

- These medications reduce the number of attacks and probably slow progression
- These medications do not:
  - Cure the disease
  - Make people feel better
  - Alleviate symptoms
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 are likely to remain.
- There are a variety of medications and management strategies to manage the symptoms that occur.
Which symptoms are treatable with medication or other strategies?

- Fatigue (most common)
- Vision problems
- Stiffness (*spasticity*)
- Bladder/bowel dysfunction
- Sexual problems
- Pain
- Emotional changes (depression, mood swings)
- Walking difficulties (weakness, imbalance)
- Cognitive changes (attention, memory, processing)
- Speech difficulties
What can I do to feel my best?

- Balance activity with rest
- Talk with your doctor about the right type/amount of exercise.
- Eat a balanced low-fat, high-fiber diet.
- Avoid heat if you are heat-sensitive.
- Drink plenty of fluids to maintain bladder health and avoid constipation.
- Follow the standard preventive health measures recommended for your age group.
What else can I do?

• Reach out to your support system; no one needs to be alone in coping with MS.
• Stay connected with others; avoid isolation.
• Become an educated consumer.
• Make thoughtful decisions:
  ▪ Talking about your diagnosis with others
  ▪ Making employment decisions
  ▪ Planning wisely for the future
• Be aware of common emotional reactions.
What else can I do?

- Pay attention to signs of depression
  - Depression differs from normal grieving
  - Depression is more common in MS than in other chronic illnesses (thought to be a symptom of MS as well as a reaction to it)
  - More than 50% of people with MS will experience a significant depression at some point along the way
  - Depression can occur at any time—even as a first symptom of MS
What can I do about depression?

• Recognize the symptoms (*lasting longer than two weeks*)
  ▪ Loss of interest in pleasurable things
  ▪ Significant changes in appetite, sleep patterns
  ▪ Intense feelings of sadness or irritability

• Talk to your doctor
  ▪ Depression is treatable
  ▪ Depression responds best to a combination of medication and counseling
Who is on the MS health care team?

- Person with MS
- Physician (neurologist and/or physiatrist)
- Nurse
- Physical therapist
- Occupational therapist
- Speech/language pathologist
- Psychologist or neuropsychologist
- Social worker
- Pharmacist
- Urologist
MS: What you need to know

- Questions?
Join the movement!

The National MS Society's vision is:
A World Free of MS.

The Society's mission is:
We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

Thank you for your attendance!