

# UNDERSTANDING MULTIPLE SCLEROSIS



A Patient Guide





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This booklet will help you learn about multiple sclerosis (MS). You will find out what causes it, how it affects your body, and how today's treatments can help you live well with MS. Remember: MS is manageable, and many people with MS lead full, active lives.

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# WHAT IS MULTIPLE SCLEROSIS?



**Multiple sclerosis (MS)** is a chronic disease that affects the central nervous system - your brain, spinal cord, and optic nerves. In MS, the immune system mistakenly attacks the protective coating around nerve fibers called myelin.

Think of it this way: Your nerves are like electrical wires, and myelin is like the insulation around them. When myelin is damaged, the electrical signals can't travel properly. This causes the symptoms of MS. The word "sclerosis" means scarring - the "multiple" refers to the many areas of scarring that can occur.

## Key Terms to Know

**Multiple Sclerosis (MS):** A chronic autoimmune disease affecting the central nervous system.

**Myelin:** The protective coating around nerve fibers that helps signals travel quickly.

**Central Nervous System (CNS):** The brain and spinal cord.

**Lesions (Plaques):** Areas of damage or scarring in the brain or spinal cord caused by MS.

**Relapse (Flare, Exacerbation):** A period when MS symptoms get worse or new symptoms appear.

### References:

1. National Multiple Sclerosis Society. "What is MS?" [nationalmssociety.org](http://nationalmssociety.org).
2. National Institute of Neurological Disorders and Stroke. "Multiple Sclerosis." NINDS, NIH.
3. Mayo Clinic. "Multiple Sclerosis." [MayoClinic.org](http://MayoClinic.org).



## HOW MS AFFECTS THE BODY



MS can affect many different parts of the body because the central nervous system controls everything you do.

### The Immune System Attack

In MS, immune cells cross into the brain and spinal cord where they don't belong. They attack myelin, causing inflammation and damage. Over time, the nerve fibers themselves can also be damaged.

### What Can Be Affected

**Vision:** Optic neuritis (inflammation of optic nerve), double vision, eye pain

**Movement:** Weakness, difficulty walking, coordination problems, spasticity

**Sensation:** Numbness, tingling, pain, sensitivity to heat

**Bladder and Bowel:** Urgency, frequency, constipation

**Thinking and Memory:** Cognitive changes, difficulty concentrating, "brain fog"

**Emotions:** Depression, anxiety, mood changes

**Fatigue:** One of the most common and disabling symptoms

**Important:** No two people experience MS the same way. Your symptoms depend on where the damage occurs in your nervous system.

#### References:

1. National MS Society. "MS Symptoms." [nationalmssociety.org](http://nationalmssociety.org).



## TYPES OF MS



There are four main types of MS:

RELAPSING-REMITTING MS (RRMS)	<p>The most common form - about 85% of people are diagnosed with RRMS.</p> <ul style="list-style-type: none"><li>• Clear relapses (flares) when symptoms get worse</li><li>• Periods of remission when symptoms improve or go away</li><li>• May have full or partial recovery after relapses</li></ul>
SECONDARY PROGRESSIVE MS (SPMS)	<p>Many people with RRMS eventually transition to SPMS.</p> <ul style="list-style-type: none"><li>• Gradual worsening of disability over time</li><li>• May or may not have relapses</li><li>• Fewer periods of remission</li></ul>
PRIMARY PROGRESSIVE MS (PPMS)	<p>About 10-15% of people have PPMS from the start.</p> <ul style="list-style-type: none"><li>• Gradual worsening from the beginning</li><li>• No clear relapses or remissions</li><li>• May have occasional plateaus</li></ul>
PROGRESSIVE-RELAPSING MS (PRMS)	<p>The rarest form.</p> <ul style="list-style-type: none"><li>• Steady progression from the start</li><li>• Also has acute relapses</li></ul>
CLINICALLY ISOLATED SYNDROME (CIS)	<p>A first episode of MS-like symptoms. May or may not develop into MS.</p>

References:

1. National MS Society. "Types of MS." [nationalmssociety.org](http://nationalmssociety.org).



## SIGNS & SYMPTOMS



MS symptoms vary widely from person to person:

### Common Early Symptoms

- Vision problems (blurred vision, eye pain, double vision)
- Numbness or tingling (often in face, arms, legs, fingers)
- Fatigue (overwhelming tiredness)
- Weakness in arms or legs
- Balance problems or dizziness

### Other Symptoms

- Muscle stiffness or spasms (spasticity)
- Difficulty walking
- Bladder problems (urgency, frequency, incontinence)
- Bowel problems (constipation)
- Pain (nerve pain, muscle pain)
- Cognitive changes (memory, concentration, word-finding)
- Depression and emotional changes
- Sexual dysfunction
- Speech problems
- Difficulty swallowing
- Tremor

### Uhthoff's Phenomenon

Heat can temporarily worsen MS symptoms. This may happen with hot weather, exercise, fever, or hot baths. Symptoms improve when you cool down.

### Lhermitte's Sign

An electric shock-like sensation down the spine or limbs when bending the neck. Common in MS.

#### References:

1. National MS Society. "MS Symptoms." [nationalmssociety.org](http://nationalmssociety.org).
2. Mayo Clinic. "MS Symptoms." [MayoClinic.org](http://MayoClinic.org).



## CAUSES AND RISK FACTORS

The exact cause of MS is unknown, but research points to several factors:

### Immune System

- MS is an autoimmune disease
- The immune system attacks myelin by mistake
- What triggers this attack is not fully understood

### Genetics

- MS is not directly inherited
- Having a close relative with MS increases risk
- Multiple genes are involved

### Environment

- More common farther from the equator
- Low vitamin D levels may increase risk
- Epstein-Barr virus (causes mono) linked to higher risk
- Smoking increases risk and worsens disease

### Risk Factors

- Age: Most commonly diagnosed between 20-50
- Sex: Women are 2-3 times more likely to have RRMS
- Family history: Higher risk if parent or sibling has MS
- Geography: More common in temperate climates
- Smoking: Increases risk and speeds progression
- Certain infections: Epstein-Barr virus
- Low vitamin D
- Obesity in childhood/adolescence

**Important:** MS is not contagious. You cannot catch it from someone.

#### References:

1. National MS Society. "What Causes MS?" [nationalmssociety.org](http://nationalmssociety.org).



# DIAGNOSIS



## How is MS Diagnosed?

There is no single test for MS. Diagnosis is based on evidence of damage in at least two separate areas of the CNS at different points in time:

### Neurological Exam

Your neurologist will test:

- Reflexes and muscle strength
- Balance and coordination
- Vision and eye movements
- Sensation
- Speech and swallowing

### MRI (Magnetic Resonance Imaging)

The most important test for MS diagnosis.

- Shows lesions (areas of damage) in brain and spinal cord
- Can show new vs. old lesions
- Used for diagnosis and monitoring

### Lumbar Puncture (Spinal Tap)

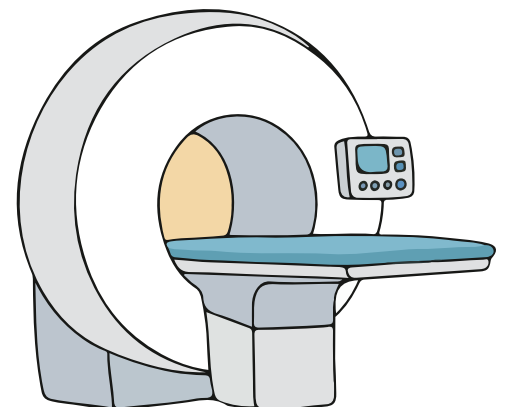
- Checks spinal fluid for antibodies (oligoclonal bands)
- Helps confirm MS and rule out other conditions

### Evoked Potentials

- Tests how quickly nerves send signals
- Visual evoked potentials (VEP) most commonly used

### Blood Tests

- Rule out other conditions with similar symptoms
- No blood test can diagnose MS



#### References:

1. Pediatric Endocrine Society. "Diagnosis of GHD." [pedsendo.org](http://pedsendo.org).
2. Hormone Health Network. "Testing for GHD." Endocrine Society.



# WHAT TO EXPECT

## Disease Course

MS affects everyone differently. With today's treatments, many people live full, active lives.

### MS is Unpredictable

- Symptoms and progression vary greatly
- Some people have mild symptoms for years
- Others may have more frequent relapses
- There's no way to predict your exact course

### Relapses (Flares)

- New symptoms or worsening of old symptoms
- Last at least 24 hours (usually days to weeks)
- May be followed by full or partial recovery
- Should not be caused by fever or infection

### The Good News

- Early treatment can slow disease progression
- More treatment options than ever before
- Many people with MS work, raise families, and stay active
- Life expectancy is only slightly reduced
- Research is advancing rapidly

### Working with Your Care Team

Your MS care team may include:

- Neurologist (often an MS specialist)
- MS nurse
- Physical and occupational therapists
- Mental health professionals
- Specialty pharmacy

References:

1. National MS Society. "What to Expect." [nationalmssociety.org](http://nationalmssociety.org).



# TREATMENT OPTIONS

There is no cure for MS yet, but treatment can help manage the disease.

## Treatment Goals

- Reduce frequency and severity of relapses
- Slow progression of disability
- Manage symptoms
- Improve quality of life

Three Types of Treatment	
Disease-Modifying Therapies (DMTs)	<ul style="list-style-type: none"><li>• The main treatment for MS</li><li>• Reduce relapses and slow progression</li><li>• Work best when started early</li><li>• Many options available (see next page)</li></ul>
Relapse Management	<ul style="list-style-type: none"><li>• High-dose corticosteroids (methylprednisolone/Solu-Medrol)</li><li>• Given IV over 3-5 days</li><li>• Shortens relapse duration</li><li>• Does not affect long-term outcome</li></ul>
Symptom Management	<ul style="list-style-type: none"><li>• Medications for specific symptoms</li><li>• Physical therapy</li><li>• Occupational therapy</li><li>• Speech therapy</li><li>• Mental health support</li></ul>

## Rehabilitation

Physical therapy, occupational therapy, and speech therapy can help maintain function and improve quality of life.

### References:

1. National MS Society. "Treating MS." [nationalmssociety.org](http://nationalmssociety.org).

# DISEASE-MODIFYING THERAPIES (DMTs)

There are now over 20 FDA-approved DMTs for MS:

## INJECTABLE MEDICATIONS

- Interferons: Avonex, Rebif, Betaseron, Plegridy, Extavia
- Glatiramer acetate: Copaxone, Glatopa
- Ofatumumab (Kesimpta) - monthly self-injection



## ORAL MEDICATIONS (Pills)

- Fingolimod (Gilenya)
- Siponimod (Mayzent)
- Ozanimod (Zeposia)
- Ponesimod (Ponvory)
- Teriflunomide (Aubagio)
- Dimethyl fumarate (Tecfidera)
- Diroximel fumarate (Vumerity)
- Monomethyl fumarate (Bafiertam)
- Cladribine (Mavenclad)



## INFUSION MEDICATIONS (IV)

- Natalizumab (Tysabri)
- Ocrelizumab (Ocrevus)
- Ublituximab (Briumvi)
- Alemtuzumab (Lemtrada)



## Choosing a DMT

Your neurologist will recommend a DMT based on:

- Type and activity of your MS
- Side effect profile
- How it's given (pill, injection, infusion)
- Your lifestyle and preferences
- Other health conditions
- Pregnancy planning

### References:

1. National MS Society. "Disease-Modifying Therapies." [nationalmssociety.org](http://nationalmssociety.org).



# MANAGING SYMPTOMS



There are four main types of MS:

Fatigue	<ul style="list-style-type: none"><li>• Energy conservation techniques</li><li>• Exercise (as tolerated)</li><li>• Good sleep habits</li><li>• Medications: amantadine, modafinil</li></ul>
Spasticity (Muscle Stiffness)	<ul style="list-style-type: none"><li>• Stretching and physical therapy</li><li>• Medications: baclofen, tizanidine</li><li>• Botox injections (for severe cases)</li></ul>
Walking Problems	<ul style="list-style-type: none"><li>• Physical therapy</li><li>• Dalfampridine (Ampyra) - improves walking speed</li><li>• Assistive devices (cane, walker) when needed</li></ul>
Bladder Problems	<ul style="list-style-type: none"><li>• Timed voiding, pelvic floor exercises</li><li>• Medications for urgency/frequency</li><li>• Intermittent catheterization if needed</li></ul>
Pain	<ul style="list-style-type: none"><li>• Medications for nerve pain (gabapentin, pregabalin)</li><li>• Physical therapy</li></ul>
Depression	<ul style="list-style-type: none"><li>• Very common in MS - seek help</li><li>• Therapy and/or antidepressant medications</li></ul>
Cognitive Changes	<ul style="list-style-type: none"><li>• Cognitive rehabilitation</li><li>• Organizational strategies</li><li>• Mental exercises</li></ul>

References:

1. National MS Society. "Managing Symptoms." [nationalmssociety.org](http://nationalmssociety.org).



## LIVING WITH MS



Many people with MS live full, active, and meaningful lives:

### Stay Active

- Exercise helps with fatigue, mood, and overall health
- Swimming and water exercises are great (cool water)
- Work with a physical therapist to find what works
- Listen to your body and rest when needed

### Beat the Heat

- Heat can worsen symptoms temporarily
- Stay cool in hot weather
- Use cooling vests if needed
- Take cool showers

### Healthy Lifestyle

- Don't smoke - smoking worsens MS
- Eat a balanced diet
- Consider vitamin D supplementation (ask your doctor)
- Limit alcohol
- Get enough sleep

### Emotional Wellbeing

- Depression and anxiety are common - seek help
- Connect with others who have MS
- Join a support group
- Consider counseling

### Work and Family

- Many people with MS continue to work
- Workplace accommodations may help
- MS doesn't prevent having children
- Plan pregnancies with your neurologist

#### References:

1. National MS Society. "Living Well with MS." [nationalmssociety.org](http://nationalmssociety.org).



# TIPS FOR TAKING YOUR MEDICATION



## DO:

- Take your DMT consistently - it works best with regular use
- Store medication properly (many need refrigeration)
- Let injectable medication reach room temperature before use
- Rotate injection sites
- Keep all monitoring appointments and lab tests
- Report side effects to your doctor
- Get recommended vaccines before starting certain DMTs

### For Injectable DMTs

- Ice the area before injecting
- Rotate sites (thighs, abdomen, arms, buttocks)
- Report persistent injection site reactions

### For Infusion DMTs

- Plan for infusion time at the clinic
- Pre-medications may help prevent reactions
- Report any symptoms during or after infusion

### If You Miss a Dose

Follow the specific instructions for your medication or call your doctor/pharmacy.



## DON'T:

- Stop your DMT without talking to your doctor
- Skip doses
- Miss monitoring appointments
- Get live vaccines while on most DMTs
- Become pregnant without planning (some DMTs can harm the baby)

#### References:

1. National MS Society. "Medication Tips." [nationalmssociety.org](http://nationalmssociety.org).



## WHEN TO CALL YOUR DOCTOR



### ! CALL 911 OR GO TO THE EMERGENCY ROOM IF:

- Sudden severe symptoms
- Difficulty breathing
- Severe allergic reaction to medication
- Sudden confusion or changes in consciousness
- Thoughts of self-harm

### ! CALL YOUR NEUROLOGIST IF:

#### Possible Relapse:

- New neurological symptoms lasting more than 24 hours
- Significant worsening of existing symptoms
- Vision changes
- New weakness or numbness
- Worsening balance or walking

#### Other Concerns:

- Side effects from your DMT
- Signs of infection (fever, chills) while on DMT
- Worsening fatigue or depression
- Bladder or bowel problems
- Questions about your treatment
- Planning pregnancy

**Note:** If you have a fever or infection, your MS symptoms may temporarily worsen. This is called a "pseudo-relapse" and usually improves when the infection is treated.



*Keep Your Regular Appointments!*

*Regular MRIs and check-ups help monitor your MS even if you feel fine.*

#### References:

1. National MS Society. "When to Call Your Doctor." [nationalmssociety.org](http://nationalmssociety.org).



# GLOSSARY



CNS	Central nervous system (brain and spinal cord)
DMT	Disease-modifying therapy
EXACERBATION	Another word for relapse or flare
LESION	Area of damage in the brain or spinal cord
MRI	Magnetic resonance imaging - scan to see the brain and spinal cord
MS	Multiple sclerosis
MYELIN	Protective coating around nerve fibers
NEUROLOGIST	Doctor specializing in the nervous system
PLAQUE	Another word for lesion
PPMS	Primary progressive MS
RELAPSE	Period when symptoms get worse or new symptoms appear
REMISSION	Period when symptoms improve or go away
RRMS	Relapsing-remitting MS
SPMS	Secondary progressive MS
SPASTICITY	Muscle stiffness and spasms



## RESOURCES



### Learn More:

- National Multiple Sclerosis Society: [nationalmssociety.org](http://nationalmssociety.org)  
- MS Navigator Program: 1-800-344-4867
- Multiple Sclerosis Foundation: [msfocus.org](http://msfocus.org)
- Multiple Sclerosis Association of America: [mymsaa.org](http://mymsaa.org)
- Can Do Multiple Sclerosis: [cando-ms.org](http://cando-ms.org)
- National Institute of Neurological Disorders and Stroke: [ninds.nih.gov](http://ninds.nih.gov)
- Mayo Clinic - Multiple Sclerosis: [mayoclinic.org](http://mayoclinic.org)
- MS Healthline: [healthline.com/health/multiple-sclerosis](http://healthline.com/health/multiple-sclerosis)
- Accelerated Cure Project for MS: [acceleratedcure.org](http://acceleratedcure.org)



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