



**National
Multiple Sclerosis
Society**

**Providing Quality Care
to People with MS:**

In-Service Training

National Multiple Sclerosis Society

- Client Education & Services
- Research
- Advocacy
- Professional Education



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

The National MS Society, Greater Northwest Chapter educates, inspires and empowers those affected by multiple sclerosis. Headquartered in Seattle, the chapter serves over 12,000 people living with MS and more than 80,000 others including friends, caregivers and health care professionals throughout Alaska, Montana and in Western and Central Washington.

We believe that people with MS deserve options, support and hope to live better with their disease...that every person in our community can play a role in improving the lives of those affected by MS...and that a world free of MS is within our grasp.

We move our mission forward through Client Education & Services, Research, Advocacy and Professional Education.

Long-term Care and MS

- **60%** of people with MS have activity limitation
- **20-25%** need long-term care services
- **14,000** in nursing homes
- **60%** of nursing home residents with MS under 60 years of age



Many people assume that long term care is provided exclusively for elders and primarily in nursing homes. In fact, long term care refers to a wide range of settings and services—the home, adult day programs, assisted living, supportive housing and nursing homes. People with chronic illness and disabilities can require long term care services *at any age*, and that care is provided by both paid and unpaid caregivers.

The National MS Society wants options for people with MS- Consumer choice is one of the principles supported by the Society. People with MS must be free to choose from a full range of age-appropriate and affordable home, community-based, and facility-based health and social service options to meet individual needs and preferences. All of these long-term care services must be committed to preserving autonomy and maximizing self-determination.

Home services that can help people with MS remain at home as long as possible

Adult Day Programs to provide a chance for the person with MS to be with others and to give time to family caregivers for work, family and leisure activities

Assisted Living for those more independent and self-directed but not able to live alone

Quality nursing homes when people need 24 hr. skilled care

Our Goals

- Increase your understanding of MS
- Support your provision of sensitive, quality and appropriate care
- Help you feel more comfortable serving this population
- Be knowledgeable of resources available through the National MS Society



This slide highlights the goals of this training.

What is your connection?



- Does anyone here know a person with MS?
- Has anyone taken care of a person with MS?



What experiences have you had with people living with MS?

From these experiences, can you identify any particular issues or challenges related to the disease?

MS vs. Geriatric: A Study of Nursing Home Residents

- Younger
- More physically dependent
- More symptoms of depression
- More cognitively intact
- More ties to the community
- Longer lengths of stay



Here we have a glimpse at how people living with MS might differ from a typical population in a nursing home setting. This profile is probably reflective of people with MS needing LTC services in all settings- Assisted Living; Adult Day Programs; Home Care

It's a Younger Population- Often non-elderly population in their 30s, 40s and 50s

It's a more Physically Dependent population- the MS population tends to have more physical disability than the frail elderly-

They tend to use more wheeled mobility, transfer aides, assistive devices

They also tend to be heavier, more challenging in terms of transfers

More depression- 50% of people with MS have a major depressive episode

This can bring both physiological and psychological impacts

More cognitively intact- Not the dementia of the elderly; usually remain intellectually alert

More ties to the community- families are sometime still intact and younger children are in the picture

Longer lengths of stay- Because progression can take place early on in the disease, individuals may reside in a LTC setting for decades

What is MS?



- Neurological Disease
- Misguided Immune cells
- Multiple Scars
- Unpredictable
- Variable
- Often Progressive



Very unpredictable neurological disease- Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. World-wide, MS affects about 2.5 million people. There remains a lot we still don't understand about the disease. Multiple sclerosis is a chronic disease of the central nervous system (the brain, optic nerves, and spinal cord). It is thought to be an autoimmune disorder. This means the immune system incorrectly attacks the person's healthy tissue.

Misguided immune cells, instead of attacking bacteria, viruses, and other invaders of the body system, attack the body itself

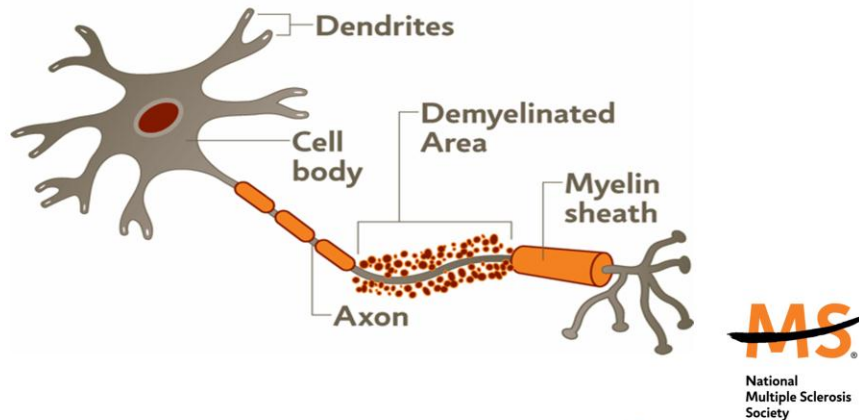
With MS, they attack the protective myelin surrounding nerve fibers in central nervous system, including the Brain and spinal cord, and can also damage the fibers themselves. These inflammatory attacks cause scarring at multiple sites—multiple scars (MS). There can be some repair of the damaged myelin, but damage is often faster than restoration. Nerve damage is irreversible. Damage causes the symptoms. Messages from the brain to the body and back get lost or distorted

Randomness of the disease is greatest challenge. "I never know what will visit me in the night"- said a young man with MS. Variability- unable to be predicted; People with MS are all different- A person with MS can vary in what they can do day to day, hour to hour

Often progressive, either initially, or later

Axonal Damage in Multiple Sclerosis

DEMYELINATED NEURON



- What happens in MS?
 - Misguided immune cells cross the blood-brain barrier into the central nervous system.
 - The attack in the CNS appears initially to be targeted against the myelin sheath, the fat and protein coating that insulates nerve fibers, and against myelin-making cells called oligodendrocytes.
 - Nerve fibers also become targets of the immune attack in MS.
 - The damage caused by the immune attack leads to the symptoms of MS.

Who Gets MS?

- MS is significantly more common (at least 2-3 times) in women than men
- Usually diagnosed between 20 and 50
- About 200 people diagnosed every week
- Genetic component, but not hereditary
- More common in Caucasians, especially those of northern European ancestry



Who gets MS?

- Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. Worldwide, MS affects about 2.5 million people. Because the Centers for Disease Control and Prevention (CDC) does not require U.S. physicians to report new cases, and because symptoms can be completely invisible, the numbers can only be estimated.
- MS is an adult onset disability, with most people diagnosed between the ages of 20 and 50, although individuals as young as two and as old as 75 have developed it.
- MS is not considered a fatal disease as the vast majority of people with it live a normal life-span. But they may struggle to live as productively as they desire, often facing increasing limitations.
- Anyone may develop MS but there are some patterns.
- More common in women than men (2-3:1).
- Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited.
- MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of northern European ancestry.
- More common in temperate areas of the world.

Symptoms of MS*

- Fatigue
- Spasticity
- Loss of Balance
- Visual Impairment
- Bowel Dysfunction
- Bladder Dysfunction
- Tremor
- Pain
- Weakness
- Numbness
- Impaired Cognition
- Swallowing Difficulty
- Speech Impairment
- Paralysis
- Depression

*Heat can worsen many symptoms



Fatigue- Overwhelming lack of physical and/or mental energy; variable

Spasticity- Muscle stiffness, tightness; involuntary contractions; variable

Balance- Standing/ walking balance, or seating balance; safety concern

Visual -Rarely total blindness; double vision, clouding, jerking eye movements

Bladder & Bowel- Urgency & incontinence, or hesitancy & retention; high risk of UTIs that have serious implications for MS and require immediate attention

Tremor- Involuntary shaking; more pronounced when reaching

Pain- Tingling, burning; stabbing facial pain; postural problems

Weakness- Can affect upper body strength, transfers; can also impact respiratory muscles, resulting in inadequate breathing & coughing

Numbness- Lack of sensation; skin integrity an issue, risk of pressure ulcers; may be no awareness of injury

Cognition-Intellect usually intact; May be memory (especially short term), judgment, attention, word finding difficulty.

Swallowing-May be tendency to choke; need time/concentration when eating

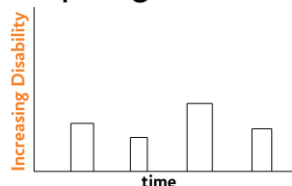
Speech- Ranges-mild slurring/ volume/ lack of speech

Paralysis- Loss of voluntary functioning-may not be able to shift weight

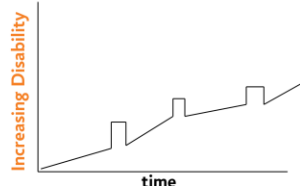
Depression- Disease process as well as reaction to it-very prevalent

Patterns of MS

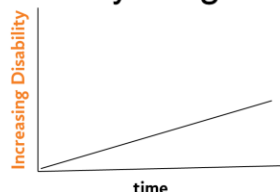
- Relapsing-Remitting



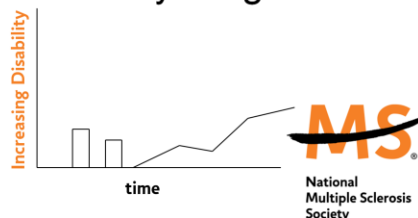
- Progressive Relapsing



- Primary Progressive



- Secondary Progressive



Relapsing/remitting-Clearly defined flare-ups (85% initially R/R)

People with this type of MS experience clearly defined attacks of worsening neurologic function. These attacks—which are called relapses, flare-ups, or exacerbations—are followed by partial or complete recovery periods (remissions), during which no disease progression occurs. Approximately 85% of people are initially diagnosed with relapsing-remitting MS.

Secondary Progressive- Initially R/R, followed by steady worsening (50% R/R)

Following an initial period of relapsing-remitting MS, many people develop a secondary-progressive disease course in which the disease worsens more steadily, with or without occasional flare-ups, minor recoveries (remissions), or plateaus. Before the disease-modifying medications became available, approximately 50% of people with relapsing-remitting MS developed this form of the disease within 10 years.

Primary Progressive- Continuous worsening from onset (10%)

This disease course is characterized by slowly worsening neurologic function from the beginning—with no distinct relapses or remissions. The rate of progression may vary over time, with occasional plateaus and temporary minor improvements. Approximately 10% of people are diagnosed with primary-progressive MS.

Progressive Relapsing- Steady worsening, but flare-ups too (5%)

In this relatively rare course of MS (5%), people experience steadily worsening disease from the beginning, but with clear attacks of worsening neurologic function along the way. They may or may not experience some recovery following these relapses, but the disease continues to progress without remissions.

Since no two people have exactly the same experience of MS, the disease course may look very different from one person to another.

Treatments for MS

- Disease-modifying therapies
- Symptom Management
- Corticosteroids

No cure, yet.



Although there is still no cure for MS, effective strategies are available to modify the disease course, treat exacerbations (also called attacks, relapses, or flare-ups), manage symptoms, improve function and safety, and provide emotional support. In combination, these treatments enhance the quality of life for people living with MS.

DMTs or Disease Modifying Therapies- These agents can reduce the frequency and severity of attacks. They can reduce the accumulation of lesions and they appear to slow down the accumulation of disability.

FDA-Approved Disease-Modifying Agents: Avonex, Betaseron, Copaxone, Extavia, Gilenya, Novantrone, Rebif, Tysabri

Symptom Management- Many treatments available to address the symptoms of MS. Symptoms of MS are highly variable from person to person and from time to time in the same individual. While symptoms can range from mild to severe, most can be successfully managed with strategies that include medication, self-care techniques, rehabilitation (with a physical or occupation therapist, speech/language pathologist, cognitive remediation specialist, among others), and the use of assistive devices.

Cortico(steroids) are used to reduce the inflammation from exacerbations more quickly

Emotional & Family Issues



- On-going Losses
- Depression/ Painful Emotions
- Cognitive Impairment
- Striving for Independence
- Family Concerns
- Financial Stress



On-going losses- Physical, family life, imagined life as a healthy individual, work life, community life, recreational activities, independence

Depression- More prevalent in MS than in other neurological disorders

Emotions- Fear, guilt, frustration, grief, anxiety, desperation- Since disease changes all the time, emotional work is never done

Cognitive Issues- Usually alert and oriented, short-term memory, judgment, organizational abilities, attention span may be impaired. Correlates to lesion load but not level of disability. Self-report may not be accurate

Striving for Independence- Usually of sound mind; want to direct their care

They will fight for the highest level of independence they can maintain

They will push to do things they can't do- want normalcy, dignity

Since they have had to become increasingly dependent on aides and other assistance, they take pride in managing and controlling the situation as much as possible- can at times be difficult for staff

Family Concerns- MS is a family disease. Different, maybe conflicting, coping styles, may be children, elderly parents in the picture

Drain on family resources- time, money, energy

Training Video

People with MS and their aides talk about
receiving and giving hands-on care



Please refer to the online video at this time.

Discussion Questions

- What symptoms did you notice or hear about in the video?
- What special equipment did you see?
- Does anyone here have experience taking care of someone who uses power equipment?
- What is the most important message that the video gave to you?



What You Can Do

- Be knowledgeable of MS and its symptoms
- Be sensitive to the losses and sadness that people with MS experience
- Understand the variability of the disease
- Understand that people with MS want to be as independent as they possibly can



We keep our communities moving forward by breaking down barriers and providing opportunities so that everyone who wants to do something about MS can contribute. Join the movement today and see how you can make a difference in the lives of the over 12,000 Washington, Montana and Alaska families living with MS.

What You Can Do

- Contact the Information Resource Center for information, resources, and support for people living with MS and their families 1-800-344-4867, Press Option 1 or visit us at www.msnorthwest.org
- Reach out to the Professional Resource Center at HealthProf_info@nmss.org



The Information Resource Center (IRC) is a great place to get started.

The Professional Resource Center (PRC) is a hub of information geared towards clinicians supporting people living with MS.

What did you learn?



Reflect on what you learned today.

Thank you!

We believe . . .

that people with MS deserve options, support

and hope to live better with their disease . . .

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in improving the lives of those affected by MS . . .

and that a world free of MS is within our grasp.



Thank you. We look forward to hearing your feedback on this training and how we can support you and the people you serve living with MS.

Please complete the evaluations and return to:

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