

Living with Multiple Sclerosis

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December 13, 2012

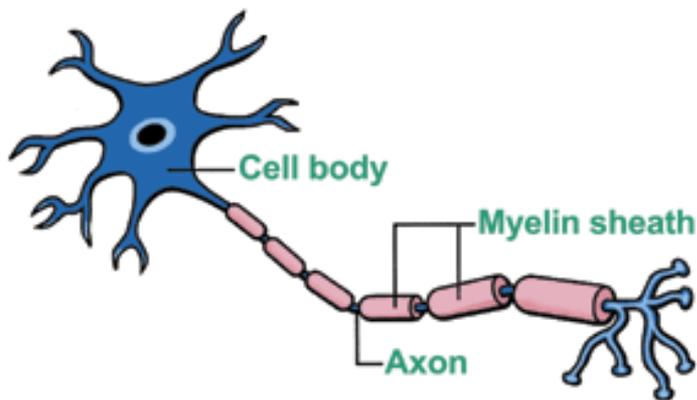
Outline

- About Multiple Sclerosis
 - What is Multiple Sclerosis
 - MS Facts
- My Experience
- Financial Burden of multiple sclerosis
- Long Term Care Issues

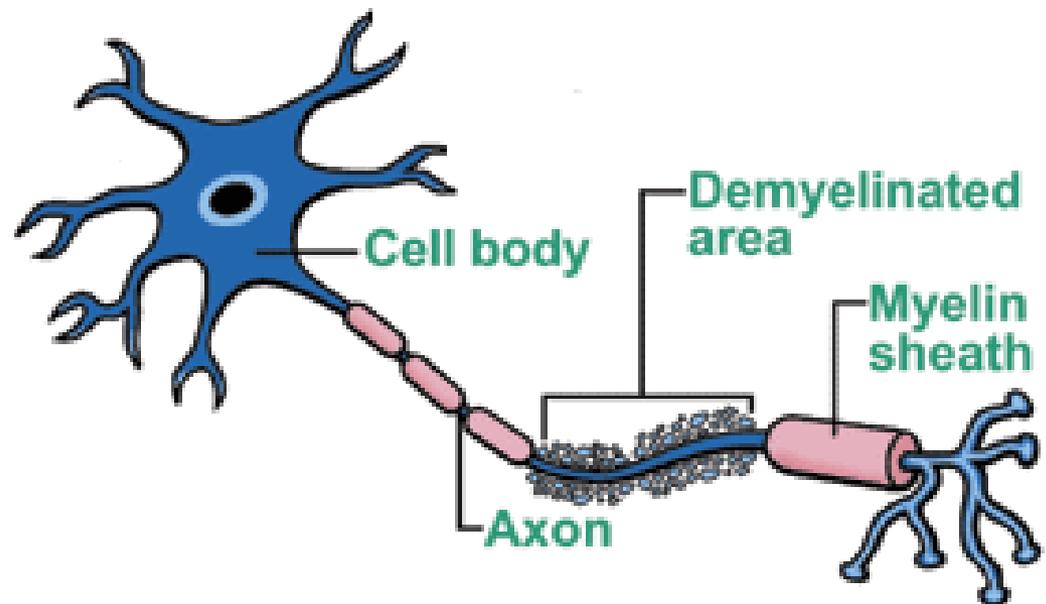
- The National MS Society
 - Vision and Mission
 - MS Research
 - Programs and Services

What is Multiple Sclerosis ?

Multiple Sclerosis is an unpredictable, often disabling disease of the central nervous system. It interrupts the flow of information between the brain and the body, and it stops people from moving. Symptoms range from numbness to tingling to blindness to paralysis.



Functional
nerve cell



Nerve cell with
MS damage

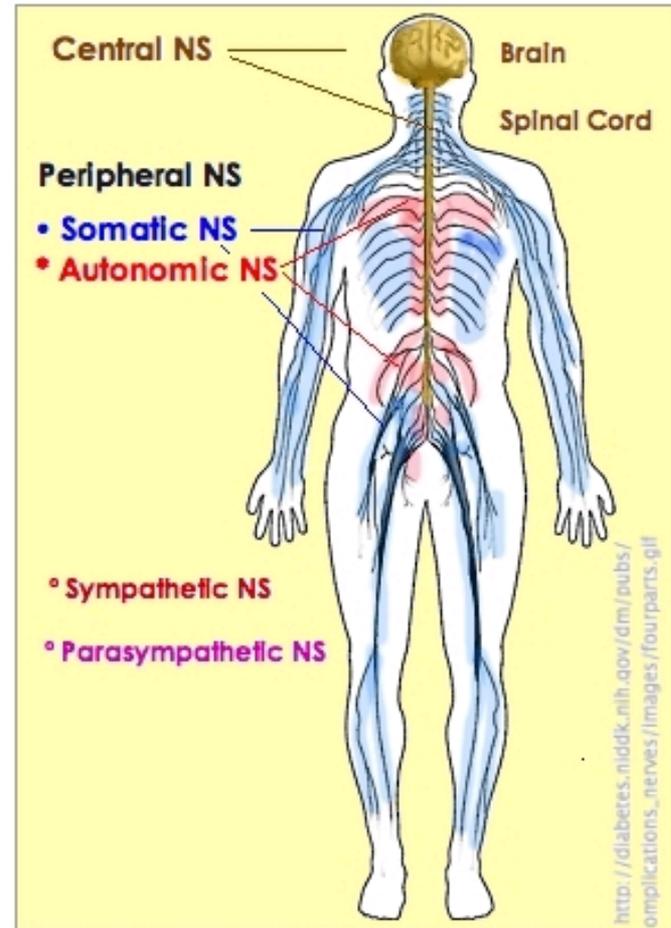
The Human Nervous System

Areas affected by MS

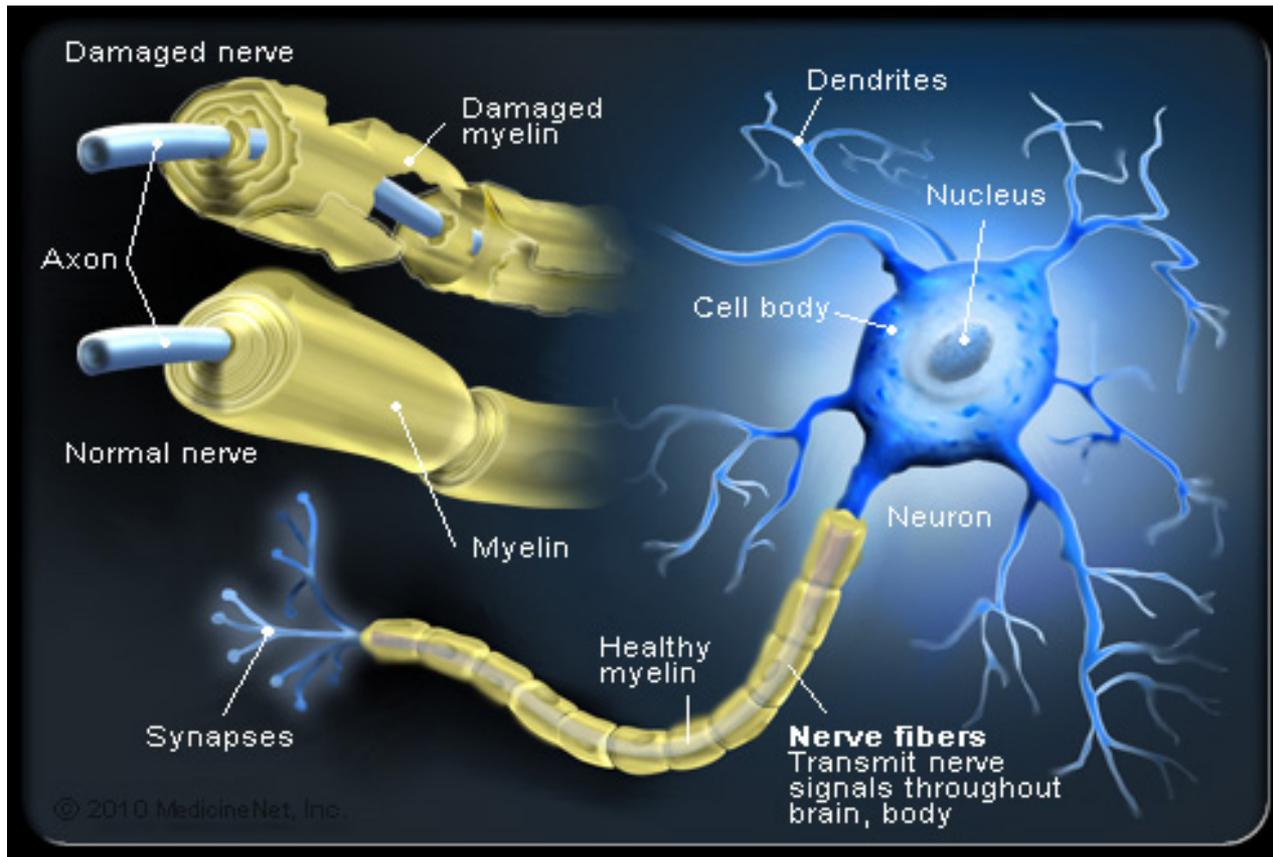
Brain

Spinal cord

Optic nerves



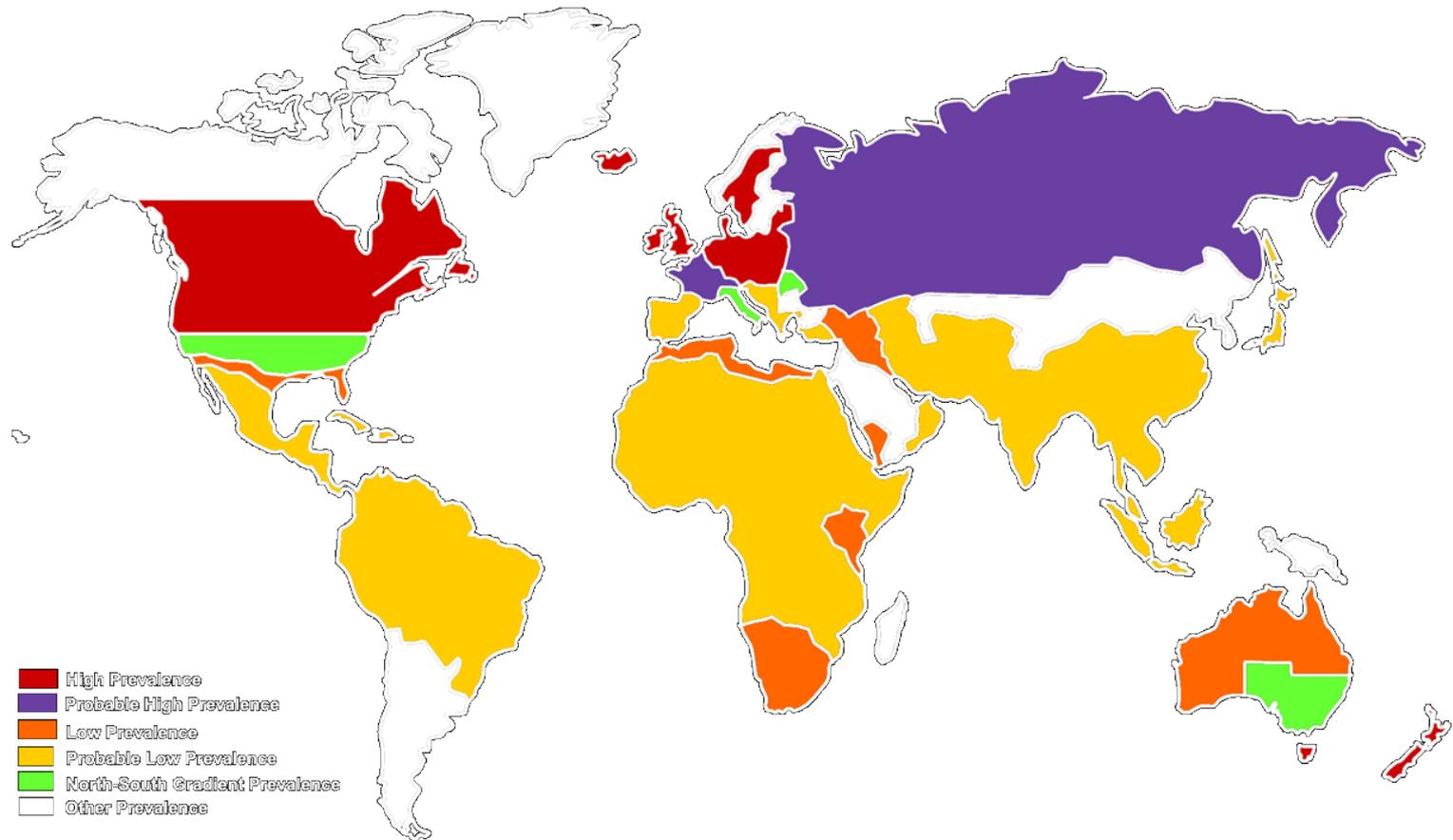
When Multiple Sclerosis Attacks



How Common is MS and Who Gets It?

- Over 20,00 people in Illinois
- Approximately 400,000 individuals in the U.S.
- Occurs most frequently between ages 25 - 35
- Female: male ratio = 2:1
- More frequent in populations native to areas further away from the equator

Risk of Developing MS and Region of Origin



Predisposition

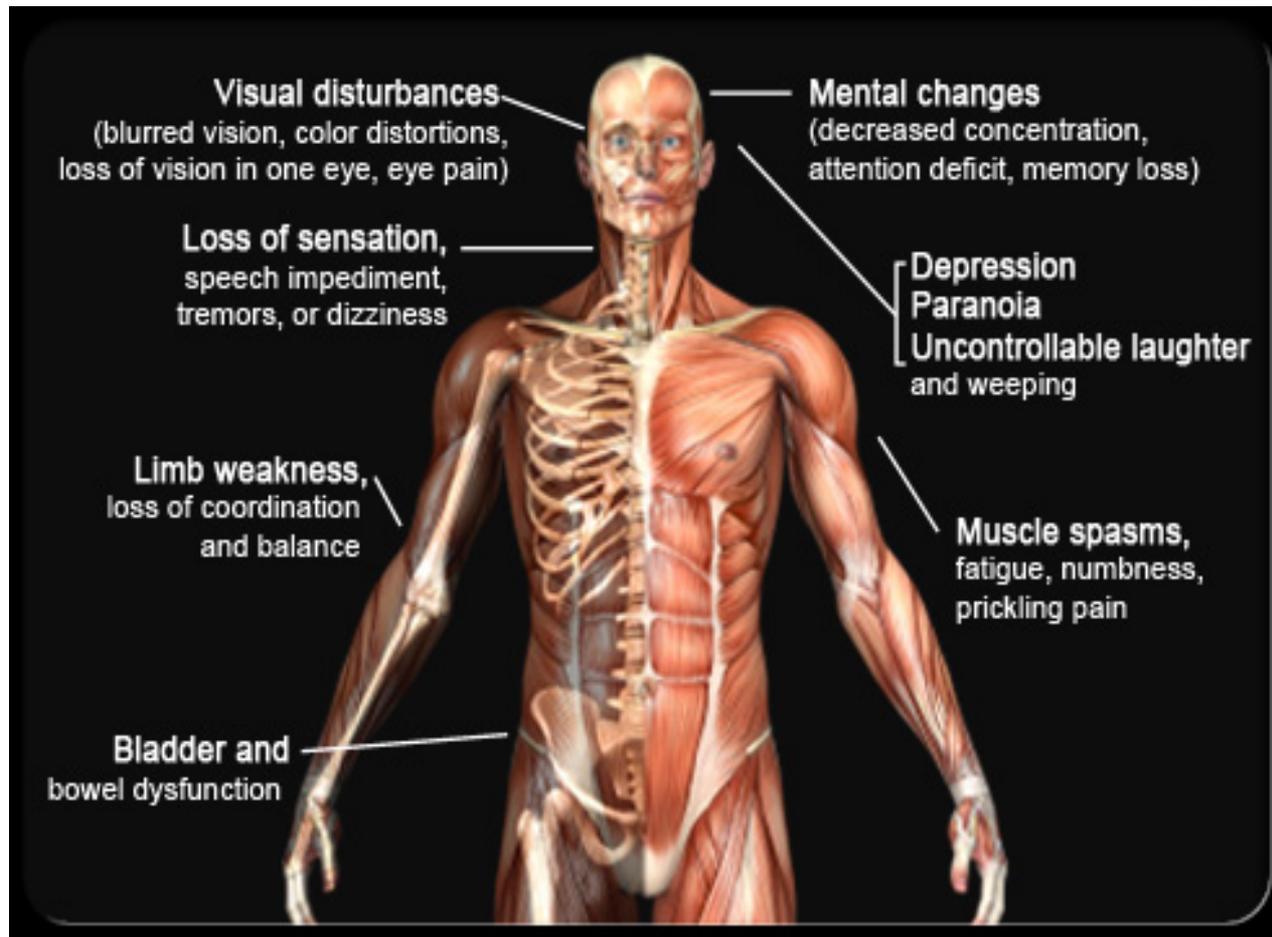


Signs & Symptoms of MS

- Blurred vision
- Loss of balance
- Poor coordination
- Slurred speech
- Tremors
- Numbness
- Extreme fatigue
- Problems with memory and concentration,
- Paralysis, difficulty walking
- Blindness

Many other medical problems may occur, which can come and go or in some cases be permanent.

Symptoms



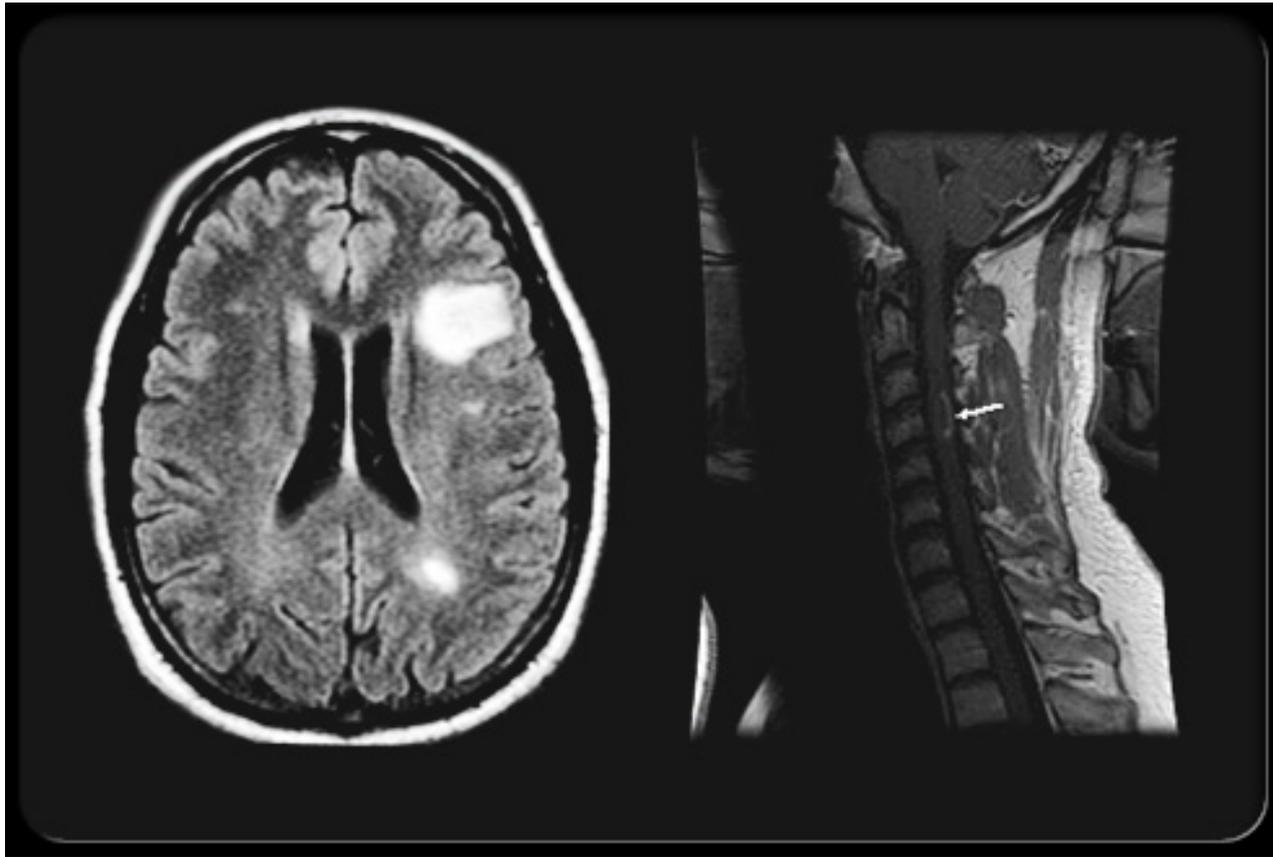
How Is MS Diagnosed?

- Find evidence of damage in at least two separate areas of the central nervous system (CNS), which includes the brain, spinal cord and optic nerves AND
- Find evidence that the damage occurred at least one month apart AND
- Rule out all other possible diagnoses

The Tools for Making a Diagnosis

- Neurological examination
- Magnetic resonance imaging (MRI)
- Lumbar puncture (spinal tap):
occasionally performed
- Visual Evoked Potential (VEP)
- Blood tests

Magnetic Resonance Imaging in MS



How is MS Treated and Managed?

Drug therapy

- Treat new attacks (exacerbations)

- Prevent the occurrence of future attacks

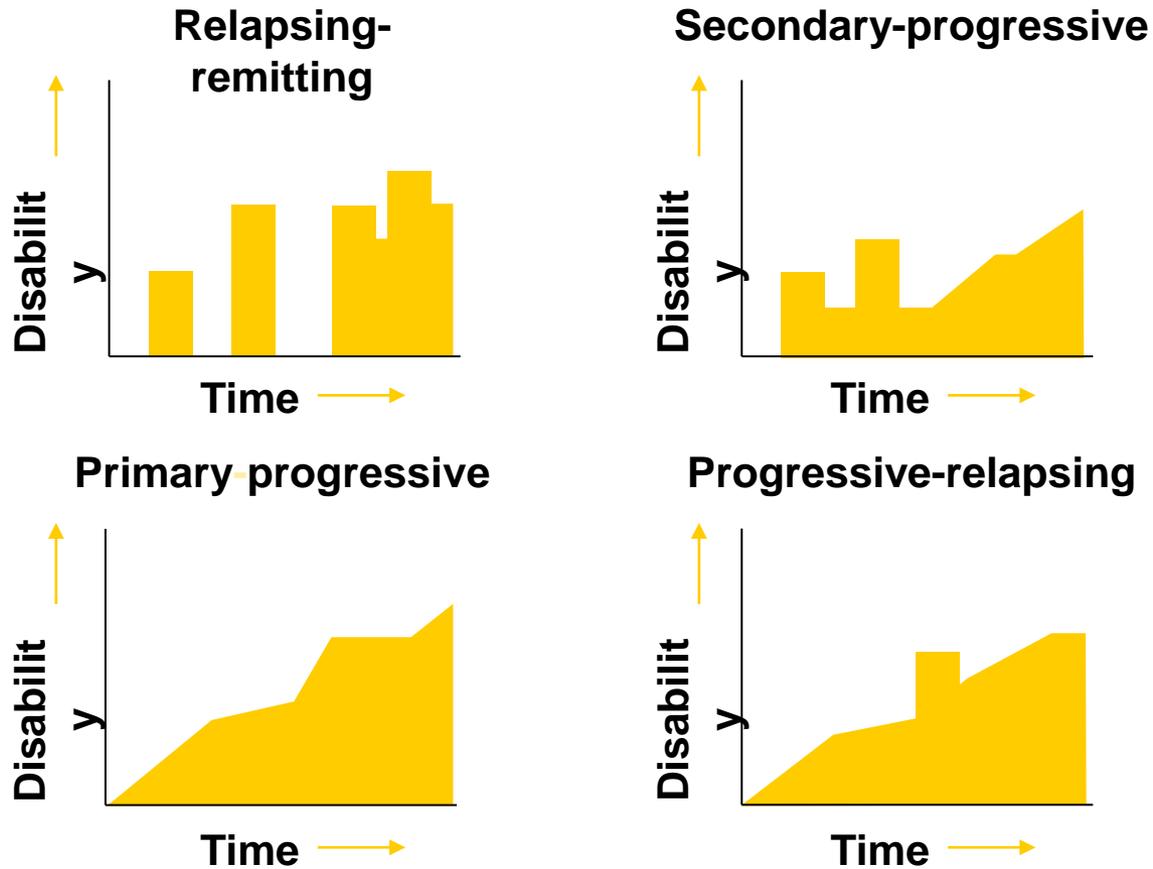
- Slow or prevent disease progression

- Treat the chronic symptoms of the disease

Physical therapy

Psychosocial support

Disease Course



Summary

- MS is an inflammatory disease of the CNS that affects females more frequently than males.
- The cause of MS appears to be a combination of genetic and environmental factors.
- The symptoms of MS can be quite variable.
- MRI is a sensitive test for making the diagnosis of MS.
- Treatments are available for reducing the number of MS attacks and for slowing MS disease progression.

Financial Burden

OVERVIEW OF COSTS

- Among people with MS, 5% of family incomes and 25% of individual incomes fall below the federal poverty level. (Minden et al, 2006)
- Compared to those with relapsing-remitting MS, people with primary progressive MS are more likely to be unemployed (82% vs 42%) and have lower family income. (Sonya Sifika Study, 2006)

Financial Burden

OVERVIEW OF COSTS

- The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice those for persons with relatively mild disease. (Kobelt, et al, 2004)
- Compared to an individual with an EDSS score of 2, costs for an individual with an EDSS score of 8 are almost three times as high. (Lipsy et al, 2009)

Financial Burden

Out of Pocket Medical Costs and Their Impact

- Among common diagnoses, non stroke neurologic illnesses such as **multiple sclerosis** were associated with the **highest out-of-pocket** expenditures (mean **\$34,167**), followed by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955).
- A recent study of medical bankruptcy (Himmelstein et al, 2009) found that 62.1% of all personal bankruptcies in the U.S. were related to medical costs.

Financial Burden

Out of Pocket Medical Costs and Their Impact

- Median out of pocket costs for health care among people with MS (excluding insurance premiums) was almost twice as much as the general population (Minden et al, 2007).
- In over a third of cases, people with MS and their families paid 100% of the cost of mobility aids such as canes, crutches, walkers, and wheelchairs. (Iezzoni, 2006)

Financial Burden

Age as it Affects MS Costs

- People with MS who are 65 or older are more likely to be unemployed, have lower incomes, live alone, have more trouble with walking, bowel and bladder function, and need help with activities such as travel, shopping, bathing, dressing, and using a toilet. (Minden et al, 2004)
- Among persons with MS over the age of 55, one in five report unmet needs concerning wellness or health promotion services. (Finlayson, 2005)

Financial Burden

Employment

- Although almost all people with MS have a work history and labor force participation at the time of diagnosis is comparable to that in the general population,
- over time the ability of people with MS to remain in the labor force declines steadily.
- decline may be as much as three percentage points per year following diagnosis.
- just slightly more than 40% of the MS population is working. (Minden et al, 2006; Sonya Slifka, 2006)

Financial Burden

Long Term Care

- More than a quarter of people with MS use some form of home care but over 80 of this care is provided by unpaid caregivers, mainly family members and, in many cases, youngsters.
(Whetten-Goldstein et al, 1998; Sonya Slifka, 2006)
- Almost 30% of informal caregivers reported also using a paid housekeeper and 30% reported using a paid nurse or aide.
(Buchanan et al, 2009b)

Financial Burden

Long Term Care

- 10% of informal caregivers report that they cannot work due to their caregiving responsibilities. (Buchanan et al, 2009b)
- In a survey of caregivers' perception of predictors of nursing home placement, aging, bowel dysfunction, poorer health, functional decline in the person with MS, and caregiver burden were associated with increased probability of future admission. Higher family income and greater satisfaction with access to MS-focused care were associated with lower risk of nursing home admission. (Buchanan et al, 2010)

Financial Burden

Multiple sclerosis directly impacts the financial stability of the person diagnosed, and his or her family. Factors that contribute:

- Median out-of-pocket medical expenses (Minden et al, 2007)
- Inability to work due to disease progression (Minden et al, 2006)
- Mobility aids (Iezzoni, 2006)
- Paid nurse or aide (Buchanan, 2009)

Multiple sclerosis is associated with the highest out-of-pocket expenditures among common, non-stroke neurologic illnesses.

Medical costs account for more than half of all personal bankruptcies in the U.S.

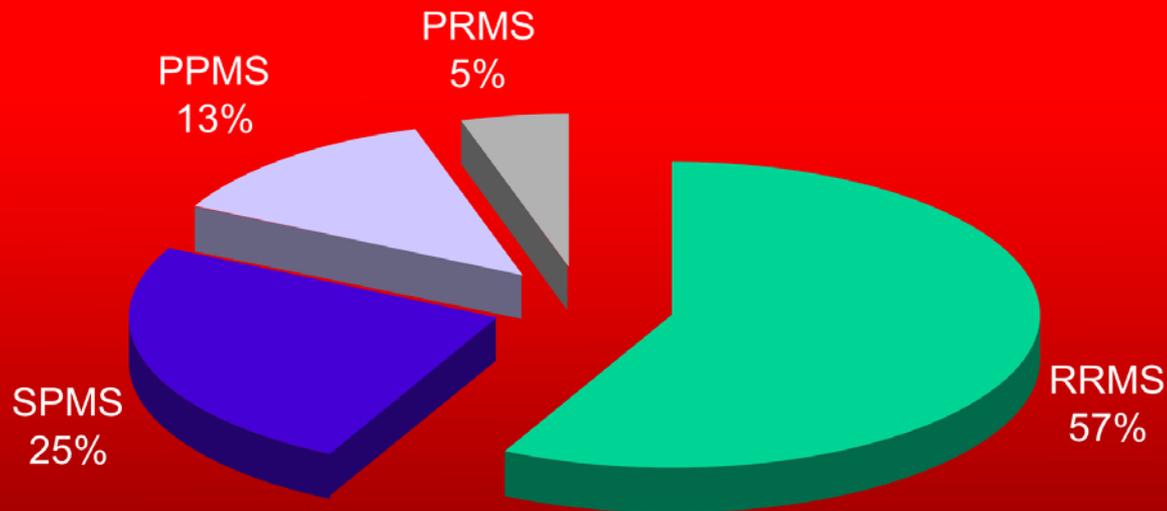
Summary

- Persons with MS have a wide range of challenges that lend themselves to home and community based services
- A high proportion of persons with MS need and use home and community based care
- Most home care is provided by family and friends
- Do not qualify for government assistance
 - Personal Assets – 401k, life insurance policy
 - Spousal Assets

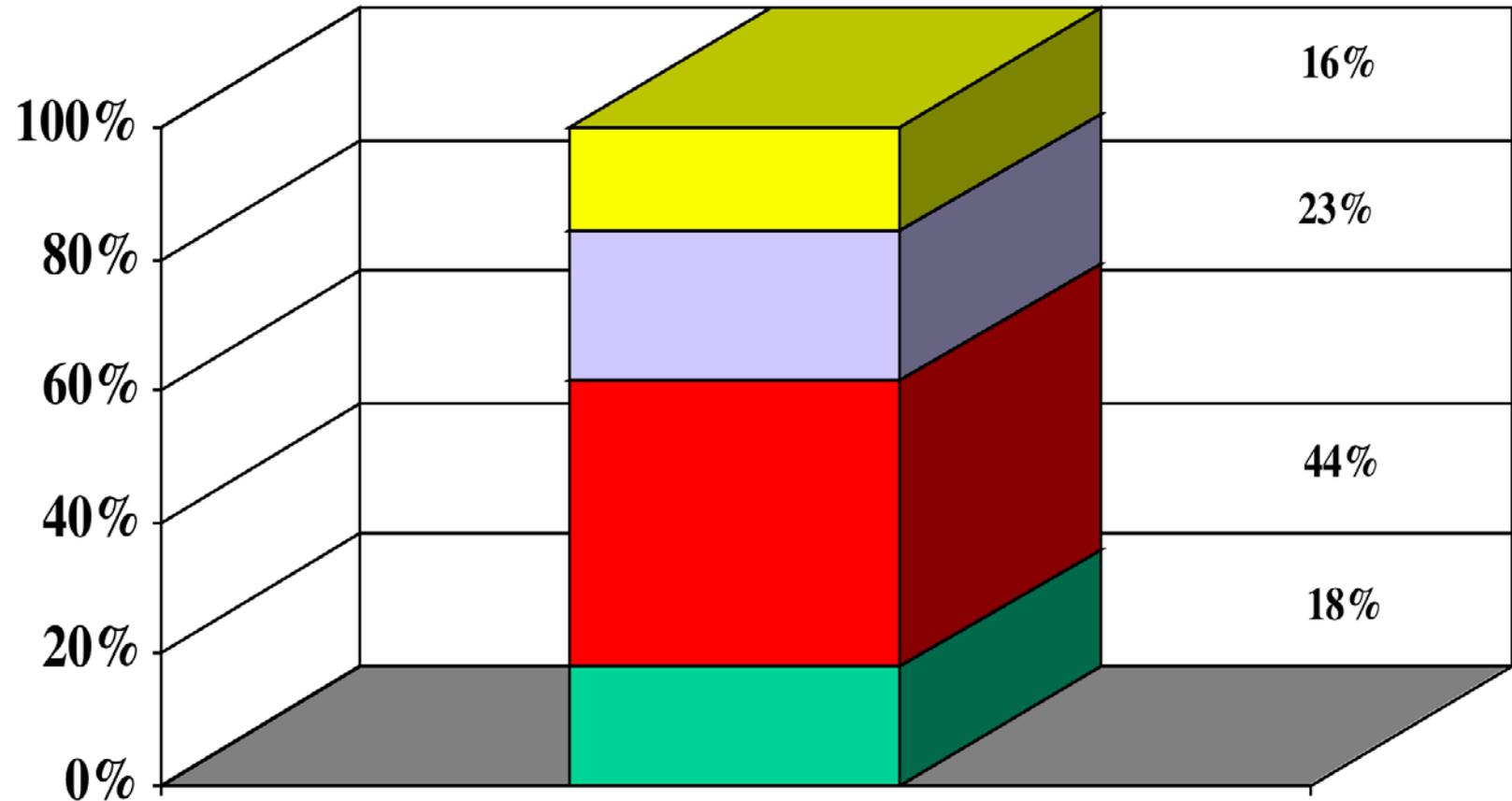
Why is LTC an Issue in MS?

- Course of MS
- Disability
- Limitations

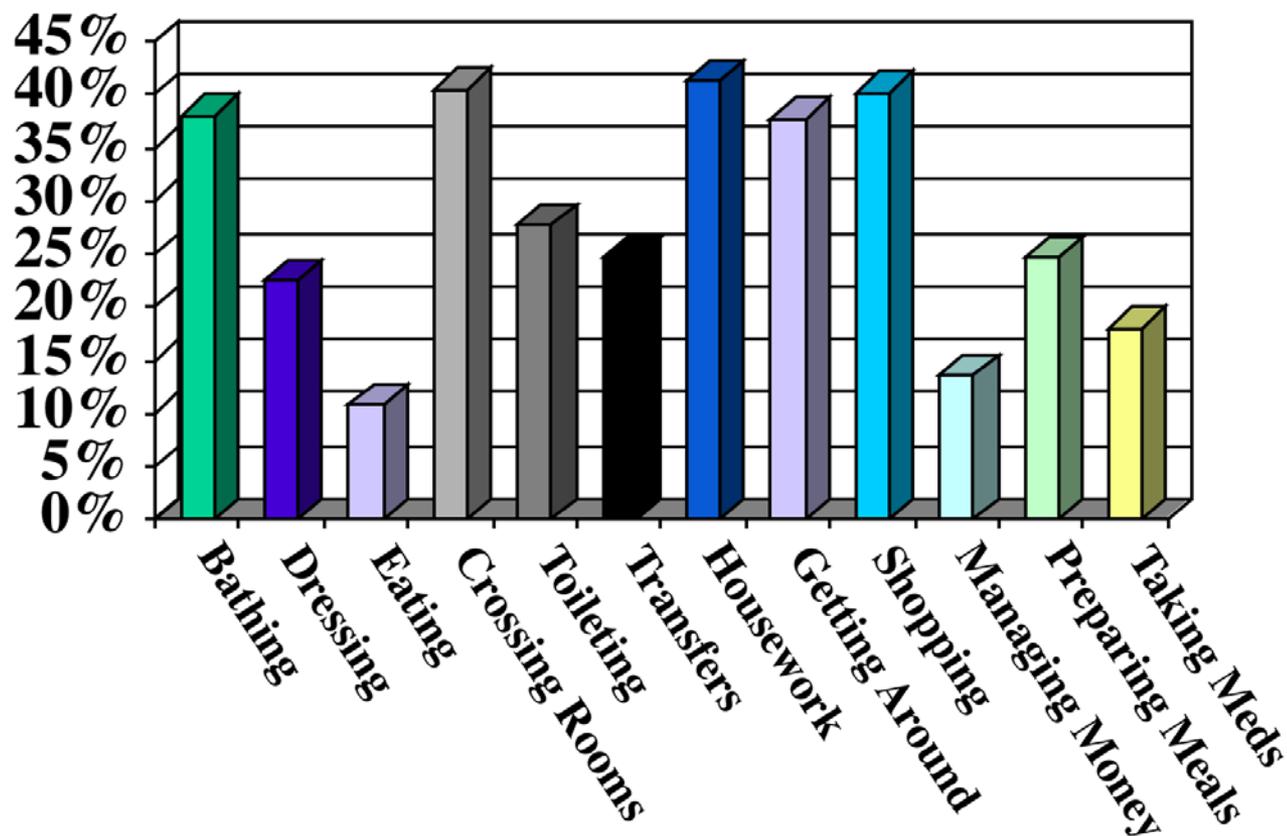
What Does Course Have to Do with It?



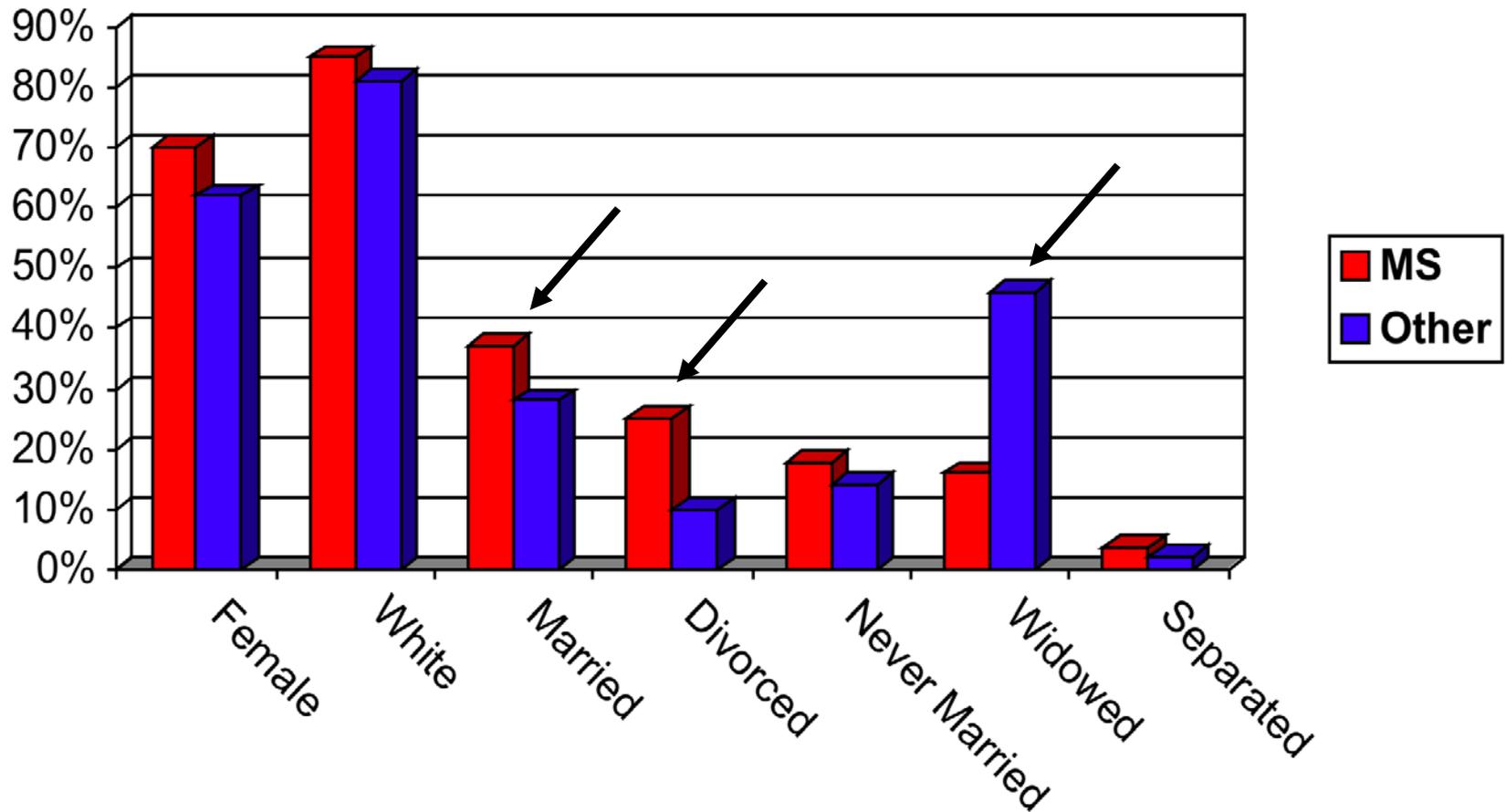
How Severe is Disability in MS?



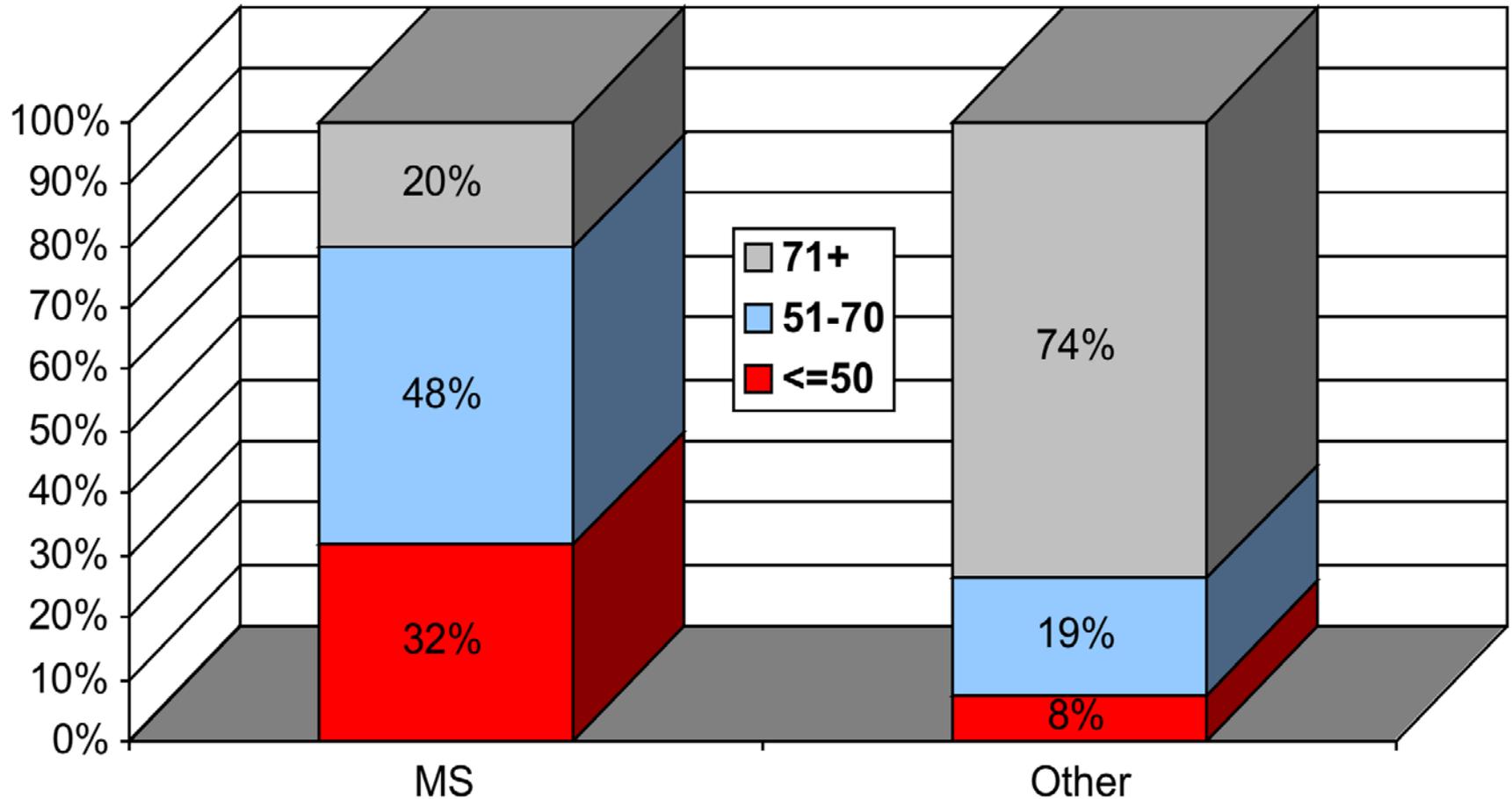
What are the Limitations for Which People with MS Need Help?



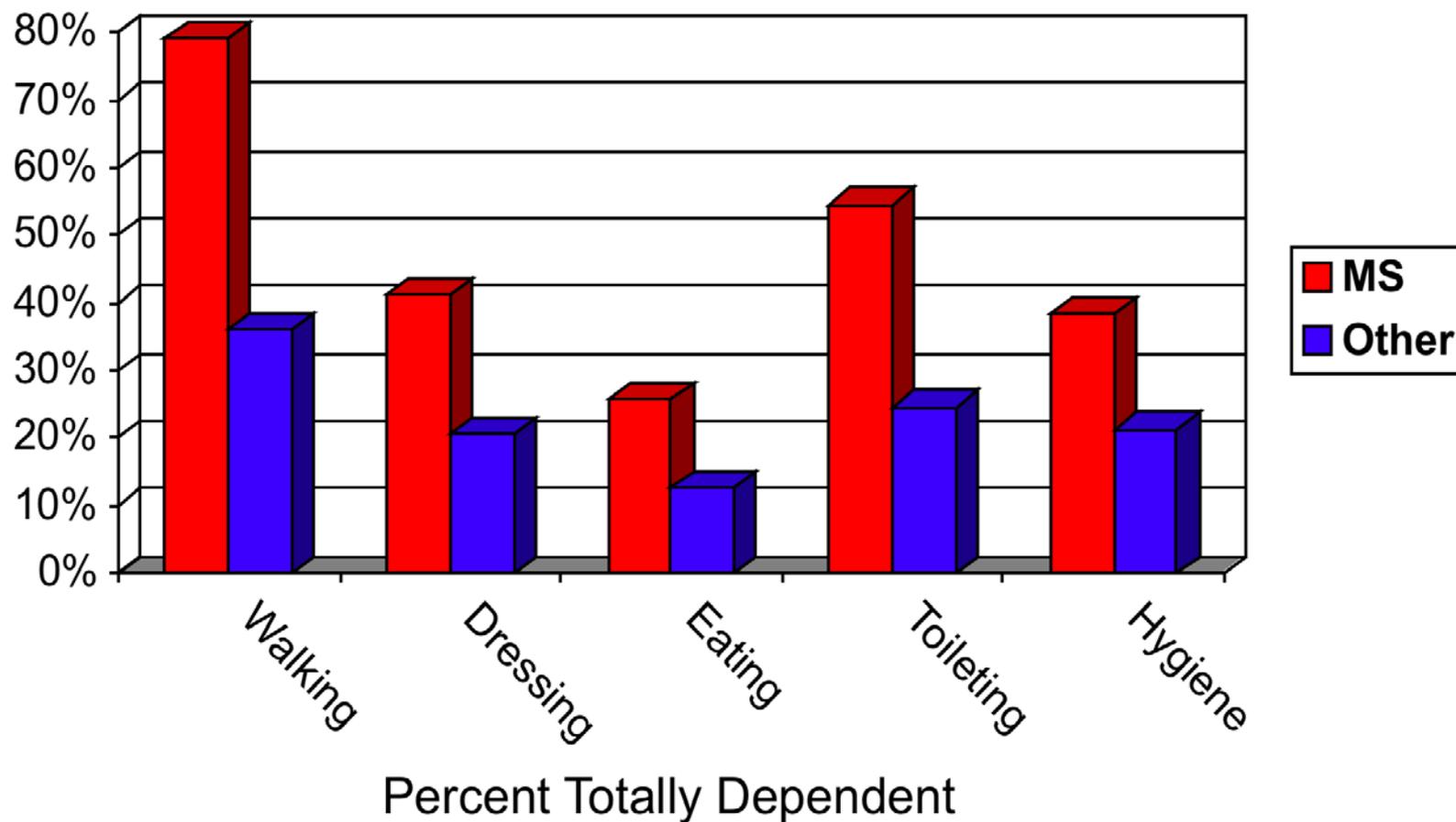
Demographics of MS and Other Residents Admitted to U.S. Nursing Homes: 1998-2000



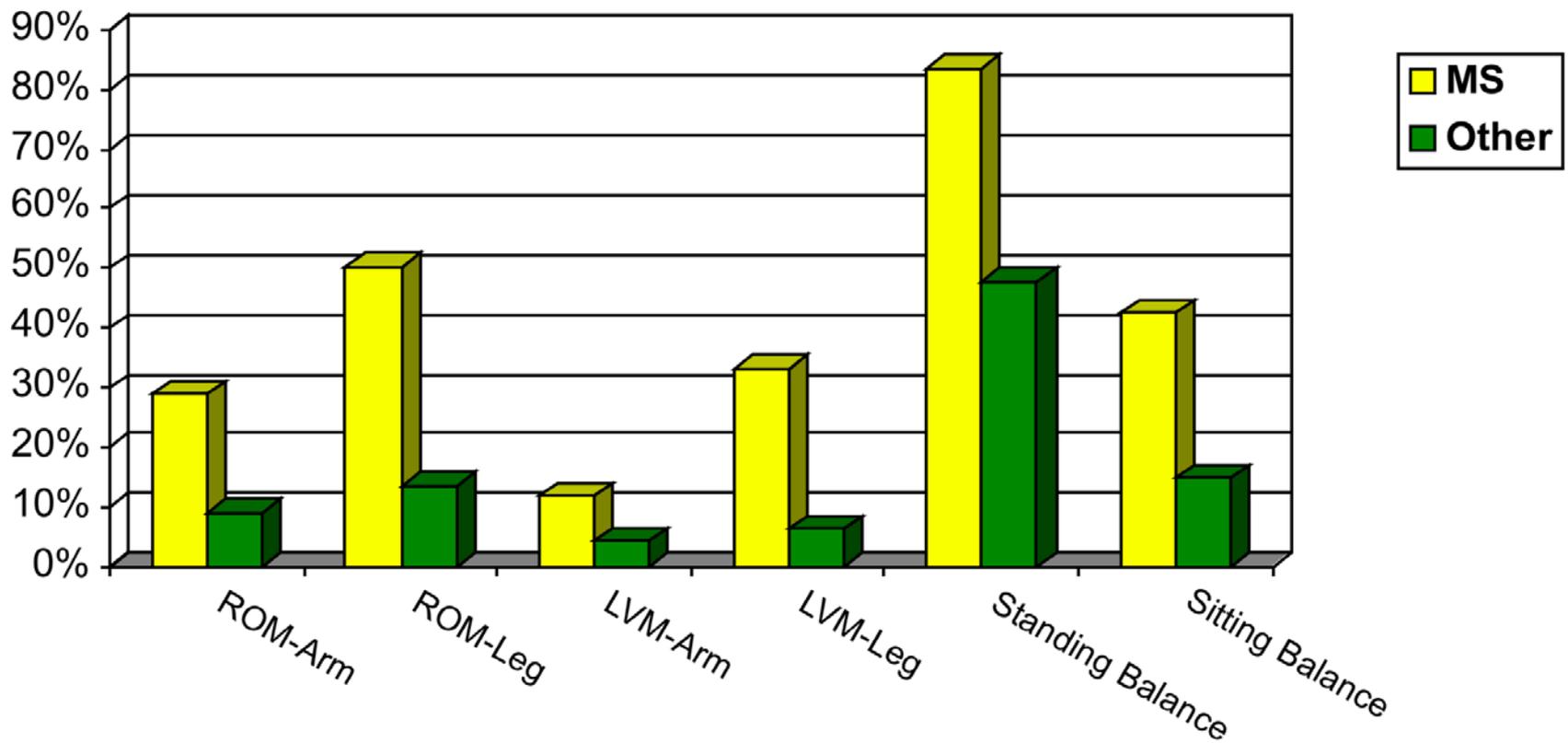
What is the Age Distribution of MS NH Residents Compared to Others?



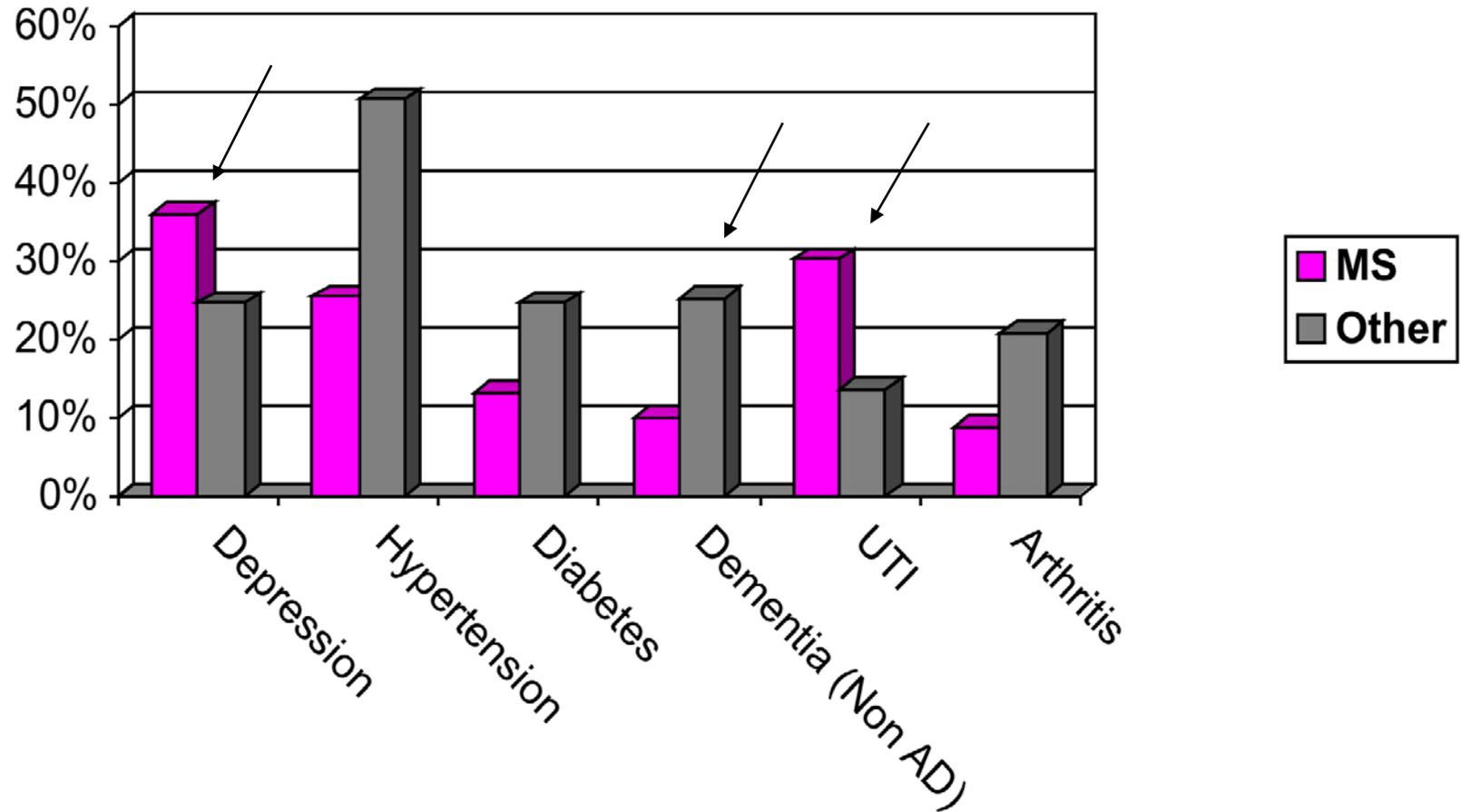
Compared to Other NH Residents, How Dependent are MS Residents in Activities of Daily Living?



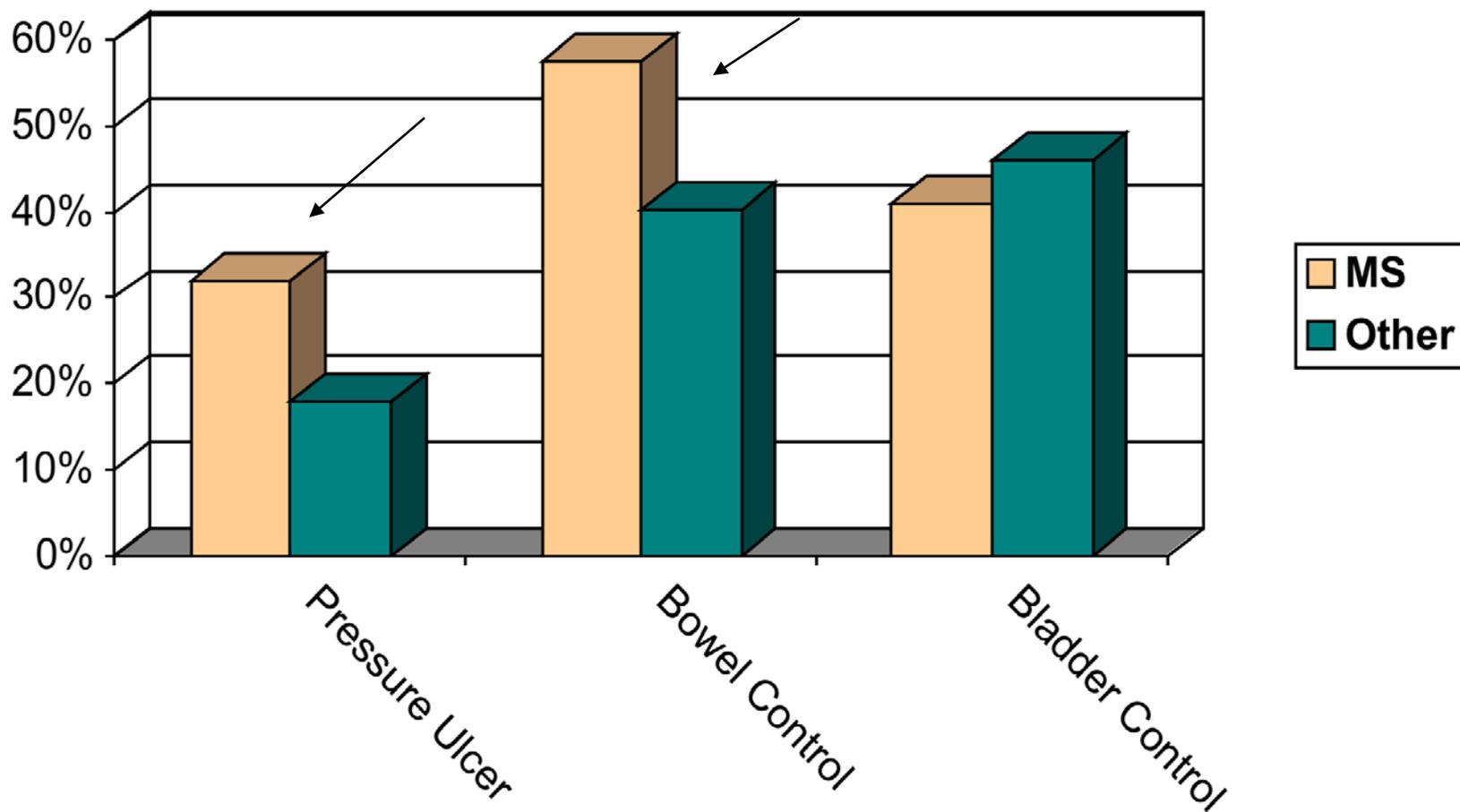
Compared to Other NH Residents, How Limited are MS Residents in Physical Functioning?



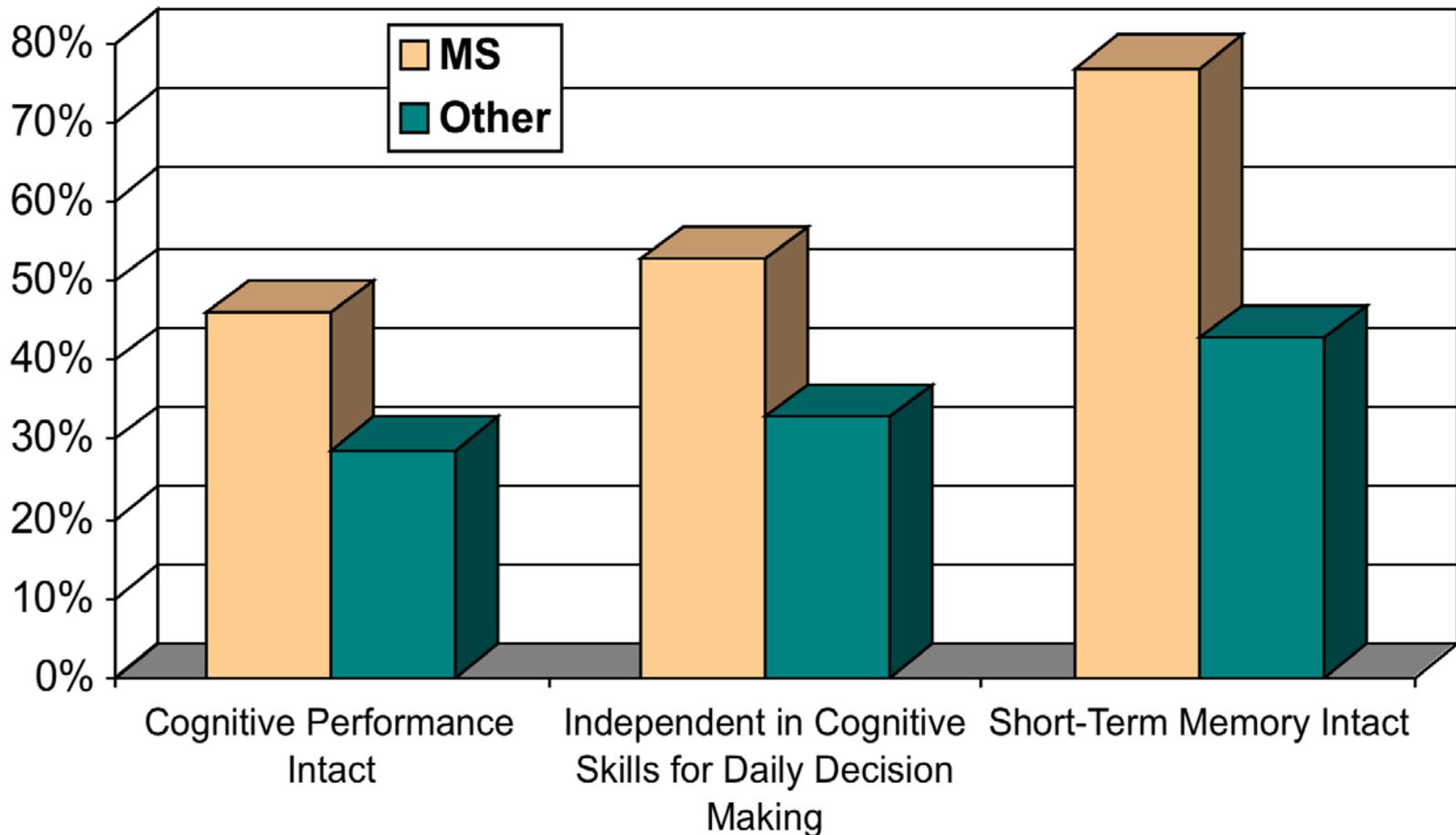
Compared to Other NH Residents, What are Some Common Conditions Affecting MS Residents?



Compared to Other NH Residents, What are Some Other Problems Affecting MS Residents?



What is the Cognitive Status of MS NH Residents Compared to Others?



Summary

- Substantial numbers of PwMS reside in Nursing homes
- younger than other residents but more physically disabled and dependent
- more intact cognitively
- suffer from depression at a high rate with treatment mostly by medication

Home Care in MS

20-30% of PwMS use some form of home care, depending on definition

More likely to use home care if . . .

- Not married

- Lower income

- Unemployed

- Non-white

- More disabled, difficulty walking

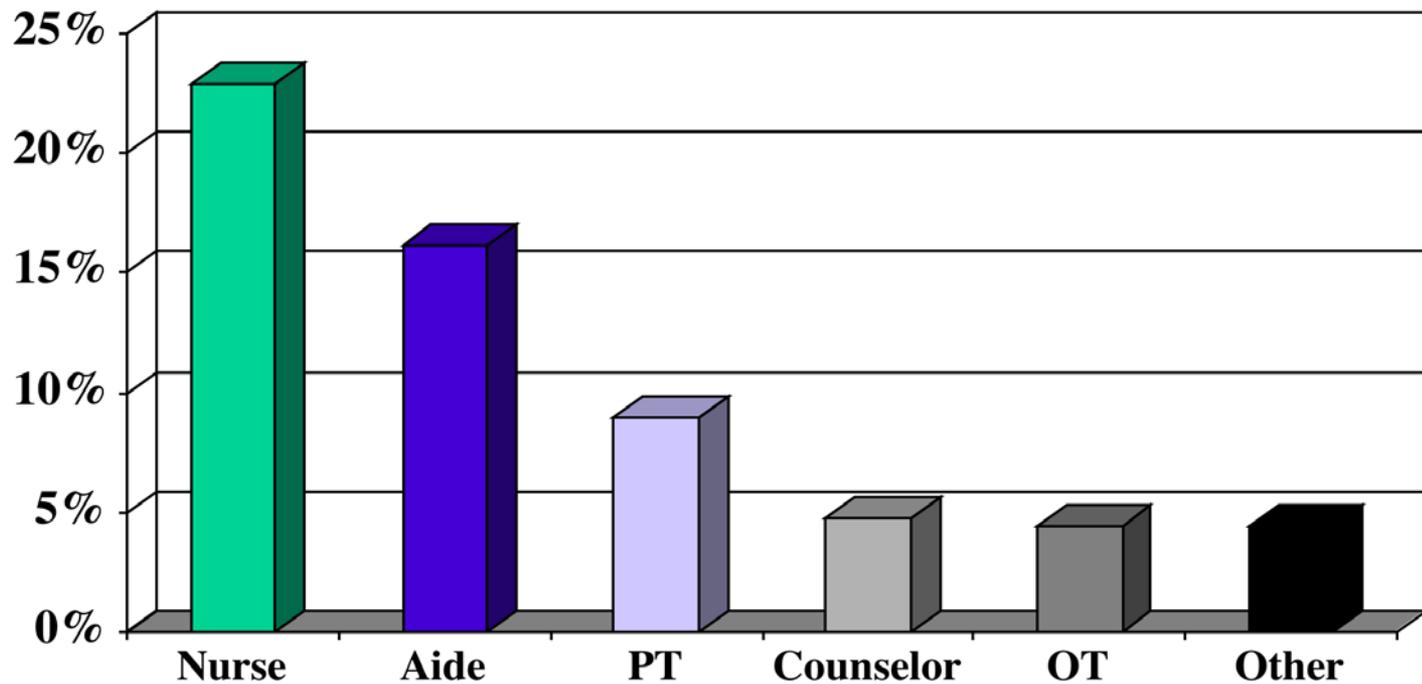
- Need help with ADL

- Receives care from a neurologist

- Fair to poor health status

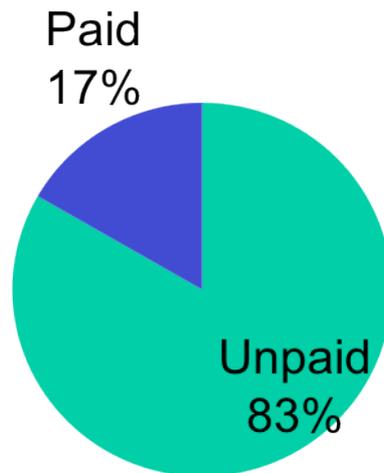
- MS for < 1 year

Home Care Services Used by PwMS

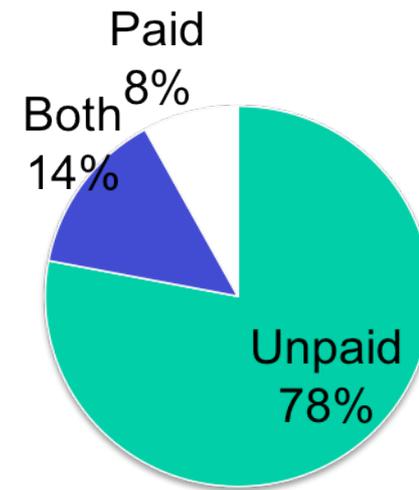


Who Provides Home Care in the U.S. for PwMS?

MS



All OTHERS



The National MS Society

Vision:

To create a world free of MS.

Mission:

We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS. We envision a world free of MS and move toward that end by driving change through advocacy, facilitating professional education, collaborating with others and by providing helpful programs and services.

Multiple Sclerosis stops people from moving.

We exist to make sure it doesn't.

Client Services

“Thank you for Opening a Brand New World for ME!!!”- Jim Champion, living with MS.

“...after moving-in, we began looking for a SAFE WAY for me to get (to the basement) ... it was either too expensive, or would ruin our house because of major excavation etc. As a result, I have only been down there 5 (times)...”

“It feels like a brand new home, and I still find myself mesmerized that I now have the freedom and dignity to go ANYWHERE I want in my own home. You have also made it much safer for us during tornado season!”



Jim Champion- living with MS

Programs

MS Research Symposium

- Held annually in October
- Provides education to 500 people affected by MS.
- Keynote Speaker discussing updates in MS Research
- Training to MS Support Group Facilitators

