Driving with Multiple Scle<u>rosis</u>

National Multiple Sclerosis Society

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Driving with Multiple Sclerosis

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Introduction

If you are reading this booklet you may have questions or concerns about how MS might affect your ability to drive now or in the future. Driving — one of the many ways we maintain our independence — is also one of the most complex activities in our daily lives. In the same way that other things we do can be affected by MS, the ability to drive can also be altered. Although symptoms associated with MS can affect the skills necessary for safe driving, adaptive automobile equipment is available to help you keep driving safely. Here we review the skills necessary for safe driving, important information about driving evaluations, different types of adaptive auto equipment, and Department of Motor Vehicle policies. Lastly, in an effort to maintain your independence if driving is no longer an option, other transportation options are reviewed.

Ways in which MS symptoms may affect your driving ability and safety

Research has shown that a person's driving performance may be negatively affected by symptoms associated with MS. For example, recent studies show that both cognitive changes and spasticity (muscle stiffness or spasms) affect driving performance, putting the person at an increased risk for an automobile crash. In addition, difficulties with information processing and visual-spatial skills are associated with decreased driving performance. In other words, MS can impact many functions necessary for safe driving. Changes in MS over time may result in difficulty operating a vehicle. Your ability to drive safely may be affected if you experience any of the following:

- Difficulty getting into or out of a vehicle
- Muscle weakness or stiffness/spasms/cramps or pain, particularly in the arms or right foot
- Loss of sensation in the feet or hands
- Impaired coordination
- Slowed reaction time
- Fatigue
- Seizures or loss of consciousness
- Blurred vision, blind spots, double vision, loss of color vision
- Cognitive problems such as short-term memory loss; disorientation while driving such as forgetting your destination, getting confused about where you are or missing exits; poor concentration; inability to multitask; and confusion about how to turn the car on or off

Mood changes: depression and/or problems controlling anger

Even if your MS symptoms seem to be mild and manageable, other indications that your driving safety may already be compromised include automobile crashes or near misses, moving violations, and the unwillingness of others to be a passenger while you are driving.

Medical considerations

The severity of MS symptoms can vary considerably over time. Most people with MS experience exacerbations (also called attacks or relapses). During exacerbations driving may be difficult or unsafe, but may return to normal as the exacerbation ends and symptoms improve. However people with progressive forms of MS may experience a slow worsening of abilities that can permanently affect driving.

In addition, symptoms can fluctuate significantly during the course of a day. For example, a person's energy level is typically at its best during the first few hours after awakening, but declines as the day goes on. Planning daily activities around these fluctuations of energy is critical to optimizing personal safety and that of others while you are driving. Medications are available to help manage MSrelated fatigue, so it is important to talk with your doctor about your treatment options and the best strategies for managing your fatigue effectively.

People with MS may be taking several medications to manage symptoms such as spasticity, mood changes, bladder problems, walking problems or pain. With increasing numbers of such medications, and with increasing doses, the likelihood increases that they could affect wakefulness, concentration, coordination and reaction time. If you think that medication side effects may be affecting your driving, talk with your healthcare provider about treatment options you can consider to minimize their impact on your driving.

Driving evaluations

If you or others are concerned about your ability to drive, you may consider obtaining a comprehensive driving evaluation. Driving evaluations help pinpoint any challenges you may be experiencing, as well as the appropriate adaptive equipment to keep you safely on the road.

Driver rehabilitation clinics are often located in medical centers but may also be available in your community. A driving evaluation is performed by a driver rehabilitation specialist (DRS) or certified driver rehabilitation specialist (CDRS). A DRS or CDRS is typically an occupational therapist with specialized training in driver rehabilitation. The driving evaluation assesses your driving skills, and, if appropriate, also provides a recommendation for an appropriate vehicle type and adapted automobile equipment to meet your needs. Since the driving evaluation is usually performed by a therapist using specialized equipment, it is more comprehensive than a typical Department of Motor Vehicle (DMV) road test.

While the length of the evaluation varies, you should expect it to last about two hours; it includes an **office-based assessment** and a **behind-the-wheel evaluation**. The office-based assessment includes a review of your medical and driving history, and a look at how MS affects your performance with other activities such as bathing, dressing or medication management. You will be asked about specific problems you may have with driving, any citations you may have received while driving, motor vehicle crashes or near misses. In addition the following will be assessed:

- Functions such as strength, range of movement, coordination, sensation and motor speed
- Vision including visual acuity, depth perception, color vision and road sign recognition
- Cognitive performance to determine how quickly your brain processes information and how MS may be affecting memory, visual searching and visual-spatial relations

If you demonstrate adequate vision, cognition and motor function during the office-based assessment, a behind-thewheel road test will be performed, usually in the facility vehicle. The road test will generally begin in low traffic areas and proceed to more complex or higher traffic areas. Your ability to safely operate the car will be evaluated, including:

- Ability to transfer safely in and out of the vehicle
- Ability to stow any assistive devices like a wheelchair, walker, cane
- Ability to follow the rules of the road
- Reaction time in identifying potential hazards on the road
- Reaction time maneuvering the vehicle and moving your foot back and forth between the gas and brake pedals
- Visual searching, scanning and attention abilities
- Use of good judgment before executing a maneuver (e.g., a left turn)
- Ability to multi-task
- Ability to stay within a lane and to change lanes safely
- Safety awareness while driving
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Adaptive automobile equipment

Specialized adaptive equipment may be recommended to help you adjust for deficits that interfere with your driving; these could include:

- Mechanical hand controls to operate the gas and brake
- Digital driving ring to operate the gas and brake (more expensive than mechanical hand controls)
- Spinner knob to turn the steering wheel
- Adaptive steering and/or braking mechanisms that require less effort
- Hi-tech driving equipment for gas, brake and steering control using a joystick or other one-handed devices may be an option for those with more involved physical impairments, although extensive training is required and the costs may be quite high
- Wide angle rear view mirror, larger outside driver and passenger side mirrors and/or a multi-panel rear view mirror
- Specialized seats to ease vehicle transfers
- Lifts for stowing wheelchairs and assistive devices
- Lowered-floor vans equipped with a ramp or lift to accommodate a wheelchair

Once the driver rehabilitation specialist has recommended specific auto equipment, you will need training on how to use the equipment properly and safely. The training is usually performed in the facility vehicle. Length of training varies depending on the type of equipment and the individual's learning style. Training generally concludes when you have demonstrated safe operation of the equipment on all types of roadways. A mobility equipment dealer can then install the adaptive equipment in your car.

After your training is completed, the next step is a road test at your local DMV to demonstrate your ability to use the equipment safely. In many cases, the DRS who trained you will take you to the DMV so that you can be tested in the same vehicle in which you were trained, or you can take the test in your own adapted vehicle. The DMV then indicates on your driver's license that you are required to drive with specialized auto equipment.

As with any medical condition that may affect your ability to drive, a re-evaluation of your driving skills and/or use of adaptive driving equipment may be necessary if your symptoms progress over time.

To locate a DRS or CDRS for a driving evaluation, please contact the Association for Driver Rehabilitation Specialists (ADED) at 866-672-9466 (**aded.net/?page=725**) or the American Occupational Therapy Association (AOTA) at 301-652-6611 (**aota.org/olderdriver**).

A driving evaluation can cost \$350 to \$500 and is generally not covered by insurance.

Selecting and funding specialized automobile adaptive equipment

The National Mobility Equipment Dealers Association (NMEDA) sets the industry standards for adapted vehicles and provides a list of certified dealers that sell adapted vehicles and perform mobility equipment installations (**nmeda.com**). It is important to get any adaptive auto equipment installed by a certified dealer in order to ensure safety.

The cost of vehicle modifications varies greatly depending on the type of equipment recommended. Whether you are purchasing a new vehicle or would like to add adaptive auto equipment to your existing vehicle, there are public and private opportunities for funding:

- If you are purchasing a new vehicle, rebates for adaptive auto equipment are available through:
 - > General Motors (gmmobility.com)
 - > Ford (fordmobilitymotoring.com)
 - > Toyota (toyotamobility.com)
 - > Chrysler (chryslerautomobility.com)
 - Honda (automobiles.honda.com/information/ mobility-assistance.aspx)

- If you plan to use your vehicle to maintain employment, contact your State Vocational Rehabilitation Agency office to see if they are able to assist with the cost. (askjan.org/cgi-win/ TypeQuery.exe?902)
- If you are a veteran and considered service connected for specific conditions, you may be eligible to apply for an Automobile Adaptive Equipment grant through the Department of Veterans Affairs. (www.benefits.gov/benefits/benefit-details/278)
- The MS Foundation Assistive Technology program may help with a limited expense (e.g., if you need assistance purchasing a piece of medical equipment or other MS-related expense). (msfocus.org/Assistive-Technology-Program.aspx)
- Vehicle modifications are an eligible item for application through the National MS Society's financial assistance program. Financial assistance is dependent on funds available. (800-344-4687)
- Local service organizations (such as the Lions, Elks, Kiwanis or Rotary Club) in your area may be willing to assist you with funding.
- Check with a qualified accountant to determine if the vehicle modifications and/or equipment might be eligible for a tax credit.

State Department of Motor Vehicles (DMV) policy

States vary widely in their regulations concerning drivers with medical conditions. Most states rely on the individual driver to disclose medical conditions that may affect driving ability and safety, and failure of a driver to disclose medical conditions that might affect driving may result in legal penalties and also denial of insurance claims. Although a diagnosis of MS itself does not automatically preclude you from driving, the loss of function associated with MS may affect driving skills. Each state has its own procedures for re-evaluation of driving skills or reinstating driving privileges; this usually requires your doctor to complete a medical report form clearing you medically to drive. However, if your physician is unable or unwilling to complete this medical report, a formal driving evaluation by a DRS or CDRS may be an alternative. In addition, you may still be required to pass a state road test once your doctor has signed a medical clearance form. You should contact your state DMV for specific information.

It's not uncommon for people to put off renewing their license until the last minute. Keep in mind that if a medical review is required, it could take time. Be sure to apply for your renewal prior to the expiration date on your license — if you let your driver's license expire, it is unlikely that you will be provided with a temporary license to use during your medical review process. Discuss your renewal in advance with your healthcare provider so you will have quick access to your medical records if necessary.

Safety eligibility requirements may be imposed to receive a driver's license if they are based on actual risks and not on mere speculation, stereotypes or generalizations about individuals with disabilities. If your license is denied or revoked, utilize the process for driving privilege appeal if necessary. Be an activist and involve your local legislators in the process so that they are aware of the challenges that individuals with MS and other chronic diseases face when navigating state agencies.

Disabled parking placards

Disabled parking is sometimes a necessity for people living with MS. People may not realize at first that they are eligible. The medical requirements vary by state. As a general rule, the use of any assistive device such as a wheelchair, crutches or cane would qualify a person for disabled parking. Many states also include certain cardiovascular conditions, respiratory problems and conditions that cause pain while walking or otherwise require the person to rest after walking a very short distance. Age and weakness may also be covered.

Being able to park closer to your destination can save you energy and allow you to run errands, shop, go to doctor appointments, travel or participate in other activities. If you feel your mobility is significantly impaired and that you would benefit from a placard, talk to your doctor. Your doctor can sign the paperwork for you to get a disabled parking placard if you are eligible. States vary in how they administer disabled parking placards. Some states charge a processing fee, while others offer disabled parking permits for free. Some states require a doctor's prescription along with an application. Some applications can be downloaded online. Contact your state DMV for details.

The availability of reserved parking spaces is regulated by both federal and state laws. Under the Americans with Disabilities Act (ADA) any place of business or other location that provides parking to the public must designate a number of disabled-accessible spaces that is proportionate to the total number of spaces available at the facility. Generally at least one space is available at any public parking location, with more being required based on the size of the parking lot and in some cases the type of location, such as a healthcare facility. If you have questions about accessible parking in the areas you frequent, contact your local city motor vehicle office.

WHEN DISABLED PARKING SPACES ARE MISUSED

The abuse of disabled parking spaces is a common problem most often an able-bodied person who pulls into a disabled parking space "for just a minute or two" or uses a disabled placard without having a disability. Law enforcement officials have difficulty detecting this type of abuse and generally give little importance to the problem. And because punishment is minimal, there is little incentive for people not to exploit the parking system. As a result, people who need those parking spaces to accomplish necessary daily tasks are often unable to get them.

The more people who report the problem, the more likely it is to be addressed. To report disabled parking abuse, write down the vehicle's license plate number, the placard number, if applicable, and the location. Contact local law enforcement and/or local DMV. Many states have a special department dedicated to investigating misuse of disabled parking privileges. Remember that individual disabilities are not always visible, so reporting should be based on facts or personal knowledge rather than suspicions, and no violation is worth putting yourself in harm's way. If you encounter someone who is hostile towards you, it's better to just drop the matter. And if you encounter repeated violations at your place of employment or where you live, you may feel more comfortable talking to your employer or landlord about the problem.

And remember that you may be questioned or criticized by others for using a disabled parking space if your MS symptoms are not clearly visible. So it's a good idea to be prepared to educate the person about MS or provide a piece of literature about invisible symptoms.

Commercial Driver's License (CDL)

If driving is a critical part of your job, you may be concerned how MS may affect your employment. The most important thing to keep in mind is safety. According to the Federal Motor Carrier Safety Administration (FMCSA), as long as MS symptoms and/or treatment are not impeding your ability to operate a vehicle safely, and you are physically qualified to do so, you can apply for and/or be considered to keep or renew an interstate CDL.

The FMCSA has set guidelines (a medical certification process) for CDL drivers who operate in interstate commerce. The medical certification process requires each driver to complete the health history section on the medical examination report, which includes disclosing any illness in the past five years.

A medical examiner will conduct a physical exam. The medical examiner is expected to be knowledgeable about the necessary physical skills for a commercial vehicle driver, and the FMCSA relies on the medical examiner's clinical judgment to decide whether additional information should be obtained from the driver's treating physician. If it is determined that your MS and/or treatment does not interfere with your safe driving ability, then you can receive a Medical Examiner's Certificate indicating that you meet the minimum requirements to obtain a commercial driver's license (http://bit.ly/2aeXBNK).

Many states mirror the FMCSA requirements for drivers, though each state decides its own medical certification requirements. Individual carriers may also have more stringent medical certification requirements than those specified by FMCSA.

Teenagers and first-time drivers

If you are a teenager or first-time driver, you should check with your healthcare provider in order to address any concerns related to how your symptoms may impact driving. Once your doctor has cleared you medically to drive, you would be wise to contact a local driver rehabilitation specialist for a driving evaluation including any equipment recommendations or vehicle modifications you may need.

Tips on remaining safe while driving

Since the symptoms of MS often are not only relapsing or remitting, but also can fluctuate from day to day and during a single day, your ability to drive may also fluctuate. The following tips may be helpful:

- Don't drive when you are having a bad day
- Keep your trips short if fatigue is an issue; avoid driving when you know your fatigue is severe

- Avoid driving during periods of heavy traffic
- Avoid driving in bad weather
- Avoid distractions such as eating, arguing with passengers or using a cell phone. Talking on a cell phone or texting while driving have been shown to increase the risk of fatal crashes and are now illegal in many states.
- Avoid driving when you have another illness (e.g., flu), because MS symptoms are often worse when your body is under increased stress

What if I decide, or am told, it's no longer safe to drive?

Part of being independent is recognizing when one is no longer safe to perform certain activities. Just as you might plan for other circumstances associated with a disease (e.g., receiving assistance with activities of daily living, modifying your home for accessibility), planning for the day when driving is no longer possible can help ease the transition from driver to passenger. People may be at increased risk of depression when they stop driving. If you find yourself having difficulty accepting the loss of driving, you might want to consider talking with a therapist. Talking about your feelings may be helpful in dealing with your grief over the loss of driving. And talking with your insurance agent or attorney may be helpful if you are having difficulty understanding why others have concerns about your driving safety.

Alternative Transportation

Many people consider driving to be essential to their independence; however, people can lead very complete lives without driving in every setting. Should you give up driving, transportation and paratransit systems are available in many areas. Paratransit is a van and taxi program for people unable to independently use public transit because of a disability or disabling health condition. Since 1990, the Americans with Disabilities Act (ADA) has required that all public transit agencies provide paratransit services to qualified people with disabilities. In addition, although many transportation providers advertise their services for older adults, they will frequently accommodate younger individuals with disabilities. When looking for alternatives to driving you may consider exploring the following:

- Ask a friend or family member for a ride; consider offering to pay for the gasoline
- Take a taxi cab
- Ask about volunteer drivers at your local community center, place of worship or local service organization
- Check with your city's public transportation agency for information about paratransit and accessible transportation options in the area
- Check with your state agency responsible for making sure people with disabilities have transportation
- Contact the National Aging and Disability Transportation Center (NADTC), an agency that promotes the availability

and accessibility of transportation options for people with disabilities. **nadtc.org**

 Contact the National MS Society for a list of local transportation programs and providers.

Resources

National MS Society nationalMSsociety.org 800-344-4867

The Society has many resources outside of what is covered in this booklet (for example, finding new or used accessible vehicles, renting an accessible vehicle, loan programs for accessible vehicles, and accessible travel).

AAA Foundation for Traffic Safety

AAAFoundation.org

Provides pamphlets on "Distractions in Everyday Driving" and "How to Avoid Drowsy Driving" (enter titles in the search bar).

AARP

Offers information on driving safety courses, safety tips for older drivers, knowing when to limit or stop driving, and many other safe driving topics.

aarp.org/home-garden/transportation/driver_safety

The Hartford

thehartford.com/mature-market-excellence

Helpful articles for keeping people safe on the road.

Notes

The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient's use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.

The Society publishes many other resources about various aspects of MS. Visit **nationalMSsociety.org/brochures** or call 1-800-344-4867.

Other popular resources include:

- ADA and People with MS
- Depression and Multiple Sclerosis
- Fatigue: What You Should Know
- Living with MS
- Multiple Sclerosis and Your Emotions

The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.



National Multiple Sclerosis Society

For more information:

nationalMSsociety.org 1-800-344-4867