## How to Choose the Mobility Device that is Right for You A GUIDE FOR PEOPLE WITH MS

MANAGING MAJOR CHANGES



Jason (cover photo), diagnosed in 2005. Kim (top), diagnosed in 1986. John (second from top), diagnosed in 2001. Ray (middle), diagnosed in 2003. Michael (second from bottom), diagnosed in 2004. Ginny (bottom), diagnosed in 1990.

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# Who should read this guide?

- People with multiple sclerosis (MS)
- Family, friends, personal care attendants, and others who help you with your personal care
- Medical and rehabilitation providers with whom you come in contact, including physicians, nurses, occupational therapists, physical therapists, rehabilitation engineers, and assistive technology suppliers
- Anyone who is interested in learning more about mobility options for people with MS

# Why is this guide valuable?

- Eighty percent of people with MS experience problems with walking within 10–15 years of disease onset.
- Common symptoms of MS, including weakness (decreased strength), poor balance, spasticity (increased muscle stiffness or tone), and fatigue (feeling of tiredness), can increase your risk for falls.
- Many falls can be prevented with the use of the appropriate mobility device.
- Safety and independence can be enhanced with the use of the right mobility device.
- Mobility devices can help to conserve energy and increase activity levels.

The purpose of this guide is to help you become familiar with the types of equipment (assistive and mobility devices) that are currently available to enhance your mobility, and the potential benefits and limitations of each one. The guide serves as a resource for you and your healthcare provider to assist you in choosing the right mobility device for you. We recommend that you take this guide with you to your appointment with your healthcare providers when looking for the mobility device that best meets your needs.

# What is multiple sclerosis?

Multiple sclerosis (or MS) is a chronic, often disabling disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord, and optic nerves. People with MS typically experience one of four disease courses — relapsing-remitting, primary-progressive, secondary-progressive, or progressive relapsing — each of which might be mild, moderate, or severe. Depending on the disease course a person has, symptoms can come and go, come and stay, or progress more steadily over time. The progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another. The National MS Society can help you find a physician and other healthcare providers with MS expertise in your area, answer your questions, and direct you to resources in your community. Call 1-800-344-4867 or email **generalmailbox@nmss.org** to connect with an MS Navigator<sup>®</sup>.

### What are common MS symptoms that affect mobility?

Common symptoms of MS that can affect your ability to walk *safely*, *independently*, and *efficiently* include:

- Muscle weakness
- Pain
- Loss of balance
- Poor coordination
- Numbness/tingling in your feet and legs
- Extreme fatigue or feelings of tiredness
- Increased muscle tone or stiffness (spasticity)
- Impaired vision
- Cognitive difficulties

The course of MS is unpredictable and the severity of symptoms and the rate of progression vary from one person to another. For any given individual, symptoms can vary over the course of a day and from week to week or month to month. The progressive nature of MS with exacerbations (also called attacks or relapses that cause a sudden onset of new symptoms or worsening of old symptoms) and remissions (in which symptoms return to their previous level or stabilize) — may make it difficult to adjust to changes in your mobility. However adjusting to these changes is essential for your safety and comfort.

What common MS symptoms can increase your risk for falls & decrease your independence in activities of daily living (ADLs)?

All of the symptoms listed above can increase your risk of falls. Fatigue is one of the most common and disabling symptoms of MS. MS fatigue — also referred to as lassitude — is a feeling of extreme tiredness or exhaustion that can affect your physical and mental functioning. Approximately 80% of people with MS report having fatigue on a regular basis — and this fatigue can directly affect your ability to walk and increase your risk of falls. Falls can cause secondary problems such as bone fractures, hospitalization, and possibly increase your dependency on others. Having a fear of falling can limit your willingness to go out in the community independently, which can increase your frustration level and feelings of isolation, and put you at greater risk for depression.

#### **IMPORTANT:**

If you are stumbling or falling, or have a fear of falling, you should contact your physician and request a mobility evaluation with a physical or occupational therapist. A careful evaluation will help determine whether the use of an assistive or mobility device might solve or decrease your risk of falling.

### What types of assistive & mobility devices are available?

When rehabilitation with a physical or occupational therapist does not improve walking to a sufficient degree, mobility can often be enhanced with the use of a mobility device. Finding a mobility device that is suitable and appropriate to your particular needs is very important. Without the proper devices, your mobility problems are likely to interfere with your participation in home, work, family, social and leisure activities.

A large number of assistive and mobility devices are currently available on the market. Your healthcare providers can prescribe the device(s) that best meet your needs. We will discuss the available options in order, starting from the basic, low-tech mobility devices, and leading up to the more advanced, hightech devices. This order does not necessarily reflect the order in which you might use these devices; a person with steadier disease progression may follow a similar order, while someone else might use different devices depending upon his or her activities at home, at work, or in the community.

- Orthoses (braces)
- Functional electrical stimulation (FES)
- Canes
- Crutches
- Walkers and wheeled walkers (rollators)
- Manual chairs
- Pushrim-activated power-assist wheelchairs
- Motorized scooters
- Power wheelchairs

#### Orthoses (braces)

Orthoses — or braces — are available in many types and styles. An ankle foot orthosis (AFO) is the brace most commonly used to support the ankle and foot and prevent foot drop. Foot drop is a condition caused by weakness or paralysis of the muscles involved in lifting the front part of the foot during walking. An AFO helps to prevent tripping and falling by preventing the toe from dropping and catching on the floor, carpet, curb, or other obstacle — thereby providing for adequate foot clearance when walking. Some AFOs are solid (see Fig. 1A and 1B) and some have ankle hinges to provide a different kind of support. AFOs are available in different materials (metal, plastic, or carbon fiber) and can be custom made for a more personalized fit.

It is very important that you receive a proper evaluation for any AFO — by a physiatrist, physical therapist and/or an orthotist who is knowledgeable about MS.

Figure 1A: Post leaf spring AFO



#### Figure 1B: Carbon AFO



#### What are the benefits of using an AFO?

- AFOs are designed to support your ankle and foot when walking.
- AFOs help to maintain your ankles in a correct position.
- AFOs are worn inside of your shoe and, depending on the material from which they're construction, can be made to remain hidden from view.

#### What are the limitations of using an AFO?

- AFOs do not provide adequate support if you have weakness in your legs or poor balance when standing. In those situations, other types of braces may be needed.
- AFOs are often used in combination with another mobility device.
- AFOs cannot be made to fit all deformities of the ankle.
- AFOs will not fit into every pair of shoes you might want to wear.

# How do I know whether an AFO is the right device for me?

- An AFO may be indicated if you experience "foot drop" or a weak ankle that causes you to drag your foot and trip or fall when walking.
- An AFO can also be used to position and support your foot on the foot rest of a wheelchair.
- Either an articulated or rigid AFO may be recommended depending on the flexibility of your ankle.
- If you continue to trip or fall when wearing an AFO, it may be time to be evaluated for a more supportive mobility device.

# Functional electrical stimulation (FES)

Functional electrical stimulation (FES) is a technique that uses mild electrical currents to stimulate the nerves that activate muscles weakened or paralyzed by injury or disease. In MS, FES can be used to help people who have difficulty lifting their foot independently when they walk (referred to as "foot drop"). A small, self-contained device — attached to the leg below the knee — sends low-level electrical impulses to the peroneal (sometimes called fibular) nerve, which signals leg muscles to lift the foot. The FES device that is used to help with foot drop is battery-operated, lightweight, and wireless (*Figure 2*).

#### Figure 2: FES device



# What are the benefits of using an FES device?

- FES may help to activate muscles of the leg and foot while you walk.
- FES may help you to move your foot and leg more smoothly and safely when you walk.
- FES may help you to walk for longer distances before getting tired.
- FES is generally easy to wear.

# What are the limitations to using an FES device?

- For the FES device to work correctly, the nerves and muscles located below your knee must be in good enough condition to receive and respond to the electrical signal sent by the device.
- Because of the variability and progression of symptoms in MS, a variety of complications may limit or prevent the correct use of an FES device.

# How do I know whether an FES device is right for me?

- FES may be useful if you have a "foot drop" or a weak ankle that causes you to drag your foot and trip or fall when walking.
- FES is not effective if your ankle is not flexible.
- If you continue to trip or fall when using an FES device, it may be time to be evaluated for a more supportive mobility device.
- Before purchasing an FES device, it is important to be evaluated by a physical therapist or orthotist to determine if you are a suitable candidate.

#### Canes

Canes are readily available in different lengths, styles, colors, and materials — and come with different adjustability options and handle options. Many can be purchased off the shelf at retail stores and drugstores. Canes come in two major types:

Single-point canes: These canes, with a single point touching the floor, are the most common (*Figure 3A*).

Figure 3A: Single-point cane



 Multi-point or quad canes: These canes have multiple support points touching the floor, which make them able to stand on their own and provide additional support for the user. The quad cane has four points touching the floor (Figure 3B).

Figure 3B: Quad cane



#### **SAFETY TIP:**

A quad cane may slow your walking a bit. To walk safely with this type of cane, it is important for all points of the cane to come in contact with the ground.

#### What are the benefits of using a cane?

- If you feel unsteady when you walk, a cane can help prevent you from losing your balance.
- Canes are very portable because they tend to be very light weight. Some models can be folded when not in use.

#### What are the limitations of using a cane?

- Canes only provide support to one side of your body.
- If used incorrectly, a cane can increase your risk of falling.
- If the cane is not adjusted to the correct height, you may experience back, shoulder, elbow, and/or wrist pain. A physiatrist or physical therapist can recommend the appropriate style and size cane for you and train you in its proper use.

# How do I know whether a cane is the right mobility device for me?

- If you can walk by yourself but feel that you need extra support for balance, a cane might be the right device for you.
- However, it may be time to be evaluated for a more supportive mobility device if, while walking with a cane, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - > are falling or have a fear of falling
  - are unable to walk independently for short distances in a reasonable time period
  - become very tired after walking short distances
  - experience hand or wrist pain, or back or knee pain related to using the cane

#### **SAFETY TIP:**

Make sure you hold the cane on the stronger side of your body. For example, if you have weakness or pain in your left side, hold the cane with your right hand to help compensate for the weakness on your opposite side.

#### Crutches

Two types of crutches are available — each of which is named by the location of its use:

 Underarm: Underarm crutches are often used on a temporary basis for lower extremity weakness or injuries (*Figure 4A*).

Figure 4A: Underarm crutch



Forearm (Loftstrand): Forearm crutches (one or two) are more often used for long-term use because they have arm cuffs that cradle the forearms, and handgrips for support. Forearm crutches are more comfortable than underarm crutches because they are used by slipping the arms into cuffs and holding the grip (*Figure 4B*) rather than by fitting into the armpit.

#### Figure 4B: Forearm (Loftstrand) crutch



#### What are the benefits of using crutches?

- Crutches can provide stability when you walk, especially when one is used on each side.
- Crutches make your base of support wider when you walk, reducing your risk of falls.
- Crutches help to off load your body weight from your legs as you walk.
- Crutches are height-adjustable.

#### What are the limitations of using crutches?

- If the crutches are not adjusted to the correct height, you may experience back, shoulder, elbow, and/or wrist pain. A physiatrist or physical therapist can recommend the appropriate style and size crutches for you and train you in their proper use.
- Your posture may be affected with the use of crutches as you lean forward for support.
- Because crutches need to be held in place and upright, their use requires good shoulder, arm, and hand function.

# How do I know whether crutches are the right mobility device for me?

- Crutches might be indicated for you if:
  - you can walk by yourself but feel that you need extra support for balance on one or both sides of your body
  - you have good arm, shoulder, and hand function to control the crutches
- It may be time to be evaluated for a more supportive mobility device if, while walking with crutches, you:
  - hesitate to participate, or stop participating, in the activities you want to do in a day
  - > are falling or have a fear of falling
  - are unable to walk short distances with crutches in a reasonable time period
  - are experiencing back, shoulder, arm, or wrist pain
  - become very tired after walking short distances with crutches

# Walkers and wheeled walkers (rollators)

In comparison to canes and crutches, walkers have a wide base of support. Walkers come in two basic types, each with many different variations:

Standard walker: A standard walker has a basic aluminum frame that folds, is height-adjustable, and is available with or without wheels. To use a walker without wheels, you need to lift it and move it forward as you walk. A wheeled walker can be pushed forward without lifting (*Figure 5A*).

Figure 5A: Wheeled walker



Rollator: This type of wheeled walker is designed to be easier to maneuver than the standard walker, and usually has several additional features that may include larger caster wheels, a seat bench, basket, and handbrakes (Figure 5B).

#### Figure 5B: Rollator



# What are the benefits of using a walker or rollator?

- Walkers and rollators can provide stability when you walk.
- Walkers and rollators provide a wider base of support when you walk, reducing your risk for falls.
- Walkers and rollators can be folded and are portable.
- Walkers and rollators are height-adjustable.

# What are the limitations to using a walker or rollator?

- If the walker or rollator is not adjusted to the correct height, you may experience back, shoulder, elbow and/or wrist pain. A physiatrist or physical therapist can recommend the appropriate equipment for you and train you in its proper use.
- Your posture may be affected with the use of a walker or rollator as you lean forward for support.
- Walkers and rollators require the use of both arms to be used effectively.

# How do I know whether a walker or rollator is the right mobility device for me?

- A walker or rollator might be indicated for you if:
  - you can walk by yourself but feel that you need extra support for balance on both sides of your body
  - you find that you are continuously holding onto the walls and furniture within your home for support
  - you have good arm and hand function to move the walker or rollator forward while walking
- If you occasionally get tired and require frequent rest periods when out in the community, a rollator with a built-in seat may be a good option for you.
- It may be time to be evaluated for a more appropriate mobility device if, while using a walker or rollator, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - > are falling or have a fear of falling
  - are unable to independently walk with a walker or rollator for short distances in a reasonable time period
  - are experiencing back, shoulder, arm, and/or wrist pain
  - become very tired after walking short distances with a walker or rollator

#### **SAFETY TIP:**

To avoid falls or injury, put the brakes on before you sit down or stand up from the seat of your rollator. Do not push or pull someone seated in a rollator.

#### Manual wheelchairs

Manual wheelchairs are designed to provide mobility from a seated position. Manual wheelchairs can be self-propelled by rotating the hand rims with your arms *(Figure 6A).* "Attendant-propelled" or "transport" wheelchairs — which are designed for an attendant or caregiver to push — are also available.

Figure 6A: Manual Wheelchairs



Manual wheelchairs come in different styles, including the traditional folding frame chair and a rigid non-folding chair. To reduce the energy required, current research suggests that a person who is able to self-propel a manual wheelchair should use the lightest possible wheelchair (*Figure 6B*) with adjustable wheels and seating components.

Figure 6B: Manual Wheelchair — Lightweight



# What are the benefits of using a manual wheelchair?

- A manual wheelchair:
  - enhances mobility and enables you to move around in a safe and efficient manner
  - > can help decrease your risk of falls
  - offers some level of physical activity (not exercise) as you use your arms to propel the chair
  - can usually be stowed in a vehicle for transport
  - requires less maintenance than powered mobility options

# What are the limitations to using a manual wheelchair?

- You may feel tired from self-propelling a manual wheelchair.
- You may not have the endurance to propel the manual wheelchair across surfaces encountered on a daily basis — such as ramps, carpet, grass, and gravel.
- If your manual wheelchair has not been set up to fit you properly, you may have difficulty propelling the wheels — which would put you at increased risk for shoulder, elbow, and wrist injuries, and associated pain. A physiatrist or a physical or occupational therapist can work with you to ensure that you are using the appropriate chair for your needs.
- If your home environment is inaccessible with steps, narrow halls or doorways, or significant inclines, you might be unable to move around independently with your manual wheelchair.

#### How do I know whether a manual wheelchair is the right mobility device for me?

- A manual wheelchair is indicated when:
  - you are no longer able to walk functional distances independently in a safe and efficient manner — meaning that you cannot go from point A to point B without getting too tired and/or experiencing increased fear of falling
  - you can use a manual wheelchair within your home and work environment

- It may be time to be evaluated for a more supportive mobility device if, when using a manual wheelchair, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - are unable to independently self-propel your wheelchair for short distances
  - become very tired after propelling your wheelchair for short distances
  - > experience shoulder, hand, or wrist pain
  - are unable to transfer in and out of the wheelchair as needed throughout the day
  - are unable to change positions while sitting in your wheelchair

# What is the correct way to propel a manual wheelchair?

Before you start using a manual wheelchair, ask your therapist to teach you how to correctly propel yourself in the wheelchair. Propelling a wheelchair incorrectly may lead to injury and/or pain in your shoulders, arms, and wrist.

While propelling your wheelchair, try to use long, smooth strokes. Longer strokes mean less repetition when you self-propel, resulting in less stress to your shoulders, arms, and wrist.

#### **IMPORTANT:**

The Paralyzed Veterans of America (PVA) website has publications and guidelines (http://www.pva.org/site/c.ajIRK9NJ LcJ2E/b.7516865/k.4100/Publications\_ Available\_in\_Print.htm) that you may find helpful. "Upper Limb Function: What You Should Know" (2900-184) describes how to preserve your arms while propelling a manual wheelchair.

#### **SAFETY TIP:**

To avoid falls, put the brakes on before getting in or out of your chair.

"Popping a wheelie" is a maneuver in which the front tires of the wheelchair are raised from the ground for a period of time. This maneuver is used to:

- go up and down curbs
- rest when leaning against a wall
- turn in a very tight space
- travel down a steep ramp

#### **SAFETY TIPS:**

- "Popping a wheelie" is a maneuver that should be used with caution, and only after proper training.
- The purpose of front or rear anti-tippers is to prevent your wheelchair from tipping backwards. It is recommended that you use rear anti-tippers if you are unable to "pop a wheelie" independently or feel unstable in your wheelchair.
- If you have been given a manual wheelchair from a friend of family member, consult a therapist before you use it to make sure it fits you properly and meets your needs.

# Pushrim-activated power-assist wheelchair (PAPAW)

PAPAWs were developed to help people who have difficulty propelling a manual wheelchair over surfaces encountered on a daily basis, such as ramps, carpets, grass, curb cuts, and gravel. PAPAWs are units for manual wheelchairs that include specialized wheels with battery-operated motors mounted on the frame. They have sensors on the wheels' pushrims that amplify the user's strength when propelling the chair — thereby allowing a person to use less energy to propel the wheelchair and making it easier to travel over different surfaces.

#### What are the benefits of using a PAPAW?

- When activated, PAPAWs may increase your activity level and independence in your daily activities.
- The battery-operated motors attached to the wheelchair make it easier to self-propel over difficult terrain, including carpets, gravel, grass, curb cuts and ramps.
- Use of a PAPAW can help you to conserve energy and propel the wheelchair faster and for longer distances with less physical effort.
- A PAPAW can reduce the risk of injury to your arms because it requires less force to propel and reduces the number of pushes needed to go the same distance in a manual wheelchair.

# What are the limitations to using a PAPAW?

- PAPAW wheels are heavy and may add 37–53 pounds to the weight of the wheelchair. This added weight makes it more difficult to independently lift and stow the wheelchair in a vehicle.
- Due to the weight that the PAPAW adds to the manual wheelchair, propulsion is actually more difficult when the system is turned off or if the battery is not charged.
- The PAPAW system increases the width of a manual wheelchair by 1.5 inches. Depending on your home environment, it might be difficult to maneuver the PAPAW through hallways and doorways.

# How do I know whether a PAPAW is the right mobility device for me?

- A PAPAW is indicated for you if:
  - you are becoming increasingly tired while propelling your manual wheelchair and do not have the energy to participate in activities that are important to you
  - you find it difficult to propel a regular manual wheelchair up ramps or across other surfaces because of weakness or pain in your shoulders or arms
- It may be time to be evaluated for a more supportive mobility device if, while using a PAPAW, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - are unable to independently propel your PAPAW over short distances in a reasonable time period
  - become very tired after propelling your PAPAW over carpets, gravel, grass, curb cuts, and ramps
  - experience back, shoulder, hand, or wrist pain
  - are unable to transfer in and out of the wheelchair as needed throughout the day
  - are unable to change positions while sitting in your wheelchair

#### **SAFETY TIPS:**

- Until you are very familiar and comfortable with how the PAPAW works, it is recommended that you use your rear anti-tippers to prevent your chair from tipping over backwards while using it.
- Always check your batteries before you leave the house to make sure you have enough battery reserve to do your activities throughout the day.

#### **Motorized scooters**

Scooters — also known as power-operated vehicles — are controlled through a mechanical tiller system. They are available with three or four wheels and most can be disassembled for transport. Scooters can be found in different sizes and with different weight capacities.

The seat swivels sideways to help you sit down and stand up. A scooter is turned on and off with a small key. Scooters have a forward and backward switch (tiller) that requires you to have good control and coordination of your hands and fingers. A rehabilitation professional can work with you to assess your physical needs and home environment to ensure that a motorized scooter will meet your mobility needs within your current environment at home and work *(Figure 7).* 

#### Figure 7: Motorized scooter (3-wheeled)



#### What are the benefits to using a scooter?

- Scooters are battery-powered devices that operate by pressing hand throttles and are steered by controlling the tiller mechanism.
- Powered mobility devices help you to conserve energy because they require less physical effort to operate than walking or propelling a manual wheelchair.
- Many scooters (not all) can be disassembled for stowing in your vehicle.
- Scooters allow you to travel longer distances independently.

# What are the limitations to using a scooter?

- The length of some types of scooters can make it difficult to drive and turn around in small spaces. For these maneuvers, you will need good coordination and strength to control your arms and hands.
- Scooters offer limited seating options and cannot be modified to provide additional support if your physical condition changes.

- If you have problems with balance, it might be difficult for you to get in and out of the scooter safely.
- Scooters can be unstable when making turns, depending on the speed you are going and the surfaces over which you are driving. Fourwheeled models are somewhat more stable than three-wheeled models.
- Scooters can be difficult to disassemble and stow in a vehicle.
- If your home environment is inaccessible with steps and narrow halls or doorways, you might be unable to move around independently with your scooter.

# How do I know whether a scooter is the right mobility device for me?

- A scooter may be indicated for you if you:
  - are able to sit down and stand up from a chair safely and independently
  - have enough strength and coordination in your arms to operate the scooter's tiller steering mechanism
  - have good trunk control and good balance while sitting
- It may be time to be evaluated for a more supportive mobility device if, while using a scooter, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - are unable to drive and control the tiller independently
  - can't sit comfortably in your scooter because your condition has changed
  - > become very tired while driving your scooter

- feel pain in your arms and hands from driving the scooter
- find that your hands and fingers are too weak to control the tiller
- begin to have more difficulty remaining balanced in the seat

#### SAFETY TIPS:

- To disassemble and assemble a scooter, you will need either adequate strength and balance to do it independently because the activity requires lifting, bending, and reaching — or you must have the ability to instruct someone else on how to perform this task for you.
- Always check your batteries before you leave the house to make sure you have enough battery reserve for the day's activities.

#### **Power Wheelchairs**

Power wheelchairs are battery-driven mobility devices.

# What types of power wheelchairs are available?

Power wheelchairs are available in three different types according to the location of the drive wheels — rear-wheel, mid-wheel, and front-wheel. Many different options are available for power wheelchairs because they are designed to accommodate a wide range of needs. It is important to work with a physiatrist, physical therapist or other assistive technology professional (ATP) to identify the best style of power wheelchair for you, and to ensure that its size, functionality, and seating are suited to your needs.

The available seating systems range from basic "captain" or van-style seating to more advanced custom seat cushions and backrests with power seat functions *(Figure 8).* 

Figure 8: Power wheelchairs



#### How are power wheelchairs operated?

The standard option for operating a power wheelchair is a control interface (control mechanism) mounted on one of the armrests with a proportional joystick and a set of buttons. However, the location and type of control interface can be customized to meet your individual needs — and many different options are available to make it possible for you to operate the power wheelchair independently.

#### **IMPORTANT:**

If it is determined by you and your therapist that a basic power wheelchair is the appropriate device, be sure that you opt for a model, steering mechanism, and seating system that can be modified in the future if needed. This will allow for the wheelchair to continue meeting your needs if and when your condition and abilities change.

# What are the benefits of using a basic power wheelchair?

- A basic power wheelchair helps you conserve energy because it requires less physical effort to operate than propelling a manual wheelchair or operating a scooter tiller.
- It may increase your activity level and independence.
- A basic power wheelchair makes it easier to go over difficult terrain, such as carpets, gravel, grass, curb cuts, and ramps.
- These wheelchairs are easier to maneuver within the home environment and in the community because the turning radius is often much smaller than the turning radius of a scooter.
- A basic power wheelchair allows you to travel longer distances independently.

# What are the limitations to using a basic power wheelchair?

- Many basic power wheelchairs cannot be modified to add power seat functions if and when they are needed.
- These wheelchairs are very heavy.
- Most power wheelchairs cannot be disassembled for transport and generally require the use of ramps or automated lifts with an accessible van.
- Power wheelchairs require maintenance and repairs to keep them in working order.
- If your home environment is inaccessible, with steps and narrow halls or doorways, you may be unable to move around independently with your power wheelchair.

#### How do I know whether a basic power wheelchair is the right mobility device for me?

- A basic power wheelchair is indicated for you if:
  - you are getting increasingly tired and do not have the energy to propel a manual wheelchair
  - you are at high risk for developing upper extremity injury from propelling a manual wheelchair
  - you feel progressively weaker (with increased fatigue) and have less energy for your daily activities
  - you have been using a scooter but are unable to continue doing so because of a decline in your physical condition

- you use a scooter that is difficult to maneuver in your home
- you need more trunk support to maintain proper posture and balance
- It may be time to be evaluated for a more appropriate mobility device, seating system, or control interface if, while using a basic power wheelchair, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - are unable to drive and control your power wheelchair independently
  - have experienced a change in your physical status and can no longer sit comfortably in your current power wheelchair
  - are unable to independently sit down and stand up from your power wheelchair
  - are unable to transfer in and out of the wheelchair as needed throughout the day
  - are unable to change positions while sitting in your wheelchair

# What are power wheelchairs with specialized seating?

Power wheelchairs with specialized or rehabilitation seating can be customized to meet your individual needs. These wheelchairs can accommodate the use of the power seat functions described below.  Tilt in space — allows your body's position in the chair to stay exactly the same while the entire seating system is tilted backwards (Figure 9).

Figure 9: Tilt-in space power chairs



 Recline — allows a change in the angle of the back in relation to the seat. This makes it possible for you to lay back as you would in a recliner (Figure 10).

Figure 10: Reclining power chair



• Elevating leg rests — allows you to raise and lower your legs (*Figure 11*).

Figure 11: Power chair with elevating leg rests



 Seat elevator — allows you to raise and lower the entire seating system (Figure 12).

Figure 12: Power chair with a seat elevator



• **Stand** — a feature that gives you the option to go from a seated (*Figure 13A*) to a standing position (*Figure 13B*) while still in the wheelchair.

Figure 13A: Seated position



Figure 13B: Standing position



Power seat functions can be used separately or in combination, depending on your needs, and can assist you to independently adjust your body position, relieve pressure spots on your buttocks and thighs, participate in activities of daily living, and manage pain, spasticity (muscle tone) and lower extremity swelling.

#### What are the benefits of using a power wheelchair with a specialized seating system?

- The seating system can be customized to your individual needs in order to provide adequate support.
- A power wheelchair with a specialized seating system allows you to change positions throughout the day while still sitting in the wheelchair.
- A specialized seating system offers you the ability to modify the seating system to provide increased support if your condition changes.
- The control interface of power wheelchairs with a specialized seating system can be customized to your individual needs to allow for independent mobility.
- The turning radius of most power wheelchairs is smaller than the turning radius of a scooter.
- A power wheelchair with a specialized seating system allows you to travel longer distances independently.

#### What are the limitations to using a power wheelchair with a specialized seating system?

- A power wheelchair with a specialized seating system is very heavy.
- Most power wheelchairs cannot be disassembled for transport and generally require the use of ramps or automated lifts with an accessible van.
- Power wheelchairs require maintenance and repairs to keep them in working order.
- If your home environment is inaccessible with steps and narrow halls or doorways, you may be unable to move around independently with your power wheelchair.

#### How do I know whether a power wheelchair with a specialized seating system is the right mobility device for me?

- A power wheelchair with a specialized seating system is indicated for you if:
  - you are at high risk for developing pressure ulcers because you cannot shift your weight independently
  - you cannot transfer in and out of your basic power wheelchair by yourself as needed throughout the day
  - you feel progressively weaker and have less energy to do your daily activities

#### SAFETY TIP:

If your power wheelchair has power seat functions, it is important that you learn how to use them safely and correctly.

- It may be time to be evaluated for a different mobility device, seating system, or control interface if, while using a power wheelchair with a specialized seating system, you:
  - hesitate to participate, or stop participating in the activities that you want to do in a day
  - are unable to drive and control your power wheelchair independently
  - have experienced a change in your physical status and can no longer sit comfortably in your current power wheelchair
  - are unable to transfer in and out of the wheelchair and shift your weight as needed throughout the day
  - are unable to change positions while sitting in your wheelchair

### What is involved in assistive technology service delivery?

Assistive technology (AT) clinics are sites that specialize in AT prescriptions to improve each client's mobility in her/his home and in the community. These specialized clinics are often located in rehabilitation centers and outpatient clinics.

A group of specialized professionals knowledgeable and experienced in their field are usually involved in the process of AT service delivery to help you find the most appropriate mobility device.

#### **IMPORTANT:**

When looking for a mobility device, it is important to seek out a face-to-face evaluation with a therapist who specializes in seating and mobility.

# Who are assistive technology professionals?

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) provides *assistive technology professional* (ATP) credentials to knowledgeable clinicians, suppliers, and engineers. An ATP is a professional who analyzes the person's needs and assists with the selection of the appropriate device. The team of ATs can include: therapists (physical therapist and/or occupational therapist), physician, rehabilitation technician supplier, rehabilitation engineer, manufacturer representative and, most importantly, *you*.

In the ideal situation:

- A therapist familiar with MS will provide a complete physical evaluation and recommend the most appropriate device that will enable you to conduct your regular activities as safely and independently as possible.
- A physician will evaluate your medical and physical condition and work with your therapist to identify the most appropriate mobility device for you.

- A rehabilitation technician supplier is a professional that works initially with you and your therapist to choose the right device and then assists with maintenance and repairs over the life of your device.
- A rehabilitation engineer will work closely with the rehabilitation technician supplier to identify possible modifications that could or should be made to your device.
- A manufacturer representative offers expertise on the products that they represent. In addition, they can provide information on what, if any, modifications can be made on the mobility device you are considering.

#### **IMPORTANT:**

It is important to highlight that YOU are the most important person in this process. All the professionals involved want to make sure that you select a mobility device that fits you well and that maintains or adds to your quality of life.

#### What does a typical evaluation for a wheeled mobility device include?

- A typical mobility device evaluation starts with a medical and physical evaluation by the therapist to assess your:
  - Medical condition
  - > Physical status
  - > Problems with your current device
  - > Functional abilities
  - > Performance of daily activities
  - > Community activities
  - > Home and work environment
  - > Transportation options
  - Goals to achieve with your new mobility device
- A physician will evaluate your medical condition(s) as it relates to your seating and mobility needs.
- Ideally, the clinic will have appropriate devices available on site for you to try. A follow-up visit may be needed if the right equipment is not available during the initial evaluation.
- Following your clinic visit, the rehabilitation technician supplier will bring the recommended device to your home to evaluate the fit and compatibility of the device for use in your home environment.

#### **IMPORTANT:**

- Before making a final decision, ask to try out the recommended device (or one similar to it) in your home and car.
- You should not be asked to make a final decision during your first visit to the AT clinic. You should be allowed some time to consider the benefits and limitations of each device and how it will fit with your lifestyle. If you are not comfortable with the recommendations, you are encouraged to take an active role in the decision-making process.
- If you are currently working or looking for a job, and do not have access to an AT clinic that provides the services described in this guide, contact the Office of Vocational Rehabilitation (OVR) to see if they offer these services.
- After you try the device in your home environment, the AT professionals complete a letter of medical necessity, detailing all of the information that has been gathered by the team, and submit it to your insurance company or alternative funding agency for a mobility device request for approval.
- Insurance companies may initially deny the prescribed device. Through a formal appeals process, the therapist or physician can assist you to appeal this decision if you wish.

- Once your wheeled mobility device is approved, it is important that you receive the device at the same AT clinic where you were evaluated. During the final fitting and training you will receive, the therapist and rehabilitation technician supplier can go over final adjustments with you to make sure that the device is set up properly for you.
- The delivery of the device will depend on the outcome of the final fitting and training and, ultimately, upon your final approval.

#### **SAFETY TIPS:**

- If you have experienced a change in your physical status, are uncomfortable in your seating system, or have problems operating your power wheelchair, contact your physician or therapist who can assist you by evaluating the problem and suggesting appropriate modifications.
- If you require maintenance or repair of your device, contact your rehabilitation technician supplier.

# Where can I find an assistive technology professional?

Your physician can refer you to a specialized seating and mobility clinic in your area, or you can contact RESNA for a referral (703-524-6686) or http://web.resna.org/member \_directory/individual/index.dot.

# What can I do to prepare for a mobility device evaluation?

During your evaluation, you will need to provide information about your physical status and your ability to carry out your activities at home, at work, and in the community. Taking the time to organize your thoughts will help you be more prepared. Here are some suggestions:

- If you already use a mobility device, have it available for the evaluation.
- Create a list of items and features that you like and do not like about your current device.
- It is a good idea to bring a family member or friend to the evaluation with you.
- Keep an open mind in order to learn about the relative benefits and limitations of each mobility device option.

Consider the following questions that you may be asked during your evaluation:

- What are the problems with your current mobility device?
- Are your home and work environments wheelchair-accessible? Keep in mind that you should be able to use your mobility device whenever and wherever you want to go.
- How would a mobility device help you to carry out your daily activities independently, safely, and with less expenditure of energy?

#### **IMPORTANT:**

If you already use a wheeled mobility device, or are thinking about being evaluated for one, the UsersFirst<sup>™</sup> Mobility Map (www.usersfirst.org/resources/ mobilitymap/) from United Spinal Association can assist you. The Mobility Map is designed to help you find answers to common questions about getting and using a wheelchair. Each chapter guides you step-by-step through the path of getting a wheelchair.

In preparation for your evaluation, fill out the Wheelchair Checklist (www.usersfirst.org/forms/wheel chair\_checklist.html) to take with you to your evaluation.

- Will you be able to transport the mobility device that you are considering?
- Would you need a ramp or hoyer lift?
- Does your transportation vehicle allow you to drive your mobility device into the vehicle, if needed?
- What are your goals for the new mobility device?

# Final Remarks

It is important to recognize and acknowledge changes in your physical condition. If you feel that you are getting weaker and are unable to do the activities you used to do, it is time to consider another mobility device that better accommodates your needs.

- Before you make a decision about which device you would like to have or purchase, you should contact your primary care physician (PCP) and ask for a referral to a specialized seating clinic.
- During a mobility device prescription process, the benefits to your health and quality of life should remain the highest priority. Reimbursement policy should not lead the prescription process.
- Because MS is often a progressive condition, it is not uncommon for people to use more than one device over the course of their lives. In addition, many people use multiple devices over the course of a single day or week, depending on their physical condition and the types of activities in which they're engaged.

- In the event you are given a mobility device by a friend or family member (e.g., a cane or walker), you are still eligible to obtain a mobility device that gives you more support and saves your energy (e.g., a manual wheelchair) through your insurance company. In those instances, you can alternate the use of both devices according to your need throughout the day.
- If you are looking for a power-operated device (e.g., scooter or power wheelchair) make sure you have considered how you will transport the device.
- All mobility devices are designed to function according to a maximum weight capacity as determined by the manufacturer. Check your current weight in order to be sure that you fit within the weight capacity of the recommended device.

### Notes

#### Things I want to remember:

#### Questions I need to ask:

#### **Resources I need to find:**

#### Miscellaneous:

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The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

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 health care professional and contacting the National MS Society at national MSsociety.org or 1-800-344-4867 (1-800-FIGHT-MS).

The Society publishes many other pamphlets and articles about various aspects of MS. Visit national MS society.org/brochures to download them, or call an MS Navigator<sup>®</sup> at 1-800-344-4867 to have copies mailed to you.

#### Some of our popular pamphlets include:

- Exercise as Part of Everyday Life
- Taming Stress in Multiple Sclerosis
- Managing MS Through Rehabilitation
- Living with MS
- Minimizing Your Risk of Falls: A Guide for People with MS

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