A few words before you get started...

Receiving a diagnosis of MS can feel overwhelming. After all, it’s a disease that impacts mobility, and could take away some of your ability to do day-to-day activities. The good news? There are lots of things you can do to help fight MS. You can be an active participant in effectively managing your own disease. And that’s where this guidebook can help you.

This guidebook contains information about:

• What causes MS
• Common symptoms of MS
• How to manage specific MS symptoms
• Diet and exercise
• Tests you can use to measure and track your mobility

If you have any questions, don’t hesitate to ask a member of your healthcare team at your next appointment. They’re there to help!
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What “mobility” means

“Mobility” means different things to everyone. For some people, it means being able to go on long runs or hikes, while for others it means being able to walk and perform their daily activities just like they always have. No matter what mobility means to different people, the ability to get from A to B is something that’s important to all of us.

**MS and damage to nerves**

Multiple Sclerosis (MS) affects nerve cells, or neurons, that carry messages to and from your brain and the rest of your body.

In MS, it’s thought that your body’s immune system attacks and destroys the myelin sheath that surrounds the nerve. This damage to nerves weakens, distorts or blocks the messages travelling along it. As a result, the nerves can’t communicate properly, causing a variety of symptoms.

The specific symptoms depend on which nerves are damaged. Damage to certain nerves could interfere with functions that impair mobility, such as muscle strength, co-ordination or eye function.

**Symptoms that can affect your mobility**

Just one symptom, or a combination of symptoms and deficits, caused by MS can influence mobility. These are discussed below.

**Fatigue**

- Fatigue is often described as an overwhelming sense of tiredness for no apparent reason
- Fatigue may be caused by a combination of damage to the central nervous system as a result of the MS disease process, certain MS symptoms like muscle weakness, or other factors such as sleep disturbances or a lack of exercise due to other MS symptoms
- Fatigue may also cause other symptoms (such as difficulties with balance, vision or concentration) to get worse temporarily
- Fatigue occurs whether or not MS is present (e.g., following exertion or a lack of sleep). However, in MS, fatigue is out of proportion to the activities taking place
Changes in vision and visual problems
- Damage to the nerve pathways that control eye movement may cause a lack of co-ordination between the two eyes, resulting in double vision or jerky eye movements
- Inflammation of the optic nerve can cause the development of pain, colour disturbances or blurred vision over a few days
- Vision problems may be unrelated to MS, and if you wore glasses before your diagnosis you should continue to visit your optician regularly

Muscle spasms and spasticity
- Damage to nerves in your spinal cord can affect muscle movements when the damage occurs between the brain and the point where the nerve from the muscle joins the spinal cord
- This can cause your muscles to contract tightly and painfully, which is known as spasm
- The damage can also cause your muscles to stay contracted and become stiff and resistant to movement, which is known as spasticity

Muscle weakness
- Muscle weakness is caused by the poor transmission of messages along damaged nerves within the spinal cord
- Weakness in your arms and legs may cause you to experience difficulty walking or make your legs feel heavy
- Muscle weakness is often associated with fatigue
- Muscle weakness can also occur after exercise or lifting/carrying heavy objects

Decreased balance and dizziness
- Damage to the complex nerve pathways in the brain that co-ordinate vision and other inputs needed to maintain balance can cause dizziness or problems with balance
- Other symptoms like tremor or muscle spasms may also influence your balance as the muscles in your legs don’t respond to signals from your brain like they normally do
**Tremor**

- Tremor is an uncontrollable shaking or trembling movement that can occur in various parts of the body
- Tremor is caused by damage to the area of the brain responsible for balance, movement and posture
- Not every tremor is related to MS; for example, you might notice shaking or trembling after drinking beverages that contain caffeine

**Changes in sensation and pain**

- Damage to nerves can cause abnormal sensations like burning, aching, tingling, ‘electric shock’ type sensations, numbness or pins and needles; these may also feel painful
- Other symptoms such as muscle weakness, spasticity and difficulty balancing may affect your posture, which could also cause pain

**Managing the symptoms**

The symptoms of MS are unpredictable: they vary greatly from person to person, can range from mild to severe and may come and go. It is unlikely that you will develop all of the symptoms discussed above, but you may experience some of these symptoms at some point. However, it’s also important to remember that not every new symptom is caused by MS and changes you notice in your mobility may not be related to MS.

If you experience any of these symptoms, talk to your doctor or healthcare team. They can help to identify the cause and may recommend exercises or provide helpful tips for managing the symptoms.
Mobility assessment tests

What are MS assessment tests?

When researching Multiple Sclerosis (MS), you may come across descriptions of assessment tests. A range of different tests and scoring systems are used to evaluate the impact of MS, such as your level of mobility or how you manage your everyday activities. The scores may be based on symptoms, performance in tests or questions answered by you.

These assessments may also be used to help your doctor to recommend different treatments for you. Repeating the tests regularly can help track changes in your level of mobility and other aspects relating to your quality of life over time.

Some mobility tests are simple enough to do yourself as part of your daily or weekly routine. By making a note of the results of the tests between appointments, and discussing them with your healthcare team at your next visit, you can help them get a better picture of how your mobility impairment affects your daily life.

Different tests are used at different centres. A few examples of assessment tests are described in the next few pages.

Mobility assessment

Multiple Sclerosis Walking Scale (MSWS-12)

The MSWS-12 is used to measure your walking ability.

Your doctor will ask you to complete a questionnaire about MS and your walking in the last two weeks. The questionnaire includes 12 questions, and you will be asked to rate how much of an impact your MS has had on certain issues related to walking from ‘Not at all’ to ‘Extremely’. The types of questions you will be asked are:

- In the past two weeks, how much has your MS limited how far you are able to walk?
- In the past two weeks, how much has your MS made standing when doing things more difficult?
- In the past two weeks, how much has your MS made you concentrate on your walking?

The answers are added up to come to a total score out of a maximum of 60. The higher the score, the greater the impact MS is having on your walking ability.
General assessment

Expanded Disability Status Scale (EDSS)

The EDSS is a tool used to assess your mental and physical ability and assign it a numerical score.

Your doctor will carry out an examination, looking at your general ability and also at specific areas such as visual, sensory and bowel and bladder function.

The score increases the more your ability is affected. For example, a score of 1 means ‘no disability’, a score of 6 means ‘needing assistance’ such as a cane to walk and a score of 9 means that a person is confined to bed.

It is important to remember that 75% of people with MS will never need to use a wheelchair, so very few people will ever have a score higher than 6. In fact, nearly 60% of people with MS will still have an EDSS score of 6 or below, 15 years after diagnosis.

Expanded Disability Status Scale

Adapted from Kurtzke JF. Neurology. 1983; 33:1444–1452
**Keeping track of your mobility**

Please ask your doctor, nurse or physiotherapist about any assessment tests they think would be useful to use at your appointments. The tests can be very helpful for seeing how you’re doing and for noticing any changes in your symptoms.

You can also keep an eye on your symptoms yourself by being aware of any changes you notice during regular activities that involve a set distance. For example, you may notice running errands takes longer than normal, you need to take more rests or you feel more tired afterwards. Any changes in your symptoms can be discussed at your next visit.
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Multiple Sclerosis (MS) and everyday life

If MS starts to have an impact on your mobility, it can turn many aspects of everyday life into challenges. For example, you may find that you have less energy than before to do things around the house; running errands may become more difficult and at work you may find getting around is not straightforward anymore.

Of course, the things you can do will depend on the stage of MS and the severity of your symptoms. The symptoms of MS are unpredictable: they vary greatly from person to person, can range from mild to severe and may come and go. It is also important to remember that not every new symptom or change you notice in your mobility is related to MS.

This leaflet has a combination of practical tips for managing everyday tasks when your mobility is affected, as well as advice on what you can do to be as mobile as possible.

Your physical health is closely linked with diet and state of mind, so a holistic approach to mobility is strongly recommended.

Making sure you get enough rest

Rest improves overall endurance and leaves strength for enjoyable activities. It’s important therefore to allow time to rest when planning a day’s activities:

- Plan ahead – make a daily or weekly schedule of activities to be done
- Spread heavy and light tasks through the day
- Pace activity – rest BEFORE you get tired
- Take five or ten minute rest periods during an activity
- Learn activity tolerance – see if a given activity can be broken down into a series of smaller tasks or if others can assist in its performance
- Set priorities – focus on items that are priorities or that must be done and learn to let go of any guilt that may be associated with not finishing tasks as the result of fatigue
Practical tips for everyday life

There are lots of ways to make it easier to manage everyday tasks when your mobility is affected. These suggestions will help you conserve energy, which can reduce fatigue.

Out and about

• Many pharmacies offer a delivery service, so if you have any regular prescriptions, you can usually have these dropped off at your home – ask your doctor or nurse if you’re unsure how to use such a service

• Use a mobility aid at home to help conserve your energy for the type of outings you like best, maybe choosing a present or looking for something to wear for a special occasion

• Do some research about facilities in advance if you are going somewhere for the first time. A map or diagram can help you plan your trip efficiently. Are there elevators, steps, escalators or ramps?

• If you can drive, you might want to consider getting an automatic. If your legs get weak it could help you maintain your independence

• If you’re going on a journey by plane or train, it’s also important to plan ahead: make sure you have plenty of time to make any necessary connections and find out if there are elevators or ramps if you need them

Shopping for groceries

• Plan menus before you go to the grocery store and take a list with you

• Use the same grocery store on a regular basis so you know where various items are located

• Use internet shopping/home delivery wherever possible

Kitchen and cooking arrangements

• Store items that are most commonly used on shelves that are in easy reach and that minimize the need to reach or bend

• Keep pots and pans near the stove

• Use trays or wheeled carts to move numerous and/or heavy items
Meal preparation
• Have good lighting and ventilation in the cooking area
• Gather all items needed to prepare a meal then sit during preparation
• Select foods that require minimal preparation such as dehydrated, frozen, canned or packaged foods
• Prepare twice as much food as you need at one sitting, then freeze half for later use
• Use a microwave to cut down on cooking time
• Slide heavy items across the kitchen top instead of lifting them

Cleaning
• Spread cleaning tasks out over a period of time, rather than doing it all in one go
• Alternate heavy cleaning tasks with light ones
• Where necessary, use brushes or mops with extended handles to avoid bending or reaching

Laundry
• Wash one or two loads as they accumulate rather than doing multiple loads less often
• Collect clothes in one place, such as a laundry basket, then transfer them to the laundry area, in a wheeled cart if possible
• If the laundry area is in the basement, plan ahead to remain there until the laundry is done, and set aside a place to relax while you wait
• Sit down while ironing (set the ironing board at a low height if possible)
• Buy clothes that require minimal maintenance

Gardening
• Use a tray or wheelbarrow to move numerous and/or heavy items

Dressing
• Lay out clothing for the next day before going to bed
• Sit down while dressing whenever possible
• When dressing, dress the weaker side first and when undressing, undress the stronger side first
• Use a long-handled shoe horn to avoid bending
• Get Velcro fastenings or something equally easy to fasten and take off; this could make it easier to get dressed, undressed and go to the toilet
Bathing and showering

- Organize toiletries together by the bathtub or shower
- Use grab bars to help you get in and out of the bathtub
- If possible, use a stool when showering or having a bath
- Avoid hot water when having a bath as it can increase fatigue
- If you use the bathtub and find it difficult to feel the temperature of the water, get a thermometer you can place in the bathtub to tell you if it is too hot

Climbing the stairs

- When going upstairs step up with the stronger leg first and when going downstairs step down with the weaker leg first; this makes your strong leg do the work of lifting and lowering
- The phrase ‘up with the good, down with the bad’ makes this easy to remember

Infant and child care

- Make sure you always use your leg and arm muscles, rather than your back muscles, when lifting an infant or child
- Wash, change and dress an infant at waist height

Working at a desk

- Arrange your desk and chair heights to make sure you maintain the proper posture
- Use a chair with good back support
- Arrange filing cabinets, computers and other equipment so they are as accessible as possible
- Use a phone with a ‘hands free’ function for long conversations
**MS and work**

Everybody experiences MS differently, so some will find they can continue to work as before, and others will have to make changes and adjustments.

It may be that you can negotiate with your employer so that you can work from home when necessary, or you might have your work station adjusted or moved to a more accessible place.

If you cannot continue in your current profession, you may be able to do some kind of volunteering or charity work, which keeps you in contact with other people and doing something positive.

**Using mobility aids**

The decision to start using a mobility aid can be a big one, but the right aid and the right attitude can make all the difference in helping you to be mobile.

Using a mobility device shouldn’t feel like you are ‘admitting defeat’ or ‘giving in’ – instead try to see your mobility device as a tool to maximize your mobility, conserve your energy and let you do more.

A walking aid can reduce your energy expenditure. Using a walking stick in the morning for everyday tasks can allow you to have enough energy to enjoy other activities more, get more done or allow you to walk unaided later in the day.

You can use your mobility tool to best suit your needs and lifestyle, for example, when you relapse or are having a bad day or during the day to help save your energy for a special occasion in the evening.

As well as improving your mobility, a walking aid can act as a visual cue to help other people notice that you might need a seat on the bus or bit of extra time to get upstairs, or understand why you might not be as quick or as strong as they are expecting.

The important thing to remember is that the idea is to get to where you want to go – it doesn’t matter how you get there.

**Making sure you get enough exercise**

While it is important to rest and avoid fatigue, it is also a good idea to include a certain amount of exercise in your daily routine.

Like medication, the type and amount of exercise should be prescribed by a doctor or physical therapist who knows how to develop exercises for a specific individual.
If you do any activity alongside that which has been prescribed, it’s important to keep the following points in mind:

• Try keeping track of your mobility so that you can see how much exercise is beneficial and when you are at risk of overdoing it

• If you do an activity and then feel exhausted in the days and weeks that follow, you may need to moderate it to achieve the right amount that makes you feel uplifted and energized

• Try and do some gentle stretching exercises every morning

• Swimming is a wonderful activity, as it is good for the whole body and the water supports you, which can relieve symptoms such as feelings of heaviness in the limbs

• Include exercise in your daily routine – discuss the type and amount of exercise with your doctor, nurse or physiotherapist

• Talk to your physiotherapist about exercises to improve muscle strength and function

**Yoga and MS**

One of the best types of exercise for addressing the symptoms of MS is yoga. It is gentle and particularly helpful for promoting mobility and strength. The postures, breathing and meditation can also assist with mental relaxation and promoting a positive state of mind.

If you don’t like the first class you try, find a different class. It may take you several till you find the right one for you. It is most important to have a rapport with your teacher.

Tell the teacher you have MS – it is important so they can adapt the postures and keep the room cool. They are used to hearing about peoples’ physical conditions and will keep it confidential if you want them to.

Attending a small group or private class really helps get the body in the best poses possible. There are some good DVDs, but take a class as well. It is important for the teacher to be there to help adjust your poses where necessary.
Tips for maintaining a healthy diet

- It’s important to provide your body with the right ‘fuel’
- Eat regular meals to maintain energy levels
- Eat a wide variety of foods
- Avoid too much fat (especially saturated fats), cholesterol, salt and simple sugar
- If you drink alcohol, try to do so in moderation
- Drink plenty of water

You could also talk to your doctor or nurse if you want to try taking supplements to make sure you’re getting vital nutrients. They may be able to refer you to a dietician if necessary.

Reducing spasticity (stiffness)

- Develop a thorough stretching program that includes a series of exercises, performed in a sitting or lying position, that allow gravity to aid the stretching of specific muscles
- Certain muscles may be relaxed more effectively while lying on your stomach or side
- The simplest way to reduce spasticity is by passive stretching, in which each affected joint is slowly moved into a position that stretches the spastic muscles
- Exercising in a pool may also be extremely beneficial because the buoyancy of the water allows movements to be performed with less energy
- A physiotherapist may be able to recommend exercises for you to do at home to help with spasticity
- Specific mechanical aids are available to correct certain types of spasticity – for example a toe-spreader or finger spreader can be used to relax tightness in the feet or hands to increase mobility
- Spasticity is often managed with medications – if you suffer from spasticity, please ask your doctor which treatment would be best for you
Managing tremor

Tremor – an oscillating movement of the arms, legs and occasionally the head – is a symptom that can affect mobility. While tremor may come and go, it is one of the most frustrating symptoms to treat.

As with all symptoms, a correct diagnosis must be made before management decisions can be made, but here are a few things that can be done to manage tremor:

• Exercises involving balance or coordination including:
  – **Patterning** – repetition of basic movement patterns, usually assisted by a therapist, until they become automatic
  
  – **Vestibular stimulation** – increasing the amount of stimulation received by the balance centres in your brain, usually involving rocking, swinging or spinning
  
  – Your doctor, nurse or physiotherapist may be able to help you with specific exercises such as using a Swiss ball

• Medication – as prescribed by your doctor

• Mechanical approaches such as:
  
  – **Immobilization** – the placement of a rigid brace across a joint, fixing it in a specific position, relieving the severity of tremor by reducing random movement of the joint
  
  – **Weighting** – the addition of weight to a part of the body to provide increased control over its movements

Monitor your mobility

• Ask your doctor about any assessment tests they think may be useful to help monitor your mobility

• Keep an eye on your symptoms yourself by being aware of any changes you notice while carrying out day-to-day activities, such as if you need to take more rests or you feel more tired afterwards

Get the most out of your appointment with your doctor

• Keep a note of anything you want to ask about or discuss at your next appointment

• Take a friend or family member with you so that they can help you describe your symptoms

• During your appointment, write down the answers to your questions so you can go over the information again later
**Staying positive**

Finally, it is vital to have a strategy for coping with your ‘dark’ days. Fear of the future, mobility issues, fatigue… sometimes even the most positive person in the world can find it hard to hold it together when living with MS.

If you can build a support network, this might be one of the best ways of getting through the tough times. If you have regular contact with family and friends, that’s fantastic, but in this day and age it’s not always possible to see as much of your loved ones as you’d like.

The great news is that there are online MS communities that you can tap into any time you need. The support you can get from MS-specific websites and chatrooms is phenomenal.

You can send messages and hear back from someone who understands what you’re going through – even if they’re on the other side of the world.

You may wish to record your thoughts, and raise any questions or concerns at your next doctor or nurse appointment. You can also ask your healthcare team to help you find your local MS support group.

Stay in touch with the world and stay as active as you can!

More detailed information can be found at:

[www.mobilitymattersinMS.ca](http://www.mobilitymattersinMS.ca)
Maximizing your mobility

“For MS patients, starting training early is paramount in order to improve overall function and mobility.”

Bernd Anderseck PT MSc
Team Neurorehabilitation Clinic, Valens, Switzerland

The importance of being physically active

A diagnosis of MS tends to shine a spotlight on the issue of mobility. Everyone living with MS will have different experiences and every individual’s level of activity will vary.

Activity levels can be directly related to the length of time you have been living with MS, your age and even environmental factors such as climate and season.

One thing that’s certain is that the more active you can be, the greater the benefits you should experience in both the short and the long term.

Some of the benefits of improving mobility in MS:

• Maintaining or increasing muscle strength
• ‘Feel good’ factor
• Being independent whenever possible, i.e. going out shopping for yourself and enjoying a social life

Important note: Please check with your healthcare professional before undertaking any form of exercise.
Questions for your healthcare professional: