Managing Progressive MS

National
Multiple Sclerosis
Society

RICK
DIAGNOSED IN 1991

Managing Progressive MS

BY KAYE HOOPER, RN, MPH

Reviewed by: Adrienne Boissy, MD; James Bowen, MD; Barbara Giesser, MD; Rosalind Kalb, PhD; Sue Kushner, MS, PT; Christine Smith, OTR/L, MSCS and Jerry Wolinksy, MD.

Table of Contents

Introduction

You may have lived with relapsing-remitting multiple sclerosis for some time and are now experiencing a progressive course of MS with few or no relapses (secondary progressive MS). Or, you may have had progressive MS from the onset (primary progressive MS) and now face new problems and worsening symptoms. Everyone is different, and each person travels a unique road living with MS.

Although this road can be rough—unpredictable, challenging, frustrating and exhausting—it may also offer opportunities for self-discovery, creative problem-solving and enhanced resilience. Developing and strengthening personal coping strategies enables many people to manage the challenges of MS, appreciate life and maintain a sense of purpose. One powerful strategy is to identify attainable goals and celebrate your victories and achievements in relation to these goals; identifying what you can do fosters a more positive outlook.

You'll feel more confident once you understand strategies for living with progressive MS in independent or supported home environments, and connected to people and services that may help you make choices, establish a comfortable and safe place to live, and plan your future. Your needs and circumstances may change over time, so what is a good solution for you now may need to be adjusted or changed later.

What is progressive MS?

In MS, four disease courses have been defined:

- **Clinically Isolated Syndrome (CIS):** a first episode of neurologic symptoms caused by inflammation and demyelination in the central nervous system. A person with CIS may or may not go on to develop MS.
- **Relapsing-Remitting MS (RRMS):** characterized by clearly defined acute relapses (also called attacks or exacerbations that describe a period of a few days, weeks or months with new MS symptoms or recently worsening symptoms that are not provoked by a non-MS cause such as a fever) followed by either complete or partial remission of symptoms. Between these attacks, the disease appears to be stable without worsening of symptoms. About 85% of people start their disease course with this form of MS.
- **Secondary Progressive MS (SPMS):** Most people who are diagnosed with RRMS will eventually transition to a secondary progressive course in which there is a progressive worsening of neurologic function (accumulation of disability) over time. Acute relapses of MS symptoms and/or new MRI activity may or may not occur in addition to this slow worsening.
- **Primary Progressive MS (PPMS):** characterized by slowly worsening symptoms from onset, without any acute relapses. Some people with this disease course will have a relapse sometime after the progressive pattern is established or new MRI activity may be seen at times during the disease course indicating active disease. Approximately 15% of people are diagnosed with PPMS.

For more information, visit **nationalMSsociety.org/types**.

MS can worsen over time, regardless of disease course, and relapsing and progressive forms of MS can all result in disability.

The primary difference between relapsing and progressive MS is that acute relapses are much less common in progressive MS. Acute relapses are known to be caused by inflammation. Although inflammation is present to some degree in all of the disease courses, it plays less of a role in progressive MS.

What happens in progressive MS?

Even in the earliest stages of MS, damage occurs within the central nervous system (the brain, optic nerves and spinal cord). Myelin, a fatty material that insulates and supports the nerve fibers (called axons), is attacked by the immune system, and the axons are damaged as well. Areas of demyelination tend not to repair themselves sufficiently, and with each attack, more lesions, or areas of damage, tend to occur.

In progressive MS—which manifests differently in each person—symptoms slowly increase over months to years, independent of whether relapses are occurring. Whether your MS is “secondary progressive” or “primary progressive,” “progressive” does not equate with severe disability.

Factors contributing to progression

Although MS is chronic disease that progresses for most people over time, several factors have been shown to contribute to disease progression.

- **Co-existing health conditions**—referred to as “co-morbidities”—can compromise your overall health. Co-morbidities are more common in MS than in the general population and are associated with more rapid disease progression, an increased risk of hospitalization, a reduced quality of life and a shortened lifespan. The most common co-morbidities are vascular conditions, such as high risk of heart disease and elevated cholesterol; diabetes; psychiatric conditions, such as depression, anxiety and other mood changes; and chronic lung disease.
- **Smoking**, including exposure to second-hand smoke, is known to increase risk of developing MS and of disease progression. In addition, smoking contributes to the co-morbidities. Quitting smoking has a protective effect by slowing disease progression and delaying the transition from relapsing-remitting MS to secondary progressive MS.
- **Low vitamin D** has been shown to be associated with higher levels of disability, as well as an increased risk of developing MS. It may also contribute to disease progression.

Types of symptoms

Primary symptoms directly caused by MS include vision problems, weakness, impaired mobility, poor balance, bladder and bowel dysfunction, slow or slurred speech, numbness, tremor, pain, swallowing difficulties, sexual dysfunction, reduced lung function, depression, and cognitive changes. Any of these symptoms may occur in progressive MS, perhaps stabilizing for periods of time, but slowly worsening overall.

Secondary symptoms are complications that arise from the primary symptoms. As examples, urinary tract infections can be a result of bladder dysfunction, impaired balance can lead to falls, and inactivity can lead to problems with posture, joint mobility or bone health. Paralysis or poor mobility can create a risk for skin breakdown (pressure ulcers). Problems with swallowing may cause respiratory infections and poor nutrition. Cardiovascular fitness may be compromised due to inactivity or inability to engage in aerobic activity. Weight gain may also be a negative outcome from inactivity.

The repercussions of these symptoms can feel overwhelming. Increased effort is required to deal with them, which can take a toll on your energy. It is normal to feel stressed and fatigued when faced with such challenges.

Tertiary symptoms are the "trickle down" effects of the disease on your life. These symptoms include social, vocational and psychological complications. For example, if you are no longer able to drive or walk, you may not be able to hold down your usual job. The stresses and strains of dealing with MS often alter social networks and strain relationships. Problems with bladder or bowel control, tremor or swallowing may cause people to withdraw from social interactions and become isolated.

Depression—one of the most common symptoms of MS—may be a primary or a tertiary symptom as it can be caused by the disease process itself or triggered by the burdens discussed above.

Healthcare

Optimal care for a person with progressive MS involves several strategies that need to be integrated into an overall treatment plan. In addition to managing the disease course, work with your healthcare team to manage symptoms, engage in preventive care strategies, identify and treat any co-existing health conditions, and use complementary, non-traditional treatments wisely.

It is important for care to be coordinated—which can be a challenge in today's healthcare system. If care is provided through a comprehensive care center with many services under one roof, care coordination may be the role of a team member. However, when care is provided by different specialists in the community, keeping everyone informed is more challenging and may require that you participate in coordinating your care. Your physician or nurse and the National MS Society will help.

If you do not receive care at a multidisciplinary MS center, create your own multidisciplinary team in cooperation with your neurologist or primary care physician within the limits of your insurance coverage. For certain needs, you may seek care outside your coverage, if that can be managed.

Engaging in preventive care strategies is as important for people with MS as it is for everyone in the general population. Having MS does not protect from other health conditions such as cancer, heart disease and stroke, which means that having a primary care physician as well as a neurologist, eating a healthy diet, getting adequate exercise, managing stress and getting all the recommended screenings for a person of your age and sex are all important for overall health.

Treating co-morbid conditions not only helps achieve optimal health but also has a positive impact on MS. Too often, people with MS, their family members and healthcare providers tend to attribute any health problems to MS. Because of this, significant health problems may be misdiagnosed or ignored. Given that people with MS are at increased risk for co-existing health conditions, regular visits to your primary care provider—internist, family physician or nurse practitioner—are essential for identifying and treating any other health conditions you may have.

The MS healthcare team

Whether MS is progressive or not, it is a complex and unpredictable condition—often requiring the attention of many specialists.

As you read the list below, know that there are many people able and eager to partner with you to manage your MS; however, it may take some time to identify the healthcare professionals who best fit your needs and personal style. In MS, like any other condition, your healthcare team wants to address your physical and emotional needs. For a chronic disease, you will want solid relationships with a few key providers who can accompany you on this journey. Who these people are at any given time may vary, and you may need more or fewer of them at different times.

These are the key professional roles:

- **Neurologist** — in addition to establishing the initial diagnosis, your neurologist prescribes treatments to manage your symptoms and disease course. Regular visits to the neurologist are recommended to assess and monitor MS. The neurologist will refer you to other specialists if and when they are needed. In some practices, ongoing care may be managed by both the neurologist and an advanced practice clinician, such as a nurse practitioner or a physician assistant.
- **Primary care provider** — provides primary care including preventive care, management of illnesses, general health checkups and immunizations. If you rely on your neurologist for primary healthcare, preventive care may be

neglected and other health issues may be missed. Attend to your bone health, cardiovascular health and cancer screenings. Preventative care guidelines can be obtained at **nationalMSsociety.org/compcare** or 1-800-344-4867.

- **Urologist**: a physician who specializes in treating the male and female urinary tract (bladder, kidneys and urethra). Urologists evaluate and treat bladder symptoms as well as sexual dysfunction in men.
- **MS nurse** — coordinates healthcare services. The nurse oversees initial and long-term management issues, provides education including administration of medications, assists with side effect and MS symptom management, and advocates on your behalf with insurance companies and other agencies. Since many offices do not have a nurse on staff, some of these important functions may not be done, so contact the MS Society if you need assistance with care management.
- **Physical therapist (PT)** — provides assessment and management strategies to enhance physical functioning and mobility. PTs recommend personalized exercise programs to maintain or restore mobility, build stamina, promote safety and independence, and prevent unnecessary complications. The PT will prescribe exercise to maintain range of motion and healthy heart and lung function, ease spasticity and tremor, and prevent or reduce serious problems such as contractures (frozen joints) and osteoporosis. PTs provide information on equipment such as wheelchairs, scooters, transfer devices, canes, braces and walkers. They teach safe, effective ways to use these devices, including the best ways to transfer in and out of a bed, car, shower and more. As your needs and abilities

change, your PT program can be revised to accommodate those changes.

- **Occupational therapist (OT)** — focuses primarily on skills related to activities of daily living and participation in important life roles at home and at work. OTs provide expertise in tools, techniques or equipment to conserve energy and compensate for disabilities that interfere with dressing, grooming, personal hygiene, eating, driving, using computers and other everyday activities. They may consult with architects or builders about renovations and home adaptations to support independence. OTs may also evaluate and treat cognitive problems.
- **Speech/language pathologist (SLP)** — evaluates and treats speech and swallowing problems. SLPs perform swallowing evaluations and train you and your carepartners* about safe swallowing techniques, appropriate food consistency and management of a feeding tube if necessary. SLPs provide speech therapy to help improve voice quality and volume and, when needed, teach the use of speech amplifiers, phone aids and communication devices. Like OTs, SLPs may evaluate and treat cognitive problems.
- **Social worker** — assesses social needs and links you to appropriate resources related to income maintenance, health insurance, applications for disability entitlement programs, housing, long-term care options, living wills and estate planning. Social workers also provide one-on-one counseling and facilitate support group discussions.

---

* **Carepartner** refers to a family member or friend who provides care for the person with MS.

- **Counselor** — these mental health professionals—including psychologists, social workers and counselors—help you and your family enhance coping and problem-solving skills, grieve for losses, handle communication and relationship issues, learn to live with uncertainty, and find ways to stay active and engaged in meaningful activities.
- **Neuropsychologist** — specializes in the assessment and treatment of cognitive problems. The neuropsychologist evaluates cognitive functions—including memory, processing speed, attention and concentration, problem-solving and decision making—and recommends strategies to address or compensate for impairments identified in the neuropsychological testing.
- **Spiritual advisors** — helps make sense of MS within a personal worldview. The choice of advisors and the sources of support are intensely personal, but the need to pay attention to this aspect of life with MS cannot be over-emphasized.

Effective healthcare is best achieved by coordinated input from a range of specialist providers. Contact the relevant professional early and to put a plan into action. Prompt attention to a problem can often reduce its impact on your life.

Managing the disease course

More than a dozen medications have been approved by the Food and Drug Administration (FDA) to treat the MS disease course. Each of these disease-modifying therapies

(DMTs) is approved to treat relapsing forms of MS, which include secondary progressive or primary progressive MS in those people who experience relapses.

- One DMT, Lemtrada®, is generally recommended for people who have tried at least two other MS medications without receiving sufficient benefit from them.
- Ocrevus™ is approved for the treatment of patients with relapsing-remitting MS and primary progressive MS.
- Novantrone® is specifically approved for secondary-progressive and worsening relapsing-remitting MS; however, this medication is used less frequently in MS today due to serious side effects and risks that are associated with it.

To date, most of these treatments have been tested primarily in relapsing forms of MS.

In addition to the FDA-approved medications, other medications are used "off-label" with varying degrees of success.

While there are currently no effective medical treatments to reverse or repair the damage from MS in the central nervous system, the available medications and management strategies can help to lessen the impact of the disease and enhance quality of life.

Evidence is emerging on the role of hematopoietic stem cell transplantation (HSCT) as an MS treatment. Current research suggests that the treatment may be most effective in relapsing forms of MS. As HSCT is considered experimental, health insurance may not cover the procedure and follow-up care. Other stem cell research is also underway to learn if and how stem cells might be used to slow MS disease activity and repair damage to the nervous system.

Research continues for treatments targeting relapsing as well as progressive forms of MS. For the most up-to-date information, visit **nationalMSsociety.org/progressiveMS** in addition to having a full discussion with your physician.

Research: clinical trials

Clinical trials are challenging in progressive forms of MS, as it is often difficult to measure the changes that are associated with this disease course—and treatment outcomes—in a two- or three-year trial. Longer trials are generally not feasible. However, despite the challenges, a number of agents have been tested and are currently under investigation for progressive MS. Additionally, the International Progressive MS Alliance is funding worldwide research to help researchers better understand progressive MS and identify effective treatments for this MS disease course.

Volunteering in a clinical trial is an invaluable contribution to the MS knowledge bank but may offer only limited personal benefit. Trials often generate data that will help future generations with MS. If there is a secondary benefit for the participants, so much the better, but that isn't the primary goal of research.

Ultimately, the knowledge gained from clinical trials helps everyone. Even if you never participate in a trial, there are reasons to be hopeful. Researchers around the world are at work on the whole spectrum of MS—advances are being made every year.

To find out if there is a clinical trial for which you could volunteer, talk to your doctor, contact the National MS Society and visit **nationalMSsociety.org/research** to keep up with the newest developments in MS research and treatments. Visit **nationalMSsociety.org/researchparticipation**.

Traditional and non-traditional medicine

When there are no approved medications, or when the traditionally available medications don't slow the disease or provide sufficient relief, people often look to non-traditional medicines. When these treatments are used in conjunction with the therapies prescribed by your physician(s), they are referred to as "complementary." When they are used instead of prescribed treatments, they are referred to as "alternative."

When considering any form of non-traditional medicine, ask the same kinds of questions you would ask when starting a new treatment prescribed by a physician. These interventions may make a real contribution to coping successfully with symptoms, but, like any medication, they are not totally risk-free.

Discuss with your healthcare providers any non-traditional therapies you are using in case some may cause unwanted interactions.

Managing complex symptoms

Symptoms of MS are due to damage in the brain and the spinal cord associated with demyelination and nerve fiber (axonal) damage. Any symptom associated with MS can occur whether the disease course is relapsing or progressive. The key difference is that symptoms (and functional abilities) tend to worsen gradually over time in progressive forms of MS rather than emerging during a relapse and then gradually subsiding once the relapse is over.

Fatigue

An overwhelming tiredness, without any tiring activity, affects about 85% or more of people with any type of MS.

Primary fatigue is a direct result of damage within the central nervous system.

Secondary fatigue stems from indirect factors including sleeplessness because of spasms, pain or too many nighttime trips to the bathroom; infections that cause body temperature to increase; and medications with fatigue as a side effect.

Even though this may not make sense, a regular exercise program has been proven to reduce fatigue. Certain medications, including amantadine and modafinil (Provigil®) may also be beneficial.

Fatigue can also be managed by using energy-saving techniques. Medications, neurologists, nurses, occupational therapists, physical therapists, mental health counselors and independent living specialists can all help develop your personal energy-saving plan. Ask your doctor or call the Society for referrals.

Temperature sensitivity

With MS, an increase in body temperature can cause a temporary increase in the intensity of any current symptom and may cause old symptoms to temporarily reemerge. Symptoms such as fatigue, spasms, slurred speech, visual disturbances or weakness are commonly affected by exposure to heat. Nerve conductivity slows down when body temperature rises even a little.

If you are heat sensitive, take advantage of fans, air conditioners, cool water, icy drinks or cool showers—anything that works. And keep out of the sun in the middle of the day. Commercially available cooling garments, including special vests, hats, wristbands and jackets can also reduce the risk of worsening symptoms on hot days and make outside activities more enjoyable.

Discuss exercise options with your physical therapist, occupational therapist or other healthcare professional to find ways to exercise and keep your body temperature down at the same time.

Depression and other mood changes

Stress is a fact of life. Sometimes it makes us spring into action, but other times it crushes us. Managing stress is part of successful living for everyone with MS.

Depression, on the other hand, is not a fact of life, but is extremely common among people with MS no matter what the disease course may be. Symptoms of depression can look a lot like stress symptoms, and depression can also be confused with lack of deep sleep, fatigue or cognitive issues.

Consult your healthcare professional if you find yourself sleeping too much, not sleeping enough, losing appetite, gaining weight, or feeling agitated, irritable, worthless, or blue most of the day for more than two weeks. Call the National Suicide Prevention lifeline at 1-800-273-8255 immediately if you are having thoughts of death or suicide. Stress can be managed—and depression can be effectively treated through a number of different strategies.

Cognition

Cognitive changes affect 65% or more of people with MS and can occur at any time in the course of the disease. The changes are relatively mild for most people, involving memory lapses, problems with attention, slowed information-processing and word-finding difficulties. But even mild problems can cause frustration and may affect employment, driving, communication and relationships.

If you or your family feel that your cognitive function is changing—or you notice that you are having performance difficulties at work—bring these issues up with your doctor. Testing can be done to identify cognitive strengths and challenges and often effective management strategies can be used to manage the challenges.

About 5-10% of people with MS experience severe cognitive impairment. They may require structured environments and supervision. Those who are severely impaired may have great difficulty recognizing the extent of their problems.

Pain

As with cognitive problems, MS pain is not related to the degree of disability or the disease course. People with mild relapsing-remitting disease may have stubborn MS pain while those with severe progressive MS and many disabilities may have little or none.

Pain can be a direct result of nerve damage in the brain and spinal cord, or it may be a side effect of walking problems, abnormal posture or immobility. Nerve pain and musculoskeletal pain require completely different treatments, so accurate diagnosis is the key first step. Either kind of pain can be so severe and constant that it limits daily life.

Musculoskeletal pain usually responds well to both physical and occupational therapy and over-the-counter pain medications. However, chronic nerve pain—which does not respond to over-the-counter pain relievers or rehabilitation—may require different intervention. Certain types of anti-depressant medications can help with the management of nerve pain as can certain anti-seizure medications. For some people evaluation and management in a specialty pain clinic is needed. If a multidisciplinary pain clinic is not an option due to expense or distance, communicate your needs to your neurologist and the Society for help in identifying local resources.

Spasticity

Spasticity, which is very common in MS, is a tight or stiff sensation in the muscles that may cause a limb to feel heavy and difficult to move. Spasticity can cause spasms—painful cramping sensations of the muscles—that can occur at any time but most commonly at night. Spasms may cause a limb to kick out or jerk towards the body. Spasms can disrupt usual activities, cause discomfort and interrupt sleep. Spasticity is managed with a combination of stretching, physical therapy, exercise, adaptive devices and medications.

Severe spasticity can cause problems with positioning, sitting or lying down, and may impede personal care. This in turn increases the risk of pressure sores and other skin problems. Untreated spasticity may cause permanent joint contractures (stiff or frozen joints). However, a certain amount of spasticity may also help some people. The increased stiffness in the arms or legs can provide stability during transfers or daily chores. This advantage needs to be balanced against the benefits of medications that make the limbs looser.

- Regular stretching is just as effective whether it is active (you move independently) or passive (a helper moves your limbs). If you need a helper, a physical therapist or an MS nurse can teach you and your helper how to do the exercises safely and comfortably. A little training goes a long way toward ensuring confidence and preventing accidental injury.
- Spastic limbs also benefit from exercise in a cool swimming pool. The ideal temperature is between 80 to 84 degrees Fahrenheit. Water supports body weight, enabling wider motions than can be done on dry land.
- Baclofen, the most commonly used anti-spasticity medication, works by reducing nerve transmission in the central nervous system so muscles are less likely to contract and be stiff. Baclofen can make some people sleepy and some people may feel weak when muscle stiffness is reduced. A mechanical pump, about three inches across, can be surgically implanted in the abdomen to deliver baclofen in very small doses via a thin tube directly into the space around the spinal cord in the lower part of the back. This delivery method offers optimal spasticity management while limiting sedating side effects. There are potential risks including infection, pump failure and dislodgement of the tube. The pump needs to be refilled by a doctor or nurse at regular

intervals with a professional assessment of the dosing level at each refill.

- Other anti-spasticity medications that are often prescribed for people with MS include tizanidine, diazepam and clonazepam. Each of these medications has benefits as well as side effects that must be discussed prior to taking any one of them. Botulinum toxin (Botox®) injections, which are used to reduce spasticity in individual muscles in the face, neck arm or leg, work by blocking nerve messages that activate muscles. This temporarily reduces stiffness in that muscle. The full effect of botulinum toxin injections takes about 2-4 weeks, and the anti-spasticity effects may last about 3-6 months. Side effect may include muscle weakness and pain or bruising at the injection site.

Spasticity at night may require special positioning or the use of splints or padded braces. If you or your partner notices spasticity or periodic leg movements at night, discuss this with your healthcare provider. Your partner may be more aware of this than you—you wake up tired but are not quite aware of how frequently deep sleep is being disrupted by these movements.

Very rarely, surgery is recommended for painful spasticity that does not respond to other measures.

Weakness

The causes of weakness vary from one person to another, including slowed transmission of nerve signals from the brain to the muscle, nerve fiber fatigue, and/or spasticity that interferes with the ability to move normally. A physical therapist or occupational therapist can help identify the source(s) of the weakness and recommend appropriate exercises, mobility aids and other strategies to reduce or manage it effectively.

Strengthening exercises may be recommended using small weights, exercise machines, exercise bands or other resistive devices. Water aerobics and other forms of aquatic exercise can also help with weakness. If particular muscles cannot be strengthened because of impaired transmission of nerve impulses, surrounding muscles can be strengthened in order to compensate. For example, if the ankle muscles are weak, the focus of exercise may be on strengthening the knees or hips to make up for the ankle weakness. Or if the lower extremities are weak, a primary goal of exercise will be to keep the upper extremities strong in order to help maintain mobility.

In addition to these rehabilitation strategies, the medication dalfampridine (Ampyra®) is approved for use in MS to improve walking speed. This medication appears to be effective for about 30% of people. A trial of dalfampridine can determine whether the medication improves walking.

The important thing is to correctly identify the type of weakness you are experiencing so that appropriate interventions can be identified. This is best accomplished by a physical therapist or other rehabilitation specialist who is knowledgeable about MS. Periodic assessment may be needed as physical status changes.

Bladder problems

Problems vary, but can include an overactive bladder that causes a sense of urgency and frequency, or the opposite problem of incomplete emptying of the bladder that often leads to bladder infections. In either case, loss of bladder control is possible.

Bladder problems may cause you to feel tied to the house and wary about going anywhere. During the day, repeated journeys to the bathroom use up precious energy. Frequent nighttime trips (even to a bedside commode) increase fatigue and irritability for you and your partner, and may increase the chance of falls. Loss of bladder control can also increase the risk of pressure sores and skin breakdown.

Early intervention can often normalize bladder function and prevent serious complications. Treatment plans usually require a combination of strategies. A urologist, MS nurse or continence specialist should be involved in ongoing management of persistent bladder issues.

Adequate fluid intake is essential to irrigate the bladder and reduce the risk of infection and stone formation, and to avoid dehydration and constipation.

Some of the management strategies include:

- Bladder "training" and scheduled voiding (ask your healthcare provider)
- Pelvic floor physical therapy
- Nerve stimulation of the posterior tibial nerve (in the inside of the lower leg) that can reduce bladder overactivity
- Limiting alcohol and caffeinated drinks that can irritate the bladder
- Avoiding constipation with a good bowel program (see page 25)
- Daily cranberry tablets—cranberry prevents bacteria from sticking to the bladder lining and helps prevent infections
- Drinking plenty of water before mid-afternoon to avoid multiple bathroom trips at night
- Medications prescribed by the neurologist or urologist that reduce bladder overactivity
- The use of pads and absorbent products for security

Intermittent catheterization (IC) or intermittent self-catheterization (ISC) is a quick, efficient way of emptying the bladder that can be done independently (by you) or by a caregiver or carepartner*. IC involves inserting a small hollow tube into the bladder one or more times a day to drain the urine that remains after urination. This procedure is often prescribed by the urologist and training is often provided by a nurse.

---

* **Caregiver** refers to a paid professional who provides care for the person with MS; **carepartner** refers to a family member or friend who provides care for the person with MS.

If IC is not effective for managing the bladder problem, or you are unable to manage the procedure, an indwelling catheter may be a safe option. Once the healthcare professional has inserted the catheter into the bladder through the urethra, an indwelling catheter remains in place, draining the urine into a disposable collection bag. The urine drains by gravity, so the collection bag should always remain lower than the bladder to avoid backflow.

Indwelling catheters require monitoring and care to avoid complications such as infections and bladder stones. For long-term management with an indwelling catheter, a suprapubic catheter is often used to manage and helps avoid complications of an indwelling catheter, such as irritation to the urethra and bladder infections. During a minor surgical procedure, a flexible tube is inserted into the bladder through an incision in the lower abdomen. The bladder empties via this tube into a collection bag.

Your healthcare team can work with you to assess your bladder problems and discuss the options and management strategies that would be best for you.

Bowel problems

Constipation, which is very common in MS, may be caused by decreased intestinal movement, limited physical activity, poor diet and decreased fluid intake. Pelvic floor muscles weakened by MS can also make having a bowel movement more difficult.

Some strategies for a healthy bowel are:

- Follow the practice of having a bowel movement at a consistent time of day, usually after breakfast, when the normal reflex for bowel activity takes place
- Reduce caffeine and alcohol intake—these can worsen bowel problems
- Increase fluids by drinking water, diluted fruit juices and non-caffeinated hot drinks
- Increase fiber intake or consume a natural laxative such as prunes on a regular basis
- Use protective undergarments with disposable linings
- Be patient. It takes time to establish regular bowel habits—often weeks before you can feel comfortable with your daily routine

If the strategies above are not effective, inform your primary care physical or your neurologist. If left untreated, constipation can be severe and cause an impaction. Impaction occurs when a hard mass of stool presses on the internal sphincter and cannot pass through; softer or liquid stool leaks out around the impacted stool. This may require medical intervention.

Diarrhea or fecal incontinence can be a consequence of constipation.

In addition, chronic constipation or having a chronically full bowel can cause other MS symptoms such as lower extremity spasticity to feel worse.

Changes in bowel habits can be caused by other problems. Colon cancer, allergies, viruses and other infections can cause diarrhea and constipation, so always discuss new bowel problems with your healthcare professional. Not every problem you have is caused by MS—and this is particularly true as you age.

Challenges with personal hygiene

We all need regular cleansing with soap and water. Showers, bed baths or sponge baths are essential to keep skin clean and healthy. So too are daily dental hygiene, hair care and toileting. Should MS compromise the strength and coordination skills needed to accomplish these tasks, there are assistive devices that help you remain independent or ease the tasks of caregivers or carepartners.

Occupational therapists are the experts in assistive devices for personal hygiene and bathroom adjustments that make toilet functions more effective and safe. They have extensive practical information on devices and techniques.

If you need help with basic activities, get advice and inform yourself about all available options. Working together, you and your caregiver or carepartner can develop a hygiene system that works for you, while allowing you to maintain as much independence and privacy as possible.

Listed below are a few bathroom devices to discuss with your OT or other professional advisors. Some have a minimal cost, while others are expensive.

- Hoists or lifts for transferring between chair/bed/toilet/shower
- Grab rails for stability and mobility so that you can move, roll, transfer and access all areas of your body
- Long handled scrubbers and body washers for reaching faraway parts more easily
- Raised toilet, which requires less bending, extensive movements or leg strength
- Toilet railings for safely getting on and off
- A multipurpose commode chair—to be used as a bedside commode, a shower chair, or placed over the toilet as an elevated toilet seat
- Push-button self-cleansing device, installed on a toilet, which washes and dries the perianal area with jets of warm water and warm air

Sexual issues

Even in early MS, there may be physical changes that make sexual activity difficult or uncomfortable—and worsening MS may increase the problems. This subject may get little or no attention when you see your neurologist, so you may need to bring it up. Many issues that interfere with sexual activity can be managed with medication or positioning change to reduce spasticity or IC to avoid bladder control issues. Changing the time of day for sexual activity may help with fatigue issues. Water soluble lubricants can help with dryness and increasing stimulation can help with diminished sensation. Challenges related to having an indwelling catheter or other bladder or bowel problems, should be discussed with your neurologist or nurse. Depending on the type(s) of difficulties you are experiencing, your neurologist or nurse may refer you to a urologist, who is a specialist in the male and female urinary system and is also trained to treat male erectile dysfunction.

Swallowing problems

Choking and coughing when eating or drinking can be dangerous, as well as disturbing. If you experience these problems, a speech/language pathologist (SLP) can assess your needs and recommend management strategies. Your doctor can refer you for a swallowing evaluation and treatment.

The SLP can help you choose the right foods and teach you how to prepare them properly. He or she will also help you and your caregiver or carepartner learn the best positioning for safe swallowing to prevent complications such as respiratory infections (caused by food particles in the lungs) and malnutrition.

If thin liquids, such as water and juice, are difficult to manage, thickened liquids or foods that are stewed, mashed or blended may be helpful and safer. Foods that crumble easily may need to be avoided. Consider smaller, more frequent meals, and take smaller bites to avoid fatigue from chewing and swallowing.

In rare situations, MS overwhelms swallowing function. A feeding tube may be surgically inserted to bring food and liquid directly to the stomach. This is a frightening thought for many and must be discussed in detail with the doctor. A decision about what type of feeding tube to use should be made in consultations with a knowledgeable MS specialist.

Speech problems

Some people with MS experience episodes of speech difficulties. These may come and go, or they may remain and perhaps worsen over time. Consult with a speech/language pathologist—with professional help, you can learn how to use their existing communication abilities to the fullest. Voice amplifiers may be useful if articulation of words is adequate. Sometimes speech problems are eased when you speak more slowly, use shorter sentences, and choose words that are easy to pronounce.

To express themselves more clearly and to share complex information, people with speech limitations often need assistive communication devices. These tools range from paper and pen, to "magic slates," to sophisticated laptop computers. People with disabilities can control computers using adapted keyboards, sticks held in the mouth, or wireless devices worn on the head or eyeglasses. There are even computer controls that operate by eye blink. TTY/TT systems and free translation services enable phone use for those who speak too softly or slowly for a regular phone. For those with profound disabilities, there are communication boards. The user gazes at letters, symbols, words or phrases to communicate basic messages.

Skin care

A pressure sore is an injury to the skin and the tissue under the skin caused by too much pressure for too long. The pressure prevents blood from getting to the skin, so the skin dies. Normally the nerves send messages of pain or discomfort to the brain to signal the need to change position. Damage from MS interrupts these signals so that you may not be aware of any skin problems they cannot see. And even if you sense discomfort or the need to change position, the ability to move independently may be compromised.

In people with restricted mobility, the shoulders, elbows, hips, buttocks, ankles and heels are at high risk for pressure and breakdown. People with MS who are immobile most of the day, even if they are not in bed, are at risk of pressure ulcers (also known as bed sores).

Pressure ulcers can occur for other reasons as well:

- Shearing is a kind of pressure injury that happens when the skin moves one way and the bone underneath moves another. Shearing happens if you slouch or slide when you are seated, for example.
- An abrasion can occur when you are pulled or pull yourself across a surface instead of lifting. This is an example of friction injury.
- High pressure, such as a bump or fall, can cause damage to the skin that may not show up right away.
- Loss of bowel or bladder control can irritate the skin and cause a rash or sore.

A pressure care plan helps avoid these problems. Speak to your physical therapist or nurse to get the best advice about you and your carepartner or caregivers can work together to prevent most skin problems from occurring, including:

- Eating an adequate diet (good nutrition is essential for healthy skin)
- Managing bladder and bowel problems to keep skin dry and clean
- Treating spasticity with medication and regular physical therapy
- Wearing appropriate clothing made from soft and unbinding materials, with a roomy cut to accommodate sitting
- Protecting bony prominences like the hip or ankle bones with padded boots or cushions, and gently massaging these areas to help keep the skin and joint healthy

Some added ways to avoid pressure sores include:

- Perform wheelchair pushups and position changes in the chair at regular intervals. Aim for an hourly pushup or a roll from side to side to relieve the area and allow air to flow. How frequently you can do this depends on body weight, the wheelchair support and cushioning, upper limb strength, and whether skin is intact and dry.
- Use appropriate cushions to relieve pressure (there are many types available).
- Use lifts or hoists to make changing position easier and to prevent shearing during transfers.

- Inspect the whole body daily to detect any changes in color or broken areas in the skin. A caregiver or carepartner is essential for checking areas that are not visible to the individual.
- Treat any problem area immediately, including resting the area by removing all pressure and contacting a physician or wound specialist.

How can I stay resilient?

Some days you feel up to the challenge of living with MS, while other days you want to retreat. For some people, having MS puts their priorities into perspective; for others, it may feel more like an obstacle in the way of all their plans and dreams. For anyone, feelings of sadness, loss, anger, anxiety or guilt can be experienced intermittently over the disease course.

Living with MS is a process—and you must arm yourself for the hard days and allow yourself to celebrate the good days. If at any point the feelings become overwhelming or unmanageable, let your healthcare provider know s/he can refer you to a counselor for the help and support you need.

Disability may occur despite the best management strategies, interventions and treatments used early on in the disease. Despite your best efforts and those of your health professionals and family, the disease may take its own course. MS isn't a disease that can be completely controlled.

Finding ways to be productive and fulfilled, to reshape your life and to regain self-esteem that may have been lost because of MS often involves developing mental, emotional and spiritual "muscles" you may not have used before. These goals are not achieved quickly. But people can, and do, pass through crisis periods. Some find resilience in their faith, support groups, writing or by tapping their sense of humor. Others do so with the help and support of family and friends. They report joys and a deep sense of achievement along the way. Spiritual advisors and/or professional counselors may be a critical resource in helping you and your family—who also live with the disease—to explore ways to adapt.

Even if you cannot use one of the disease-modifying therapies, there are many things you can do to minimize the impact of symptoms on your life, guard your health, improve your quality of life and maximize your ability to function

Family matters

Where to live to get the care you need

Some people manage independent lives with major disabilities by employing personal care attendants, housekeepers and home health aides to maximum advantage. Others manage well with the help of partners and loved ones. Still, others come to decide that their needs are best met in a residential long-term care facility. The goal of any of these arrangements is to avoid situations that are unstable, draining and even dangerous.

When you have questions about in-home or long-term care, contact the Society at 1-800-344-4867.

If you are receiving long-term support services, either in the community or in a residential setting, be sure the supervisor of care has a copy of the Society's publications developed to enhance quality of care in those settings. (Visit **nationalMSsociety.org/profpublications**.) They include:

- "Nursing Home Care of Individuals with Multiple Sclerosis"
- "Assisted Living for Individuals with Multiple Sclerosis"
- "Serving Individuals with Multiple Sclerosis in Adult Day Programs"
- "Serving Individuals with Multiple Sclerosis in the Home"

All the options require some degree of flexibility.

Staying at home will mean making changes. Home adaptations do more than fight fatigue—they offer safety, ease of movement and comfort. An occupational or physical therapist can assess what can be done to modify your home. The changes may not be as expensive or ugly as you may fear. Some renovations, such as a roll-in shower, are costly; others, such as ramps, may be available as a volunteer project. Grab bars, available in attractive colors, require professional installation, but replacing doorknobs with lever handles is a weekend do-it-yourselfer's project.

MONEY MATTERS

Discuss equipment purchases and renovations with your tax advisor, your healthcare provider, your insurance company and the Society. If you are employed, discuss your needs with your state vocational rehabilitation program.

Equipment and renovations to meet medical needs, with documentation from healthcare professionals, are usually tax-deductible medical expenses. Equipment or renovations that enable you to be gainfully employed may be funded by a state vocational rehab program or by your insurance policy. The Society may know about community resources, including volunteers to help.

Carepartners

Caring for a loved one with a disabling chronic disease at home can be challenging and exhausting and at the same time deeply satisfying. The realities of the daily routine have a huge impact on both the person with MS—who loses some degree of independence—and the carepartners/family members who take on significant responsibility. MS is changeable and unpredictable, and people experience good and bad days. One day the person with MS may need help with transferring from the bed to a chair, and other better days, they can move easily on their own.

If disability is significant, there is a great deal for the carepartners to manage:

- Personal care such as dressing, bathing, grooming, eating, toileting, exercising, transportation and taking medication
- Daily activities such as work, recreation, entertainment, exercise, hobbies, private time and religious practice
- Household tasks including general cleaning, shopping, cooking, laundry, bill-paying, childcare, yard work, house maintenance and transportation
- Training and supporting other caregivers/carepartners, whether paid or volunteers, family members or employees, to ensure comfort and safety for all

No solitary carepartner can do it all!

The healthcare team can provide tips and teach techniques for bathing, dressing, toileting and safe transfers. The National MS Society and other area resources can provide education so that the safest and best practices are used from the beginning. The Society is also a source of self-help groups, peer counseling, volunteers, and referral to area resources such as home health service providers, adult day programs and respite care.

Sexual issues for partners

When MS becomes more severe, carepartners who are also spouses or partners can face more hurdles in their sexual relationship. It's hard to "switch gears" if the carepartner bathes, toilets, grooms and dresses the partner. The couple may need new “cues” to initiate intimacy and set the stage for romance.

Psychological and social issues may make the person with MS feel inadequate and unlovable. Consider a trained counselor who can help a couple work through these delicate and important matters. When the issues are brought out into the open, it takes the burden off both partners. Open and honest communication about sexual needs and pleasures without fear of ridicule or embarrassment is the crucial first step.

It’s a partnership

Even with good information and equipment, carepartners cannot do everything alone. The potential for frustration, burn-out and even abuse is too great. The person with MS and the carepartner need to be there for each other. Feelings of anger and frustration need a safe outlet. The carepartner needs emotional support, time off, and a trusted counselor or advisor. Finding these necessary resources should involve a call to the Society.

Living with progressive MS can truly be unpredictable and exhausting. But meeting the challenges offers deep rewards for the person with MS, family members and carepartners.

Resources

- **Abledata**, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research—part of the U.S. Department of Health and Human Services' Administration for Community Living, is a premier source of information on adaptive technology on the Web. The site lists more than 20,000 products, with descriptions, prices, ordering instructions and installation information. Go to **abledata.com**, or call 800-227-0216 (V); 703-992-8313 (TTY)
- **Centers for Independent Living.** The National Council on Independent Living links some 700 private, nonprofit community organizations by and for people with disabilities. These centers offer technical advice, training, and advocacy to enable people to live safely outside institutions. Go to **ncil.org** or look in the phone directory under Independent Living Center. 202-207-0334 (V); 202-207-0341 (TTY); or toll free 877-525-3400.

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:

- MS and the Mind
- Exercise as a Part of Everyday Life
- Urinary Dysfunction and MS

- Bowel Problems: The Basic Facts
- Fatigue: What You Should Know
- Stretching for People with MS
- Stretching with a Helper for People with MS
- How to Choose the Mobility Device that is Right for You
- Controlling Spasticity in MS
- **nationalMSsociety.org/educationalvideos**.

Ampyra® is a registered trademark of Acorda Therapeutics, Inc.
Botox® is a registered trademark of Allergan, Inc.
Lemtrada® is a registered trademark of Genzyme Corporation.
Provigil® is a registered trademark of Cephalon, Inc.
Zenapax® is a registered trademark of Hoffmann-La Roche Inc.

Notes

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's mission is: People affected by MS can 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 programs and services designed to help people with MS and their families move their lives forward.

National
Multiple Sclerosis
Society

nationalMSsociety.org
1-800-344-4867

services_managingPrgsiveMS_pub_09/18