

# Managing Progressive MS

MANAGING MAJOR CHANGES



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Multiple Sclerosis  
Society

Michael (front cover), diagnosed in 2004.

# Managing Progressive MS

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# Introduction

Most people reading this booklet will have lived for years with relapsing-remitting MS and are now facing a progressive course of MS with few or no remissions (secondary-progressive MS). Other readers may have had progressive MS from the onset (primary-progressive MS) but now face new problems and worsening symptoms. Everyone is different and each person travels a unique road living with MS.

This road can be rough: unpredictable, challenging, frustrating and exhausting. But it may lead to deep meaning and self-discovery. Developing and strengthening personal coping strategies enables many people to appreciate life and maintain a sense of purpose despite this chronic illness.

It is important for everyone to strive for a positive outlook — and to recognize and applaud one's own personal victories and achievements.

This booklet aims to document some of the strategies for living with advanced MS in independent or supported home environments. It will point you 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 will probably change over time, so what is a good solution for you now may need to be adjusted or changed later on.

Throughout this booklet there will be references to literature on specific topics, helpful organizations and Web sites. All National MS Society publications referred to can be obtained at [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures) or [nationalMSSociety.org/PRCPublications](http://nationalMSSociety.org/PRCPublications), or by calling your chapter at 800-344-4867 (800-FIGHT-MS).

## What is progressive MS?

The term progressive MS causes a great deal of confusion and concern for people, so it's important to clarify what the term actually means. In MS, four disease types have been defined:

- **Relapsing-Remitting MS (RRMS):** RRMS is characterized by clearly defined acute relapses (also called *attacks* or *exacerbations*) followed by either complete or partial remission of symptoms. Between these attacks, the disease does not worsen or progress. About 85% of people are diagnosed with this form of MS.
- **Primary-Progressive MS (PPMS):** PPMS is characterized by progression of disability from onset, without any acute relapses. Approximately 10% of people are diagnosed with PPMS.

- **Secondary-Progressive MS (SPMS):** SPMS follows after an initial period of relapsing-remitting MS. Typically, SPMS is characterized by less recovery following attacks, gradual worsening during *and between* attacks, and/or fewer and fewer attacks (or none at all) accompanied by progressive disability. Most people who are diagnosed with RRMS will make the transition SPMS at some point.
- **Progressive-Relapsing MS (PRMS):** This very rare form of MS (5%) is characterized by progression from onset with occasional acute relapses along the way.

These disease types were identified as a means for classifying people who shared a similar disease course in order to reduce variability among subjects in clinical trials. Reducing the variability made it possible to determine the effectiveness and safety of MS medications more accurately, using fewer trial participants.

All forms of MS can worsen over time and all forms of MS can result in disability. In fact, all forms progress at about the same rate, so having a diagnosis of progressive MS does not imply that it is more severe or likely to worsen more rapidly.

The primary difference between the four types is the presence or absence of acute relapses. Acute relapses are known to be caused by immune system activity. Today we have several approved medications that are effective in reducing immune system activity and therefore reducing the number of relapses.

Disease progression that occurs in the absence of relapses is less well understood, and it is unclear at this time whether medications that reduce immune system activity can slow progressive forms of MS. Learning more about progressive forms of MS is a key priority for researchers and the National MS Society.

## 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 nerve fibers (called axons), is attacked 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.

Progressive MS manifests itself differently in each person. Whether your MS is “secondary-progressive,” which follows a period of “relapsing-remitting” MS, or “primary-progressive,” meaning it has been slowly progressing from the beginning, it is important to realize that “progressive” does not necessarily imply severe disability. But it does mean that there are few or no relapses, and few or no recovery or remission periods when major symptoms abate.

While there are currently no effective medical treatments to repair nerves or reverse permanent losses of function, there are many useful strategies and treatments. It is possible to alleviate many symptoms, to improve some functions, and — just as important — to compensate for disabilities and thus lessen their impact on your life.

**Primary symptoms** directly caused by MS include weakness, numbness, tremor, loss of vision, pain, mobility problems, poor balance, bladder and bowel dysfunction, sexual dysfunction and cognition changes. These symptoms, common in relapsing-remitting MS, continue in progressive MS. They tend to worsen gradually over time. This downward course may stabilize at any point. This doesn't mean it goes away, but rather that adjustments and accommodations have come to feel natural.

Permanent functional losses occur in progressive MS. Some permanent losses may occur in relapsing-remitting MS as well, as not everyone recovers completely following an acute attack (or relapse). However, relapsing-remitting MS is known for periods of improvement that are not as apparent in progressive MS.

**Secondary symptoms** are complications that arise from the primary symptoms. Urinary tract infections can be a result of bladder dysfunction, for example; poor balance and inactivity can cause problems with posture, joint mobility or bone health. Paralysis or poor mobility creates a risk for skin breakdown (pressure sores). Problems with swallowing may cause respiratory infections and poor nutrition.

The repercussions of these symptoms hit hard. 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 stress and strain of dealing with MS often alters social networks and sometimes fractures relationships. Problems with bladder control, tremor or swallowing may cause people to withdraw from social interactions and become isolated.

Depression is fairly common in people with MS. Depression 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.

# Medical issues

## The health care team — who does what?

Let's start by clarifying the professionals you may need to help you handle MS symptoms. Whether MS is progressive or not, it is a complex and unpredictable condition — often requiring the attention of many specialists.

You may receive care at a multidisciplinary MS center. If you do not, you need to create a multidisciplinary team, working with your neurologist or primary-care physician and within the limits of your insurance coverage. For certain needs, you may seek care outside your coverage, if that can be managed. If you have created your own team, you may also need to initiate coordination among the members. Your nurse and National MS Society chapter will help. Many chapters provide “case management” programs or referrals to community care managers. Your chapter is familiar with the MS specialists practicing in your area.

## These are the key professional roles:

- **Neurologist** — in addition to establishing the initial diagnosis, prescribes treatments for MS and symptom management. Regular annual visits to the neurologist are recommended for assessment and monitoring of MS. The neurologist will refer you to other specialists such as an urologist, gastroenterologist, gynecologist, psychiatrist or pain specialist, if and when they are needed.

- **Family physician** — provides primary health care including general health checkups, immunizations and preventive care. Society research suggests that people with more severe progressive MS tend to rely on their neurologists for primary health care — which is generally not the best strategy. Be sure you attend to preventive health issues. The Society has developed preventative health care guidelines that can be obtained on our Web site or by calling your chapter.
- **MS nurse** — coordinates health care services. The nurse oversees initial and long-term management issues, teaches self-care including administration of medications, and advocates on your behalf for needs with insurance companies and other agencies.
- **Physical therapist (PT)** — focuses on exercise programs to maintain mobility and optimize function. When the disease process is in more of a progressive stage, the physical therapist will prescribe exercise to maintain range of motion and healthy heart and lung function, reduce and prevent serious complications such as contractures (frozen joints) and osteoporosis, and ease spasticity and tremor. 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. PTs help their clients create personal exercise programs for increasing stamina, optimizing mobility and preventing unnecessary complications. PT interventions are important throughout the course of MS. As a person's needs and abilities change, his or her program can be revised to accommodate those changes.

- **Occupational therapist (OT)** — focuses primarily on skills related to activities of daily living and engagement in important life roles. In the progressive stage of MS, OTs are specialists 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 ordinary 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 by training the person with MS and caregivers/family members about eating safety, how to prepare easy-to-swallow food, and how to manage feeding tubes if necessary. They teach the use of speech amplifiers or telephone aids, communication devices and, like OTs, may evaluate and treat cognitive problems.
- **Social worker** — assesses social needs and links clients to appropriate resources in areas of income maintenance, health insurance, applying 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.
- **Counselor** — mental health professionals help individuals and family members develop problem-solving skills, grieve for losses, recreate self-esteem, handle changing relationships, learn to live with uncertainty, and find ways to be productive.

- **Neuropsychologist** — specializes in psychological and cognitive problems. The neuropsychologist will set up programs to address or compensate for impairments identified in comprehensive neuropsychological testing.
- **Spiritual advisors** — may help make sense of MS within a personal worldview. The choice of advisors and the sources of support are intensely personal matters, but the need to pay attention to this aspect of life with MS cannot be over-emphasized.

In MS, effective health care is best achieved by coordinated input from a range of specialist providers. It is important to 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.

### What medical treatments help progressive MS?

This is an important question to discuss with a knowledgeable MS specialist. Although there are some treatments for progressive MS, you may or may not be a suitable candidate for them, depending on your particular situation. Your physician may suggest starting or staying with one of the disease-modifying drugs.

The interferon medications (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Extavia<sup>®</sup> and Rebif<sup>®</sup>) are approved by the Food and Drug Administration (FDA) for all relapsing forms of MS, including secondary-progressive MS in those people who are still experiencing

relapses. Natalizumab (Tysabri®) and fingolimod (Gilenya®) are also FDA-approved for all relapsing forms of MS. Mitoxantrone (Novantrone®) is approved for secondary-progressive, progressive-relapsing, and worsening relapsing-remitting disease. Although not specifically approved for MS, methotrexate and cyclophosphamide have also been used with varying degrees of success. Tysabri, Novantrone, methotrexate and cyclophosphamide all pose the risk of possible serious side effects.

Experimental treatments, including bone marrow transplantation and a procedure called plasmapheresis (plasma exchange), have had very mixed results. These approaches have many risks and insurance may not cover them.

To date, all of these treatments have been tested primarily in relapsing forms of MS. Primary-progressive MS is more challenging to study in clinical trials because the absence of acute relapses makes it difficult to measure treatment outcomes in the course of a two- or three-year trial. While PPMS appears to be less responsive to treatment, improved research methods and additional clinical trials will identify effective treatment options for this form of MS as well.

As of the printing of this publication, other medications and combinations are in various stages of clinical trials or are under review by the FDA, potentially offering new options to modify the course of MS. Among the more interesting therapies in clinical trials are those using monoclonal antibodies — products of the biomedicine revolution.

They include CamPath® 1H (alemtuzumab), Zenapax® (daclizumab) and others. For the most up-to-date information, be in touch with your chapter or visit [nationalMSSociety.org/ProgressiveMS](http://nationalMSSociety.org/ProgressiveMS) in addition to having a full discussion with your physician.

### Should you volunteer for a clinical trial?

Clinical trials are essential for scientists to understand MS, to develop better treatments, and ultimately to find a cure. Because MS is such a complex disease and affects individuals so differently, it is expected that people participating in trials will have different outcomes. In other words, some individuals may benefit more than others. Moreover, only some people will receive the test treatment, while others will receive a placebo or sham treatment, or perhaps another MS medication with which the test treatment is being compared. Every effort is made in these trials to prevent anyone from knowing who receives what while the trial continues.

Volunteering in a clinical trial is an invaluable contribution to the MS knowledge bank *but may offer only limited personal benefit*. And many trials are limited to people with relapsing-remitting MS.

Some people with progressive MS feel research ignores them. Progressive MS moves very slowly, and presents fewer clear “markers” by which to measure the effectiveness of a new treatment. Therefore, many clinical trials are structured for volunteers with relapsing-remitting MS, where the benefits, if any, will be seen sooner and more clearly.

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 and important 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 your National MS Society chapter and visit the Research section on the Society’s Web site. This site is also an excellent way of keeping up with the newest developments in MS research and treatments. You may want to read the Society’s booklet, *“Participating in Clinical Trials”* to learn about the process of clinical trial participation and how to decide if a study is right for you.

## Handling MS day to day

### The emotional roller coaster

Some days you feel up to the challenge while other days you want to retreat. Feelings of grief, loss, anger, disbelief, fear, sadness, anxiety and guilt can be constant companions. You think you have gotten over a challenge and then it raises its head again.

Living with MS is a process — and you have to arm yourself for the hard days and allow yourself to celebrate the good days.

Severe 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.

Finding ways to be productive and fulfilled, to reshape your life and 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. Most 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 individuals with MS and their family members — 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.

## Complementary and alternative medicine (CAM)

People with MS are frequent consumers of CAM — and with care and caution, this is appropriate. CAM should always be used alongside prescribed medicines and therapies. When you decide to try any complementary or alternative therapy, your health care team needs to be fully informed.

When you are considering using any form of CAM, it's a good idea to ask the same kinds of questions you would ask when starting a new treatment prescribed by a physician. In other words, it's best to approach CAMs with healthy, informed caution. CAMs may make a real contribution to coping successfully with symptoms, but they are not totally risk-free. Be particularly cautious — and skeptical — about any CAM that claims to cure your MS.

The booklet *“Clear Thinking about Alternative Therapies”* is a good place to start your exploration. It is available on the Society's Web site or by calling your chapter. The Society also recommends the Web site managed by Dr. Allen Bowling ([www.neurologycare.net/cam](http://www.neurologycare.net/cam)), which provides comprehensive information about CAM.

# Symptom management when the road gets rougher

Some of the more difficult symptoms of MS are not tied to progressive disease, and may be familiar to you. But symptoms may become harder to manage if problems mount up.

## Fatigue

An overwhelming tiredness, without any tiring activity, affects about 85% 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 seem counter to good sense, a regular exercise program has been proven to reduce fatigue. Certain medications, including amantadine and modafinil (Provigil®) may also be beneficial. And, most importantly, fatigue can be managed by using energy-saving techniques. If your disability has increased, saving energy is now vitally important.

In addition to self-help and medications (explained in the Society publication, *“Fatigue: What You Should Know”*) neurologists, nurses, occupational therapists, physical therapists, mental health counselors and independent living specialists can all contribute to developing your personal energy-saving plan. Ask your doctor or call your chapter for referrals.

## Keeping cool

With MS, an increase in body temperature can cause a temporary increase in symptoms such as fatigue, spasms, slurred speech, visual disturbances or weakness. Nerve conductivity slows down when an individual’s body temperature rises even a little.

If you are heat sensitive, use fans, air conditioners, cool water, icy drinks, 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, while making outside activities more enjoyable.

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

## Stress and depression

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 — including the person newly diagnosed with relapsing-remitting MS and the person living with severe, progressive MS.

Depression, on the other hand, is not a fact of life, but it is extremely common among people with MS at any stage. 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 health care 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 immediately if you are having thoughts of death or suicide. Stress can be managed — and depression can be treated with medication and counseling.

## Cognition

Cognitive changes are not linked to progressive disease. They affect up to 50% of everyone with MS and can occur at any time in the course of the disease. The changes are mild for most people and involve memory lapses, problems with attention, word-finding difficulties, and the like. But even mild problems may affect employment, driving, communication and relationships.

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. The Society booklet, *“Solving Cognitive Problems,”* presents a comprehensive overview and discusses testing and cognitive rehabilitation.

## Pain

As with cognitive problems, MS pain is not related to the degree of disability or the stage of the disease. 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 physical therapy and over-the-counter pain medications. However, chronic nerve pain — which does not respond to over-the-counter pain relievers — may warrant a workup at a specialty pain clinic. There, a multidisciplinary team with expertise in the management of complex pain will create an individualized treatment plan to meet your needs.

If a multidisciplinary pain clinic is not an option due to expense or distance, communicate your needs to your neurologist and your Society chapter for help in identifying local resources.

## Spasticity

Spasticity is also common in MS and is managed with a combination of medications, physical therapy, exercise, stretching, adaptive devices and rehabilitation. The Society booklet, *“Controlling Spasticity in MS,”* provides a good overview.

Severe spasticity can cause serious 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 help stabilize a person 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, you probably need a session with a physical therapist or an MS nurse to teach your helper. A little training goes a long way toward ensuring confidence and preventing accidental injury.

Spastic limbs also benefit from exercise programs in a cool swimming pool. A temperature of 85 degrees or lower is best. Water supports body weight, enabling wider motions than can be done on dry land.

Baclofen is the most commonly used anti-spasticity medication, but in higher doses oral baclofen becomes increasingly sedating. A pump, about three inches across, can be surgically implanted in the abdomen to deliver baclofen (and sometimes drugs to control pain) in very small doses via a thin tube directly into the intrathecal space surrounding the spinal cord. A test dose is required before the pump can be implanted.

This delivery method limits 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 spasticity medications that may be helpful include diazepam, dantrolene and tizanidine. Botulinum toxin (Botox®) injections, which are used to reduce spasticity in an individual muscle, temporarily paralyze the selected muscle to allow free movement. This therapy, which is costly and may not be covered by insurance, is not appropriate for large groups of muscles. The effects of a Botox injection last three to six months.

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, be sure to discuss this with an MS nurse. A partner may be more aware of this than the person with MS who wakes up tired but is 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

Most people with MS will experience some degree of weakness over the course of the disease. The causes of weakness vary from one person to another, including slowed transmission of nerve signals from the brain to the muscle, fatigue, and/or spasticity that interferes with the ability to move normally. A physical therapist can help identify the source(s) of the weakness and recommend appropriate exercises 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. So, 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.

The important thing is to correctly identify the type of weakness a person is experiencing so that appropriate interventions can be identified. Periodic assessment may be needed as a person's physical status changes.

## Bladder problems

Many people with MS know every bathroom facility along all their frequently traveled routes. If problems are continual, a person may 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 individuals and their partners and may increase the chance of falls. Loss of bladder control can also increase the risk of pressure sores and skin breakdown.

Good bladder management is the answer. Depending on the individual, it is usually a combination of management strategies, including a prescription medication such as oxybutynin, tolterodine, trospium chloride or solfenicen succinate. An urologist, MS nurse or continence specialist should be involved in ongoing management of bladder issues if they are severe or persistent.

### Some of the strategies include:

- Bladder "training" and scheduled voiding. (Ask your nurse.)
- Limiting alcohol and caffeinated drinks that can irritate the bladder.
- Avoiding constipation with a good bowel program. (See page 28.)
- Daily cranberry tablets. Cranberry prevents bacteria from sticking to the bladder lining and helps prevent infections.
- Drinking six to eight glasses of water a day. Fluids are essential to keeping the bladder functioning properly and avoiding infections, dehydration and constipation.
- The use of pads and absorbent products for security.
- Catheterization to drain the bladder. This is a highly effective management technique and there are several options depending on your need.

### Intermittent catheterization (IC)

Intermittent catheterization (IC) or intermittent self-catheterization (ISC) is a quick, efficient way of emptying the bladder that can be done independently by the individual, or by a caregiver. In both cases, an MS nurse can provide the necessary training.

A small tube (catheter) is inserted into the bladder through the urethra. This allows urine to drain into the toilet. The process takes less than 10 minutes. It is done every four to six hours throughout the day and then just prior to sleep.

This schedule can vary with individuals. IC, which poses little risk of infection if clean technique is followed, and is not painful, allows a person with MS to remain dry. After overcoming an initial natural reluctance, people find IC to be comfortable and easy to manage.

Difficulties with hand function, weakness or tremor, or problems transferring on and off a toilet may make IC inappropriate for some people.

### Indwelling Catheter

For people who are unable to manage IC, an indwelling catheter may be the safest or most practical next choice. Once the health care 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 person's bladder to avoid backflow.

Indwelling catheters require monitoring and care so complications such as infections and bladder stones are avoided. Silicone catheters are changed every three to four weeks or at regular intervals to avoid infections.

The same fluid intake recommended above (6–8 glasses) is essential in order to irrigate the bladder and reduce the risk of infection and stone formation. Carbonated drinks should be avoided as they make the urine alkaline, which encourages stones.

Low-grade infections are common with indwelling catheters, so long-term antiseptic treatment or short-term antibiotics may be required.

### Suprapubic catheters

For those with more advanced MS bladder problems, a suprapubic catheter can be the answer. This involves minor surgery. 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 which is usually fastened to the leg. This technique may be more appropriate for long-term management as it is associated with fewer complications than an indwelling catheter.

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

## Personal hygiene

We all need daily 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 individuals remain independent or ease the burden on caregivers.

Occupational therapists are the experts in the area of 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 a caregiver or visiting nurse to help with basic activities, get advice and inform yourself about all available options. Working together, you and your caregiver can develop a hygiene system that works for you, while allowing you to maintain as much independence and privacy as possible.

Here 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 — 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.

## 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.

A bowel program may include use of stool softeners with bulk-forming laxatives, suppositories or enemas. Some of the other strategies are similar to the bladder checklist above:

- Follow the practice of having a bowel movement at the same time every day, usually after breakfast, when the normal reflex for bowel activity takes place.
- Reduce caffeine and alcohol — these can worsen bowel problems.
- Increase fluids by drinking water, diluted fruit juices and non-caffeinated hot drinks.

- 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 constipation is severe, there may be a need for manual stimulation to empty the bowel. This will require wearing a plastic glove. Insert a gloved finger into the rectum and rotate it gently around the anus rim. This can stimulate the bowel and help open the anal muscles.

Diarrhea or fecal incontinence can occur as a consequence of constipation. When a hard mass of stool presses on the internal sphincter and cannot pass through (known as impaction), a softer stool leaks out around this impacted stool. An enema or suppository should be administered to empty the colon of the fecal mass. It may take a number of days to completely empty an impacted bowel, following which it is important to establish a regular pattern of bowel emptying.

It is also important to remember that 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 health care professional. Not every problem you have is caused by MS.

## Sexual issues

Even in early MS, there may be physical changes that make sexual activity difficult or uncomfortable. Worsening MS may increase problems. Since your physician or nurse may not bring up the sexual issues related to having an indwelling catheter or other bowel or bladder problems, you may need to start the discussion. Depending on the type(s) of difficulties you are experiencing, your neurologist or nurse may refer you to an urologist, who is a specialist in the male and female urinary system and is also trained to treat male erectile dysfunction. You may want to start your exploration with the Society's booklet, "Intimacy and Sexuality in MS," which contains helpful facts and resources.

## Swallowing problems

This is a serious issue. Choking and coughing when eating or drinking can be dangerous as well as disturbing. If you have these problems, you need to consult a speech/language pathologist to assess your needs.

By choosing the right foods, preparing them properly, and learning the best body postures for eating or drinking, you can avoid complications such as respiratory infections (caused by food particles in the lungs) and malnutrition.

People with MS-related swallowing problems are often advised to choose thicker fluids and stewed, mashed or blended foods that need less chewing, while avoiding foods that crumble easily. It may also be advisable to eat smaller, more frequent meals, and to take smaller bites to avoid fatigue from chewing and swallowing.

In rare situations, MS overwhelms swallowing reflexes. Then a feeding tube may be surgically inserted to bring food and liquid directly to the stomach. 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. Consultation with a speech/language pathologist is important. With professional help, people can learn how to use their existing communication abilities to the fullest. Voice amplifiers may be useful if a person's articulation of words is adequate. Sometimes speech problems are eased when the individual learns to 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 telephone use for those who speak too softly or slowly for a regular telephone. 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 any redness or break in the skin caused by too much pressure for too long a period of time. 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. People with MS who are immobile most of the day, even if they are not in bed, are at risk of pressure sores, also known as pressure ulcers or bed sores.

Pressure sores 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.

A pressure care plan helps avoid these problems. Speak to your physical therapist or nurse to get the best advice. You will learn ways that the person with MS and the 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 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 massage these areas to help keep the skin and joint healthy.

Some added ways to avoid pressure sores include:

- Doing 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 a person can do this depends on body weight, the wheelchair support and cushioning, upper limb strength, and whether skin is intact and dry.
- Using appropriate cushions to relieve pressure there are many types available.
- Using lifts or hoists to make changing position easier and to prevent shearing during transfers.
- Inspecting the whole body daily to detect any changes in color or broken areas. A caregiver is essential for checking areas that are not visible to the individual.
- Treating any problem area immediately, including resting the area by removing all pressure and contacting a physician or wound specialist.

## Family matters

### Where to live to get the care one needs

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. In the middle are people whose arrangements are unstable, draining and even dangerous.

See the National MS Society handout called *“Hiring Help at Home”* (Visit [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures). Look under *“Managing Major Changes”*). It includes checklists to help assess needs, sample job description forms for use in hiring and a sample employment contract, along with suggestions on recruiting voluntary or paid help at home.

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/PRCpublications](http://nationalMSSociety.org/PRCpublications). 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 is the specialist who assesses 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.

The National MS Society booklet *“At Home with MS”* is a good starting point. It lists resources for equipment, plans and volunteers.

### Money matters

Be sure to discuss equipment purchases and renovations with your tax advisor, your health care provider, your insurance company and your Society chapter. If you are employed, discuss your needs with your state vocational rehabilitation program.

Equipment and renovations to meet medical needs, with documentation from health care 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. Your Society chapter may know about community resources, including volunteers to help.

## Caregivers

Caring for a loved one with a disabling chronic disease at home can be deeply satisfying and at the same time challenging and exhausting. The realities of the daily routine have a huge impact on both the person with MS — who loses some degree of independence — and the caregiver/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 can't help with transferring from the bed to a chair but can make the move easily on a better day.

If disability is significant, there is a great deal for the caregivers 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, religious practice.
- Household tasks including general cleaning, shopping, cooking, laundry, bill-paying, childcare, yard work, house maintenance, transportation.
- Training and supporting other caregivers, whether paid or volunteers, family members or employees, to ensure comfort and safety for all. No solitary caregiver can do it all!

The medical 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 for caregivers and individuals with MS 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, caregivers who are also spouses or partners face more hurdles in their sexual relationship. It's hard to switch gears if the caregiver 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. What can be done to manage these problems? The Society booklet *“Intimacy and Sexuality in MS”* recommends considering a trained sexual counselor. Counselors can help couples 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.

## Your relationship matters

*Relationship Matters: A Program for Couples Living with MS* takes couples a few steps beyond just general knowledge of the disease to a place where they can successfully address the challenges that MS may bring to their relationship. The program helps couples improve communication skills, enrich their relationship and manage MS as a team.

If you feel like your marriage or relationship could benefit from this opportunity, please call us at 1-800-FIGHT MS (1-800-344-4867) to find out if your chapter offers a couples workshop or tele-class series.

## It's a partnership

Even with good information and equipment, caregivers cannot do everything alone. The potential for frustration, burn-out and even abuse is too great. The person with MS and the caregiver need to be there for each other. Feelings of anger and frustration need a safe outlet. The caregiver needs emotional support, time off, and a trusted counselor or advisor. Finding these necessary resources should involve a call to the nearest Society chapter. Many have programs for family caregivers. The Society booklet *"A Guide for Caregivers"* includes a valuable resource section.

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 caregivers.

## Resources

**Abledata**, sponsored by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, 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](http://abledata.com). 800-227-0216 (V); 301-608-8912 (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](http://ncil.org) or look in the telephone directory under Independent Living Center. 202.207.0334 (V); 202.207.0340 (TTY); or toll free 877.525.3400.

## Webcasts, Podcasts and Transcripts

*Primary-Progressive MS: Perspectives on Moving Forward (Introduction — Part 6).* Go to [nationalMSsociety.org/MS-LearnOnline](http://nationalMSsociety.org/MS-LearnOnline). Click on Progressive MS in the green side bar. Then go to Feature Presentation (center of page) and scroll down to the Perspectives on Moving Forward series. Click the title to view the webcast. Transcripts and Podcasts are also available by clicking on the links.

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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.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures) to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

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 [nationalMSSociety.org](http://nationalMSSociety.org) or 1-800-344-4867 (1-800-FIGHT-MS).

### Some of our popular pamphlets include:

- A Guide for Caregivers
- Choosing the Right Health Care Provider
- At Home with MS: Adapting Your Environment
- So You Have Progressive MS?

**MS STOPS PEOPLE FROM MOVING.  
WE EXIST TO MAKE  
SURE IT DOESN'T.  
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