

So, You Have Multiple Sclerosis...

What's Next?





INTRODUCTION

Who are you? You have recently been diagnosed with Multiple Sclerosis (MS) or are close to someone who has just been diagnosed with MS, and are likely to be feeling overwhelmed and confused right now. You probably have many questions about the disease and are looking for accurate sources of information to help you understand your situation.

Who are we? We are the Accelerated Cure Project for Multiple Sclerosis — a group of people who are affected by MS, and are committed to determining the causes of MS, which we believe is the fastest route to curing the disease.

What do we have in common? Our group shares a common experience with those who are newly diagnosed with MS. Each one of us remembers the time around our diagnosis as being one of great fear and a period of searching for answers that weren't always there.

How can this booklet help? We decided to compile a publication which, while it could never have all the answers, should help you begin to understand what is happening as a result of your new MS diagnosis. Each section stands alone, so you can read the whole booklet or a section at a time, according to your interest or need. There is also a list of resources at the end of this booklet to help you find additional information.

We recommend you read the "Quickstart" section first, perhaps leaving the more detailed sections for another time.

QUICKSTART: WHAT DOES THE DIAGNOSIS MEAN FOR YOU?

Multiple Sclerosis (MS) tends to be different for everyone who has it, but there are some common themes we'd like to share with you. First of all, MS in and of itself is not a fatal disease. MS is a serious disease – for some of us it can result in significant disability. However, the good news is that with proper medical and health care, including good nutrition and regular exercise, we can expect to live a normal life span with MS.

MS is a disease of the central nervous system (CNS) which interferes with communication between your brain and your body. For some reason, one or more areas in your brain or spinal cord have become acutely inflamed (like a bruise) and the myelin (or insulation) around the nerves in the area of the inflammation has been partially damaged. As a result, the messages traveling up and down the pathways of your nervous system get interrupted, leading to one or more of your MS symptoms. MS involves periodic attacks of these symptoms, attacks that vary in frequency, type, and severity.

An MS attack, also known as an exacerbation, flare-up, or relapse, is a development of new symptoms or worsening of old symptoms that lasts longer than 48 hours. Typically, MS symptoms worsen over a period of several days to several weeks and improve partially or completely over several weeks or months. An attack can also be associated with several different symptoms worsening at the same time.

MS symptoms may be sensory (such as tingling, numbness, or burning), motor (such as weakness), or cognitive/emotional (such as memory problems or depression). They may involve any part of the body, and often they involve the eyes. Symptoms may come and go, varying over the course of hours to days, or they may occur, disappear, and never return. In some situations, they may occur and never improve. **Because medications are available that can help during a relapse, it is important to be aware of any changes and report them to your doctor or nurse practitioner right away.**

We don't know what precipitates an MS attack, but attacks seem to be more common following infections such as those of the upper respiratory system or urinary tract. Additionally, some people with MS find that attacks are more common when they are stressed. Overheating can temporarily bring on or worsen symptoms, creating pseudo-exacerbations. These are not true exacerbations and they tend to improve after cooling off, but they can still create sizeable problems, so people with MS are advised to find ways to stay cool in hot, humid environments.

A very common symptom of MS, which may or may not occur during an exacerbation, is intermittent fatigue. This variable feature of the disease is not well understood. Fatigue is often the most difficult thing for people with MS and their friends and families to understand. We often say, "Why can't I run up the stairs now, when I was able to this morning?" or "Wow, I carried in all of those groceries from the car today when I felt like I couldn't even get off the couch yesterday!" Another common feature of MS is change in cognitive ability, which may be either a temporary or more permanent aspect of the disease. If you have recently experienced mild cognitive changes such as slowed thinking or loss of some short-term memory – saying to yourself or others, "I just can't think straight" – it might be due to your MS.

As far as MS treatments go, the news is mixed. As of this writing, there is no cure for MS. There are disease-modifying drugs, and there are treatments for acute and chronic symptoms. Your neurologist probably will have discussed these with you. There is also a large community devoted to people with MS, including not only clinicians and health services providers, but support and advocacy groups as well. We recommend that you look into finding one or more of these groups that feels like a good fit for you, remembering that you don't have to "go it alone."

In summary, you have - through no fault of your own - an arbitrary and capricious disease, and you may feel like you've lost the ability to make any plans for the future. But wait! You can begin to prepare for possible changes in your future without being certain that those changes are going to occur. If you think about it, since no one (with or without MS) knows what will happen tomorrow, you have a head start. People with MS tend to become very good problem-solvers. Our advice is to keep a sense of humor and remember that this disease is manageable, especially after you develop problem-solving skills and accurately identify your resources. Also keep in mind that proper treatment of MS can reduce some of the unpredictability.

At the end of this booklet, we've tried to provide you with a number of Internet sites and other resources to access more information. Please remember as you continue learning about MS that information is only as good as its source. What follows is general information about MS, along with tips for dealing with MS and learning how to keep it in the background of an otherwise full and happy life.



WHAT IS MS?

There are many things we know about MS, and many things we do not know. There are also things about MS that are probable (based on evidence to date) but have not been proven. We attempt to distinguish the known from the unknown in the following section.

THE KNOWN

MS damages myelin sheaths around nerves. In MS, the myelin sheath around nerves in areas of the brain and spinal cord is damaged, and a scar (also called a lesion or plaque) is formed. Because myelin serves as a kind of insulation for nerve fibers allowing rapid conduction of electrical signals, when it is damaged the signals cannot pass normally. They are slowed, lost altogether, or they pass abnormally to an adjacent nerve. For example, if the area of the brain controlling your right elbow is damaged, you may be unable to bend your right elbow or do so only weakly. In addition to damaging the myelin sheath, MS also involves damage to the nerves themselves, which, if extensive enough, may lead to a lasting loss of function.

MS is more common in women than men. There is nearly a 2 to 1 female to male ratio.

MS is most commonly diagnosed in young adulthood. This is known as one of the “tragedies of MS.” The disease tends to occur when we are young and rushing about creating careers, homes and families. However, people in all age groups including children have been diagnosed with MS. Diagnosis may even be more common in younger people now because greater awareness of MS and availability of MRI have made it possible to diagnose more people at the very first stages.

MS is more common in higher latitudes. Incidence of MS appears to climb toward the earth’s poles, meaning that MS is more common at northern and southern latitudes than around the equator. It’s not yet known whether this is due to genetic factors, environmental factors, or other factors like differences in health care availability. To help answer this question, researchers have studied people who have moved from one place to another in an attempt to determine whether they became more or less susceptible to MS in their new location. Results from these studies have been mixed, but they do raise the question of whether some type of environmental exposure early in life acts as an important trigger for MS.

MS can run in families. Although there are people with MS who have no family history of the disease, genetic factors contribute to the risk of developing MS. Therefore, if you have MS, your first-degree relatives (parents, siblings, children) have a greater risk (approximately 20 in 1,000) than the general population (approximately 1 in 1,000) of developing the disease. Of course, this risk is still relatively small and the age, gender, and geographic factors described above also play a role.

THE UNKNOWN

What causes MS. This is the great unknown. One thing that is almost certain is that there is more than one factor involved in the illness. The causes of MS may be genetic, infectious, toxic, nutritional, and/or traumatic (injury) in nature. MS may even be a group of diseases with different causes. We at the Accelerated Cure Project believe that MS will not be cured until the causes are understood. We are working toward that end by developing a Cure Map, which is a detailed plan of research to determine the causes of MS, and an MS Repository, a collection of samples and data to be used in finding the causes of MS. You can view our progress on this on our web site (www.acceleratedcure.org).



What is responsible for the damage that occurs in MS. As with the causes of MS, very little is known about what is responsible for the damage to our myelin and nerves. The factors that drive the chronic nerve damage in MS may be different from the factors that set off the disease in the first place. You will hear that MS may be an autoimmune disease, in other words, a disease where your own

immune system incorrectly attacks a healthy part of your body. This has traditionally been thought to be the explanation for MS because of the presence of immune cells in plaques. The trouble is that it is not clear whether those immune cells actually cause MS or are there in response to something else. Another theory is that something is wrong with the cells that produce the myelin sheaths.

How to cure or permanently stop the progress of MS. Unfortunately, there is no permanent treatment specifically for MS at this time. There are drugs that have been found to help in acute attacks, and drugs that may reduce the number of attacks. There are also a number of drugs that are used to control some of the symptoms (see "Treatments"). None of the treatments currently available reliably halt the progression of disability.

What your experience with MS will be like. Your MS symptoms will probably fit one of three main groups:

- 1) Relapsing-remitting: people have one attack or recurrent attacks and recover to a varying degree after each one – this is by far the largest group
- 2) Secondary progressive: after some period of relapsing-remitting disease, people have fewer recurrent attacks but fail to recover completely after each one, with a general continual worsening of symptoms
- 3) Primary progressive: from the start, the disease is very aggressive and people do not recover lost functions

One of the most frustrating things for people with MS and their loved ones to deal with is the uncertainty about when the next relapse will occur, what it will be like, how long it will last, and so on. This uncertainty is one of the greatest challenges to be faced by people with MS, as well as their loved ones, their friends, and even their co-workers.

SOME MS SYMPTOMS

MS is different for everyone, but the disease has some preferences for particular areas of the nervous system. Thus, there are some symptoms that are recognized as typical. This does not mean that you are definitely going to experience these symptoms – there may be some on this list that will never affect you at all. You will also find that symptoms can vary widely in terms of severity, with some possibly having a significant effect on your life and others being milder and easier to manage. Keep in mind that these symptoms can have other non-MS causes as well, so be sure to explore all possibilities with your doctor.

Fatigue. This is the most commonly reported symptom of MS. Fatigue tends to peak in the afternoon and improve in the early evening. It can be quite variable, meaning that it may be profound one day, or hour, and gone the next.

Sensory problems. These can cover one patch of skin, an entire limb, or all or part of the torso, head or face. Problems can range from anesthesia (no feeling), to a burning sensation or just impaired sensation. These altered sensations may be transitory or long lasting. A common sensory symptom is Lhermitte's sign, a shooting electrical sensation down the back of the body when the neck is flexed.

Weakness. This is an irritating symptom of MS. It can also be transitory or long lasting, is exacerbated by heat and is the main cause of disability in MS. Weakness is not necessarily associated with an acute exacerbation.

Vision problems. Most people with MS have some difficulty with vision at one time or another. This can range from double vision to optic neuritis (inflammation of the optic nerve) causing visual loss. These symptoms are usually transitory and may worsen with fatigue.

Loss of balance and coordination. Balance problems may cause a person with MS to sway or stagger when they walk. More than a few people with MS have had people inquire whether they are drunk!

Cognitive issues. People with MS may have problems with memory, reasoning, and speed of information processing. These are usually temporary and/or mild in nature.

Emotional changes. People with MS often report feeling depressed, anxious, stressed or moody. Some of these changes may be due to the difficulties of dealing with MS, while others may be due to actual damage occurring inside the brain. Some of the medications prescribed for MS may also affect emotions, for instance by causing depression.

Bowel/bladder dysfunction. Both are very common in people with MS. MS can cause a “neurogenic bladder” (a bladder with abnormal nerve function). Symptoms include frequency, urgency, dribbling, hesitancy, and incontinence. Constipation is also a very common complaint with MS.

Sexual dysfunction. People with MS may experience sexual dysfunction including a decrease or loss of sex drive, decreased sensation, or diminished capacity for orgasm.

Speech and swallowing. Lesions that involve the cranial nerves (the nerves that control the head) can cause difficulty speaking, making a person's speech slow or slurred. Similarly, lesions in the same area can cause difficulty swallowing, resulting in coughing and sputtering.

WHERE TO GET INFORMATION ABOUT MS

There are many places to get information about MS as well as many types of information, such as medical treatises and stories of other people with MS. The quality of the information out there varies greatly depending on its source. When looking into a topic, try to seek out many sources rather than just one.

Your healthcare providers. The information you get from a healthcare provider is usually reliable, but it might be limited. The world of medicine today requires that patients be seen in as short a time as possible. This means that doctors are able to spend less and less time with their patients.

Family/friends. Depending on their level of expertise, family and friends may also be helpful resources for information. Bear in mind that although these people love you and will probably be eager to give you advice, only you can determine what is in your best interest.

The Internet. A search for MS on the Internet will yield thousands of sites, not all of which are accurate, helpful, or reliable. At the end of this brochure we've given you some Internet sites we believe are reliable. Always remember that information on the Internet is only as good as its source.

Libraries. The Internet has become a popular resource, but for many people with MS, whether due to visual problems, lack of hand coordination, pain, or fatigue, using a computer may be difficult. For these individuals, use of a traditional library and interlibrary loan services may offer a helpful and reliable resource. Don't rule it out!

Other people with MS. One of the most useful resources you will find is the community of other people with MS. They can share their information and experience with you, in addition to offering emotional support and encouragement. In return, be prepared: Sometime soon, someone may call you, frantic, maybe in tears, and say, "I've just been diagnosed with MS. What should I do?!" Suddenly you are the expert. This

is where many of us have found that helping other people is a way of helping ourselves. Be sure to let this person know that you're speaking from your own experience and that theirs may be different.

Support groups. Some people find support groups to be very helpful; others don't. If you decide to look for a group, it's probably a good idea to choose one whose members are close to you in stage of the disease or issue of concern. To sit in a room full of scooters and wheelchairs isn't likely to help your outlook if you're currently walking without difficulty. Likewise, if you're not currently working, a group that primarily discusses workplace issues may not be right for you.

MS-related events. Attending MS-related events such as industry sponsored presentations can also be a good way to meet other people with MS.

MS organizations. A variety of nonprofit organizations advocate for people with MS and raise a great deal of money for MS support. You will find a listing of some of the better-known organizations at the end of this booklet. It's definitely worth contacting them to see what they have to offer you, both now and later as your needs change.

MEDICAL TREATMENTS FOR MS

There are many treatment options available for MS, both conventional and unconventional. Keep in mind that if you decide to use any “untested” compounds or follow untested procedures, you need to consider the following factors: safety, effectiveness, cost, and quality-of-life trade-offs. Anecdotal information rarely provides you with all the data you need to assess these areas. Even “all natural” products and supplements can be dangerous, expensive, ineffective, or painful.

CONVENTIONAL:

ABCR drugs (disease-modifiers): This group of drugs – Avonex (Interferon beta-1a), Betaseron (Interferon beta-1b), Copaxone (glatiramer acetate), Rebif (Interferon beta-1a) — became available for us in the 1990’s. ABCR drugs are not a cure; instead, they are considered disease-modifiers because they have been shown to reduce the number of attacks in studies of relapsing-remitting MS patients. It has become nearly routine for a newly diagnosed person to begin taking one of these preparations shortly after diagnosis. Unfortunately, they are all given by injection, they are very expensive, and they all, to a greater or lesser degree, have some side effects. If you are instructed to take one of these drugs, make sure that you understand exactly how to prepare and administer them, as well as what side effects to watch for. A number of resources are available for you and your family to learn about self injection, something that has become even easier with new auto-injector methods. Check with your health providers or the manufacturers about resources for learning these and other important techniques.

Tysabri: This is another disease-modifying drug that was made available to people with MS in November 2004. Unfortunately, after only three months, data emerged linking Tysabri with another serious neurological disease called PML and it was removed from the market. The drug’s manufacturers, Biogen Idec and Elan Corporation, are currently reviewing all of the available safety data on Tysabri and may reintroduce the drug based on the results. You can find the current status of Tysabri by asking your neurologist or by going to www.tysabri.com.

Steroids: Used for acute flares/attacks of MS, steroids (Solumedrol, Decadron, Prednisone for example) can be given intravenously (IV) or by mouth (PO). They are used to shorten the duration and reduce the severity of the attack. Although well tolerated by most, these drugs can also result in significant side effects in some people.

Chemotherapeutics: Several drugs used to treat certain forms of cancer are increasingly being used if MS becomes more severe. These include cyclophosphamide (Cytosan), methotrexate (Matrex), and mitoxantrone (Novantrone). Again, the side effects of these drugs can be significant.

Immunoglobulins: This is another approach involving the use of blood proteins to provide protection against disease. They are given intravenously and generally used for those with more severe disease.

Symptom-specific treatments: There are many symptom-specific remedies with varying degrees of efficacy that can be used for spasticity, fatigue, bladder problems, depression, and other MS symptoms. Some of the remedies are pharmacological (such as baclofen and dantrolene), and others are non-pharmacological, such as cooling suits (explained below). The wide availability of symptom-specific treatments highlights the need for you to be in close communication with your healthcare provider if you are experiencing discomfort in any way.

New developments: The prospects for a newly diagnosed person with MS are more hopeful than ever before. After many years of “no news” on the MS research front, a number of new developmental drugs have been announced that may be very helpful. Once again, however, there is currently no cure. We at the Accelerated Cure Project believe that a truly effective cure will not be found until we know what causes the disease. In the meantime, you can stay apprised of recent developments by regularly checking our news portal <http://msnews.acceleratedcure.org>.

MEDICAL TREATMENTS FOR MS

UNCONVENTIONAL:

CAM (Complementary and Alternative Medicine):

Complementary and alternative therapies can be used in conjunction with or instead of conventional medicine. This is a category of medical therapies that includes some very old and some very new methods of treating people with disease. An increasing number of physicians are seeking out additional training in alternative therapies. Why? Because patients are seeking it out in large numbers. A recent study appearing in the journal *Multiple Sclerosis* found that more than half of all people with MS have sought out alternative therapies at one time or another. Doctors are realizing that this is a very motivated group, so motivated that they are spending billions of dollars of their own money annually in search of better health. If you're interested, seek out further information, but be aware that there are some charlatans (quacks) out there.

A few of the major CAM therapies are discussed below:

Homeopathy: Homeopathy is a form of "alternative" medicine that has been around for hundreds of years. Two centuries ago, a physician in Germany experimented with a vast number of natural remedies and authored the "Materia Medica." Curiously, he found that infinitesimal doses of many substances were more effective than large doses. Indeed, large doses of some homeopathic remedies are extremely toxic (arsenic, for example!). Lately, homeopathic medicine has undergone a resurgence. Can homeopathic remedies help you and your MS? Maybe yes and maybe no – since appropriate drug trials have not yet been done, there is no data to tell how likely it is that a specific homeopathic remedy will help you. Homeopathic remedies are generally not dangerous, although an over-reliance on homeopathic medicine to the exclusion of taking standard pharmaceuticals for a condition could be quite harmful.



Traditional Chinese medicine: The body is understood quite differently by traditional Chinese medicine, which has been handed down from practitioner to practitioner for many centuries. Far more importance is given to the individual patient as opposed to the body system that is ailing. Thus, a practitioner may treat two people with the same condition completely differently. A problem frequently cited by doctors regarding traditional Chinese medicine is that the remedies (mostly of natural origin) are not standardized the way "approved" medications are in the United States. Each preparation may contain many components and the ratios of each component may vary from dose to dose. One infamous case concerned a preparation later found to contain ephedrine, a compound that can cause heart palpitations. Chinese practitioners are, on the whole, very well trained, many of them in both traditional and modern medicine.

Acupuncture: This form of ancient medicine has recently found its way into the mainstream. Acupuncture involves the insertion of very fine needles over various places in the body. These places are along the lines of “chi” which represent energy flow in the body. There have been a number of well-conducted clinical trials that have found acupuncture to be effective for a variety of complaints related to MS.

Chiropractic treatment: The idea behind chiropractic treatment is that pain or dysfunction caused by misaligned vertebrae in the spinal column can be relieved by adjustments that realign the vertebrae. Chiropractic care is often sought out by people with MS for symptomatic relief, although as with many of the treatments in this section, the evidence for its benefits in MS is largely anecdotal.

Energy medicine: There are various forms of energy medicine, including reiki, craniosacral therapy, reflexology, and many more. Many people believe them to be effective, but there are no studies to prove this.

Vedic medicine: Vedic medicine is a comprehensive traditional system of natural medicine designed to balance overall health and to relieve symptoms of chronic diseases, such as MS. Vedic medicine is reportedly the oldest continuously practiced medical system with its heritage in ancient civilizations of India. Using pulse diagnosis and other well-established diagnostic and clinical assessment techniques, Vedic practitioners prescribe a variety of techniques that results in an individualized treatment plan. These treatment plans, which vary from disease to disease, often include dietary modifications and Vedic exercise according to body type, transcendental meditation, dietary herbs, and herbal oil and massage treatments. A number of studies have been published, with others underway, to address the efficacy and safety of this holistic health care technique. Some people with MS have reportedly found Vedic medicine a helpful adjunct to their Western therapy.

Apitherapy: This therapy involves being stung by a bee (yes, an actual bee!) or injected with extracted bee venom, and is thought by some to be helpful in MS as well as other conditions such as arthritis. Before embarking on this painful therapy, it might be wise to seek out the evidence. In particular, be aware that many people have allergies to bee stings with potentially serious consequences.

HOW TO KEEP UP WITH NEW INFORMATION: There are several web sites that provide information on MS therapies, including treatments that are currently available, those in clinical trial, and those still under development. Our “Resources” section at the end of this booklet provides pointers to some of these sites.

HOW NOT TO KEEP UP WITH NEW INFORMATION: “My cousin’s friend was cured by...” This is an amazingly common opener heard by people with MS, followed nearly always by an account of a miraculous cure achieved by some therapy. Keep in mind, there’s no cure... yet.

OTHER WAYS TO ENHANCE YOUR HEALTH AND WELL-BEING

Fit people feel healthier. By maintaining good general health habits such as exercise, good nutrition and other healthful practices, you can ameliorate many of the effects of MS.

Exercise: If we can stress anything to you, it is the importance of developing a regular exercise program, if you don't already have one. As we've noted before, getting overheated is not a good idea if you have MS because of the possibility of temporarily worsening symptoms ("pseudo-exacerbation"), but a very vigorous workout can be done in an air-conditioned environment or a cool swimming pool. In fact, exercise may actually retard or interrupt the atrophy of the nervous system in MS, because exercise increases the body's production of a compound which encourages nerve growth. **The rule as regards MS and exercise is: "use it or lose it."** Muscles that are affected by MS will atrophy (shriveled up) if they are not used. If you find you can no longer do the kinds of exercise you used to do (such as running), look into alternative forms of exercise, such as water therapy, horseback riding, etc. There are physical therapists and assistive technologies to help you adapt how you exercise.

Diet/Nutrition: Many people agree that diet and nutrition are enormously important in MS. This makes intuitive sense – what you put inside your body has to affect how it works. Many kinds of special diets and nutritional supplements – such as omega 3 fatty acids and vitamin D – have been proposed and tested in MS, but so far none has been clinically proven as beneficial. The problem is that no one knows what it is that makes you sick or well in the case of MS, and that makes it difficult to design a diet to correct the problem.

However, there are a few dietary guidelines that will help you manage your disease and overall health. First, you should eat sensibly, exercise, and avoid weight gain. Obesity, now recognized as a national epidemic, can substantially limit your mobility as well as lead to a number of other disorders.

Second, as someone living with a challenged physical condition, it's important to make sure that your diet is nutritionally complete. While many of us seem to have a sensible diet, too often we are actually deficient in essential nutrients that our systems require to function optimally. Make sure that you are taking in all

of the important nutrients so that your body has what it needs for nerve conduction, remyelination and muscle stamina. If you're unsure about whether your diet is nutritionally complete, find a nutritionist who can give you a thorough analysis focused on the specific needs of your disease. In addition, know that certain drugs can deplete you of nutrients, so it's a good idea to check with your pharmacist about the nutritional impact of any drug you are prescribed.

Yoga can be very helpful to people with MS. There are many different forms available; consult the instructors at your local studio to find one that's right for you. If you are sensitive to heat or strenuous physical exertion, you may want to avoid forms like Power or Bikram yoga which involve vigorous exercise in a warm room. Props are commonly used to provide extra support for poses, but it's always wise to let your instructor know if you have any problem with balance or fatigue.

Massage: A massage can relax muscle spasms, and can really benefit people with MS. Plus, the sense of well-being that a good massage can bring often feels much better than anything a pill can do.

Stress reduction: For people who experience stress-triggered exacerbations, it is likely that stress reduction techniques would be helpful. Specially trained therapists and counselors can help with this on a one-to-one basis or with others in a group setting.

Cooling suits/vests: Cooling is an especially useful treatment for people with MS who have trouble with heat. Heat slows down nerve transmission even in healthy people, and this effect is much more severe in people whose nerves have been damaged by MS. People with MS have reported a great increase in mobility following cooling treatments. Some have even walked for the first time in years following their first cooling treatment. Both active and passive cooling devices are available. Active cooling devices use a pump to circulate ice water through a vest and hood. The benefits of a few minutes of cooling this way can last for several hours. Passive cooling vests, with pockets for cold gel packs, are also available. They are less effective, but more portable. For even greater convenience, there are also neck wraps, which look like narrow ties and retain water when soaked.

The following is some general information and tips on dealing with healthcare providers and how to get and keep health insurance.

MEDICAL CARE

Neurologists - Your neurologist may be your major clinical provider for MS. He or she may specialize in caring for MS patients or may be a general neurologist. Opinions vary about which is best. Some people prefer an MS specialist, who may be more up-to-date on the latest advances in MS. Others prefer to see a general neurologist for a variety of reasons, such as personal comfort or trust. One thing is certain: You must feel comfortable talking to this person, even about the most intimate details of your life.

Nurse practitioners, clinical nurse-specialists, and physician assistants - Your neurology clinic may have a nurse practitioner (NP) who will help provide your care. NPs are registered nurses with advanced graduate level education who can perform many of the same functions as an MD. You might also have access to a clinical nurse-specialist (CNS), a nurse with advanced graduate education whose role is often to augment the care provided by MDs and NPs. Some clinics have physician assistants (PAs), who are licensed to practice medicine with physician supervision and who function in a variety of roles. Many people with MS report that their NP, CNS, or PA is more approachable, more accessible, and able to spend more time with them than their doctor.

Primary care providers - Most healthcare plans require that you have a PCP (Primary Care Provider), which is actually a very good idea for people with chronic illness because the PCP looks after “all” of you. Ordinarily your PCP (MD, NP, or PA) provides overall preventive health and medical care, not just medical care and treatment for your MS. Their role is particularly important when it comes to distinguishing MS symptoms from symptoms or signs of other common medical problems. If you need a referral to see any specialist (including a neurologist), a PCP is the provider you will need to see first. Again, it is vital

that you are comfortable with, like, and trust this person. Some PCPs might even specialize in providing care for people with MS, or with chronic diseases or disability, which could be especially beneficial.

How and when to access health care providers -

Having MS is, as you will hear time and time again, like traveling an unknown road. Make sure that you know how to reach your guides. When you choose your caretakers, ask them how to contact them—or anyone who may be covering for them—on days, nights, weekends, and holidays. Know how to get appointments and prescription refills, and, most importantly, what to consider a relapse and what actions to take when you have one. When you talk with your doctor, it's often helpful to have made up a list of questions in advance so nothing is forgotten.



How to fire providers/caretakers and find new ones -

Suppose you just don't feel comfortable with your doctors? Don't suffer along with them because you've heard that "they're the best." They might be the best for someone else but not for you. It doesn't have to be a bitter parting of the ways. Most doctors understand that the relationship between them and their patients, particularly long-term ones, is very important. If they don't understand this, then you've definitely got the wrong doctor! Find out what other caretakers are available to you (most health plans have many options) and make the change. Make sure your records are transferred if you're changing hospital affiliations.

Below is a list of useful tips for dealing with doctors:

- **Get a second opinion, even if you really like your doctor. MS is an important diagnosis.**
- **Get doctors you really love and feel comfortable with and change if you don't.**
- **Seek out others with the same diagnosis. They have done a lot of footwork you can piggyback on. They've seen and learned things that could take you years to find out on your own.**
- **Keep copies of your medical records, test results, MRI reports and films, etc. This will allow you to switch caregivers more easily and to avoid a painful situation if your records become lost. You have the right to request copies of your medical records, so feel free to ask for copies of all test results and notes after every visit.**
- **Prepare for future relapses/attacks. Ask your neurologist what he/she considers a relapse, what you should do when it happens, and how to get in touch after-hours and on weekends and holidays.**
- **Take time to absorb the impact of the diagnosis. Be aware that your diagnosis might not really "hit you" until several months after it is made. Even if you feel that you've dealt with it all very well, it will take some time for you to accept the news. Your doctor should be tuned into the fact that you are taking in as much as you can, as fast as you can.**

- **Ask for a plan. Ask your MS health care provider to create a plan for your treatment. This should include determining how and when to measure the effectiveness and your tolerance of your treatment regimen, and what alternatives are available if you need to change treatments.**

To make the best use of your time with your doctor, it's always a good idea to come prepared with a list of things to ask for or discuss, and to take notes during the visit for future reference. We have developed a form that you can use for this purpose – go to www.acceleratedcure.org/downloads/doctor-visit-form.pdf to download and print it out. You may also want to bring someone with you to your medical appointments to remind you of what you wanted to discuss and help you remember what the doctor said.

OTHER HEALTHCARE PROVIDERS

Mental health providers (psychiatrists, psychologists, social workers, other counselors)

In the "bad old days", a diagnosis of MS often came after a prolonged period (sometimes years) of peculiar symptoms that could not be explained. Patients often were referred to at least one psychiatrist before they learned that they really were feeling that funny numbness and weren't crazy. Nowadays, the diagnosis often comes much sooner, but MS is still associated with significant occurrence of depression. Many people have found it very helpful to talk regularly with someone who can help them integrate the illness into their lives. Antidepressant drugs may be recommended, and in many cases will be very helpful.

Rehabilitation services (physiatrists, physical therapists, occupational therapists)

You may never need rehab specialists, but if you do, they are invaluable. A group of professionals devoted to helping you carry out your various functions as well as you can (generally without medications) will be available to you when and if

needed. Your care in a rehab center is usually orchestrated by a rehabilitation doctor who works with physical therapists, occupational therapists, and various other service providers. They can help you by evaluating your current situation and suggesting exercises, tools, and modifications to your environment in order to make life easier.

Home care vs. hospitals

Home care, as hard as it may be to think about now, is available if you should someday require more continual care. Home care assumes that you are comfortable getting therapy at home. If you've ever been confined to a hospital room with a snoring roommate who keeps the TV on 24 hours a day, home care involving a nurse from the VNA (Visiting Nurse Association) coming to your home to administer treatments, check labs, and just generally see how you are doing, could be a very welcome alternative.

HEALTH INSURANCE

Getting it, and keeping it

You should not automatically lose your health insurance just because you now have an illness. However, health insurance is now an issue for you and you may have to maneuver to keep the coverage you need, especially in the current national healthcare environment. Hopefully you already have health insurance, but if you don't, all is not lost. Health insurers may be able to deny you coverage if you have a "pre-existing medical condition," which you now do, but you can check your state laws to see what rules exist regarding denial of coverage. For example, in Massachusetts, if you move directly from one health insurance to another, the new insurer cannot deny you. Or if you go to work for a large employer (such as a school, university, or the state or federal government), their insurer cannot deny you. Again, check your state laws. If you are married or in a domestic partnership, another way to get health insurance without denial may be to have your spouse or partner take family insurance coverage.

In addition, you may now qualify (after a waiting period) for Medicare, but keep in mind that prescription drug benefits under Medicare are still being phased in. Medicaid with prescription drug coverage is also available, but you must prove that you have financial need. Lastly, and not generally well known, is "free care" available to very low-income residents. This is only available in certain states, and often there is a limit on prescription drug coverage. Consult your primary care provider or neurologist with further questions about the availability of free care.

Dealing with agents on the phone

Make sure that every time you talk to insurance company agents you write down their full name and the date and time that you spoke to them, as well as approval numbers associated with the matter at hand. Explain to them that you need this information in order to keep the many facets of your health care clear. Try not to get frustrated or angry with these agents when they seemingly make you jump through hoops to get coverage; they are only doing their jobs.

What to do when they deny a claim

First off, don't lose your cool! These notices invariably arrive on Fridays and when you call the company, all you get is voicemail, leaving you the whole weekend to worry about it. Again, when you reach them, document your conversation, and make sure you understand the stated reason for the denial. If you don't, ask to speak to a supervisor. Very often a claim is denied because there was a misunderstanding or omission of information needed for a complete application. Politely ask how you can rectify the situation. Even if it means a few more annoying phone calls, make them, and if necessary, appeal the decision as many times as allowed. If you aren't successful with the insurance company or you need help, especially with an appeal, contact the MS Society for legal assistance.

Living with MS can bring about new challenges in your relationship with your family, friends, and coworkers. You may also face issues in the future that involve choice of housing, disability, and legal matters.

Family

Partners: The diagnosis of MS can be very difficult for a partner to hear (let alone you!). Depending on their experience of the disease, the news may conjure up some frightening futures for them. Probably the best way to share this burden with your partner is to make sure they, like you, are fully educated and that they know how to access further information. Talk openly with them about your concerns and encourage them to talk openly with you about theirs. Sometimes it may help to bring in a third party, such as a counselor, to make these discussions easier.

Dependence: This can become a huge issue for the person with MS and their loved ones. MS tends to strike people at a time in their lives when they are productively involved in schooling, work, and/or family. Having to ask for help is enormously difficult for someone used to taking care of themselves and often everyone else as well. Being put in this position, through no fault of their own, can make people with MS feel that they are or will be a burden to loved ones. This feeling can drive a wedge into relationships if those involved let it. Alternatively, some people with MS allow themselves to think too negatively. They “become” the disease and withdraw from life, preferring to let those around them take up all the duties they once had, even if they are able to do them. This can also be very destructive to relationships.

Physical intimacy: This can also become an issue for people with MS and their partners. Arousal may become impaired by neurological damage in both men and women. However, effective therapies are often available. More difficult to talk about may be how a caregiver (and care receiver) feels when put in the position of having to help with the intimate details of his or her partner’s life. This may be a situation in which it is useful to involve a third party (counselor).

Pregnancy: There are two concerns here. The first is the question, “Can I pass MS on to my child?” Based on evidence from family studies, your child has around a 1 in 50 chance of developing MS. If you are a woman with MS who decides to get pregnant, the next question might be: “Will pregnancy make my MS worse?” Studies have shown that during pregnancy there is less risk of an MS attack. However, the situation reverses in the post-partum period (three months after the baby’s birth) when the risk of MS attack is increased. Moreover, you may need to discontinue some or all MS medications while you are pregnant or trying to get pregnant. Make sure to speak with your OB-GYN provider (doctor or midwife) as well as your MS healthcare provider when you are thinking about getting pregnant to review your treatment regimen for its effects on pregnancy and childbirth.

Breastfeeding: The value of breastfeeding your child is immeasurable. Just because you have MS doesn’t mean that you cannot breastfeed safely, and there are many reasons why it is beneficial to you and your baby. As with pregnancy, medication and treatment modifications might be needed which makes it important to coordinate your breastfeeding plans with your healthcare team.

Childcare issues: Childcare plans definitely need to be considered in advance of the baby’s arrival. If you decide to have a child, it’s probably a good idea to make sure you have back-up caregivers in place after the baby is born. Be aware that fatigue – part of every new parent’s burden – may be worse for you, so it’s particularly important to allow family and friends to help.

Children and what to tell them: Babies don’t ask questions, but children do. Be prepared for the children in your life to ask a variety of questions about your condition. Young children will probably benefit most from simple, concrete answers and reassurances. If you’re going to tell them you are ill, you must let them know you are not going to die from the disease. An older child or teenager can be told more and may even

feel empowered by being able to help you out in some way. Involving your child in your therapy (helping to get your medication ready, putting the bandage on, etc.) helps make MS just another part of life.

Parents and siblings: Our experience with these loved ones is fairly uniform. Your family loves you and is upset that this has happened to you. They may overcompensate by trying to be too helpful, suggesting better doctors, treatments, etc. The best way to deal with this is to make sure they are as well educated as you are about the disease. It can be very valuable for the whole family to get involved in an MS support organization and attend events together.

Friends: Friends are generally willing to give whatever help you need. Again, it helps if they understand the disease. Be aware, however, that different people can have very different images in their minds about what having MS means. If they have encountered someone severely crippled by the illness, they may assume this is going to happen to you. Similarly, if they've met someone who had only mild disease, they may wonder what all the fuss is about and have a hard time understanding your concerns.

Work

Disclosure vs. non-disclosure: This is always a big issue for the newly diagnosed. Should you tell or not? Probably the best approach is to tell when you have to. Your fear is undoubtedly that if you let your employers know about your illness, they will fire you or make it impossible for you to advance your career. The ADA (Americans with Disabilities Act) has made this less likely, but other reasons may be given for your termination ("downsizing") or lack of promotion. If you feel you're being unfairly discriminated against, use the ADA, and if possible do so with legal guidance. (Note that there are government agencies set up to help answer your questions about your rights under the ADA, so it may be worth consulting them before approaching your employer.)



Coworkers: Responses from coworkers may vary. All of us have had the experience of extraordinary compassion shown to us by coworkers who ride their bikes, walk the Walks and generally raise money for MS. If you work in a particularly high-pressure environment, however, you may find that people you thought were your good friends are drawing back from you. There is a reason for this. For instance, if for some reason you can't shoulder the full workload, your coworkers may be afraid it will fall on them. Deal with this up front, and ask them what their concerns are. You may want to reassure them that you'll do everything you can to make sure their workload is not increased. They might also share the same fears for you shown by your family and friends.

The ADA and "reasonable accommodations": Here's your leverage to make sure the workload is fairly distributed. The ADA mandates that your employer modify your workplace in such a way that makes it

possible for you to work. This may mean anything from providing an access ramp, to allowing you to be seated while you work. Become familiar with this law; it is an incredibly powerful tool. (Note that this is not limited to physical adaptations but also includes things like schedule modifications or working from home.)

When to quit (and look for something else): There may be some situations where the ADA can no longer help you. If you are a major league baseball player, it's pretty safe to assume that having MS will interfere with your ability to do your job. If you are a brain surgeon, the same is true. Be prepared for the possibility of retiring earlier than you otherwise might. Always have an alternate occupation in mind—one that you love. And remember, just because you're retired doesn't mean your life is over!

Planning for possible future disability

Disability: Disability is not an inevitable feature of MS, but it is a possibility, and one that can be particularly worrisome. If you are currently experiencing some level of disability, remember to use your resources! They're all around you: family, friends, and medical people. They're all waiting to help you. You only have to ask. If you're not currently experiencing any disability, we hope you will stay that way, but it's a good idea to be aware of your options now should the situation someday change. Here are just a few tips to keep in mind:

Consider accessibility when making a move: Living in a hot, 5th floor walk-up probably is not a good idea for you. It might be fine...but if there's an alternative, take it. Air conditioning is a must in climates that get hot and humid.

Social Security Disability Insurance (SSDI): This is available to you if you have paid a certain threshold in taxes. You can apply when and if you are unable to work. Be aware, however, that payments do not begin until you have been out of work for six months. Also, the amount of money you get from Social Security will seem like a meager amount if you have been making a full-time wage.

Disability insurance: This is a great idea if you have it already. If you don't have disability insurance, you will not be able to pick it up easily because of your "pre-existing condition." There is, however, an exception to this, a bit like health insurance. If you go to work for a large employer (university, city, federal government, etc.), it is highly unlikely that you will be turned down, but be aware that there may be a long period in which you must work full-time before you become eligible.

Long term care insurance: If you own a Long Term Care insurance policy then you should be congratulated for thinking ahead! Your policy will help cover some of the high costs of assistance you might need at home or in a facility, should your disability prevent you from performing the normal activities of daily living (such as eating, bathing and dressing) by yourself. If you don't have Long Term Care insurance in place, you may have a harder time qualifying for it or find that your options are more limited because of your pre-existing condition of MS. However, this would be a good time to encourage your family members to look into purchasing a policy, so they can count on coverage in case they ever need long term care in the future.

Assistive devices: There are a wide variety of devices and adaptive technologies designed to let people with disabilities perform their everyday activities. These include mobility devices (scooters, wheelchairs), computer accessories, car adaptations to enable driving, low-vision resources, and more. If and when you need one of these devices, set aside the junk mail you may have been receiving and seek out the help of a rehab specialist. They'll know exactly what you need, where to find a reputable dealer, and whether your device can be paid for by health insurance.

Healthcare proxy: Everyone should consider this issue, even if they don't have MS. Whom would you want to make decisions for you if you were incapacitated for some reason? Consider carefully who this might be and discuss with him/her how you would want to be treated in such an event. You can get the form from your healthcare provider and you, your proxy, and two witnesses must sign it.

IN CONCLUSION

Tips on planning for the unknown future

Learning to live with an unknown future can be life-changing, good or bad, and it's really up to you what you choose. Remember that everybody's future is unknown. Try to be flexible. When planning for an event in the future, don't envision it happening only one way. Get used to thinking of many different ways to achieve the same goals, and you'll find that you're confident even when faced with what other people might consider great odds. Remember: You can't choose what happens to you, but you can choose how you respond to it!

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The Accelerated Cure Project brochure committee:
Maggie Harling, MD, Cynthia King, Art Mellor,
Lisa Paine, CNM, DrPH, Hollie Schmidt



Contributors and editors:

N. Katherine Brown, Diana Channell, Molly Corbett, Virginia Corsi, Alexa Degenhardt, MD, Robin Dolan, Virginia Fairburn, David Flannery, Elliot Frohman, MD, PhD, David Holzman, Linda P. Hughes, MS, FNP-C, Emily Jones, R. Philip Kinkel, MD, Cathie Knickelbine, Leslie Kussmann, Jonathan Levine, Judy Levine, Vincent Macaluso, MD, Janelle Martin, Kelly McGowan, Brenda Nichols, Michael Pittera, David Jared Rintell, PhD, Ann Rogers, MEd, Saud Sadiq, MD, Lisa Sheehan-Hicks, David Shute, Timothy Vartanian, MD, PhD

We welcome your comments on this brochure! We hope you found this brochure helpful. If you could take a moment to send us any feedback, suggestions, or corrections you have, we would greatly appreciate it. Because our knowledge about MS is continually changing, we plan to update this brochure periodically to make sure it stays accurate and continues to meet the needs of people with MS.

Please send all comments to:
E-mail: info@acceleratedcure.org
Phone: +1-781-487-0008
Fax: +1-781-487-0009
US Mail:
Accelerated Cure Project
300 Fifth Avenue
Waltham, MA 02451

REFERENCE/RESOURCES

We're providing a list of resources to get you started. This list is not comprehensive; there are plenty of other sites available. Each site listed below is responsible for the information they have on it. The Accelerated Cure Project does not endorse these sites, we simply include them because some of us have found them useful at some point in time. An up-to-date version of our MS resource list will be located on our web site, currently located at <http://www.acceleratedcure.org/msresources/other.php>

Web Sites

MS information sites

<http://www.mult-sclerosis.org>

One of the best overall information sites for MS on the web. Although this site is not currently being updated, it still contains a wealth of information.

<http://msnews.acceleratedcure.org>

The Accelerated Cure Project's site for daily updates of news regarding MS ranging from new research, to stories on people with MS. Includes the ability to comment on posted stories and receive them by email.

<http://www.ncbi.nih.gov/entrez/query.fcgi>

Pub Med is an online database of medical research paper abstracts. Useful for searching for studies done on a particular topic and keeping up with new research results.

http://dir.yahoo.com/Health/Diseases_and_Conditions/Multiple_Sclerosis__MS_/

One of many compendiums created by Internet portals such as Yahoo!, AOL, MSN, etc. A good starting place for finding more than what's presented in our list.

<http://www.acceleratedcure.org/msresources/other.php>

Accelerated Cure Project keeps an updated list of interesting web and other resources.

Government MS sites

http://www.ninds.nih.gov/health_and_medical/disorders/multiple_sclerosis.htm

<http://www.niaid.nih.gov/default.htm>

The National Institutes of Health (NIH) are the main research arm of the government. NINDS and NIAID are the two subsections of the NIH that regularly do work on MS. Their respective sites have quite a bit of information on MS.

<http://www.clinicaltrials.gov/ct/gui/c/b>

This site lets you search for clinical trials that are going on in MS.

Nonprofit MS organizations

<http://www.acceleratedcure.org>

Accelerated Cure Project

We're a national nonprofit organization dedicated to curing Multiple Sclerosis (MS) by determining its causes. We also conduct community-building and educational programs (such as the production of this brochure!).

<http://www.nmss.org>

The National MS Society supports research efforts, educates, provides a variety of empowering programs, organizes fund-raising events, and advocates for people with disabilities.

<http://www.msaa.com>

The mission of the Multiple Sclerosis Association of America is to ease the day-to-day challenges of individuals with multiple sclerosis and their caregivers.

<http://www.msfocus.org>

The MS Foundation is a service-based organization whose primary mission is to ensure the best quality of life for those coping with MS by providing comprehensive support and educational programs.

<http://www.erasems.org>

The Nancy Davis Foundation for Multiple Sclerosis is dedicated to the treatment and ultimate cure of MS; its core focus is the funding of research at the nation's top MS research centers.

<http://www.myelinrepair.org>

The mission of the Myelin Repair Foundation is to rapidly accelerate the discovery of myelin repair treatments to improve the lives of people suffering from MS.

<http://www.myelin.org>

The Myelin Project is an international grassroots organization whose mission is to accelerate medical research on myelin repair.

<http://www.mscares.org/>

The Consortium of Multiple Sclerosis Centers provides leadership in clinical research and education; develops vehicles to share information and knowledge among members; disseminates information to the health care community and to persons affected by Multiple Sclerosis; and develops and implements mechanisms to influence health care delivery.

http://www.mscares.org/patient.cfm?doc_id=64

The NARCOMS MS Patient Registry was created to help facilitate multi-center research in the broad field of Multiple Sclerosis, and currently contains information contributed from over 20,000 participants.

<http://www.pva.org/>

The Paralyzed Veterans of America is a congressionally chartered veterans service organization founded in 1946 to serve veterans of the armed forces who have experienced spinal cord injury or dysfunction.

<http://www.pva.org/prof/ms/mspubs.htm>

The MS Council of the PVA develops clinical practice guidelines for MS professionals and guides for consumers.

Pharmaceutical company sites

The MS pharmaceutical companies typically have a number of web sites that can be useful to you. One site will be for their company, one for the drug, and one as a patient support program.

Berlex Laboratories (makers of Betaseron™):

<http://www.berlex.com>

<http://www.betaseron.com>

<http://www.mspathways.com>

<http://www.multiplesclerosis.com>

Biogen Idec (makers of Avonex™ and Tysabri™):

<http://www.biogenidec.com>

<http://www.avonex.com>

<http://www.tysabri.com>

<http://www.msactivesource.com>

Serono (makers of Rebif™ and Novantrone™):

<http://www.serono.com>

<http://www.rebif.com>

<http://www.mslifelines.com>

<http://www.novantrone.com>

Teva Neuroscience (makers of Copaxone™):

<http://www.tevaneuro.com>

<http://www.copaxone.com>

<http://www.mswatch.com>

Non-pharmaceutical therapies

<http://www.mscooling.org/index.html>

The MS Cooling Foundation provides education and information on the benefits of cooling therapy.

<http://www.lancasterhealth.com/newsletter/index.html>

The newsletter of the Maharishi Vedic Health Center in Lancaster, Massachusetts

<http://www.ms-cam.org/>

A site maintained by the Rocky Mountain MS Center with reviews of a large number of complementary and alternative therapies

REFERENCE/RESOURCES

Online forums

<http://msnews.acceleratedcure.org>

The Accelerated Cure Project's online portal provides daily MS news updates with the ability to participate in online discussions about posted stories.

[Newsgroup alt.support.mult-sclerosis](http://alt.support.mult-sclerosis)

A Usenet-based newsgroup focused on MS.

There are also chat groups at Yahoo, AOL, etc.

<http://www.thisisms.com/>

An online forum for sharing and discussing news related to MS research.

Other helpful sites

Below is a list of non-MS sites that can be useful to you.

<http://www.google.com>

One of the best search engines for quickly locating things on the web. If you aren't currently using this as your main search method, we recommend you try it out.

<http://www.quackwatch.org/>

A good site to look up unconventional treatments and doctors that you may hear of.

<http://www.snopes.com>

Another good debunking site to track down hoaxes, urban legends, and other claims of dubious veracity. Good for checking out claims of miracle cures or surprising "causes" of diseases.

<http://www.charitywatch.org/>

<http://www.guidestar.org/>

Charity Watch and Guidestar are two good sites for checking up on nonprofits before giving them significant contributions.

<http://cancerweb.ncl.ac.uk/omd/>

This is one of several medical dictionaries available for free on the Web.

<http://www.disabilitysecrets.com>

A helpful guide written by a former Social Security disability examiner that explains the ins and outs of applying for Social Security disability benefits.

Books

Medical

Multiple Sclerosis Current Status and Strategies for the Future by Institute of Medicine published by National Academy Press, 2001.

A detailed overview of where things stood for MS in 2001, and a high-level overview of many of the problems that need to be addressed.

McAlpine's Multiple Sclerosis (Third Edition) by Alastair Compston et al, published by Churchill Livingstone, 1998.

The definitive text book on MS. Not an easy read, but a rather comprehensive history and discussion of the disease.

For the newly diagnosed

Multiple Sclerosis: An Essential Guide for the Newly Diagnosed by Margaret Blackstone, published by Marlowe & Company, 2002.

Written by a woman with MS, it captures a lot of the things you need to consider and know about when first diagnosed with MS.

Multiple Sclerosis: A Guide for the Newly Diagnosed (2nd Edition) by Nancy J. Holland, et al, published by Demos Medical Publishing, 2001.

An excellent overview of MS suitable for someone just diagnosed.

Human interest

Fall Down Laughing by David L. Lander, published by Tarcher Putnam, 2000.

The story of David Lander's (Squiggy from Laverne and Shirley) battle with MS. A quick, touching, and fun read.

People with MS with the Courage to Give by Jackie Waldman, published by Conari Press, 2003.

Short biographies of people with MS who decided to make a difference in spite of their illness.

Other

Searching on Amazon.com or other book web sites and reading the comments of others is a good way to find other MS books. Also, asking other people with MS about the books they may have read and sharing books with others is a good way to augment your personal library.

Journals

There are a number of scientific journals that regularly publish results relating to MS. Among them are:

Multiple Sclerosis

http://www.arnoldpublishers.com/journals/pages/mul_scl/

The Journal of Neuroimmunology

<http://www.elsevier.nl/inca/publications/store/5/0/6/0/2/3/>

Brain

<http://brain.oupjournals.org/>

Journal of Neurology, Neurosurgery & Psychiatry

<http://jnnp.bmjournals.com/>

Neurology

<http://www.neurology.org/>

Newsletters

Most MS organizations and pharmaceutical companies offer mailed print newsletters on a regular basis. You can usually sign up on the web or by calling them. It can be helpful to get a few of these for different perspectives. In addition, if you are on these mailing lists you will often also get invited to the various events these organizations hold, many of which have excellent educational value and the opportunity to meet others with MS. You can sign up for the Accelerated Cure Project newsletter from our web site by clicking on the "Sign Up" button at the top of each page.

Conferences and Events

For the deeply interested, there are quite a few neurology conferences where breaking MS research results are presented by the research teams who found them. These are generally not for laypeople, but can be attended by anyone who feels up to the challenge.

ACTRIMS/ECTRIMS (American/European Committee for Treatment and Research in MS)

<http://www.actrims.org>

<http://www.akm.ch/english/default.htm>

AAN (American Academy of Neurology)

<http://www.aan.com/professionals/>

ANA (American Neurological Association)

<http://www.aneuroa.org/>

SFN (Society for Neuroscience)

<http://www.sfn.org>

Support Groups

Most of the nonprofit MS organizations offer some sort of get-togethers for people with MS to help each other out. These range from social events to support groups. You can find out more about them by contacting the organizations themselves, looking in the events section of your local newspapers, or asking your healthcare providers if they recommend particular gatherings.



Sponsors

The Kelly Packowski MS Foundation

The Kelly Packowski MS Foundation is proud to partner with the Accelerated Cure Project to underwrite the costs associated with printing and production of "So you Have MS... What's Next?"

In 2002, the Kelly Packowski MS Foundation was established to provide financial assistance and educational resources to families and individuals struggling with Multiple Sclerosis in New England. The Foundation strives to support those facing hardship situations as a result of the disease and to improve the overall quality of life of families most affected by it.

The Kelly Packowski MS Foundation is available to provide financial assistance to you and your family. For information on how we can help, call 866-KPMSFND or visit our website at www.kpmsfoundation.com. The grant process and applications are also available on-line.

John Hancock

John Hancock is proud to partner with the Accelerated Cure Project as they strive to cure Multiple Sclerosis. The organization captured our attention with its compassion and unique entrepreneurial spirit. As the national nonprofit partner of John Hancock Long Term Care Community Service Project, Accelerated Cure Project will receive financial support, marketing expertise, and volunteers - but it will be Hancock who really benefits from the opportunity to work closely with individuals who can increase our awareness and sensitivity to our customers' needs.

Clockwork Design Group

Clockwork Design Group is proud to design and produce all marketing materials for Accelerated Cure Project for Multiple Sclerosis, including this booklet. www.cdgi.com.

You Can Accelerate the Cure for MS

The Accelerated Cure Project is primarily supported by contributions from individuals. We spend every dollar we receive supporting our programs — so a gift of any amount is immediately applied to our work of curing Multiple Sclerosis by determining the causes.

Contributions can be made by check, credit card, stock, vehicle donation, or in-kind gift. We are a 501(c)3 nonprofit so your contribution may be tax-deductible.

Detailed information on giving is available at www.acceleratedcure.org. Credit card contributions can be made in the Contribute section.

Please make checks payable to:

Accelerated Cure Project, Inc.

300 Fifth Avenue, Waltham, MA 02451

781-487-0008

info@acceleratedcure.org

Tax ID: 04-3555864

You can sign up to receive periodic email updates, notices about volunteer opportunities, and our quarterly printed newsletter at www.acceleratedcure.org in the Sign Up section.

