Private Disability Insurance Claims: A Guide for People with MS
# Table of Contents

Introduction ..................................................... 2

Key Concepts in Private Disability Insurance Policies .......... 3

Filing Claims for Long-Term Disability: What You Need to Know 5

Glossary .............................................................. 17

Symptom Tracker .................................................. 22

## Appendices

A – *The Win-Win Approach to Reasonable Accommodations* 28
*Enhancing Productivity on Your Job,* by Richard T. Roessler, PhD and Phillip Rumrill, PhD

B – Background on the National MS Society’s Private Disability Insurance Task Force 40
Introduction

Disability insurance replaces some of the income that a sick or injured person is no longer able to earn, and can be an extremely important safeguard for people with MS and their families. Yet many have found the process of filing a claim and securing disability benefits more challenging than anticipated, and have turned to the National MS Society for guidance. This manual has been prepared to help people with MS and their caregivers:

• understand the key concepts and terminology commonly used in private disability insurance policies;
• work with their doctors regarding the timing and accuracy of their disability claim;
• assure that their claim is clear and well-documented;
• follow a step-by-step approach through the claims process;
• know what to expect if their claim is approved, and
• know where to turn if their initial claim is denied.

Readers should know that this manual focuses on private, long-term disability insurance – the type often provided as a benefit of employment or purchased individually by people who are self-employed. Information to help secure disability benefits from the Social Security Administration is available through your local chapter of the National MS Society or on-line at: www.nationalMSsociety.org/planning.
Key Concepts in Private Disability Insurance

Private disability insurance policies can vary significantly, with major implications for your personal and family finances. Understanding the provisions of your policy begins with reading it over carefully and becoming familiar with the key concepts and terminology it uses.

Note that there is an important distinction between short-term and long-term disability insurance. Short-term disability insurance provides partial income replacement for short periods of time until workers either return to work or go on long-term disability. Some states mandate employers to provide short-term disability coverage, and many more offer it as a benefit to their workers or union members.

It is not unusual for people with MS to begin pursuing long-term disability benefits after being on short-term disability and concluding that a return to work is no longer possible. Eventually, many people receiving long-term disability benefits apply for Social Security Disability as well. In fact, long-term disability plans typically require policyholders receiving benefits to apply for Social Security disability benefits within a certain amount of time after their private benefits begin, such as six months. Confusion between the various sources of disability benefits is understandable, and the National MS Society has resources to help.

As you read through your disability insurance policy, use the glossary in this guide to understand terms you might not recognize related to benefit provisions and limitations. All of the terms in bold appear in the glossary, as well as many others.
It is especially important for you to understand the following:

1. if you have short-term, and/or long-term disability benefits, and if both, how they coordinate;

2. how your policy defines ‘disability’ (e.g., the inability to perform your **own occupation**, or **any occupation**);

3. if the terms, or definition of disability in your policy may change at some point (such as switching from ‘own occupation’ to ‘any occupation’ after a certain period of time);

4. the length of time you will have to wait before your benefits begin (**elimination period**)

5. how your benefit amount will be calculated, including any **offsets** (dollars that can be deducted from your benefit); and

6. how long the benefits will last (**payment period**).

If you are still unsure about the meaning or implications of a certain provision in your policy, ask your employer’s benefits personnel or insurance broker for clarification.
Filing Claims for Long-Term Disability: What You Need to Know

Q: How should I decide when to stop working and go on disability?

A: The decision to stop working can be a complex one for many people with MS, and you should consider it carefully with your family, doctor and employer. Have you thoroughly considered other options, including all reasonable accommodations, taking an unpaid medical leave, and alternatives to your current job, such as part-time or self employment?

The National MS Society has resources to help you and others learn more about these options. Start by reviewing the brochure *The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job*, re-printed in this manual as appendix A. It is important for you to pursue any and all reasonable accommodations that could help you stay on the job. Failing to do so could be mis-interpreted by your employer or disability insurer as a lack of willingness to keep working or avoidance of your responsibilities as an employee.

Q: What steps should I take before I file for benefits?

**Step one.** If you have not already done so, get a copy of your policy and read it carefully. Make sure you understand the type of policy you have, and especially how it defines ‘disability’ so you and your doctor can discuss whether and how you might qualify. If possible, review a copy of a claim form and familiarize yourself with the information it requests and any deadlines. Most group policies require you to file within 30 days of the date you stop working. Eventually, your employer and doctor will have to fill out their own forms to complete your application for benefits. Understand that claim forms can vary significantly.
**Step two.** Call your doctor’s office and schedule an appointment to discuss your decision to apply for disability benefits. Understand that the burden is on you and your doctor to prove that you are too impaired by your MS symptoms to continue performing the required tasks of your job. You need to make sure that you and your doctor are in complete agreement about how you are going to present your claim. The tools in this manual will help you prepare for your discussion with your doctor.

**Step three.** Begin a diary of your MS symptoms using the enclosed Symptom Tracker, or something like it. You’ll want several weeks of daily records to show your doctor, so we’ve enclosed three one-week charts.

At the same time, make a list of all of the physical and cognitive demands of your typical workday, including the specific requirements of your job and the exact ways that your MS symptoms interfere with them. Use your job description, work calendar or other records to make sure you do this step thoroughly, and get help from a co-worker or family member if needed. Do not hesitate to include other things that may not appear on your job description, such as getting around the workplace, using the bathroom, telephones and computers.

**Here are two examples:**

Karen is a 39 year old development officer for a nonprofit organization in Atlanta. Diagnosed at age 26, Karen now has significant vision loss, fatigue and depression, and uses a walker. What follows is a list of specific job responsibilities from her job description and her comments about the MS symptoms that are keeping her from doing the job functions she used to be able to perform. This list can be useful in helping her doctor understand how MS is impacting her job.
<table>
<thead>
<tr>
<th>Responsibilities</th>
<th>Impact of MS symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research foundation grant opportunities, write funding proposals</td>
<td>The significant vision loss in both eyes I suffered as a result of my last exacerbation two months ago means I now have extreme difficulty reading the foundation profiles online, as well as their print materials (annual reports, applications and correspondence) or anything else that does not come in large type.</td>
</tr>
<tr>
<td>Maintain department schedule and calendar of required foundation reports, audits, site visits and other relevant deadlines.</td>
<td>Despite my colleagues’ efforts to assist by making a very large, hard copy, color-coded calendar for my office, it is nearly impossible for me to read and translate small print material onto the calendar now.</td>
</tr>
<tr>
<td>Participate in all senior staff, Board and Development Committee meetings and donor events. Develop and maintain donor recognition activities and awards. Work with events planning and communications teams on special activities and recognitions in local communities.</td>
<td>My fatigue is now making it impossible for me to work more than 4 – 5 hours without lying down, let alone the 1 – 2 evenings per week typically required for committee meetings or donor events.</td>
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</tbody>
</table>
Scott is a 52 year old stage manager for a major ballet company. Diagnosed at age 46, Scott has movement problems in his hands and arms, headaches, memory problems and frequent urinary tract infections. Using his calendar, he described to his neurologist some demands of a typical workweek.

<table>
<thead>
<tr>
<th>Responsibilities</th>
<th>Impact of MS symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strike ‘Nutcracker’ set, update inventory of all lights, sound equipment</td>
<td>I am less and less able to lift/carry equipment, and recently dropped and broke an expensive light.</td>
</tr>
<tr>
<td>Review current invoices, receipts, go over budget and actuals with Joan</td>
<td>My organizational skills are deteriorating significantly. I am losing track of smaller receipts and items without purchase orders. I am forgetting a lot more and getting confused by the paperwork.</td>
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<tr>
<td>Chicago meeting—check systems compatibility</td>
<td>Based on your recommendation that I not fly until my headaches and bladder infection are more manageable, I had to assign this task to an assistant.</td>
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</table>

Bring your completed Symptom Tracker and list of job activities to your doctor, and review them together. Ask your doctor if there are any tests he/she recommends you have to help support your claim.

**Step four.** If you have not stopped working already, do so. Ideally, you, your doctor and your employer will be in agreement on when you will stop working, although you probably will not have the luxury of planning it out to that degree. If you are still working, you and your doctor can work together to decide about when to stop
working, such as “if or when you are only able to remain alert for ‘x’ hours a day and/or when your spasticity makes it too difficult to sit at a desk”.

Q: When should I file my claim?

A: You should file right after you stop working, and before the deadline (usually a certain number of days after your last day on the job). Understand that you may be required to get more documentation to support your disability claim after the form has been submitted.

Q: What happens once I file my claim?

A: Your insurer will acknowledge receipt of your claim either in writing, or with a phone call. Be careful of anything you say to them over the phone. Use your list of job-related activities and symptoms to answer their questions accurately and thoroughly, and when you are not distracted or overly-exhausted. They may provide some information in writing about their process and timeframe for evaluating your claim, or your former employer may be able to tell you what to expect.

After you file your claim, your insurer will describe the types of documentation they want from your doctor. Based on the insurer’s requests to your doctor, he/she may now recommend you have some additional tests or assessments done to help support your claim.

Q: If I have already reduced my work schedule to accommodate my MS, should I still wait until I stop working entirely before filing my claim?

A: Possibly. However, if your policy’s waiting (or elimination) period includes time you spend working a reduced schedule (known as residual disability), you may want to file your claim before you stop
working entirely. By doing so, you will be signaling to your insurer that you have already done what you could to keep working in spite of your MS symptoms.

**Q: How will my insurer get information about me?**

**A:** You will be asked to sign and return a ‘Release of Information’ form which will give the insurer permission to obtain medical and other types of information from your doctor and others. **IMPORTANT:** Do not sign the authorization without reading it carefully. If you are concerned that some of the personal information the insurer is seeking does not seem relevant to the question of your disability (such as tax returns, driving records, or credit information), ask the insurer why such information is required. You can limit the types of information they can access about you by crossing out anything on the release form before you sign it.

**Q: What if my insurer wants me to be examined by one of their physicians?**

Your insurance company has the right to have you physically examined by a doctor of their choice although the Society strongly recommends you consider the following to strengthen your claim and your own physician’s opinion.

- See your own doctor regarding your disability claim **before** undergoing an evaluation by any other physician. It is in your best interest for your own doctor’s opinion to have the greatest weight in the claims review process, so the more informed he/she is about your condition, the better.

- You and your doctor need to be cooperative with other health professionals involved in your claim.

- Insist that the physician who examines you be a specialist in MS, and that he/she has all of your medical records before he/she performs your examination.
• Tell your insurance company that you do not want to be rushed into completing any forms at a doctor’s office, and any forms that need to be completed should be sent to you at least ten days in advance of the appointment. Take these forms seriously! The insurance company will use them.

• Both you and your physician should know that it is customary for your doctor to be sent the results of the evaluation conducted by the insurer’s physician, and that your doctor can respond to anything with which he/she disagrees. If your doctor chooses to respond, he/she should be very specific and detailed in the rebuttal.

• Keep track of any and all tests and assessments you undergo, including the type of test and its purpose, the name and qualifications of the person or facility doing the testing, the date of the test, who is evaluating the test results, where the results are sent, the amount of time involved, the cost, and anything else that seems important to you about them.

• To keep the process moving, and to demonstrate your willingness to cooperate, always ask what else your insurer may need from you or your health care professionals.

• Note that some advocates recommend that you consult with an attorney if/when your insurer tells you they want you to be evaluated by anyone other than your own doctor.

Q: How long will it take my insurer to make a decision about my claim?

A: It should take about 4 to 6 weeks for your insurer to make a determination about your claim, although they may notify you that they need additional information (and therefore time) to complete the review. If so, you can demonstrate your willingness to help by asking if they are having any difficulty obtaining information they have requested from your doctor or others. Most states
have guidelines for the amount of time allowed for making a
determination, and your state department of insurance can advise
you about the rules in your state.

Q: Can my insurer get information about me from my co-
workers, neighbors, family members or others while they are
evaluating my claim?

A: Yes! At the very least your insurer will ask your employer
questions related to your claim. But they may also use a variety
of sources and methods to gain information about you, including
private investigators, computer searches and more. This is why it is
recommended that you consider limiting the Release of Information
form your insurance company asks you to sign. Rest assured that
your insurer cannot disclose your private medical information to
anyone without your permission.

Q: How will I be notified about their decision?

A: Your insurer will notify you in writing of the determination.
This letter should clearly describe the conditions of your benefits,
including your benefit amount and frequency of payments, OR your
appeal rights if the decision is unfavorable.

Q: If my claim is approved, will I be considered permanently
disabled, or will they make me submit another claim in the
future?

A: Your insurer can re-evaluate your status and continued eligibility
for disability benefits at any time, and will likely check in with your
doctor periodically. For that reason, it is a good idea to continue
filling out the Symptom Tracker and sharing it with your doctor. It is
also important to stay on track with your doctor’s recommendations
for treatment (of any kind), and for your doctor to keep detailed
notes of your treatments, symptoms and progress. Your insurance
company will rely heavily on your doctor’s notes even after they approve your disability claim.

Q: Do I have to pay my premiums for my disability insurance if they approve my claim for benefits?

A: If your claim is approved, the premiums are usually waived as long as you are collecting disability benefits. This provision in a policy is called a ‘waiver of premium’. If your condition improves and you return to work, or the company determines that you are no longer disabled, they will notify you that you must resume paying the premiums once more.

Q: Could the terms of my benefit change at some point?

A: Yes. Most disability policies apply the ‘own occupation’ definition of disability for the first two years a policyholder is receiving benefits, but include a provision that entitles them to apply an ‘any occupation’ standard for continued benefits after that. This means that even if the insurer determined you were entitled to disability benefits because you were unable to perform the duties of your own job (or a similar job in the same occupation) when you first applied, they could later determine that you were no longer entitled to benefits if it is believed you could work in any job in any line of work.

Q: I’ve heard that private insurers can force people with MS to apply for disability benefits from the Social Security Administration. Is that true?

A: Insurers can and will encourage many of their claimants to apply for disability benefits from the Social Security Administration, and people with group disability insurance provided through an employer plan almost always have to apply for them if they are disabled for more than six months. It is in your insurer’s
interest for you to qualify for Social Security Disability Insurance or Supplemental Security Income because it would reduce or eliminate their ongoing cost in benefits to you. For this reason, your insurance company may appoint someone to represent you in your application process with the Social Security Administration, unless you have already secured an attorney or advocate to do this on your own. To qualify for Social Security disability benefits, it must be determined that the applicant is incapable of any gainful activity, or what private insurers refer to as the ‘any occupation’ standard. Guidance for people with MS applying for SSDI benefits is available on the Society’s website at: www.nationalMSsociety.org/SSDI.

Q: Can I do volunteer work while I am collecting disability benefits?

A: This frequently asked question is difficult to answer with any certainty. On the one hand, you are likely to be encouraged by many people to “do as much as you can”. On the other, by engaging in activities that could be perceived as work in any capacity you could be signaling to your insurer that you are no longer disabled, and could be putting yourself at risk for losing your disability benefits.

If you are thinking about volunteering, consider the following:

• Use the time immediately after your claim is approved to ask your insurer a range of questions about your benefits, including a hypothetical one about doing volunteer work if you felt up to it, but ask before you start.

• Choose an activity that is significantly different from your former employment, especially if your policy uses the ‘own occupation’ definition of disability.

• Use an intermediary, such as your insurance broker, to ask your insurer if you would be putting your disability benefits at risk by doing volunteer work. Unfortunately, calling your insurer yourself
might cause the company to question just how disabled you really are.

**Q: What is the likelihood that my application will be denied?**

A: It is possible that your claim will be denied. Do not lose hope. If you follow the steps we have set out above, an approved application on the first try is more likely. However, if that doesn’t happen, you will have a very good chance of winning an appeal of the denial, as long as your doctor supports your claim and you have documented the functional losses you have experienced due to MS.

**Q: What do I do if my insurer denies my application?**

A: With the help of an attorney specializing in disability insurance, file an appeal. The National MS Society encourages people with MS whose initial claim for disability benefits is denied to consult an attorney with expertise in disability law if or when their initial claim for disability benefits has been denied. Again, you may have specific deadlines for acting, so don’t delay. But don’t panic either.

Your local chapter may be able to help you identify an attorney specializing in this area who is licensed to practice in your state. Feel free to ask any attorney to whom you are referred about the following:

- their fee schedule;
- their track record of winning disability benefits on appeal;
- their experience working with disability related to MS;

Once you begin working with an attorney, you need to know:

- how his/her office is staffed;
- who will be contacting you with updates and/or questions;
- who will be in charge of your file;
• when to expect the filing of the appeal;
• what the general plan of action is; and
• exactly what else is needed from you
Glossary of disability insurance terms*

Any occupation—Although different disability policies can define this term differently, it usually means an occupation that an individual is qualified for as a result of their training, education and experience. For example, a surgeon whose policy uses the ‘any occupation’ definition of disability would not be considered disabled if he/she could be gainfully employed (see definition below) in a related area of medicine.

The any occupation definition generally includes some consideration of one’s earnings history as well, and the policy may include a specific level of income that qualifies as “gainful”. If it does specify a certain level, a good general rule is that earnings are more likely to be considered “gainful” as they approach the insured’s pre-disability earnings (typically 60% to 66 and 2/3%).

Appeal or grievance—a formal request for a re-consideration of an adverse determination made by the insurer, such as an appeal of a denied claim for benefits, provided in most disability insurance policies.

Benefit period—the maximum amount of time you may receive benefits for each continuous disability.

Benefit waiting period—also known as the elimination period, it is the period of time beginning with the first day of your disability, throughout which you must be disabled before disability benefits become payable.

Claimant—the insured person, enrollee in an employer-sponsored plan, or policyholder, submitting a claim for benefits.

*These definitions are typical of many policies but the terms may be defined differently in some policies.
**Claims Professional**—a general term applying to anyone involved in the administration and/or determination of disability insurance claims that works for or represents the insuring entity, which could include claims reviewers, physicians or other health care professionals.

**Commencement Date**—the first day of covered disability immediately following the completion of the waiting period.

**Elimination period**—the period of time you must wait, measured from the first day of an insured’s disability, before disability benefits become payable. Sometimes referred to as the ‘waiting period’, elimination periods typically vary from 30 to 180 days, and also vary in the degree to which they may be interrupted by returns to work. In many policies, the elimination period can be satisfied by partial or residual disability as well as total disability.

**ERISA**—the Employee Retirement Income Security Act is a federal law providing the legal and regulatory framework and consumer protections for group benefits provided by employers or unions, including group disability insurance.

**Gainful employment**—as determined by the percentage of the insured’s pre-disability income they earn after the onset of a disability, such as 60% of pre-disability income.

**Grace period**—the period immediately following the due date for a premium payment during which, if the payment is not made, the policy will nonetheless continue in force (typically one month).

**Group disability coverage**—disability coverage (typically referred to as “long-term disability) provided to eligible individuals by their employer or union as a benefit of employment. This coverage may be provided through a group policy purchased by the employer/union from an insurance company (an “insured plan”), or the employer/union may simply set money aside in a separate
account, plan or fund (a “self-insured”, or more accurately, “self-funded plan”).

**Individual disability insurance**—a private disability insurance policy, (commonly referred to as “disability income” or a “disability income replacement” policy) which is purchased and paid for by individuals, that can replace a percentage of lost income when the insured person becomes disabled. Individual disability policies are traditionally marketed to, and purchased by, self-employed professionals such as doctors, dentists, lawyers, etc.

**Insured**—the insured person, who may be the policyholder, or policy-owner.

**Long-term disability**—monthly benefits to help replace income lost due to a disabling condition or injury in accordance with the terms of a policy or benefit plan.

**Material and substantial duties**—a common phrase in disability insurance policies to describe one’s job-related duties that 1) are normally required for the performance of one’s regular occupation; and 2) cannot be reasonably omitted or modified.

**Non-cancelable**—A provision in the insurance policy guaranteeing that neither the policy nor the premiums can be changed provided premiums are paid by the end of the grace period (if there is one).

**Offset**—a clause in the insurance policy (or, contract) that describes what other income the claimant might receive that could be deducted from the benefit amount provided by the insurer. Disability benefits from the Social Security Administration and workers’ compensation benefits are commonly listed as offsets in group disability plans.

**Own occupation**—refers to your occupation at the time the disability begins. For example, a surgeon with a policy that uses
the ‘own occupation’ definition of disability would be totally disabled under the terms of his policy if he/she is unable to perform surgery even if he/she secured employment in another field of medicine.

Release of Information—typically a form, provided by the insurer upon receipt of a claim for benefits, which when signed by the claimant enables the insurer to obtain certain information about the claimant’s condition from the claimant’s physician and others. (See Filing Claims Q&A section for advice on how to limit these requests for confidential information.)

Reasonable accommodation—any change in the work environment that permits a person with a disability to enjoy equal employment opportunities.

Residual disability—same as partial disability, a residual disability provision may be part of the policy or a rider attached to the contract that provides a reduced basic monthly benefit if you are not totally disabled. Residual disability may include such things as: working fewer hours than normal but performing all of the tasks of your occupation, or working full time but unable to do all of the normal duties required of your occupation.

Rider—any supplemental agreement attached to and made a part of the policy that expands or limits the policy’s conditions, coverage, or benefits, such as partial/residual disability benefits, cost of living benefits, and future insurance options.

Short term disability—disability insurance to help replace lost income for a specified period of time when an illness or injury keeps you out of work for a specific period of perhaps two or three weeks, and generally not more than 26 weeks. A few states require employers to provide short term disability insurance.
Social Security Disability Insurance—a disability insurance program administered by the Social Security Administration for eligible workers unable to work due to a long-term disability (a condition preventing substantial gainful employment and expected to last for at least 12 months).

Supplemental Security Income—a federal income support program administered by the Social Security Administration which provides cash benefits to eligible individuals. Individuals must meet both categorical eligibility criteria (blind, disabled or over age 65) AND have income and assets below certain thresholds.

Survivor benefit—an amount payable to the policy-owner, the policy-owner’s estate, or the policy-owner’s designee should he/she die while receiving total disability benefits.

Total disability—the prerequisite to receipt of long-term disability benefits in most long-term disability policies. ‘Total disability’ is defined differently in different policies, and may depend on inability to do one’s “own occupation”, “regular occupation”, or “any occupation” which is reasonable as a result of one’s education, training or experience, or any substantial gainful employment.

Waiver of premiums—Exempts the insured from paying premiums after he or she has been continuously disabled for a specified period of time. If the policy has this feature, the waiver usually begins after the waiting period or elimination period.
This form is suggested as a tool to help you or your caregiver keep track of your MS symptoms. This form, or something like it, can be helpful in updating your doctor on your progress at any time, although it can be especially useful when preparing a claim for disability benefits. Either you or your caregiver can complete this form. Begin by filling in the date, then rate the severity of the symptom you are experiencing from 1 to 5, where 1 is mild and 5 is severe. See the bottom for examples.

<table>
<thead>
<tr>
<th>Area</th>
<th>SUN</th>
<th>MON</th>
<th>TUE</th>
<th>WED</th>
<th>THU</th>
<th>FRI</th>
<th>SAT</th>
<th>Add comments about your day including anything unusual.</th>
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</thead>
<tbody>
<tr>
<td>Mobility (difficulty walking or running)</td>
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<td>Hand Function (such as grabbing, holding, writing, eating or grooming)</td>
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<td>Vision (such as blurred or double vision, light sensitivity)</td>
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<td>Fatigue (lack of energy)</td>
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<td>Problems thinking (difficulty remembering, staying focused, problem-solving, recalling words)</td>
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<td>Bladder (such as frequency, urgency or hesitancy)</td>
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<td>Bowel (such as constipation or incontinence)</td>
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<td>Sensory Symptoms (such as numbness, tingling, or sensations like burning, bands or electric shocks)</td>
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### MS Symptom Tracker (continued)

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<th>Area</th>
<th>SUN</th>
<th>MON</th>
<th>TUE</th>
<th>WED</th>
<th>THU</th>
<th>FRI</th>
<th>SAT</th>
<th>Comments about your day including anything unusual.</th>
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<tbody>
<tr>
<td>Spasticity Symptoms (such as muscle tightening, leg stiffness, cramping)</td>
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<td>Pain</td>
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<td>Emotional issues (such as anxiety, depression, irritability, mood swings)</td>
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<td>Tremor/Loss of Coordination (balance problems, shaking of head, heads or legs, clumsiness)</td>
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### EXAMPLES:

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<th>8/11</th>
<th>8/12</th>
<th>Comments</th>
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## MS Symptom Tracker (continued)

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**Add comments about your day including anything unusual.**

### Area

**Spasticity Symptoms (such as muscle tightening, leg stiffness, cramping)**

**Pain**

**Emotional issues (such as anxiety, depression, irritability, mood swings)**

**Tremor/Loss of Coordination (balance problems, shaking of head, heads or legs, clumsiness)**

### EXAMPLES:

<table>
<thead>
<tr>
<th>Area</th>
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*Add comments about your day including anything unusual.*
Introduction
This booklet is for you if you are currently employed or looking for a job, and have a diagnosis of multiple sclerosis. Should problems related to your MS affect your job performance, you will need to identify job modifications—called “accommodations” in legal language—that will enable you to continue doing your job. The best argument for changing the way you do your job and/or the equipment you need to do it is to show that these accommodations will help you maintain your productivity level or become an even more productive employee.

Because everyone wins when employees maintain and enhance their productivity, we stress the importance of a “win-win” collaborative approach in discussing job accommodations with your employer. The “win-win” approach is much more likely to produce cooperative solutions to your on-the-job needs than is a legal procedure. It is also more likely to encourage a positive long-term working relationship with your employer.

Although we highly recommend this approach, we recognize that some employers may not respond to your needs for an accommodation review or for a satisfactory accommodation. We also recognize the risks involved in disclosing that you have a disability, which you must do to request an accommodation. Therefore, you first need to know your legal rights under the Americans with Disabilities Act (ADA).
What is the ADA all about?
Facts about the employment provisions of the ADA will help you participate as a knowledgeable and confident “win-win” strategist. The ADA provides civil rights protection for people with disabilities in areas that are parallel to those established by the federal government on behalf of women or minorities. One of the key provisions is Title I, the employment section, which requires employers to discuss your needs for on-the-job accommodations and to help you secure reasonable accommodations. (Note that the burden of starting the process is on you. It is not your employer’s responsibility to figure out that you need an accommodation and then offer you one.)

You are covered by Title I of the ADA if (a) you have a disabling condition (such as multiple sclerosis—see Disability, page 4), (b) you meet the employer’s requirements for a job, and (c) you have the capabilities to perform the essential functions of your current job or a job for which you wish to apply.

Employers and the ADA
All employers must comply with Title I of the ADA, except employers with fewer than 15 employees, the federal government, Native American tribes, and tax-exempt private membership clubs. Sections 501–504 of the Rehabilitation Act of 1973 prevent the federal government, federal contractors, and any programs receiving federal funds from discriminating against people with disabilities.

What does the ADA prohibit?
Simply put, the ADA prohibits discrimination in employment against otherwise qualified people with disabilities. Here are some key definitions you should know:

Disability: Physical or mental impairment that substantially limits
one or more major life activity such as walking, seeing, hearing, speaking, learning, or working.

**Qualified:** A person who satisfies the primary qualifications for a position and who can perform the essential functions of the job, with or without reasonable accommodations.

**Essential Functions:** Primary job duties, as opposed to marginal duties, that the person must be capable of performing, with or without reasonable accommodations. Essential functions may be established by a job analysis and recorded in the job description given to all prospective employees.

**Why the ADA?**
The ADA was made a law by Congress to protect people with disabilities from unfair discrimination. You should be judged on your ability to do the job, not on stereotypes about a certain diagnosis or on fears about a certain disability. MS may cause changes in your capacities over time, but there are ways to adjust for many of those changes. Furthermore, you have the legal right to a reasonable accommodation. Employers who are covered under Title I are required to consider and accommodate disability-related limitations. But these accommodations must be reasonable and not cause undue hardship for the employer. Two key phrases require more discussion: “reasonable accommodation” and “undue hardship”.

**What is a “reasonable accommodation”?**
An accommodation is a modification to the work environment or to the way an essential job function is performed. The purpose of the accommodation is to allow an otherwise qualified person to enter or to continue in employment by removing or reducing significant disability-related work limitations.
Significant work limitations occur when problems related to your disability interfere with your abilities. For example, you may find that your main work station is located too far from other areas in which you are required to work. Physical barriers such as flights of stairs or slippery floor coverings may impede your movement about the workplace. You may have problems with the equipment you must operate or the conditions under which you must operate it; for example, temperature variations, or lighting that bothers you. Finally, you may encounter certain job functions with physical requirements that constitute hazards to you or to others; for example, lifting or moving heavy objects.

The ADA describes several remedies for on-the-job barriers. They are:

• restructuring of existing facilities
• restructuring of the job
• modification of work schedules
• reassignment to another position
• modification of equipment
• installation of new equipment
• provision of qualified readers or interpreters

Below are some solutions of interest to people coping with MS. You may request a meeting with your employer to develop solutions similar to those we have described, but, as the word “reasonable” implies, an accommodation option cannot constitute an undue hardship for the employer.
<table>
<thead>
<tr>
<th>Job Function</th>
<th>MS Factor</th>
<th>Possible Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entering place of business</td>
<td>Muscular weakness</td>
<td>Restructuring of existing facilities, e.g., electronic door opener</td>
</tr>
<tr>
<td>Supervising activities in the gymnasium (climbing and standing)</td>
<td>Loss of strength in lower extremities</td>
<td>Restructuring of the job, e.g., supervising study halls instead of activities in the gymnasium</td>
</tr>
<tr>
<td>Conducting medical examinations more than 8 hours a day</td>
<td>Fatigue</td>
<td>Modification of work schedules, e.g., 8-hour day with breaks</td>
</tr>
<tr>
<td>Supervising construction operations and activities</td>
<td>Fatigue and coordination/balance problems</td>
<td>Reassignment to another position, e.g., to indoor job as manager</td>
</tr>
<tr>
<td>Turning dictation machine off</td>
<td>Numbness of hands, problems with eye/hand coordination</td>
<td>Modification of equipment, e.g., installation of foot pedal to control equipment</td>
</tr>
<tr>
<td>Remembering details, setting priorities, and developing production schedules</td>
<td>Impact on cognitive skills and short-term memory</td>
<td>Purchasing of new equipment, e.g., laptop computer or pocket-size electronic organizer</td>
</tr>
<tr>
<td>Reading reports and self-generated typing</td>
<td>Blurred vision</td>
<td>Provision of qualified readers and interpreters, e.g., reader/proofer in office when needed</td>
</tr>
</tbody>
</table>

**What does “undue hardship” mean?**
Undue hardship refers to an accommodation that would be unduly costly, extensive, or disruptive. For example, does the accommodation cost more than alternatives that are equally effective in removing work limitations? Does it require extensive renovations that will disrupt the business? Will it affect other employees or customers in a negative way? If any of the answers are yes, an employer is not required to provide the requested accommodation.
Undue hardship is decided on a case-by-case basis. Factors influencing whether a modification is considered an undue hardship on the employer include the size of the business and the availability of resources to reduce the net cost of the accommodation to the employer. An undue hardship for one business may not be an undue hardship for another. Don’t limit your range of options by deciding in advance that a certain solution constitutes an undue hardship for your employer. The “win-win” approach will help you to explore a range of options with your employer.

Planning your approach

Now that you understand the ADA’s key employment provisions and your civil rights under them, the next step involves discussing your on-the-job needs with your employer. We believe that an informal and friendly dialogue between you and your employer without mentioning the ADA is the best way to start.

But before you say anything to an employer, you should do some homework. Analyze the problems you are having. This booklet provides some suggestions about solutions. You might also want to call the nearest chapter of the National MS Society or your state’s vocational rehabilitation office to learn about additional solutions that have worked for others. In addition, contact the Job Accommodation Network, at 800-526-7234, or visit their Web site, www.jan.wvu.edu.

Many people put off dealing with employment-related problems until these reach a crisis point. It is more effective to find solutions through the accommodation process before this happens.

Generate a written list of accommodations and then analyze it carefully. Would any of these accommodations increase your productivity? Think through each accommodation in terms of its effectiveness for you. Then, consider it from your employer’s
standpoint. Would it be cost-effective? Does it alter the nature of the business? Now, write your list a second time, putting the best suggestions first.

Next, identify the appropriate person with whom you should meet. You may feel most comfortable speaking with your supervisor, but company policy may require that you discuss these issues with someone in the personnel or human resources department. Some employers insist on a written communication. Find out what is required.

You now know to whom you will speak and, after reading the next sections, you will know the points you should cover. However, most people find it difficult to discuss their MS problems with their employers. In effect, you are informing your employer that you are no longer able to do your job without the help of accommodations.

You need to establish that your disability exists, especially if you speak to a person who does not know you. But you may not need to reveal your diagnosis. In general, you are not legally required to say you have MS. However, in practice most people disclose the diagnosis.

There are advantages and disadvantages to candor. They depend on the culture of an individual work place. If other employees are using accommodations successfully, candor may be the best course. In job interviews, when your abilities are not known to your interviewer, most experts advise not revealing a diagnosis.

Start by saying simply, “I have developed a chronic medical condition.” You should prepare yourself with a letter from your physician about your disabilities. If you are not going to reveal your MS, ask your physician to describe the symptoms that impact your work activities without naming your specific disease.
Focus your presentation on the goals of your job. Then explain that an accommodation will help you overcome problems caused by your symptoms and enable you to reach your goals more effectively.

Rehearse your presentation with a friend or advisor so that you have the best possible chance for success. Remember to stress the experience you have gained as an employee. Employers do not want to lose experienced and loyal workers. Replacing an experienced employee costs time and money, and always involves an element of risk for an employer.

**Discussing the request with your employer**

Here are some tips on preparing for your meeting:

- Dress in work-appropriate clothes. Wear what you would normally wear to work.

- Arrive on time.

- Thank your employer for meeting with you. Then begin by introducing the purpose of the meeting.

- Use appropriate body language. Maintain eye contact during the conversation, squarely face your employer, lean slightly forward, nod to indicate attention, and assume a receptive facial expression.

- Use appropriate verbal language. Answer questions honestly and directly. Use non-adversarial terms: “I would like to explore with you ...,” “It makes sense for both of us to ...,” and “Together, we could come up with ....” Avoid saying “I want ...,” “I’m entitled to ....,” or “You have to ....”

- Be positive. Focus on ways that your enhanced productivity will benefit your employer. Don’t dwell on the past, and don’t react angrily to resistance.
The ADA clearly states that you should be involved in deciding what specific accommodations your employer should implement. The collaboration phase of the “win-win” process involves you and your employer working together to identify the accommodations that would benefit both of you. As you follow these guidelines, keep in mind the mutual benefit of effective on-the-job accommodations.

Remember, although the ADA requires that your employer provide a reasonable accommodation, the employer does not have to provide the most reasonable one from your point of view. It is important to be willing to compromise.

• Give your employer a copy of the list you generated at home, with accommodations ranked in order of your preference. Ask your employer to rank them in order of his/her preference, as a way to start the process.

• Compare the two lists. If you and your employer do not agree, point out again the mutual benefits of the accommodation you prefer. Attempt to convince your employer that your idea is the right one, rather than pointing out that the employer is wrong.

• Be prepared to negotiate an agreement. You can negotiate from a position of strength by keeping in mind your ADA protections. Do not state your right to appeal your employer’s decision, but remember that it does exist.

• Be open to questions from and dialogue with your employer. Don’t simply make your needs known and walk out of the room. The ongoing communication you establish through this problem will help to solve any future issues that may arise regarding on-the-job accommodations.

• Close the meeting. If you reach an agreement, be sure to discuss follow-up procedures and agree on a timetable for action. If your employer proposes an unreasonable compromise, ask for time to think it over. If you cannot agree, suggest that you both think
about it some more. In either of these cases, schedule another meeting within 10 days.

**Implementing reasonable accommodations**

In most cases, you and your employer will identify a mutually acceptable accommodation plan. Because the course of MS is unpredictable, you must monitor the effectiveness of your on-the-job accommodations and communicate frequently with your employer. Here are a few other points to remember:

- Take some time to become familiar with your accommodation. If the accommodation involves technology, ask for appropriate training.
- Be aware of changes in your medical condition and how those changes might be addressed through the “win-win” process. Remember, the ADA does not limit the number or types of accommodations that can be provided. You may need to ask for a different accommodation at a later date.
- Keep your employer informed about your condition, how your accommodations work, and your general job performance. Your employer will appreciate updates on your progress, and you both will enjoy the benefits of a good working relationship.

**But, what if ...?**

If the collaborative “win-win” strategy does not result in acceptable solutions to your needs, if you see signs of discriminatory conduct on the employer’s part, or if you believe that the accommodation your employer has chosen would not enable you to do your job, you have legal recourse.

The ADA requires your employer to respond to your request in a timely manner. If your employer does not respond within 10 working days, make a follow-up telephone call or personal contact to arrange a meeting. If you cannot negotiate a satisfactory solution
with your employer, you have the right to appeal outcomes of the “win-win” approach.

Mention the ADA if, and only if, the collaborative process breaks down and your employer is unwilling to participate any further. You may choose to file a formal complaint with the U.S. Equal Employment Opportunity Commission (EEOC). For information on the EEOC, call 1-800-669-4000 (voice) or 800-669-6820 (TTY), or visit their website at www.eeoc.gov.

Don’t delay in making contact with the EEOC if you experience problems. A charge of discrimination must be filed with the EEOC within 180 days (or about six months) from the time of the alleged discriminatory act. You may want to secure the help of a disability-rights advocate or attorney.

For more information on legal or advocacy help, contact the nearest National MS Society chapter, your state or local bar association, state or local advocates for people with disabilities, and other voluntary health agencies or client assistance projects in your area. Don’t assume legal help will be too expensive for you without investigating the resources.

We hope that the “win-win” strategy will work for you. But if it does not, you have rights under the ADA. The EEOC, disability advocates, and attorneys are available to help you protect your rights.

Filing a claim with the EEOC is free; also bear in mind that a lawsuit may result in financial restitution.

**Conclusion**

The “win-win” approach is designed to assist you in collaborating with your employer to identify and implement solutions to your on-the-job needs. **Mutually** beneficial and cost-effective steps for
maintaining your productivity on the job are the ultimate goals. By identifying your needs, understanding your legal rights under the ADA, and keeping in mind cooperative negotiation strategies for discussing accommodations with your employer, you have prepared yourself to be a confident and effective “win-win” strategist.

**Resources**

Job Accommodation Network:
800-526-7234 (V), 887-781-9403 (TTY);
[www.jan.wvu.edu](http://www.jan.wvu.edu)

800-669-4000 (V), 800-669-6820 (TTY);
[www.eeoc.gov](http://www.eeoc.gov)

Rehabilitation Research & Training Center on Workplace Supports, Virginia Commonwealth University:
804-828-1851 (V), 804-829-2494 (TTY);
[www.worksupport.com](http://www.worksupport.com)

U.S. Department of Labor, Office of Disability Employment Policy:
866-633-7365 (V), 877-889-5627 (TTY);
[www.dol.gov/odep](http://www.dol.gov/odep)

ADA&IT Technical Assistance Centers:
800-949-4232 (V/TTY);
[wwwadata.org](http://wwwadata.org)
Appendix B—Background on the Task Force on Private Disability Insurance

The National Multiple Sclerosis Society (the Society) is aware of concerns from people with MS and those who care for them about hardships related to claims for disability benefits. The Society acknowledges that the variability of physical and cognitive impairment that characterizes MS can make the objective assessment of an individual’s level of disability a complex task. Anecdotal evidence suggests that existing methods for evaluating MS-related impairments are not commonly known or utilized by insurers. Knowing when a working age person with MS is disabled and rightfully due their disability benefits is a challenge to all stakeholders involved in the process. In addition to the claimants themselves, these can include doctors and other providers of MS care, administrators of disability benefits, legal and other advocates, employers and other policyholders.

The fair and accurate review of disability claims should be based on case-by-case analysis of each claim, with consideration given to all effects of the disease and its management. Yet many people with firsthand knowledge of disability claims involving MS tell us that inadequate physician reports and uneven insurer knowledge of the disease are commonplace. Too often, this results in arbitrariness and costly claim disputes, with the burden of proof falling squarely on the person with MS.

As a source of information about MS, the Society believes that accurate and unbiased information about MS and MS-related disability can produce:

• greater understanding of the disease, its effects and treatments to elevate standards for claim evaluations among reviewers and other industry personnel;
the identification and promotion of “best practices” among physicians and their clinical colleagues in documenting MS-related impairments;

help for people with MS and their caregivers preparing disability claims and knowledge of what to expect about the process in advance;

improved communications and more realistic expectations about MS-related impairments and disability among all parties;

a reduction in the overall burden of claim disputes by people with MS; and

support for the appropriate use (integrity) of disability insurance funds and premiums as intended.

To examine these issues in greater depth, the Society convened a diverse and credible task force of disability experts, attorneys, clinicians and consumers to identify and characterize the problems, as well as make recommendations and help advance opportunities for change. The primary focus of the group’s work involves private long-term disability insurance, but also draws on and/or overlaps into public benefits, especially Social Security Disability Insurance. The Task Force provides strategic input and advice to the Society and assists in the collection, creation and dissemination of materials as necessary. To date, through the guidance of the Task Force, the Society has produced educational materials targeted to stakeholders in disability insurance claims, including claims professionals and others within the insurance industry, health care professionals serving people with MS, and people with MS.
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WE EXIST TO MAKE SURE IT DOESN’T.

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