Multiple Sclerosis
YOUR LEGAL RIGHTS
Third Edition

Lanny Perkins and Sara Perkins
Multiple Sclerosis

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THIRD EDITION

Lanny Perkins
Sara Perkins
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Preface

Why Lanny and Sara Perkins Wrote This Book

In the spring of 1978 Sara was a first-year law student at Southern Methodist University School of Law. For most students the first year of law school is a stressful time. Professors, classmates, even your own spouse may create a lot of anxiety about performance. Around Easter, Sara noticed that she was experiencing painful vision and that the pages of her textbooks were blurred. Although it is not unusual for law students to get tired and frustrated, Sara finally went to her eye doctor, who referred her to a neuro-ophthalmologist. This doctor talked about “demyelinization.” He told her the condition would probably pass and gave her a medication called prednisone. Sara did not think much more about it except for the problems she had in rescheduling her examinations.

Later in 1978 Lanny, then in a general law practice in a suburb of Dallas, Texas, was asked to represent a woman with multiple sclerosis (MS) who was being abandoned by her husband. Lanny knew very little about MS and vaguely thought that it might have something to do with the Jerry Lewis telethon. He did not associate it with any of the problems Sara had had earlier in the year.

By 1984 Sara had finished law school and was employed as a corporate attorney by a computer company in Dallas. One day in April of that year, she decided to go horseback riding. She came home complaining about dizziness and said that she had trouble staying on the horse. Sara went back to her
doctor. She learned that she was probably having an attack of what was now identified as MS. Soon she began to have problems reading and staying awake through the workday. She often would close the door to her office and take a nap to hide her condition from her co-workers.

The same week Sara went to the doctor for the second time, Lanny took on a new client who was seeking disability benefits from Social Security. Her problem was a recurrence of MS.

Over the next year Sara attempted to continue working as before. Finally, in July 1985, she found it necessary to retire on disability. Lanny and Sara both became interested in MS, attempting to research medical journal articles and abstracts on new “breakthroughs,” following attentively the progress of laboratory rats receiving drug therapies, and otherwise looking for medical panaceas.

They also got involved with the local National Multiple Sclerosis Society chapter. Sara did volunteer work and Lanny, who continued in private practice, accepted a number of MS patients as clients, with problems such as job discrimination, disability, and marital discord. Lanny and Sara were both asked to speak to support groups and at educational conferences around the state of Texas. In doing so, they became aware of the ways in which legal problems common to people with MS were influenced by the course of their medical condition.

They eventually prepared an outline of legal issues and approaches to solutions for publication. In 1988 that outline became the first edition of this book, *Multiple Sclerosis: Your Legal Rights*.

Since then Lanny and Sara have continued to work with individuals and advocacy groups to develop a better understanding of these issues. Changes in the law over the years have created more opportunities for people with MS. For instance, Sara was present in 1990 at the White House when President George Bush signed into law the Americans with Disabilities Act, which is discussed extensively in this volume. At the same time these new opportunities have also created more complex choices.

The objective of their new edition is to provide a source of basic information about legal problems that often affect people with MS and possible solutions to those problems. The authors address these issues at a level that is understandable by a lay audience. The previous editions, as well as this new edition will be helpful to people in supporting fields such as social workers, health care professionals, and lawyers who did not specialize in these areas.

It is not their intention to cause people to act as their own lawyers in complicated situations but to give them an overview of their problems so that
they can decide when to seek professional advice. The book also provides frequent references to sources of legal assistance, both from private attorneys and from governmental and nonprofit agencies.

In the nearly 10 years from the second edition to this third edition of the book Sara’s condition has significantly progressed. Changes in vision, walking, and energy levels have made daily life more difficult. This has greatly increased her interest in issues such as accessibility and drug costs. Fortunately, there are now resources available which can make our response to these kinds of problems more manageable. The more we learn about our rights and responsibilities under the law, the more useful we can be in our work, in our family life, and as citizens.

This third edition of *Multiple Sclerosis: Your Legal Rights* will help you learn about your rights and serve as a valuable resource no matter where you are in the disease process.

Lanny Perkins
Sara Perkins
This is a sample from Multiple Sclerosis
Buy Now
Introduction

The more things change, the more they stay the same!

There have been many changes in the multiple sclerosis (MS) and disability worlds since the last edition of this book was published. Some of the changes have been both good and bad, but it is important that people with MS are aware of them so they can better analyze what their options might be in certain circumstances.

Among the biggest changes are those dealing with the new Part D Medicare prescription benefit. This can present some real challenges for those people who are on or are thinking of taking the so-called A, B, C drugs as well as expensive medicines like natalizumab (Tysabri) and modafinil (Provigil).

Other important changes concern interpretations of the Americans with Disabilities Act (ADA) by the US Supreme Court. The ADA, signed into law in 1990, remains the bedrock of civil rights legislation in this country relating to the disabled. But because of its newness and complexity, its provisions are not always clear, and so will be a centerpiece of legal action for the foreseeable future.

Computers and the Internet were certainly around in 1999. Yet it is impossible to overemphasize their significance now. The resources are so varied that it is impossible to list them all. For example, people can compare the policies available to them in each state through Medicare Part D. It would be difficult to do this in any other way. The web does not answer every question, but it is a great tool to get a good deal of information quickly, especially for the physically challenged.
Some major areas of law such as bankruptcy and taxes need to be examined and updated. But the ways to think about and approach legal problems presented by the diagnosis of MS remain largely the same. This may be discouraging to some people, but it can also be empowering.
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I

Working with Doctors and Lawyers

Many of your legal and financial rights as they relate to your medical condition may depend on the right choice of doctor and lawyer. These professionals can support or work for you and your best interests, so it is important to know why and how to hire—and fire—them.

The Doctor

Most textbooks, pamphlets, and other written materials that deal with multiple sclerosis (MS) prudently counsel the individual to obtain good, regular medical care. Most doctors would advise the same. From there, sources differ. Some writers urge a team approach to treatment. Others suggest that a good general physician is adequate for ongoing treatment after an accurate diagnosis has been made. Sometimes the neurologist who has diagnosed is ready, willing, and able to monitor the patient regularly; sometimes the neurologist prefers to be involved only when there are exacerbations or serious new symptoms.

Whatever choice is made with regard to getting the best possible medical care, you should not overlook the importance your doctor may have in supporting you legally in such areas as insurance and Social Security claims, employment disputes, or legal competence issues. In addition to your hope that having the right doctor will help alleviate the physical effects of illness, having the right doctor also may greatly enhance your legal position in important
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ways; preferably before a crisis such as termination of employment occurs. The type of legal help a doctor most typically may provide includes writing clear statements as to the effects of your disease or giving written or oral testimony in support of a claim for a reasonable accommodation under the Americans with Disabilities Act (ADA) or for disability to insurers, employers, and the Social Security Administration (SSA).

In selecting a doctor, follow these tips:

1. Make sure that the doctor is interested in treating MS. Many doctors, even neurologists, for a wide variety of reasons, do not want to treat this condition.

2. See a neurologist or physiatrist (a physician whose specialty is physical medicine and rehabilitation) periodically. Many doctors, including neurologists, may say that it is not necessary to see a neurologist regularly, if ever, after diagnosis, but that a good internist is adequate. This may not be good legal advice if there is any likelihood that you will ever need medical evidence about your MS presented to a court or administrative agency. Because MS is a disease of the central nervous system, the opinion of a board-certified neurologist tends to be given greater weight by insurance companies, the SSA, and the courts. In fact, whenever a written report or affidavit is submitted in a legal or administrative proceeding, the doctor’s accreditations should be fully listed in addition to his signature.

3. See the neurologist at least three or four times a year and also whenever there are new symptoms and exacerbations. Report all symptoms. Make sure the doctor is recording them in your file. This record of your progress will be the most important proof of your condition in any later legal or administrative proceedings, such as claiming disability benefits or proving medical expense tax deductions.

4. Keep an accurate diary of your symptoms and how they affect your activities, plus any other facts that you think are important. The purpose of this record is twofold. First, it will help you remember your own progress when consulting with your doctor. Second, it may be a significant piece of evidence of the effects of the disease on your life. The entries need not be extensive, but a consistently kept record is something that will enhance your medical, legal, and financial position in the face of an unpredictable illness.
5. Do not hesitate to discuss nonmedical issues with your doctor. In fact, do so as soon as possible. If you think the doctor will not be supportive, will not be willing to write appropriate documents or testify, and/or will not be willing to see you regularly, find a new doctor. Many doctors are sympathetic in the office but are reluctant to help a patient in nonmedical matters. This may be a major obstacle in some kinds of proceedings.

6. If you find out or suspect that your doctor is not sympathetic to either the medical or the nonmedical issues of MS, or for whatever reason you are not comfortable talking with him about those matters, how do you make a change? You may ask friends or other physicians for referrals. Another excellent source for finding doctors who are interested in MS is your local National Multiple Sclerosis Society (NMSS) chapter, which should provide several referrals (you generally must make the appointment).

7. Politely request a copy of your file from the doctor whose care you are leaving to avoid repeated testing and to give your new physician a copy of the case history. You are entitled to this copy on reasonable notice. There should be no problems with this request, but if the doctor refuses, your new doctor or the local county medical society should be able to help.

Of course, nowadays choosing a doctor is often made even more difficult because of the prevalence of HMOs (Health Maintenance Organizations) and PPOs (Preferred Provider Organizations). In many cases, you are under great pressure to accept the doctor assigned you by the HMO or to see someone from the favored list provided by the PPO. In many cases, these doctors are perfectly competent from a treatment point of view, but may or may not be willing to provide the kind of cooperation you need in coping with life problems of the type discussed in this book.

We will discuss medical insurance issues in Chapter 5 (Insurance Issues). But in making your selection of a treating doctor, it is important to bear in mind the possibility that you may need more than a 5-minute personal visit and a prescription at some point in your relationship.

If you take these considerations to heart after diagnosis, you may help yourself obtain the kind of support you deserve and need to deal with the complex legal issues to which a disease such as MS may give rise.
The Lawyer

Many years ago, the New Yorker magazine published a cartoon that showed a fashionably dressed woman talking to a man at a cocktail party. The punch line read: “How did I know you’re a lawyer? Everybody’s a lawyer.” Without question, there is no country in the world that has more lawyers per capita than the United States—now approximately 1 lawyer for every 350 people nationwide; perhaps 1 lawyer for every 20 people in Washington, DC, alone. But sheer volume does not mean it is easy to find the right lawyer for the particular legal problem you may have. Many people do not know any lawyers personally. There is, quite understandably, concern and confusion about such areas as specialization, fees, and competence.

The following points should give you some guidance.

1. One lawyer may not be able to address adequately all your legal problems, although the kind of extremely specialized practice often found in medicine is not quite as common in the law. Certain legal matters discussed here, such as divorce, probably can be handled well by any experienced civil practitioner. A good civil attorney should also be able to answer common questions concerning debt, real estate, and legally related business issues. However, that same attorney may know little about employment or Social Security but may be willing to learn about them in connection with a particular case. The problem, then, is at what cost in both money and ultimate result?

2. If you are concerned about a lawyer’s experience or interest in handling a matter, first discuss it with the attorney by phone. You have no obligation to see that particular lawyer or any lawyer to whom you talk. However, if you make an appointment and do see the attorney, you may be charged for the visit whether or not you have her proceed with any other action, because the lawyer, like the physician, is selling you his time and knowledge.

3. It is perfectly acceptable and prudent to discuss fees with the lawyer by phone before you see her. In general, there are three basic methods of calculating fees: a contingency fee, meaning a percentage of money finally awarded or settled on in a case; hourly fees, which are based on the time spent on the legal matter; and a set fee for a particular job (e.g., $500 for a will or a simple divorce). Some kinds of legal problems typically are billed in a certain way. Personal injury and medical
malpractice cases often are billed on a contingency basis, plus payment by the client of some costs such as court reporters, expert witness fees, and so forth. Other matters, such as divorce, might be billed as a set fee with some hourly billing if more than a given amount of time or effort is required. In these and other cases, a lawyer often will require a retainer to begin any work, bill against it, and, if necessary, bill the client for any additional time not covered by the retainer. Fees in some matters, such as worker’s compensation and Social Security disability, are either set by statute or must be approved by a court or regulatory body.

A lawyer may ask you to sign a contract for services that sets forth the fee arrangement. This is not always done, but it is a practice of some lawyers, particularly in matters that might be expected to take a long time and involve a contingency fee.

Regardless of the type of case, a client should always understand in advance of commencing any legal action:

- What fees and charges may be expected.
- How much time will be involved.
- Who will be doing the work (the lawyer the client sees or someone else).
- What efforts are both the lawyer and the client expected to make.
- Any other issues that seem important to the client.

All good lawyers should be able to answer such questions clearly. If you understand from the outset what may be expected in your case, you will save yourself considerable anxiety, confusion, and possible expense in the future.

4. Before going to a lawyer, locate and take with you any documents, names, dates, addresses, or other information you deem to be important in your case. This may save the lawyer time and save you money.

5. Understand that however strong you believe your case is, you may not get the result you anticipate for many reasons other than poor performance by the lawyer. These might include a particular judge’s or jury’s peculiarities, the strength of the other side’s case, or the economic constraints on your pursuing your case. The lawyer who tells you that you can either win or lose any disputed matter is only being honest.

6. There are several ways to find a lawyer who handles the matter you are interested in. Besides asking friends and acquaintances for
names of competent attorneys who are interested in the legal problems of people with MS, one of the best sources of referral is the local bar association. In many cities and counties, bar associations sponsor lawyer referral services that will give you the name of a local lawyer who handles particular types of cases in your area of town. You may make an appointment to talk to the lawyer, often for a reduced price—a good value and a good way to get some basic questions answered even if you decide not to continue.

Other organizations in some parts of the country may offer similar services. You can find these in your telephone book. For example, one national referral service for attorneys who are interested in handling Social Security disability claims is the National Organization of Social Security Claimants’ Representatives, which is headquartered in New Jersey (see the Appendix). Keep in mind that most referral services are just that—they give out names of lawyers who sign up and/or pay to be listed. They do not always indicate a lawyer’s skills in a particular area of the law. Some state bar associations do provide board certifications, which may require a lawyer to have passed a written examination, to have a practice limited largely to the area of certification, to have been licensed for a minimum period of time, and to have submitted personal references from other attorneys.

7. Many organizations offer free or reduced-fee services to people who meet certain financial standards, normally involving low income levels. There may be other qualifications as well. For example, many law schools operate legal clinics for teaching purposes and are subject to certain restrictions on the type of cases handled. Further information on qualifications may be obtained directly from the organizations. Check your local telephone book. They may be of great use to those who qualify.

8. Legal guidebooks such as *The Martindale-Hubbell Law Digest* are available in local law and public libraries. These books list the names and addresses of law firms, along with biographic and other information (also see the Appendix). You should always meet with a lawyer before deciding to proceed with a major legal matter. Not only will you learn the anticipated legal steps and probable costs, but also a good attorney will give you an objective evaluation of your situation and some ideas about whether it is worthwhile to take the action you are considering. Of
course, you should not necessarily follow the advice of the first lawyer you contact; lawyers, like doctors, may have different approaches to handling a given problem. In addition, you should try to hire a lawyer whose personality and philosophy will be compatible with yours, because the lawyer-client relationship must be one of mutual trust and confidence.