

AMERICAN ACADEMY OF NEUROLOGY

# RESTLESS LEGS SYNDROME

Mark J. Buchfuhrer, MD, Wayne A. Hening, MD,  
and Clete A. Kushida, MD



COPING WITH YOUR SLEEPLESS NIGHTS



# Restless Legs Syndrome

AMERICAN ACADEMY OF NEUROLOGY (AAN)

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# Restless Legs Syndrome

## *Coping with Your Sleepless Nights*

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 A A N P R E S S  
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Medicine is an ever-changing science undergoing continual development. Research and clinical experience are continually expanding our knowledge, in particular our knowledge of proper treatment and drug therapy. The authors, editors, and publisher have made every effort to ensure that all information in this book is in accordance with the state of knowledge at the time of production of the book.

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Made in the United States of America

This book is dedicated to Orren Hawley, Virginia Wilson, and Pickett Guthrie, who brought the Restless Legs Syndrome Foundation into being, and to Arthur Walter, who first realized that patients and physicians should work together to bring relief to the millions of RLS sufferers.

I would also like to dedicate this book to my mother and father, Rose and Norbert Buchfuhrer, holocaust survivors who passed on the determination and dedication necessary to write and edit this book on RLS.





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# About the AAN Press Quality of Life Guides

## IN THE SPIRIT OF THE DOCTOR-PATIENT PARTNERSHIP

THE BETTER-INFORMED PATIENT is often able to play a vital role in his or her own care. This is especially the case with neurologic disorders, for which effective management of disease can be promoted—indeed, *enhanced*—through patient education and involvement.

In the spirit of the partnership-in-care between physicians and patients, the American Academy of Neurology Press is pleased to produce a series of “Quality of Life” guides on an array of diseases and ailments that affect the brain and central nervous system. The series, produced in partnership with Demos Medical Publishing, answers a number of basic and important questions faced by patients and their families.

Additionally, the authors, most of whom are physicians and all of whom are experts in the areas in which they write, provide a detailed discussion of the disorder, its causes, and the course it may follow. You also find strategies for coping with the disorder and handling a number of nonmedical issues.

The result: As a reader, you will be able to develop a framework for understanding the disease and become better prepared to manage the life changes associated with it.

## ABOUT THE AMERICAN ACADEMY OF NEUROLOGY (AAN)

The American Academy of Neurology is the premier organization for neurologists worldwide. In addition to support of educational and scientific advances, the AAN—along with its sister organization, the AAN Foundation—is a strong advocate of public education and a leading supporter of research for breakthroughs in neurologic patient care.

More information on the activities of the AAN is available on our website, [www.aan.com](http://www.aan.com). For a better understanding of common disorders of the brain, as well as to learn about people living with these disorders, please turn to the AAN Foundation's website, [www.thebrainmatters.org](http://www.thebrainmatters.org).

## ABOUT NEUROLOGY AND NEUROLOGISTS

Neurology is the medical specialty associated with disorders of the brain and central nervous system. Neurologists are medical doctors with specialized training in the diagnosis, treatment, and management of patients suffering from neurologic disease.

Lisa M. Shulman, MD

*Series Editor*

*AAN Press Quality of Life Guides*

# Foreword

TOO OFTEN, THE TERM “restless legs syndrome” (RLS) generates snickers of amusement from anyone who is ill informed about this puzzling condition. For years, most people with RLS suffered alone. It wasn’t until 1989 that eight RLS sufferers from across the US began exchanging letters. Medical knowledge about RLS was so limited that others afflicted with the strange-sounding disorder turned to this fledgling support group in search of coping methods and therapies. In 1992, this coalition of sleep-deprived amateurs launched the Restless Legs Syndrome Foundation, a non-profit organization, dedicated to alerting the world that restless legs syndrome is real and treatable.

Their grassroots effort soon attracted the attention of a small group of sleep researchers. This team of RLS pioneers became the nucleus of the foundation’s first medical advisory board and continues to lead the way in unraveling the mystery behind RLS.

Despite numerous studies estimating that as many as 10 percent of Americans have this potentially devastating disorder, RLS is still hardly a household word. Other than material published by the RLS foundation, people with RLS have had difficulty finding credible information about the condition. This book helps fill the need for reliable information and represents another milestone in the collaboration between patients, researchers, and clinicians. Patients and their families will appreciate the clear, concise descriptions of who gets RLS, what causes RLS, and how RLS is diagnosed. Even those who learned long ago the name of the culprit behind their sleepless nights will welcome this up-to-date review of treatment options.

Drs. Buchfuhrer, Hening, and Kushida are part of an effective partnership between patients and medical professionals that has spearheaded advances in treatment and improved life for RLS sufferers. All three have served on the foundation’s medical advisory board, written articles for the foundation’s quarterly newsletter, and answered hundreds of

questions from patients who struggle with this potentially devastating condition. Along with impressive credentials, they each have the rare ability to translate medical and scientific terms into language that is accessible to any reader.

Topics covered in this book include non-pharmacological therapies (such as alerting activities and abstaining from caffeine, nicotine and alcohol); complementary and alternative medicine (vitamins, herbal remedies, chiropractic and acupuncture); intermittent drug treatment for those with sporadic symptoms; medications for those who contend with the disruptive symptoms of restless legs on a daily basis; and the future of RLS treatment.

In keeping with their philosophy of teamwork, the authors include material from two people directly affected by the disorder. The chapter on “RLS and Relationships” is written by Ann Battenfield, herself an RLS patient and volunteer moderator for one of the RLS online discussion boards. Her section offers tips for dealing with the stress of living with the disorder. Karla Dzienkowski is the mother of a 15-year-old with RLS. She is also a registered nurse and member of the foundation’s board of directors. Her chapter on “RLS in Children and Adolescents” outlines coping strategies for families dealing with the disorder in younger patients.

Fifteen years of collaboration between patients and medical professionals have improved RLS treatments and fueled rapid progress in unraveling the science that may someday lead to a cure. The authors and contributors to this book continue to prove that teamwork is the best hope for millions of men, women, and children who must live with restless legs syndrome.

Pickett M. Guthrie, MLS  
Co-Founder Restless Legs Syndrome Foundation  
Executive Director, 1992–1996  
Member, Board of Directors, 2003–Present

# Preface

*“Restless Legs Syndrome: the most common disease you’ve never heard of.”*

ROBERT YOAKUM

Former Board Member

Restless Legs Syndrome Foundation

IF YOU ARE READING THIS BOOK then it is very likely that you or someone close to you has restless legs syndrome (RLS). It is also likely that you understand how well Robert Yoakum’s quote typifies the lack of awareness about RLS. You have probably experienced the frustration of dealing with medical professionals, most of whom have very little knowledge about or ability to treat this disease, despite its high prevalence in the U.S. population. Until recently, RLS has been the “Rodney Dangerfield” of sleep and neurologic disorders, with little respect being given to patients or even to doctors treating or researching this trivial-sounding disease. It is common for an RLS patient to be told that the problem is “all in your head” or “doesn’t exist” or that “you are just too anxious.”

The RLS Foundation, which was created in 1992, has been working very hard to change this situation. This nonprofit organization provides support for RLS patients, doctors, educators, and researchers. It has been the driving force in the effort to increase awareness of this poorly known disease.

We are now at the dawn of a new age of RLS awareness and treatment. The FDA approved the first drug to treat RLS in May 2005, and several more are pending. Having an FDA-approved drug adds to the credibility of this disease. In the next few years, RLS should become much better known and gain the recognition and respect it deserves.

Although RLS is not a curable disease, its symptoms are very treatable. With proper care, most patients can achieve dramatic relief, if not

complete resolution of their symptoms. RLS patients should not despair, but rather take a proactive approach to managing their disease. This book helps guide RLS patients through the often very difficult path of managing their disease successfully.

All aspects of RLS and periodic limb movement disorder (PLMD) are discussed in this book. Readers will become more familiar with the presentation, diagnosis, course, and causes of RLS and PLMD. The chapter on management of RLS and PLMD covers all aspects of treatment extensively. It reviews all of the helpful drug and nondrug therapies. After reading this book, patients should become very familiar and comfortable with the management of this disorder.

Although this book is meant for RLS sufferers all over the world, the drug treatment of this disease varies from country to country due to the different availability of these drugs. Narcotics are more freely prescribed in the U.S., while drugs such as cabergoline are used more in Europe where they are less expensive. RLS patients in some countries do not have access to the newer drugs like Mirapex and Requip, while we here in the U.S. do not have domperidone, an inexpensive antinausea drug that does not worsen RLS. Clearly, the choice of RLS therapies can differ significantly based on the availability of drugs and the prevailing attitudes of their use.

RLS sufferers should take an active role in managing their disease. We discuss how they should work with their doctors to achieve optimal therapy. This book gives guidelines for the very difficult task of finding and choosing the right doctor to treat RLS.

Patients often have difficulties coping with their RLS symptoms and the limitations resulting from this disease. We discuss many techniques for coping with the different aspects of life affected by RLS and PLMD, including daily activities, recreational activities, emotions, psychiatric problems, and medical procedures. RLS sufferers will also learn how to deal with relationships that are often strained by this chronic disease.

RLS in children is quite common but is less well known and diagnosed than in adults. The book covers this topic as well as the treatment of children. We encourage parents of children with RLS to read the section on how to cope with RLS in young children and teenagers.



We encourage all RLS patients to become more educated about their disease. The Appendix contains information on other sources to continue your education. Included are resources for educating your health care professional. We also encourage all RLS patients to join the RLS Foundation and a local support group. By doing so, you will help both yourself and other RLS sufferers.

We hope this book will help those suffering from RLS or PLMD to manage and live with their disease. They will learn not to be embarrassed by their strange-sounding symptoms. Instead of suffering quietly, patients will learn how to get proper care, which should relieve the symptoms of most RLS sufferers.

The future for RLS sufferers looks much brighter now. We expect that over the next decade RLS will become a well-known disease. Patients will no longer have to struggle to be diagnosed and treated for their disruptive symptoms. As research accelerates, more therapies should make effective treatment even more accessible. Because of the fast pace of change in our knowledge about this disease, some of the therapies discussed in this book may be quite different in the next few years.

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Wayne A. Hening, MD, PhD

Clete A. Kushida, MD, PhD



# Acknowledgments

I WOULD LIKE TO THANK the Restless Legs Syndrome Foundation, its founders, board of directors, advisors, and staff members, who have worked for so many years to increase the awareness of RLS, which has resulted in the demand for this book. The RLS Foundation has been integral in educating the public and medical professionals, raising money, and spearheading research on this perplexing disorder.

I would like to thank Elizabeth “Bill” Tunison, previous RLS Foundation board member and founder of the Southern California RLS Support Group, for gently but persistently guiding me into the field of RLS.

I would like to thank the family members of all the authors who supported us during the writing of the book.

I also thank my wife, Laurie Buchfuhrer, MD, for her patience and her support and her many helpful suggestions while writing this book.



# Restless Legs Syndrome



# What Are Restless Legs Syndrome and Periodic Limb Movement Disorder?

**I**F YOU ARE READING THIS BOOK you probably already know something about restless legs syndrome (RLS) and periodic limb movement disorder (PLMD). You may even know more than most physicians about these two common conditions. Despite being poorly known and understood, approximately 10 percent of the Caucasian population in the U.S. has RLS. There is a lot of confusion about RLS and PLMD, with many physicians and people mistaking one for the other. This misunderstanding arises because they often appear together, but in fact they are two separate and distinct disorders.

RLS is a *neurologic sleep and movement disorder* characterized by an almost irresistible urge or need to move the limbs, usually related to uncomfortable limb sensations, which are worse during inactivity. Movement of the limbs occurs in order to relieve the uncomfortable sensations. A person with RLS must be awake and conscious to be bothered by RLS. In order to relieve their RLS symptoms and fall asleep, people with RLS often move their limbs and toss and turn in bed, which may disturb their bed partners (Figure 1-1).

People who experience *periodic limb movements* (PLM) have limb muscle jerks that occur mostly when they are asleep and occasionally when they are awake. People with PLMD and their bed partners are usually able to sleep in spite of the leg movements, as long as the movements are not too vigorous. RLS is an awake sensory phenomenon with



**FIGURE 1-1**

My wife tells me that my legs were restless again last night. She said that she didn't sleep a wink, but I slept fine.

movement due to the sensations, whereas PLM is a sleep (and only occasionally an awake) movement phenomenon that usually has no sensory component. Confusion can arise because RLS and PLM often occur together; however, they are not identical, and it must be remembered that either can exist without the other.

Despite extensive research, the cause of RLS and PLM is still unknown. The leading hypothesis at this time involves problems with dopamine function and iron in the brain. This is discussed further in Chapter 6. Although there is no cure for RLS or PLM, current therapies should relieve most people's symptoms, as discussed further in Chapter 4.

Most cases of RLS and PLM are *primary* and occur in otherwise normal healthy individuals. *Secondary* RLS and PLM occur in association with certain underlying medical conditions, as discussed in Chapter 3.

RLS = urge to move with unpleasant limb sensations occurring while awake.



## RESTLESS LEGS SYNDROME

### Uncomfortable Limb Sensations

Although most people with RLS have difficulty describing their uncomfortable sensations, many do not describe any abnormal sensation other than the almost irresistible urge to move the affected limb. Abnormal sensations are not necessary, however, to establish the diagnosis of RLS. The medical term for these sensations is *dysesthesia*, which is defined as a “disagreeable or abnormal sensation.” Many people with RLS do not agree with the use of this term, but it is the most accurate word available to describe the sensations. RLS sufferers often describe such sensations as like ants crawling in their legs, creepy-crawly feelings, pulling sensations, water running inside their legs, or electricity in their legs. Some can only describe the sensation as an urge to move their legs. Although RLS usually starts in the legs, it can also occur in the arms or other muscles in the body as the condition progresses. Most people with RLS do not describe these sensations as painful. To better understand this, consider the analogy of how it feels to be tickled. Most of us would not describe being tickled as painful. However, if the tickling continues for too long, it can become quite bothersome and so unbearable that we might begin to consider it painful.

A minority of people experience painful symptoms, which are often described as burning, aching, or simply painful. These symptoms may occur in addition to the more typical sensations. However, in some people the painful symptoms may be the result of some separate but associated problem, such as *neuropathy* (disease of the nerves).

The large variability of the uncomfortable sensations and the difficulty in describing them contributes to problems in communicating with physicians. Many people are even reluctant to mention their symptoms because they feel they are “just too weird.” Therefore, it is not surprising that physicians often miss the diagnosis of RLS. People often diagnose themselves, typically after reading a description of RLS.

## What's in a Name?

Many people with RLS and their families have made up their own names for the disorder. Table 1-1 lists some of the colorful terms that people use to talk about the condition before they learn the commonly accepted name, RLS. Many people do not agree with the use of the term “restless legs syndrome,” because they feel it makes the condition sound trivial, which results in physicians and others not taking it seriously.

**Table 1-1** Patient's Names for RLS

|                                   |                               |                             |
|-----------------------------------|-------------------------------|-----------------------------|
| Achy knees                        | Having butterflies in my legs | Racer legs                  |
| Achy legs                         | Hopping legs                  | Racing legs                 |
| Aerobic sleeping                  | Hot legs                      | Spider legs                 |
| Alien legs                        | Itchy blood                   | Spongy leg disease          |
| Ant legs                          | Itchy chin-bone               | Stretchy legs               |
| Antsy legs                        | Jello legs                    | Symphony feet               |
| Anxious feet                      | Jiggles in my legs            | That icky twitchy leg thing |
| Anxious legs                      | Jiggy legs                    | That knee thing             |
| Bone itch                         | Jimmy legs                    | The crawlies                |
| Bugs crawling in my legs at night | Jumpies                       | The crawls                  |
| Bugs in the bones                 | Jumpy knees                   | The creepers                |
| Busy legs                         | Jumpy legs                    | The creepy crawlies legs    |
| Butterfly twitches                | Jumpy life                    | The crinkles                |
| Crawly legs                       | Kickies                       | The fidgits                 |
| Crazy leg thing                   | Kicky legs                    | The gotta moves             |
| Crazy legs                        | Last nerve disease            | The grunions                |
| Dancing legs                      | Lead legs                     | The ickies                  |
| Day crawls                        | Leaping legs                  | The itchies                 |
| Dead legs                         | Leg thrashies                 | The jerks                   |
| Edgy legs                         | Legitis                       | The jiggies                 |
| Eeeky                             | Legs are mad                  | The jitters                 |
| Feet cramps                       | Legs want to break dance      | The kicks                   |
| Fidgety legs                      | Magic legs                    | The knee jerk               |
| Flapping legs                     | Mom's leg thing               | The leggy thing             |
| Floggin legs                      | Muzzy legs                    | The misery                  |
| Funny bone legs                   | My hands and feet are nervous | The nadgers                 |
| Funny legs                        | Nervous leg syndrome          | The screeches               |
| Grasshopper legs                  | Night crawls                  | The scritchees              |
| Great RLS boogie                  | Night thrashers               | The shpilkes                |
| Happy feet                        | Nighttime jitterbug           | The stomps                  |
| Heebee-jeebees                    |                               | The tingles                 |
|                                   |                               | Walking legs                |

Groups of people with RLS have lobbied to change the name to *Ekbom's syndrome*, after Dr. Karl Ekbom, who first described RLS in 1944. Dr. Ekbom first called it *irritable legs*, but changed it to *restless legs syndrome* in 1945. Since then, the medical and scientific world has accepted and used this term, and it would be confusing to change the name again.

## The Urge to Move the Affected Limb

This cardinal symptom of RLS must be present to establish the diagnosis. Many people with RLS do not have uncomfortable limb sensations, but they all have an almost irresistible urge to move the affected limb when at rest. Many people with RLS have some control over this urge and can usually delay moving for a short time as well as choose the type of movement (walking, shaking, or rubbing their leg). This is quite similar to the urge to scratch a mosquito bite. We can voluntarily stop ourselves from scratching using our willpower but, if distracted, will immediately scratch the itchy spot. However, with RLS, if the urge to move is suppressed for too long, it becomes so intense that the person loses control and must move.

Many people say they move their affected limb because it brings complete or partial relief of the uncomfortable sensations; however, the RLS symptoms and the urge to move the limb often return once the limb is at rest again. The length of time that a person can sit or lie down before feeling the urge to move decreases as RLS worsens. This can make it impossible for them to perform sedentary activities, such as watching television or going to bed and falling asleep.

Early in the disorder, the symptoms may occur only at bedtime and can be relatively mild. Once the patient is tired enough, falling asleep at bedtime may not be a problem. However, as the disorder progresses, the RLS symptoms can become intense enough that sleep is almost impossible. As the disorder progresses, symptoms usually occur earlier in the day. People with severe RLS may even have symptoms upon awakening. RLS symptoms usually start in the legs, but as the condition worsens, the symptoms move to the arms and other muscles of the body, such as the abdomen, chest, back, neck, and even the facial muscles.

## How Does Your RLS Rate?

Many people with RLS wonder how their RLS problems compare with others'. Often the only reference point is a comparison to the level of RLS early in the course of the disorder. Speaking to other people with RLS may be helpful, but it may not help you define the level of your RLS within the spectrum of the disorder.

Several RLS rating scales are used to assess severity in medical studies. You can rate your RLS using the simple rating system shown in Table 1-2, which is based loosely on the validated Johns Hopkins restless legs severity scale that assigns severity based on the time of day that symptoms begin. This crude severity rating scale rates most people with RLS fairly well, but it does not take into account the intensity of the RLS symptoms and their effect on sleep and daytime functioning. It also excludes people who do not get symptoms at bedtime, but experience them only with prolonged sitting, such as on a long airplane trip.

**Table 1-2** Severity of RLS

| <b>Severity</b> | <b>Time of day when symptoms usually start (&gt;50 percent of the time)</b> |
|-----------------|---|
| Mild            | Bedtime symptoms only   |
| Moderate        | Evening symptoms starting after 6 P.M.                                      |
| Severe          | Afternoon symptoms starting after 12 P.M. (noon)                            |
| Very severe     | Morning symptoms  |

## The International RLS Study Group Rating Scale

The International RLS Study Group rating scale can be used to determine a more accurate severity rating. This scale, validated in 2003, is currently considered the standard scale by most RLS specialists. To evaluate the severity of your RLS, simply answer the questions below, add up the appropriate number of points, and find your severity level in Table 1-3. Use the average symptoms you experienced during the most recent 2-week period for evaluating symptom severity.