

The Problems of Sleeping with Restless Legs Syndrome

Because many doctors still aren't familiar with the diagnosis of or treatment for restless legs syndrome, the burden often falls on patients to bring it up.

For most of Kathy Page's adult life, the simple act of falling asleep has been more like a nightmare. Page, a longtime resident of Smithton, MO, suffers from restless legs syndrome (RLS), a disorder that causes an uncomfortable sensation in the legs that can only be relieved by moving.

It's a condition that affects as many as 12 million Americans yet is often misdiagnosed—and misunderstood. With a name like "restless legs syndrome," it may not sound like such a bad thing. But to those who live with it, RLS can be unbearable. According to Mark Mahowald, M.D., medical director of the Minnesota Regional Sleep Disorders Center at Hennepin County Medical Center, the disorder is characterized by an irritating, sometimes painful urge to move that worsens with inactivity and is most prevalent at night. As a result, says Dr. Mahowald, it can dramatically impact sleep, resulting in insomnia and even depression.

According to the RLS Foundation, the disorder can affect people of all ages but is most common in middle-aged adults. It often runs in families, suggesting a genetic



component, and can occur as a result of several other conditions (see "The Bedfellows of RLS" below). Many of those who suffer from RLS also have periodic limb movement disorder, a condition in which involuntary jerking movements occur every 20 to 30 seconds during sleep, sometimes throughout the night.



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Like many neurological disorders, RLS impacts people in different ways, with some experiencing more severe symptoms than others. One common experience, however, is that the more RLS patients try to relax, the worse it gets. "It starts out about half an hour after I go to bed," says Page. "I'll be lying there, and I can just feel it coming on. It's like an electrical impulse where all of a sudden it pops and your leg jerks."

It's difficult to explain to those who have never had RLS, says Page. "People don't understand—I have to move my legs. If I try to make them lie still, I'll just go crazy."

The only thing that relieves the pain is to either rub the legs or get up and walk around, says Dr. Mahowald, who is also a professor of neurology at University of Minnesota Medical School. But the relief it brings is only temporary. As soon as people with RLS lie down or fall back asleep, the cycle starts again, causing what he calls "terrible" insomnia.

Before Roger Winters of Seattle, WA, began taking medication for RLS, his sleep was being disrupted an average of about 90 times per hour, he says.

And while this activity didn't necessarily wake him, it did disrupt his sleep cycle, which prevented him from reaping the benefits of sleep.

"It's a miserable condition," says Winters, who suffered from constant fatigue before seeking treatment several years ago. "The sleep deprivation just builds up, because you're not able to relax. Even in the daytime, being in confined spaces like an airplane can be very challenging."

What keeps RLS patients awake is the sensation they feel in their legs, a feeling that is described in very unique terms by those who suffer from the disorder.

According to Dr. Mahowald, patients often explain it as a "pulling, tugging, gnawing, or creepy-crawling" feeling. "Or they'll use phrases like 'ants in my legs' and 'Pepsi Cola in my veins.' One patient said she had a shimmering feeling in her legs," he says. "They'll use bizarre adjectives, indicating that what they are experiencing is something that people who do not have RLS have never encountered."

Because the characteristics of RLS are so unique, it can be quite easy for physicians to diagnose the disorder—provided they are familiar with it. But for the many doctors who haven't heard of RLS, "you can never imagine what this could be," says Dr. Mahowald.

And that's the problem for patients like Page. When she first sought treatment, she consulted with several different doctors about her symptoms, receiving a range of opinions, from calcium deficiency to multiple sclerosis (for which she tested negative). But nothing seemed to ring a bell until she happened to see an article on RLS while in the waiting room of a neurologist's office. For Page, it was like a light bulb went on. She approached her doctor with the information she'd just found and was soon properly diagnosed.

Restless legs syndrome is not widely known among the medical community,

so the burden often falls on patients to bring it up, says Dr. Mahowald. He encourages patients to be up-front and ask their doctors if the symptoms they are experiencing sound like RLS. If they aren't satisfied with the response, they should move on until they find a neurologist or sleep specialist who does know the condition, he says.

Easing the Pain

Fortunately, says Dr. Mahowald, nailing down a diagnosis is often the most difficult part of the process. Once that has been established, patients are put on a treatment plan.

There are three classes of medications used to help manage the symptoms of RLS, Dr. Mahowald says. The most common drugs—and the only drugs approved by the FDA specifically to treat the disorder—are pramipexole and ropinirole, according to John Winkelman, M.D., medical director of the Sleep Health Center at Brigham and Women's Hospital in Boston, MA, and assistant professor of psychiatry at Harvard Medical School. Known as dopaminergic agents, these drugs are "extremely effective in reducing the sensory symptoms and the urge to move in RLS," he says. They can also improve sleep quality and are generally well tolerated by patients.

If taken over a long-term period, however, these medications can result in a condition called augmentation, in which symptoms of RLS show up earlier in the day. Roughly one-third to one-half of patients experience mild augmentation, which is manageable, says Dr. Winkelman. But the small percentage who have severe augmentation may have to discontinue the medication. In any case, he adds, it is critical that patients discuss these issues with their doctor so that adjustments can be made.

Another treatment often used includes antiseizure medications such as gabapentin and pregabalin. According to Dr. Winkelman, these medications appear to be effective in patients with RLS; however, at this time they have not been approved by the FDA for that purpose (they are approved to treat

nerve pain, among other conditions). (Discover [other articles about pregabalin for RLS](#).)

Finally, narcotic pain medications, or opiates, can be "extremely effective" in treating RLS symptoms, Dr. Winkelman says. And while some patients may be hesitant to go this route, he says, "they are used in low doses, and can be used in combination with the other treatments. Patients get substantial relief and improvement in sleep, and there is very little evidence of abuse or misuse of these medicines in patients with RLS."

As with so many conditions, there is no singular drug, or even combination of drugs, that will work for everyone. And as people like Page have learned, determining the best course of therapy can be frustrating, particularly in the beginning.

"I would try a medication for two or three months, then it wouldn't work, and I'd try a combination," Page recalls. "It's very much trial and error. You're your own guinea pig, because you're the only one who can tell whether it's working or not."

The process can be arduous, but it's important that patients work with their doctor to determine the best treatment regimen for them—and that includes not just which drugs to take, but when and how much to take them.

"There's no point in giving the medicine at times when people don't have symptoms. RLS is unlike other disorders that are present 24 hours a day, like [Parkinson's disease](#), depression, or [chronic pain](#)," says Dr. Winkelman. "You want to apply the treatments at the appropriate times to prevent or minimize the appearance of symptoms."

While for some patients the road to recovery is a long one, others respond very quickly to treatments, according to Dr. Mahowald. "We've had patients with bad RLS who've come back to us and said they never thought they'd sleep that well again." This is why he feels it is vital that healthcare

professionals are educated about RLS. "It's a condition that can be almost disabling, but it's easy to diagnose and treat."

Battling Public Opinion

One barrier still standing in the way, says Dr. Mahowald, is the fact that many people still question the disorder's legitimacy. Some even go as far as to say that RLS was invented by pharmaceutical companies, a claim he dismisses as ignorant. "We know the etiology [the cause of the condition], we know some of the pathophysiology [the disease process], and we know some of the mechanisms. There is no question that this is an organic and terrible disorder," Dr. Mahowald stresses.



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But perhaps no one is impacted more by public misunderstanding about RLS than those who suffer from the disorder.

"There's all this negative publicity surrounding RLS, and it just invalidates everything that you feel," says Page. "People tend to look at you strangely, like you're making this up and trying to get attention. If they don't have

anyone in their family who has RLS, or if they don't have it, they just don't understand."

And there are times when the public's lack of awareness about RLS can be particularly frustrating, such as when someone like Winters is traveling by plane and needs an aisle seat. In fact, he has found that when he tells flight attendants that he has Wittmaack-Ekbom syndrome (a lesser-known term for RLS) and therefore needs to be able to get up and stretch his legs, they're more likely to accommodate him. "I guess it sounds more official," says Winters. However, he does believe that in recent years, people have become better informed about RLS.

While some progress has been made in the realm of public awareness, there are still countless challenges facing people with RLS. This is why both Winters and Page devote their time to RLS Foundation support groups, which provide a forum to talk about what it's like to live with RLS, how they can communicate with families and friends about the disorder, what treatments work for them, and more.

Winters has been a leader for the Seattle and Vicinity RLS Support Group since 2002, and currently serves on the Support Group Advisory Board as part of the [RLS Foundation](#). Page is a leader for the Central Missouri RLS Support Group, as well as a regional liaison and a board member. It's an experience that she says has benefitted her as much as those who attend the meetings.

"I honestly don't know where I would be at this point—even with medication—if I didn't have support from the people I've met, both online and in person," Page says. "When you go to several doctors and they say there's nothing wrong, you begin to wonder: Is it in my head? Am I going crazy? And that's why I really think it's important to be able to talk to other people that have it, so you know you're not alone."

In addition to providing RLS sufferers with a forum, Williams believes that support groups can also encourage people who have RLS to become more educated about the disorder and get involved in advocacy and awareness efforts.

"The ongoing effort of the RLS Foundation is important. You need that network, because having RLS is aggravation in one respect or another," Williams says. "It's aggravation because you can't get to sleep. It's aggravation because the medication is not working. It's aggravation because you can't explain it to other people and comedians are making jokes and the whole world seems to be laughing at something that's a pretty serious condition. It's important for all of us to talk about RLS and keeping moving forward."

The Bedfellows Of RLS

According to the Restless Legs Syndrome Foundation, there are a number of conditions that are often associated with RLS. While RLS is often hereditary, it may also occur in conjunction with:

- Pregnancy
- Iron deficiency
- Kidney disease with dialysis
- Peripheral neuropathy
- Attention deficit disorder
- Diabetes

Taking On RLS, One Step At A Time

When people learn they have RLS, or believe they may suffer from the disorder, it can be overwhelming. Kathy Page and Roger Winters, both of whom have lived with RLS for many years, offer these words of advice.

GET DIAGNOSED: The first step, says Page, is to find a doctor who is familiar with RLS and can help you begin treatment—and don't stop until you do. If a physician doesn't know about RLS, keep going until you find one who does, or is at least willing to listen and work with you. "You have to put your foot down and say, there is something wrong here," she says. "You may not find anyone who's going to listen to you at first. But don't give up. You have to keep trying. You will find someone that will listen to you and will help. But it's going to take time."

EDUCATE YOURSELF: A good place to start is the [RLS Foundation](#) website, which offers helpful information about the disorder. "Learn all you can," says Page, "because you're going to have to educate your families, your friends, your employers and, in many cases, your doctors."

KNOW YOUR RLS: Because RLS can impact people differently, it's important to pay close attention to how you feel at all times, and make whatever changes are necessary to improve your well-being. Page suggests keeping a diary of daily activities, diet, stress levels, and whether the RLS was bothersome that night. For example, she now knows that she needs to take her medication at the same exact time every night, and that she should avoid caffeine and alcohol at night. "People have to educate themselves on what's going to trigger their RLS, what's going to make it worse, what they need to avoid and what's going to help," says Page. "It's more than just taking medication; it's a lifestyle change."

SEEK SUPPORT: Both Page and Winters strongly recommend finding a local support group (through the RLS Foundation) and attending meetings as often as possible. "You may not find anyone that has the same symptoms as you, but they still know what you're going through, and that helps so much," says Page.

SPREAD THE WORD: While public awareness of RLS may be slowly improving, it is still surprisingly low. Therefore, it's up to people who have

the disorder to reverse the trend by educating others. Winters, for example, sat down with his coworkers and explained how RLS affects him. This way, they would know why he needs to move his legs while sitting at a conference table, or why he needs to stand in the back of a room during a meeting. "Most people will understand," he says, "if you take the time to explain it to them."

GET INVOLVED: For Page, getting involved with the RLS Foundation was a no-brainer. In her family, RLS is hereditary: Her mother had it, and two of her daughters have experienced it to some extent. The more she can help spread the word, she says, the better the chances for improved treatments or even a cure. "If I just sit back and don't do anything, I'm not helping them at all," she says.

Winters chose to lend his time to the cause in hopes that others would have an easier road than he did. "You don't want any patient to be out there without information or support," he says. "They need to know that what they have is real and worthy of attention and treatment."
