PRACTICE

A PATIENT'S JOURNEY

Restless legs syndrome

This patient, who has had RLS for 12 years, describes how doctors' lack of knowledge about the condition delayed effective treatment; she urges patients and doctors alike to become better informed

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

In 2000 my life changed in a major way. Out of the blue, my legs started feeling “funny,” as if insects were crawling inside them, especially when I was watching television in the evening. I had to move them continually to get rid of these sensations, which was quite annoying for my husband sitting beside me on the sofa. Soon these sensations occurred all day long, and I began to experience what felt like electric shocks in my limbs, followed by spontaneous and uncontrollable kicking. A few weeks later this spread to my arms and torso. It made me extremely irritable.

I had always slept like a baby, but not anymore. I did sleep but was now tossing and turning during the night and was totally exhausted when I woke up, as if I had fought a war. I knew straightaway that this was serious and that I had to seek help.

Restless legs syndrome (RLS) is a chronic and often progressive neurological sensorimotor disorder that interferes with sleep. The symptoms follow a day and night pattern: mild or non-existent between 5 am and 10 am, worsening later in the day, and with serious complaints in the evening and night, when patients find they have to keep moving and have difficulty falling or staying asleep.

The name restless legs sounds trivial. Telling your friends that you can't go out with them because your legs feel funny is invariably met with a giggle. Recently, it was given a new name: Willis-Ekbom disease.

My RLS leaves me with very little energy, both physically and mentally. I had to quit the job I loved. My social life is almost non-existent; I can't keep a conversation going for very long because of poor mental energy, or go with friends to the cinema or other such things. I have lost friends. I live like a recluse and am very lucky to have a loving, caring husband.

Severe RLS is disabling. Every day, I have to deal with fatigue, difficulty concentrating, depressed mood, and sometimes excessive daytime sleepiness. Quality sleep is something I can only dream about. Every day is a battle. I have to watch carefully certain triggers that make my RLS worse: strong emotions, getting too tired, long conversations. Stress makes it dramatically worse. Patients with severe RLS who also have other major diseases, such as a heart condition or cancer, often say that RLS has the greatest impact of them all. Many think life is unbearable.

After I had had to leave my job because of RLS, I decided to share my knowledge with others by writing about my experiences. For the Dutch RLS Patients Association I answer questions from fellow sufferers, which I find very satisfying.

I have several horror scenarios about the future. What if my husband dies before me? What if my RLS gets so bad that I have no choice but to end it all? What if I need surgery? What if I develop a condition such as Alzheimer's and am no longer able to fight for myself? Will the nurses then know about my complicated medication scheme, and will they tie me up instead of letting me walk around all the time?

Dealings with doctors

I was thrilled that the first specialist I was going to visit was a respected neurologist with a sound knowledge of RLS. A sleep study was done and it turned out to be OK. I was told I did not need any treatment at all and should discontinue the sleeping pill I was taking at the time. I came home feeling very upset: no help, what now? A few weeks later I was truly desperate, and told my general practitioner I couldn't go on like this, that I had suicidal thoughts. He immediately prescribed an antidepressant. Antidepressants in many cases make RLS symptoms worse, so I refused, but he was adamant. I then indeed slept better, but still woke up exhausted. Because of this the neurologist declined to treat me anymore. So, nine months later I was still receiving no treatment and felt even more desperate.

I became an avid reader of RLS information on the internet, became a member of a large international support group, and gradually became a very well informed patient. I learnt about treatments through the “questions and answers” (Q&A) pages of a respected RLS expert in the United States.

Education proved to be useful. For instance, when a second neurologist suggested prescribing Sinemet (levodopa with carbidopa) I could inform him that in the United States this medication was no longer prescribed for daily RLS because it had an 80% chance of causing “augmentation,” a paradoxical reaction to the medication. We then tried several dopamine agonists but unfortunately nothing worked for long. In the end he referred me to a specialist at a university hospital. I have now been seeing this doctor for nine years and hope to continue with him for many more to come.

In the meantime I had gone on sick leave from work and obviously then had to deal with the company doctor. He was pleasant but knew nothing about RLS. The diagnoses he came up with were depression and burnout; he was wrong. I subsequently gave him detailed information on RLS but failed to convince him.

The next step was that I applied for disability benefit. The doctors at the social services department were completely ignorant about RLS. They stared at me blankly when I told them about my symptoms—infuriating. They were to decide on my future income with no knowledge of RLS at all. I was denied social security. I had to go to court twice to get a social security monthly income.

Education and team work

The most important thing for RLS patients to do is to educate themselves about RLS. Not only will this enable them to manage their symptoms better, it also makes them worthy discussion partners when visiting the doctor's surgery. Not every GP is knowledgeable about RLS or fully aware of the treatments available. This need not be a problem as long as he or she is willing to learn and work with the patient as a team. Thus, respectfully correcting your doctor when he or she gives you a wrong diagnosis or medication becomes a possibility. You may, however, have to look for another doctor if your complaints are dismissed as psychosomatic or the doctor is not willing to work with you.

I hope doctors will offer their patients who have severe RLS a package of medical treatment and professional psychological help to help them adjust to the dramatic change in their lives.

Hospital doctors, surgeons, and anaesthesiologists need to be well informed about RLS. They often lack the necessary knowledge about the condition and are unaware that, in patients with RLS, prescribing certain medications before and after surgery may have disastrous effects. Here, too, the patient's own role can be of the utmost importance.

Although awareness of RLS seems to be slowly increasing, there is still far too much ignorance of the condition by patients and doctors alike. This leads to unnecessary suffering, inappropriate medical interventions, prescription of unsuitable medicines, and, during surgery, unintentional harm because RLS symptoms can occur during anesthesia and so it can be hard to operate on such patients. RLS deserves to be taken seriously. When it is properly treated, society and health economics are bound to benefit.

A final word: the diseasemongering groups in this world have many times taken RLS as a glorious example of selling sickness. I sincerely hope that my story will give those supporting that movement food for thought.

Stichting Restless Legs is a Dutch patient advocacy group.

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- 2 Earley CJ, Silber MH. Restless legs syndrome: understanding its consequences and the need for better treatment. *Sleep Med* 2010;11:807-15.

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A doctor's perspective

General information

Restless legs syndrome is diagnosed on history taking and four recognised criteria: an urge to move the legs, usually accompanied by unpleasant sensations; occurrence of symptoms during rest; relief of symptoms by movement; and worsening of symptoms in the evening or night.

Severity is variable. A recent study in 2010 in western Europe found that almost 0.8% of the general population have symptoms of RLS sufficiently severe to seriously affect their quality of life.^{1,2} RLS is more prevalent in women, and prevalence increases with age. Effective drug treatments are available, but their use is limited by side effects. "Augmentation"—in which the symptoms change as a result of dopaminergic treatment—may particularly pose problems: earlier onset of symptoms (symptoms occurring earlier in the day than they did before the patient started taking dopaminergic treatment); shorter latency to occurrence of symptoms when at rest; and involvement of additional body parts (such as arms).

Although the exact cause of RLS is unknown, and objective diagnostic tests are lacking, there is no doubt that it is an organic disease: it often runs in families, and genetic loci have been identified. Impaired brain iron metabolism probably plays a part. Besides this "idiopathic," primary form, secondary forms have also been identified, notably in a setting of iron deficiency, pregnancy, neuropathy, and renal failure. Depression, anxiety, and insomnia are recognised comorbid disorders and may add substantially to the experienced impaired quality of life.²

Although RLS has been known about for centuries, and internationally accepted diagnostic criteria were formulated in the 1990s, many cases are probably undiagnosed,¹ and even if cases are diagnosed correctly, patients often receive no or inadequate treatment.

Some people think that diagnosing RLS is a nice excuse for making a profit on unnecessary drugs. For RLS such accusations have created highly negative publicity. By suggesting that RLS may well be a normal aspect of life, feelings are exploited and knowledge about the truly disabling form of the disease is disregarded. Unfortunately, feelings are hard to combat with arguments.

Specific comments

Ms Algera and I have been struggling for years to combat her severe RLS. Her report of her medical journey unfortunately reflects that of many patients with RLS. She describes how the comorbidities of RLS may be at least as disabling as the core symptoms. RLS may be difficult to treat, particularly when side effects of the dopaminergic medication such as augmentation occur; nevertheless, the comorbidities may become a more disabling problem because they seem to be even more difficult to treat. Future research will have to deal with this as well.

This story illustrates the importance of interaction between patient and doctor. In a disease defined by subjective complaints, this is crucial. Only patients can say which aspects of their disease they find hardest to cope with. I am happy that Ms Algera, although far from relieved of her RLS complaints, is willing and able to give support to fellow patients and continues to be a valuable partner for doctors and scientists in the field.

Gert Jan Lammers, neurologist and clinical neurophysiologist

Useful resources for patients and health professionals

- European Alliance for Restless Legs Syndrome ()—An umbrella organisation of European patient advocacy groups and a non-profit member of the Alliance of National Patient Organizations. It works for greater awareness of RLS and raises important matters at a European level
- RLS-UK (www.rls-uk.org)—Also known as the Ekblom Syndrome Association, it's a UK registered charity dedicated to helping people with RLS
- Restless Legs Syndrome Foundation (www.rls.org)—A non-profit US patient organisation providing the latest information about RLS
- International Restless Legs Syndrome Study Group (<http://irlsrg.org>)—An organisation of professionals committed to advancing basic and clinical research on RLS