Living with Restless Legs Syndrome
In this booklet, Jutta, Juan, Esperanza, Maria José, Valeria and Sten describe what Restless Legs Syndrome means to them, and how it has changed their lives. They have found ways to relieve some of their symptoms, improve their everyday lives, and give them confidence to face the challenges ahead. Seeing a specialist who understood the problems of RLS and knew how to tackle them was an important turning point for all the people in this booklet. None of them is completely free of symptoms, but they have made significant progress towards this goal. Each has found ways to relieve some of their symptoms, improve their everyday lives, and give them confidence to face the challenges ahead.

By reading their stories and finding out more about how RLS is diagnosed and treated, we hope that you will be able to find the same kind of help and support which is giving Jutta, Juan, Esperanza, Maria José, Valeria and Sten the opportunity to lead the lives they choose.

This publication is part of an initiative from UCB to raise awareness about RLS amongst healthcare professionals, patients and the wider public. Its aim is to enable people with RLS to recognize their symptoms and work with their doctors to help release them from the limitations that their illness puts on their daily activities.

Individual symptoms of Restless Legs Syndrome (RLS) may vary and the experiences of the people in this booklet may not be typical for all patients. This booklet from UCB includes strategies used by people with RLS to live well with their condition and should not be seen as UCB’s advice about the condition. Any approaches described in this booklet are not meant to replace those recommended by healthcare professionals.

Foreword

Tatiana Kharkavitch
Medical Director, Sleep and Movement Disorders, UCB
When Jutta first noticed the crawling sensation in her legs, she didn’t pay it much attention as it didn’t happen very often. A year later, just weeks before she and her husband were due to indulge their passion for botany and gardening with a trip to Costa Rica, Jutta became increasingly restless and suffered bad insomnia. She got on the aeroplane, hoping the holiday would help her relax:

“During the night flight, I began to feel a tingling and pulsing heat sensation under the soles of my feet. I became increasingly bothered by it and wanted to get up and move about. But people were sleeping and I didn’t want to disturb them. As the symptoms intensified, I felt like pulling my hairs out one-by-one. I had no choice but to get up and pace the aisles which gave me some relief,” Jutta recalls.

When she was told to return to her seat and stop disturbing the other passengers, Jutta describes the nightmare of having to sit out the flight, a prisoner in her own body.

When Jutta got home to Costa Rica, she became increasingly restless and suffered from bad insomnia.

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What is Restless Legs Syndrome?

No one knows exactly what causes RLS, but it is more common in women than men, and it increases with age. Many women, like Esperanza, trace the start of their RLS to being pregnant:

“My RLS started with my first pregnancy at the age of 20, and the discomfort in my legs – which felt as if something was bubbling inside – persisted and grew stronger at night. The sensation stayed with me throughout my pregnancy, but after giving birth, it gradually eased. However, when I got pregnant again the following year, the all too familiar discomfort in my legs returned, and after my third child, the restlessness in my legs seemed to become permanent.

“By the time I was 35 years old, it became nearly impossible for me to concentrate on work and I was very short with my family. I couldn’t even sit on the sofa, and when I’d go to bed at night, the real torture would begin and the desire to kick my legs came in frequent 10-second bursts.”

Maria José had symptoms of RLS even as a child, but her symptoms became much worse during her first two pregnancies:

“During my third pregnancy, my condition was at its height. The more I tried to control the inconvenient desire to move my legs, the worse the discomfort seemed to get. The only way to find any relief was to get up and move about for a while. I sometimes took cold showers at night in attempts to stop the sensations that pulsed through my legs. I had no idea what was happening to me and didn’t know what to do.”

Both Maria José’s sister and father have experienced symptoms of RLS, and the condition is known to run in families, so there is possibly a genetic link.

“I hoped that I did not have RLS. I believed that if I refused to accept that I had such a disease, I wouldn’t really have it. Little did I realize, I was deep in denial,” says Maria José.

Maria José & Maria José
Getting a diagnosis

There is no simple test for RLS. It is usually diagnosed from a description of the symptoms, especially if these are worse at night or at rest. But many people with RLS report long delays in getting a diagnosis, especially if they have trouble describing their symptoms, like Maria José:

“It was difficult for me to explain my condition to a doctor. I could not even explain what I was feeling to myself,” she says. “That fact alone made it difficult for the doctor to understand what was happening to me. Yet, I tried my best as I consulted my general practitioner, two traumatologists, and three neurologists.”

Sten, who has had RLS symptoms since childhood, experienced similar delays, but describes his relief when he finally got a diagnosis:

“The neurologist did everything to find out why I was plagued by these irritating and painful symptoms. I had numerous scans and other tests to exclude other sicknesses. I then spent a night in a sleep unit. It was a frantic night with all these cables and electrodes attached to my body, which made it impossible to sleep. In the morning I was informed that I had severe RLS, but I was happy because I had a diagnosis, and it wasn’t an ‘illusion’ after all.”

“Getting a referral to a specialist neurologist also proved the turning point for Esperanza who waited many years for her diagnosis:

“I was surprised to see that the neurologist was so young—he couldn’t have been older than 35 or 36. He told me that I’d have to be admitted to the hospital for a sleep test and other exams. We started to talk and he asked me to describe my symptoms. When I’d finished the list, he told me I had a textbook case of RLS. After a night of testing, I also learned that I’d experienced over 5,600 leg-shaking episodes in seven hours! Meaning, I didn’t get a wink of ‘quality’ sleep.”
Juan has cut back on caffeine and reduced the stress in his life, and finally found a medicine that helps him, though he still has trouble sleeping:

“My night time involuntary movements and other symptoms are a bit better and I am coping a little better with this disease. My life is still more or less the same because although this medication ‘suits’ me, it does not offer a complete cure,” he explains.

At first, Esperanza was concerned that her medicine affected her memory. But her persistence paid off when she had less need to keep shaking her legs. Unfortunately, the benefit didn’t last, and the shaking spread to virtually her entire body:

“My doctor changed my treatment once, twice, three times – but nothing seemed to help. Over the years, the endless shaking had worn my hip bone. At night, I couldn’t turn in bed because my muscles were like bars of iron. At that time, I was taking three types of tablets but it seemed as though my legs would never stop moving.”

A hip replacement has eased Esperanza’s pain though her friends still call her a ‘fidget’ because she’s always on the move. As well as finding a medicine that works for her, Valeria, who started getting RLS symptoms in her mid-40s, believes that patients can do much to educate and help themselves.

“Over the years, I have discovered a few things that work for me to help me cope better with my RLS. I’ve learned that it is better to stand in the evening (as long as I can) rather than sit. I also find it useful not to eat carbohydrates in the evening. Cutting down on alcohol and coffee also helps me. Being active (Nordic walking) and keeping myself busy with my hobbies keeps my mind off my RLS. But I know that we’re all different, and we all need to find our own way of managing our RLS symptoms.”

Juan, Esperanza, Sten, Jutta, Maria José and Valeria have all found ways to reduce their symptoms, but none has found a cure. Each has tried several different medicines with varying success.
Maria José has had the same neurologist for three years and is convinced that being able to talk to her doctor about her RLS is playing an important part in her continuing ability to manage her symptoms:

“I believe that sitting down with my doctor and patiently working things out has been so important in the treatment of my RLS. In my case, the adaptation process was slow, but now I manage to live as full a life as possible.

“By communicating openly with my doctor I found the right treatment for me, which has made a world of difference. The patient-doctor relationship is the key to the best health outcomes and, because of my relationship with my doctor, I know that all is not lost with a diagnosis of RLS.”

Many people with RLS find that keeping a diary of their symptoms, and how these affect their sleep and their ability to carry out everyday activities, helps them to discuss their progress with their doctor and find the best approach.

Talking to the doctor

Like Maria José, Juan has also discovered that establishing a good working relationship with his doctor was crucial to finding the best way to treat his RLS.

“I found a neurologist whose tenacity helped me find out what treatments were available. After testing different drugs, we found the one that has allowed a partial improvement in my condition.

“Finding the right doctor to identify what was wrong with me was an important step. The mystery symptoms had been taking an emotional toll on me. It was also helpful to know that there were some treatment options once we knew what the disease was. My current doctor is always concerned about how I am doing and making adjustments or offering suggestions when she can, and I really appreciate that!”
Juan and Sten have discovered the value of RLS support groups to be able to discuss their symptoms and learn from each other:

The need for support

The support of their husbands, wives, family and friends has proved essential to Esperanza, Sten, Jutta, Juan, Maria José and Valeria in finding ways to live with their RLS.

Maria José was wary of inconveniencing her family when she was first diagnosed, but she is now convinced of the need to share her experiences.

“I’ve shared my struggles and details about my treatment with my children, now I’m older, and I believe that talking with others about my disease gives me the support I need.” she says.

Jutta’s friends were very supportive when she needed to get up and walk around to relieve her symptoms at dinner parties and other social events, and her husband would come and find her when she needed to get up in the night:

“One night he came to check on me with a bottle of champagne and took me to our garden where we sat under the stars and enjoyed our flowers!”

After her diagnosis, Valeria’s husband was her pillar of strength, discussing her RLS with her:

“He reminded me to take my medication regularly, joined me in outdoor sporting activities and encouraged me not to lose my zest for life.”

Juan and Sten have discovered the value of RLS support groups to be able to discuss their symptoms and learn from each other:

“At the group, we encourage each other to fight against the inconveniences we have with RLS and remind each other not to give up. We talk about our treatments and how they are working for us individually,” Juan explains.

Having educated himself about RLS, Sten is keen to help others – patients and doctors – to understand more about the condition:

“The more you know, the more you understand, and the better you can manage your symptoms and live with RLS. Talking to others with RLS has helped me feel less alone. They know well the sensations I’ve had since my childhood, they understand.”
Restless Legs Syndrome

Between 3% and 9% of the general population is affected by RLS and it is more common in women than men. During sleep about 8 out of 10 people with RLS also have Periodic Limb Movement Disorder (PLMD) – sudden, uncontrolled limb movements.

The causes of RLS are unclear, but there appears to be a genetic link. RLS is also more common in pregnant women, and in people with low iron levels (anaemia) and advanced kidney disease.

RLS is diagnosed in people who have an urge to move their legs, usually accompanied by uncomfortable or unpleasant sensations in the legs, which

- Begins or worsens during periods of rest or inactivity such as lying or sitting
- Is partly or totally relieved by movement such as walking, bending, stretching, etc. at least for as long as the activity continues
- Is worse in the evening or at night than during the day, or only occurs in the evening or night.

Other factors which support the diagnosis of RLS are:

- A beneficial response to treatment that boosts levels of the nerve transmitter, dopamine, in the brain
- PLMD (during wakefulness or sleep)
- A family history of RLS.