

I have had RLS for over 20 years. When I was a child my legs were always aching. I was told it was only 'growing pains'. Mum would rub deep heat on them which gave short term relief. At around the age of 40 it got worst. My legs twitched and were aching much more than they ever had. I tried cramp zee tablets with only short term results. I went to the doctor who suggested all sorts of things that didn't apply to me. He suggested it could have been because I had a job that required me to stand all day but my legs only got restless and ached in the evening once I was in bed. The doctor told me to take magnetism tablets, again this only provided short term relief. It got to the point where I would go to bed for 90 minutes, then be up for 2 to 3 hours pacing the floor, before hoping back into bed and trying to sleep again.

After speaking to a friend of mine who was being treated in NZ with medication (that was not available in Australia) I spoke to a doctor friend of mine at church. He said that while that medication wasn't available here he could write out a script for Sifrol. In the first week, it worked wonders. I slept all night without having to get up. After years of aching and uncomfortable twitching, the relief was great but it hasn't been 'happily ever after' for me.

It has been nearly 5 years since I started taking Sifrol. I no longer have a job where I am standing all day. I'm sitting more now and by mid afternoon my legs are aching and twitching, some days they start when I am driving home. They are very painful. It's hard to concentrate. Now it's not only in my legs but it can also start in my arms if I have not taken a tablet. I suggested to my doctor that maybe I have become used to the medication but he didn't seem to think so. So now if there are days where I know I am going to be sitting for a while I will take a tablet in the morning and then again in the early evening. RLS still affects my ability to get to sleep and stay asleep. Yes, Sifrol takes the edge off, but there are still evenings where I am pacing the floor and my arms ache if the medication has not kicked in. The days that I'm ache free are rare. It is frustrating for my husband when I toss in bed and stamp/pace the floor as he feels helpless knowing that there is nothing he can do to relieve it for me.

I work in aged care. There are residents who have RLS yet I have come across staff that do not understand it. One resident was told to go back to bed when she was pacing the floor. That is the worst thing you can tell someone with RLS.

There are days I just want to chop my legs off. While medication helps to take the edge off I'm still left with a lot of pain. Hopefully one day there will be a cure.

*Written by Pam for RLS Awareness Day 2018*

