

My RLS story - Kerry

For nearly all of my life I have suffered with RLS. I am now 59 and have only been treated for it in the last 6 months. I am on Sifrol and so far so good with no side effects.

I always assumed it was my back and sciatica. I would go to my doctors with that complaint and I was treated as such. The most telling sign I now know was the fact that it could switch sides mainly left but sometimes right. How I survived I do not know. It was so bad some nights I just cried. I suffered some major depression, anorexia, suicidal thoughts, but all the time still continued to think it was my back. Spinal blocks, xrays, Tramadol, Lyrica, nothing touched it. I have had wonderful doctors who have tried and took my complaints seriously however I was giving wrong information to them. I didn't know how to communicate what was happening to me in a way that they would understand.

It was while I was researching that I found Kaye Parker who wrote the book *Restless Legs Syndrome an inside story*. I gave it to my doctors surgery and asked them all to read it.

Prior to this I had been looked at as having fibromyalgia, rheumatoid and osteo arthritis. It was actually the rheumatologist who prescribed the Sifrol. I am off all other drugs except zoloft - low dose and some magnesium.

My doctor is so happy for me that I can now separate things. I do know that some Neurophen or Panadol will help my back to a degree but knowing there is relief for this torturous and insane nightmare I now know is Restless Legs Syndrome is wonderful. I no longer go to my doctor saying please cut my legs off (sadly he thought I was joking!)

It still niggles but I am trying to keep the Sifrol dose as low as bearable so I have somewhere to go.

I have travelled again. I can stay with friends and not worry about disturbing them. I can sit at a concert (only if I have had meds prior). I can go out for dinner and sit at a table. I have a life again. I am now finding people who are suffering as well and actually starting to think it may be more common than I thought.

I am terrified of being in aged care and not being helped. I carry a St John's booklet with me saying I have Restless Legs Syndrome. Hospital was awful without knowledge. I still said it was my back! I used to fear getting old and not being able to move. I thought if I was in this much pain now I would never cope when I got older. Since being diagnosed with RLS and receiving treatment I now have some hope and positivity.

Written by Kerry for Restless Legs Syndrome Awareness Day 2019

