



Patient Information Sheet: Restless Legs Syndrome



How to manage your Restless Legs Syndrome

This patient information sheet will help you understand:

- What is Restless Legs Syndrome?
- What causes Restless Legs Syndrome?
- What can I do to manage my restless legs?
- When should I talk to my healthcare team?

This guide is for people who are participating in the Dialysis Symptom COnTrol-Restless Legs Syndrome (DISCO-RLS) Trial. It can be used by patients or their family, friends or caregivers. It does not replace advice from your healthcare team.

What is Restless Legs Syndrome?

- Restless Legs Syndrome causes an urge to move your legs (or any other body part) that is usually or not always accompanied by or felt to be caused by uncomfortable or unpleasant sensations in the legs
- It begins or is worse during periods of rest or inactivity (e.g. lying down, sitting, during dialysis)
- It is partially or totally relieved by movement such as walking or stretching at least as long as the activity continues
- It only occurs or is worse in the evening or at night than during the day
- It is not solely accounted for by another condition (e.g. muscle pain, blood vessel problems, leg swelling, arthritis, cramps, positional discomfort, nerve pain)

What Causes Restless Legs Syndrome?

- The cause of Restless Legs Syndrome is not entirely clear
- It affects up to 30% of individuals with kidney disease compared to 3-5% of the population
- It has been linked to:
 - Family history/genetics
 - Low blood iron levels
 - Anemia (low red blood cell count)
 - Pregnancy
 - Parkinson's disease
 - Inadequate dialysis



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What Can I Do To Manage My Restless Legs?

Tips to help prevent or reduce your symptoms of restless legs:

- Stop using or limit caffeine and alcohol, especially in the evening before bedtime
- Do not smoke or get help to quit smoking
- Try to do physical activity each day – find activities that you enjoy and that fit in with your daily life, such as walking or stretching (if it is safe for you as determined by your physician)
 - Being active during the day can help you sleep better at night
 - Always talk to your healthcare team about how to exercise safely
- Stretch or massage your legs with your hands
- Put a warm towel or heating pad on your legs, or take a warm shower or bath
- If warm doesn't help, try a cold compress or a cool bath
- Try massaging your legs prior to trying to fall asleep
- If you are taking medication for your restless legs, take it **exactly** as prescribed – do not wait for your restless legs to get really bad

When Should I Talk To My Doctor or Healthcare Team?

Speak to your healthcare team if restless legs are not controlled and are affecting your sleep and quality of life. Your healthcare team may talk about treatment options such as exercise (on or off of dialysis), stretching, massage, increasing your dialysis time or frequency and review your list of medications to see if anything else is contributing. Medications exist that might help with your restless legs including gabapentin and ropinirole which are being studied in the DISCO-RLS Trial.

If your restless legs are still not controlled using the tips above and the study medications are not working for you, you have the option to stop both study drugs and immediately switch to the next treatment period (e.g. “crossover”). We encourage you to continue in the study so that we are able to determine the best treatment for restless legs syndrome in dialysis patients.

Speak to your healthcare team if you develop any side effects thought to be related to study medication during the study. All side effects related to study medications are temporary and resolve with stopping the study drugs. However, there are lots of reasons patients on dialysis develop symptoms that might be side effects related to study drugs (e.g. nausea, vomiting, diarrhea, drowsiness, dizziness) including the dialysis procedure itself and other events such as infections. If you are unable to tolerate the study drugs, you can stop them and also crossover to the next treatment period when you feel ready to do so. Please contact the research staff if you choose to stop taking your study medication.