



Guidance for people with RLS requiring surgery

Why is this guidance being provided?

The experience below of a member describes what happened to him.

As soon as I woke up after the first operation, I was aware of the waves of RLS starting in my legs. This was in the early evening, and very shortly afterwards I was forced to get out of bed in order to walk. As you can imagine this was painful and I was still weak and unsteady on my feet, but I had no choice. I absolutely had to move!

This started in the evening and went on all night. And then all the following day. And all the following night, as well. In fact, this 'crisis' continued, without stopping for more than a few moments, for four days and four nights. During this time, I was unable to sleep, at all; and barely able to sit for more than a few minutes, so that I barely ate anything, while the RLS was at its worst.

What needs to be considered?

RLS-UK recognise that clinical staff in hospital may not have easy access to up-to-date information about RLS and surgery and the things that are helpful to consider when in hospital.

People with RLS need to be the champion of their own health needs when in hospital and bring information to the attention of the clinical team to help ensure that RLS is considered as seriously as the reason they are in hospital for.

Different health conditions that may lead to hospitalisation may adversely affect the absorptions of iron and thus adversely affect our RLS symptoms. Also when in hospital people are inactive, they sit and lie in bed a lot so RLS symptoms could be more severe.

Whilst Haemagloblin levels may be monitored, it is worth asking about ferritin levels as well – are they around or above 75, if not what action can be taken to improve this? If iron supplements are being taken– or an iron infusion given, is sufficient consideration being given to constipation and the problems that brings with it. Can our dietary intake in hospital help with maintaining and / or improving our iron levels such as ensuring sufficient fibre and fluids.

We also know it's best not to reduce or increase RLS medications whilst in hospital. To ensure continuity it's a good idea to take your prescription with you.

The anti nauseates routinely given with anaesthesia are a known trigger for RLS so it is important that you discuss safe alternatives with the team before your surgery. Safe alternatives include Kytril, Vistaril and Zofran.

Key points

- Plan ahead if possible
- Take your RLS medical alert card with you and at least one copy of the RLS information leaflet (RLS-UK can supply these for you)
- Inform the surgical team about your RLS
- Take a list of your medication with you to the hospital including what time you take the medication.
- Just in case the hospital does not have quick access to the RLS medication that you take – bring with your medication from home (in original packaging) and ensure that the ward staff are aware of the need for you to take your medication at the correct time.
- Be aware of your food and drink triggers to avoid while in hospital.
- If you are under the care of a neurologist, take their contact details with you in case the surgical team require further information.
- Can you do the things that help you at home when in hospital? Can you walk a bit, can you stretch, take a warm shower or massage your legs?
- The biggest issue after surgery is often the anti-nausea drugs given. Try to avoid dopamine blockers and ask for a different medication as listed above.
- Sleep is often difficult in hospital and you may require sleeping pills at night. Caution is required with regard to these. Bring ear plugs with you if they help with the environmental noise. If you have to have sleep medication avoid antihistamines or antidepressants. Ask for Zolpidem as it is RLS friendly and does not cause excessive drowsiness.

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