Question: Do many other post polio patients have restless leg syndrome? How is it usually treated?

Answer: This recent question from a reader ties perfectly into our multipart series on sleep. As you will recall, Part I discussed insomnia and problems caused by lack of restful sleep. Part II discussed Sleep Hygiene and outlined habits that can improve quality and quantity of sleep. This month we will talk about one of several underlying sleep disorders. When discussing sleep disorders, it is important to understand that most individuals do not have either a problem with Sleep Hygiene or an underlying sleep disorder. It is usually an “and/both” situation - most individuals with underlying sleep disorder also have problems with Sleep Hygiene. So before specifically talking about specific treatment of Restless Leg Syndrome (RLS) & Periodic Leg Movement Disorder (PLMD), I want to emphasize that good Sleep Hygiene is imperative for an optimal outcome. Given the fact that old habits die slowly, it may be helpful to review Part II* of our series multiple times.

So what does RLS have to do with sleep? The answer is “A Lot!”. Since part of the definition of deep sleep is lack of muscle movement, anything that prevents muscle relaxation can prevent deep sleep. PLMD is a variant of RLS in which there is a neurologic drive for movement which battles the body’s drive for complete muscle relaxation/deep sleep. If the PLMD wins then an individual may have multiple awakenings or simply a very poor quality sleep, leading to all the consequences we discussed in Part I* of our series. Interestingly, lack of sleep can make RLS/PLMD even worse, leading to a “snowball effect”. This also highlights the importance of Sleep Hygiene and some individuals with a tendency towards RLS/PLMD may need no further treatment than to improve their Sleep Hygiene. Similarly, there is a significant overlap with Sleep Apnea and PLMD such that treating the sleep apnea may lead to resolution of the PLMD.

Since Sleep Apnea and suboptimal Sleep Hygiene are quite prevalent in the post polio population, it is no wonder that RLS/PLMD is quite prevalent. Additionally, there have been theories that fatigue plays a role in creating neurologic changes in the brain that facilitate RLS/PLMD. Excessive fatigue and Post-Polio Syndrome could, therefore, be another factor increasing prevalence of this problem. The exact prevalence is hard to determine and experts can argue different figures. A very brief review of literature showed studies have been small but some have noted a prevalence of RLS/PLMD as high as 63.6% in the polio population (7.5% in “healthy controls”). Another uncontrolled study showed a prevalence of 40.4% in polio survivors.

It is widely accepted that RLS/PLMD is likely underdiagnosed in the general population. My personal opinion is that most of us have an underlying tendency towards this condition, which can be “uncovered” at different times in our life in different stressful circumstances.

So what exactly are RLS and PLMD? Both are neurologic conditions. PLMD, in simplistic terms, can be thought of as a nighttime cousin of RLS. Up to 80% of individuals with RLS also

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have PLMD but the reverse is not true and many individuals with PLMD do not have RLS. PLMD can be objectively measured in a sleep laboratory using electrodes over the muscle. Diagnosis of RLS on the other hand, is based on history and symptoms. A strong family history can also aid in the diagnosis. RLS is often unrecognized or misdiagnosed, especially when symptoms are mild or intermittent yet, other cases of RLS are quite obvious. The hallmark symptom of RLS is an irresistible urge to move which worsens at rest or when laying down. It is important to stress that the urge comes first and is followed by voluntary movement. This is in contrast to movement which is involuntary such as muscle twitching or spasm. Some individuals also complain of “itchy”, “pins and needles” or “creepy crawly” feeling in their legs. I have also had patients complain of intense aching in their legs, although this is much less common.

Restless leg syndrome is more common with other, more common, chronic diseases and medical conditions including Parkinson’s disease, kidney failure, diabetes, and peripheral neuropathy. Iron deficiency can also cause RLS and iron levels should be checked for this reversible problem. Some medications can also aggravate symptoms (check with your pharmacist) as can alcohol or caffeine.

Treatment of RLS/PLMD depends upon the severity. It is always important to address the above underlying causes first and to address Sleep Hygiene (see Part II article*). For more significant cases medications are indicated. Many primary care physicians use “dopaminergic” medications such as Mirapex or Requip and these can be quite effective. I personally favor medications such as Lyrica, Neurontin, or Horizant. The latter newer (and more difficult to obtain) but very effective. In the past, physicians used narcotics or Valium type medications. I avoid the use of these medications unless we determine them to be absolutely necessary. Given the intermittent nature of these neurologic conditions, I always encourage periodic “drug holidays” to see if the medication is still needed and close monitoring to see if dosages need to be restarted or increased. Seasonal changes and personal stress issues that affect fatigue and sleep can profoundly impact these conditions and a holistic approach might include initial medical management to control the problem with a long term goal of transitioning to nonpharmacological methods of avoiding stress and sleep deprivation.

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*Parts 1 and 2 of Dr. DeMayo’s “Sleep” Articles are available on our website: https://www.papolionetwork.org/demayo-articles.html

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1 Eur J Neurol. 2015 Mar;22(3):472-8