



Hereditary Spastic Paraplegia and Primary Lateral Sclerosis are groups of degenerative, neurological disorders causing progressive spastic weakness of the legs, arms, hands, and/or speaking and swallowing muscles. Nerve impulses do not adequately travel through the spine to those muscles, which causes spasticity in the muscles. As the degeneration continues, the spasticity and weakness increase. Gait disturbance usually progresses slowly throughout life without sudden changes. Some complicated HSP secondary features include bladder urgency and frequency, pain, epilepsy, breathing issues, eye issues, neuropathy, and dementia. In both HSP and PLS, progressive spasticity (weakness) of the legs causes difficulty walking leading to needing assistive devices such as canes, walkers, and wheelchairs. Currently there

is no treatment to prevent or reverse the damage already done to the motor neurons. Treatment is focused on symptom relief, physical therapy, assistive devices, and supportive therapy.

People with HSP and PLS sometimes struggle to get a correct diagnosis. It often takes going to multiple doctors, having numerous tests, and getting a diagnosis by excluding other conditions. Genetic testing has come a long way, but medical professionals are constantly discovering new HSP genes. Dealing with HSP and PLS sometimes causes multiple emotions, including depression. The isolation and mental exhaustion are often difficult to handle. Stress, strong emotions, and weather (cold, humid, rainy, and dampness for example) usually cause increases in symptoms.



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**Spoons**

Use this visual metaphor to explain the amount of energy you need throughout the day. Explain we start the day with the same number of teaspoons. Every activity uses up a given number of spoons. For a healthy person, showering may use 1 spoon, but for a person with HSP or PLS, it may take 3 or 4 spoons. A person who runs out of spoons must rest until their spoons can replenish. Read more about spoons at this link or scan the qr-code:



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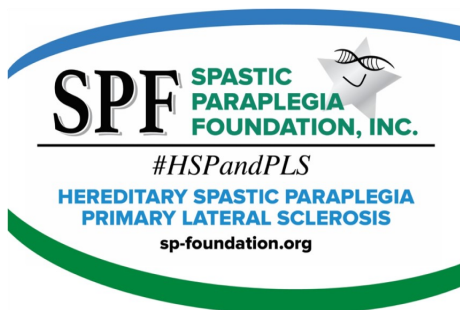
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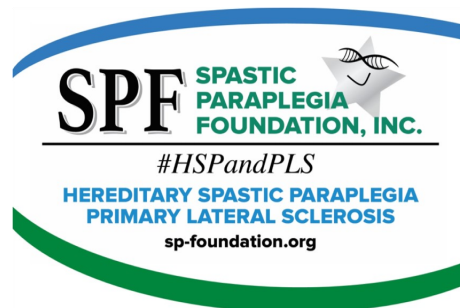
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