

Primary Lateral Sclerosis

A Patient's Guide Through the Medical Maze



Research / Education / Support

HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

www.sp-foundation.org

What are the symptoms of PLS?

The first symptoms are often **tripping** or **difficulty lifting the legs**. Other people may be the first to notice a change in the affected person's gait. Occasionally, **speaking** (dysarthria) and **swallowing** (dysphagia) difficulties, or **arm weakness** are the first symptoms. Speech problems can begin with hoarseness, a reduced rate of speaking, excessive clearing of the throat, or slurred speech when a person is tired. In some cases, speech becomes so slurred that others cannot understand it. **Drooling** can be a problem as well due to weakened bulbar muscles.

Other common symptoms are **hyperactive reflexes**.

Does stress affect my symptoms?

Many people find the tightness in their muscles worsens when they are angry, stressed, or upset. This may make it more difficult to walk/or speak. It is unknown exactly how emotions affect muscle tone, but it may involve adrenalin level. Most people also report increased stiffness in cold weather.

WHAT IS PLS?

"Primary lateral sclerosis (**PLS**) is a rare neuromuscular **disease** characterized by progressive muscle weakness in the voluntary muscles. **PLS** belongs to a group of disorders known as motor neuron **diseases**.

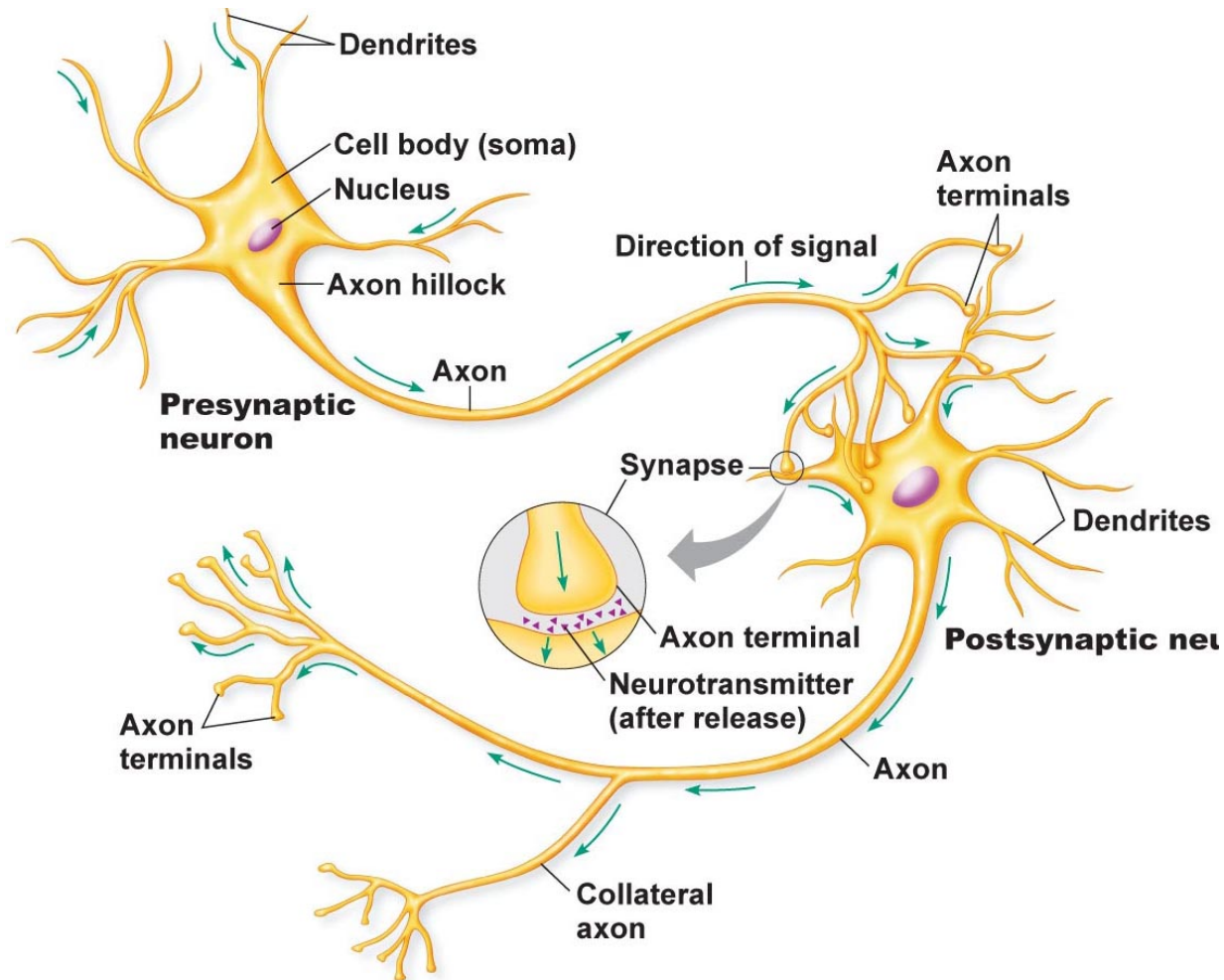
... **PLS** only affects upper motor neurons."

-Mayo Clinic

PLS is caused primarily by degeneration of the upper motor neurons in the brain and spinal cord, which results in increasing spasticity and weakness of voluntary muscles. It is often referred to as a benign variant of Amyotrophic Lateral Sclerosis (ALS, Lou Gehrig's disease).

Wherever symptoms originate, the legs, arms, hands, and speech and swallowing muscles will all eventually be affected. In time, assistive devices are needed, such as canes, walkers, or wheelchairs. Speech therapy and communication aids may become necessary as well.

BASIC CELL BIOLOGY



BASIC CELL BIOLOGY EXPLAINED

I'm sure you've gone to the doctor's office and left there just as confused as you went in—maybe more!

PLS is caused by degeneration of the upper motor neurons in the brain and spinal cord. Even though the trouble may be with your legs, upper motor neurons control voluntary movement.

The cell bodies of these neurons are located in the motor cortex area of the brain. They have long, hair-like processes called axons that travel to the brainstem and down the spinal cord.

What can I do now?

***“There’s no cure or magic pill, there are only treatments.”
-Dr. John K. Fink***



Drug Therapy

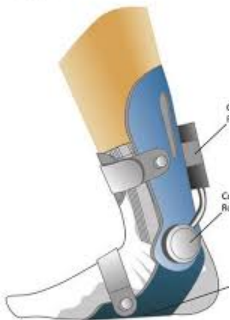
Baclofen, Xanaflex,
Gabapentin, Tizanidine
Dantrolene Sodium
Diazepam, Clonazepam, etc.



Exercise

Pilates, Yoga, Physical Therapy,
Aquatic Aerobics

Ankle-Orthosis



Assistive devices

AFOs (ankle/foot orthotic)
Canes (or forearm crutches)
Walker (walking frame)
Rollator
Scooter
Wheelchair (manual or electric)
Speaking devices



Stretching

calves
quadriceps
hip flexors
psoas muscle



Nutrition

Vegetarian
Vegan
Gluten-Free
Paleo
Mediterranean



Supplements

CoQ 10, Vitamine E, Magnesium,
Vitamine D3, Vitamine B12,
Fish Oil,
Quinine, Green Tea, Bacopa,
Ashwagandha, Oregano Oil,
Alpha-Lipoic Acid, etc.

Alternative Medicine



Healthy.
Happy.
Holistic.

- Massage Therapy
- Chiropractic Treatments
- Acupuncture
- Magnet Therapy
- Meditation
- Biofeedback
- Hyperbaric Treatment
- Alexander Technique, etc.

Where do I go for help?

NORD (National Organization for Rare Disorders) www.rarediseases.org
NEALS (Northeast Amyotrophic Lateral Sclerosis) www.alsconsortium.org
SPF (Spastic Paraplegia Foundation) www.sp-foundation.org
NIH (National Institutes of Health) www.nih.gov
Social Media – SPF Face Book page
Etc.

Where can I go for research?

www.clinicaltrial.gov

Where can I find a doctor?

Not all doctors are aware or can spot and treat HSP. Go to sp-foundation.org and click on “Find a Physician” for a list of doctors in your area.

****A tip** – carry a card in your wallet with all of your drugs and supplements listed. Include any allergies. This will save you lots of time and your doctor will appreciate knowing all of them and if any possible drug interactions.*

NAME
Address
Phone #
RX list + dosage
Allergies + reactions

What about Insurance?

Insurance companies are hard to understand normally. Add to it our complicated coverage! Basically, we’re going to say, “Try, try, try!” You are your own advocate here. Don’t let, “No” be the final word. You never know what can happen. You have nothing to lose—right? One thing that we have learned in dealing with Insurance companies, ALWAYS document WHO you talked to, WHAT TIME AND NUMBER you called, and WHAT WAS THE OUTCOME OR RESULT?



Research / Education / Support

**HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS**

www.sp-foundation.org

Spastic Paraplegia Foundation

1605 Goularte Place
Fremont CA 94539-7241

www.sp-foundation.org
UPDATED 6/2019