Primary Lateral Sclerosis

A Patient’s Guide Through the Medical Maze
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.

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.
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

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

- 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.

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?