

**YOUR SYMPTOMS ARE CLEAR.
IS THEIR CAUSE A MYSTERY?**

"FATIGUE"

**"DIFFICULTY
CLIMBING STAIRS "**

"CAN'T MOVE"

**"TROUBLE
WALKING "**

"WEAKNESS"

**"SLURRED
SPEECH "**

"FALLING"

**"CONSTANT
MOUTH DRYNESS"**

**The answer may be
Lambert-Eaton Myasthenic Syndrome
(LEMS)**

Learn if LEMS is affecting your life



What is LEMS?

Your symptoms could be explained by a rare condition called Lambert-Eaton Myasthenic Syndrome, also known as LEMS. LEMS is a rare, autoimmune disorder, which means that the body attacks its own cells.

LEMS causes your muscles to feel weak because it affects the neuromuscular junction—the place where nerve cells meet muscle cells. The nerve cells aren't able to release a chemical called acetylcholine (ACh). This important chemical helps send messages between the nerves and the muscle cells. When ACh can't be released, the muscles aren't able to work the way they should.^{1,2}

LEMS is very rare, affecting only 1 person in about 300,000 worldwide.³

Who is affected by LEMS?

LEMS can occur at any age, but is most commonly diagnosed in people who are over the age of 40.

About half of those affected by LEMS, usually people who have smoked and are 50 or older, also have, or may develop, a form of lung cancer called small cell lung cancer (SCLC). This is called paraneoplastic LEMS.

Only 300 new cases of LEMS are diagnosed in the US each year. Correct diagnosis is sometimes delayed.^{1,2}

What are the symptoms of LEMS?^{1,2}

First, you may notice that your muscles are weaker, especially those in your legs. You may find it difficult to walk, get up from a chair, climb steps, or get out of a car. You may fall—which can impact your life because you fear falling again.

Other symptoms may include:

- Tingling sensations
- Fatigue
- Slurred speech
- Trouble with your vision
- Difficulty swallowing
- Always feeling tired
- Dry mouth, eyes, skin
- Impotence
- Constipation
- Less often: weakness in the muscles of your eyes and neck

Talk to your Healthcare Provider if you experience any of these symptoms, or other symptoms that bother you.

How is LEMS diagnosed?²

LEMS can be hard to diagnose because its symptoms are similar to those of other diseases, and because it is so rare. In fact, many LEMS patients are misdiagnosed at first. Common misdiagnoses include fibromyalgia, lupus, myasthenia gravis (MG) and multiple sclerosis. MG and other conditions like Guillain-Barre syndrome, amyotrophic lateral sclerosis (ALS) or other neuro-muscular diseases, may need to be ruled out before the correct diagnosis of LEMS is reached.

Another important diagnostic fact is that about half of people with LEMS either have or will develop cancer (most frequently small cell lung cancer), so cancer testing is recommended.

If you have been diagnosed with any of these conditions, ask your Healthcare Provider to evaluate you for LEMS.

Are there tests for LEMS?

Yes, there are several different tests that help diagnose LEMS. Your Healthcare Provider will examine your degree of muscle weakness, your reflexes, and the function of your nervous system. You will likely also get electrodiagnostic tests, when the nerves are stimulated electrically and the nerve impulses in the muscles are measured. You will also get blood tests to check on the function of your immune system.

Is there treatment for LEMS?

While the FDA has not yet approved a treatment for LEMS, there are drug therapies and procedures that can help reduce your symptoms. The aim of treatment is to decrease your autoimmune response, helping to prevent your body from attacking its own cells.

Some of these treatments include:

- Steroids, which help suppress your immune system
- Intravenous immunoglobulin, which helps “mop up” immune cells
- Plasmapheresis, which filters your blood through a machine that removes overactive immune cells and then infuses the cleansed blood back into your bloodstream
- Drugs that help improve the electrical impulse between your nerve cell and muscle cells^{1,2}

“I was so relieved to find out there was a name for the symptoms I’d been having—LEMS.”

-LEMS patient

Your Healthcare Provider will determine which kind of treatment or treatments are right for you.

The good news is that research for effective treatment of LEMS is ongoing. An investigational drug is being studied to measure how well it improves the electrical impulse between nerve cells and muscle cells.

If you have cancer in addition to LEMS, treating the cancer will be the focus of your healthcare team.

“Now that I know I have LEMS, I know there are things I can do to feel better.”
-LEMS patient

What can I expect over time?

If you do not have cancer, you will continue treatment for your LEMS symptoms. Treatment is improving all the time, so you can expect to live a reasonably normal life.

If you have cancer, your healthcare providers should work together to treat your cancer and control your LEMS symptoms. In this way, you can be best treated for both your conditions.

“We are looking forward to future treatment advances for people with LEMS.”

-LEMS researcher

LEMS Patient Resources

Dysautonomia International

www.dysautonomiainternational.org

Global Genes

www.globalgenes.org

www.livingwithlems.org

Muscular Dystrophy Association (MDA)

www.mda.org

National Organization for Rare Disorders (NORD)

www.rarediseases.org

Myasthenia Gravis Foundation of America

<http://www.myasthenia.org>

Catalyst Pharmaceuticals is a biopharmaceutical company focused on developing and commercializing innovative therapies for people with rare debilitating diseases. We are honored to not only work for patients with rare diseases but to work with them towards hope for a brighter future.

The LEMS disease brochure is provided for awareness purposes by Catalyst. Please direct any questions to your physician.

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**Up to 75% of patients
may report total or partial
restrictions in activities
of daily living.²**

References: 1. Titulaer MJ, Lang B and Verschuuren JGM. Lambert-Eaton myasthenic syndrome: from clinical characteristics to therapeutic strategies. *Lancet Neurol* 2011;10:1098-107 2. Harms I, Sieb JP, Williams AE et al. Long-term disease history, clinical symptoms, health status, and healthcare utilization in patients suffering from Lambert Eaton myasthenic syndrome: Results of a patient interview survey. *J Med Econ.* 2012;15(3):521-530. 3. Orpha.net. Lambert-Eaton myasthenic syndrome. [http://www.orpha.net/consor/cgi-bin/Disease_Search.php?Ing=EN&data_id=10583&Disease_Disease_Search_diseaseGroup=Lambert-Eaton-myasthenic-syndrome&Disease_Disease_Search_diseaseType=Pat&Disease\(s\)/group%20of%20diseases=Lambert-Eaton-myasthenic-syndrome&title=Lambert-Eaton-myasthenic-syndrome&search=Disease_Search_Simple](http://www.orpha.net/consor/cgi-bin/Disease_Search.php?Ing=EN&data_id=10583&Disease_Disease_Search_diseaseGroup=Lambert-Eaton-myasthenic-syndrome&Disease_Disease_Search_diseaseType=Pat&Disease(s)/group%20of%20diseases=Lambert-Eaton-myasthenic-syndrome&title=Lambert-Eaton-myasthenic-syndrome&search=Disease_Search_Simple). Accessed April 6, 2017.