



# TURNING KNOWLEDGE INTO STRENGTH

## Managing Lambert-Eaton Myasthenic Syndrome (LEMS) Today and Tomorrow

LEMS Aware was created to deliver helpful information, resources, and connections to patients and caregivers who may be living with or affected by LEMS.

This brochure provides specific information about what to expect with LEMS and ways to help manage symptoms going forward. With the right treatment, lifestyle modifications, and planning, people with LEMS may continue to enjoy a life of activity, health, and independence.

## WHAT IS LEMS?

**LEMS IS** a rare neuromuscular disorder that causes severe, debilitating, and progressive muscle weakness—especially in the legs and hips—and fatigue

**LEMS MAY ALSO CAUSE** symptoms of dry mouth, blurred vision, impotence, and constipation in some patients

**LEMS OCCURS WHEN** the immune system disrupts communications between nerves and muscles

**LEMS IS OFTEN ASSOCIATED** with cancer, so all diagnosed patients should be screened for malignancies

**LEMS AFFECTS** men and women equally and has an estimated patient population of 3,000 people in the US

**LEMS CAN BE MANAGED** with medication and guidance from your doctor

Catalyst Pharmaceuticals does not specifically endorse the lifestyle modification suggested within this brochure.

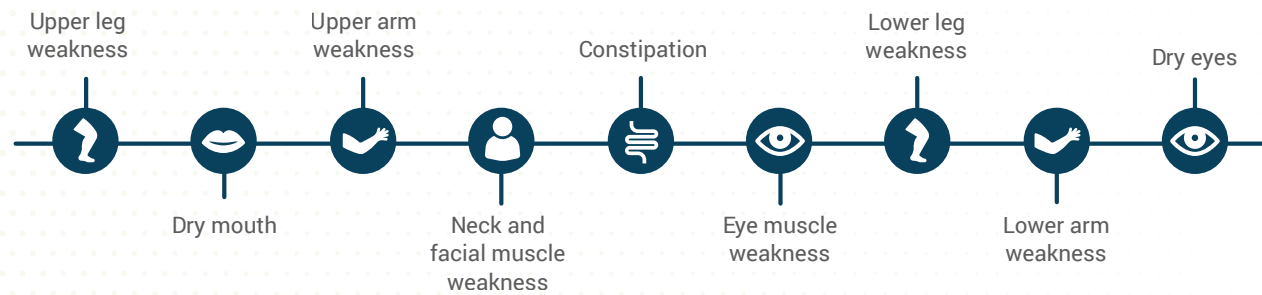
**LEMS**  
*aware*

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# HOW LEMS MAY PROGRESS

Although symptoms can vary from person to person, the first sign of LEMS is often muscle weakness in the legs and lower body. **Left untreated, LEMS symptoms may progress** and affect muscles in other areas as well as the part of the nervous system that controls autonomic bodily functions, including digestion and production of saliva and tears. Symptoms may progress more quickly in cases where cancer is involved.

## LEMS symptoms may spread and worsen\*



\*The graphic above shows what symptoms patients with LEMS may experience as the disease progresses. Not all patients will develop every symptom represented, nor will symptoms develop in the order shown above.

## Potential consequences of a delay in diagnosis or treatment of LEMS



Spread and severity of symptoms



Loss of function and mobility



Loss of independence and quality of life

## NOTICING A PROGRESSION IN YOUR SYMPTOMS? TALK TO YOUR DOCTOR

If you notice a worsening of your LEMS symptoms, such as a return of fatigue or a loss of muscle strength or mobility, reach out to your LEMS doctor immediately. A change in medicine or **a simple dose adjustment** may be all that's needed to get you feeling better again.

# MANAGING LEMS TODAY

## Medication is the foundation of LEMS symptom management

The recommended treatment for LEMS is an oral medicine known as a potassium channel blocker that is prescribed to help nerve signals reach the muscles. Sometimes, doctors will prescribe additional medications for further relief of symptoms.

### Stay on schedule

Be sure to follow your doctor's prescription as closely as possible—particularly at the start of treatment, when **your doctor may make dosage adjustments to provide you with the best relief of your symptoms.** Studies show that following an effective treatment can help you maintain your strength and muscle function.



## Lifestyle modifications may help make a difference

As with any chronic condition, there are things that you can do to help maintain your health and daily activities. Be sure to **check with your doctor** before starting any new exercise regimen or trying a change in diet.



### Exercise moderately

With your doctor's approval, consider light weight-training or physical therapy to help improve stamina and maintain muscle strength. Daily walking and breathing exercises may also increase your energy levels.



### Get enough sleep

A full night's rest may help you manage fatigue and reduce stress. To make it easier to fall asleep, try to limit alcohol, caffeine, and screen time in the evening before going to bed.



### Stay cool

Symptoms of LEMS may get worse when you become overheated or have a fever. Be careful not to overdo exercise and avoid taking hot showers or baths. Contact your doctor if you start noticing signs of a cold or flu.



### Eat a healthy diet

Be sure to include lots of fruits and vegetables to give your body the nutrients and vitamins it needs to stay energized and minimize fatigue.



# MANAGING LEMS TOMORROW



## Planning ahead can help you stay active and maintain your independence

Over time, LEMS symptoms may change or worsen, though that is hard to predict. In addition, as we age, we naturally lose muscle mass and function. Taking the time now to prepare for the future can help yourself or your loved one maintain health and functionality. Here are some steps you can take now to manage LEMS in the future.



### Keep a weekly journal of how you're feeling

Check in with yourself once a week and record how you're responding to treatment and any symptoms you may be noticing. Also, check in with your doctor regularly to see if a simple dose adjustment may provide even more relief.



### Protect against health emergencies

A medical ID bracelet or pendant can provide identification if you're ever in need of assistance and unconscious or unable to speak. Consider using a personal medical alarm help-button system such as LifeAlert® for further security and peace of mind for yourself or your loved one.



### Fall-proof your home

The last thing a LEMS patient needs is a slip and fall. Inspect your home for tripping hazards, such as slippery floors, loose rugs, or cluttered walkways. Consider adding handrails to staircases, bathrooms, and showers for added stability. Your insurance company may pay for an occupational therapist to assess your home for safety and provide suggestions for making everyday activities easier.



### Dip into some exercise

Ask your doctor, physiatrist, or physical therapist about tailoring an exercise plan for you that will keep your bones and muscles strong, flexible, and functional now and in the future.

Some patients with neuromuscular conditions have found that aquatherapy (exercise in a pool) is a low-impact way to strengthen muscles and relieve pain, stress, and fatigue.



### Make a long-term plan

Sit down with your family or caregiver and have an honest conversation about the future. Discuss your concerns, fears, and expectations, and then listen to theirs. Come up with a plan of support that everyone is comfortable with, and be sure to consider contingencies that may arise.

Life is full of demands, and change is the only constant. Planning ahead now means that no one is left behind.



**Talk to your doctor** about more ways to manage LEMS throughout your lifetime.

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