



# My Next Step

.....> **SYMPTOM-TRACKING JOURNAL**

Track your symptoms to reach the next destination point on your treatment journey

LEMS  
*aware*

# Every journey needs a journal

## WHAT ARE YOU SEARCHING FOR?

You're looking for answers about symptoms that you suspect may be Lambert-Eaton myasthenic syndrome (LEMS). Maybe you or your loved one is searching for:

- **An initial diagnosis** confirming that LEMS is the cause of those symptoms
- **A second opinion** to verify that LEMS is the right diagnosis
- **Other treatment options** for symptoms that just aren't going away

Whatever journey you're on, journaling may help.

## BENEFITS OF KEEPING A SYMPTOM JOURNAL

Maintaining good health, especially when symptoms start to interfere with daily activities, is not just the responsibility of the physician—patients and/or caregivers must also play a role. To assist your physician with your overall care, they need to know exactly what symptoms you have been experiencing.

**Details are important.** And because you may not always remember exactly what you're feeling and when, using a symptom journal to track that information is especially helpful.



# HOW TO USE THIS JOURNAL

**My Next Step** is designed to help you capture information one week at a time, while allowing for daily entries about the medicines that you or your loved one is taking and the symptoms and side effects that are occurring.

- 1 Print out both pages of each weekly entry as needed
- 2 Keep these pages handy, on a counter or on the refrigerator, where they will be easily seen
- 3 Be a faithful journal writer—use this important tool every day
- 4 Try to complete each section as fully as you can each week
- 5 At the end of each week (on Sunday), print out the next week's pages and continue tracking on that Monday

**Have questions?** See pages 24-25 for more detailed direction on using this journal.



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**WEEK 4**  
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**WEEK 5**  
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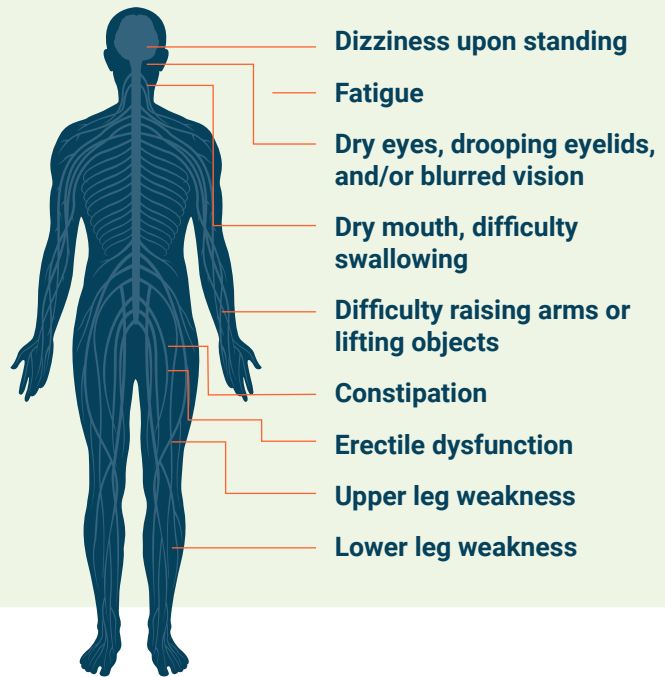
## RECOGNIZING LEMS IN YOUR LIFE

**Lambert-Eaton myasthenic syndrome (LEMS) is a rare neuromuscular disorder that causes debilitating muscle weakness and fatigue**

As the name suggests, neuromuscular disorders affect the nerves and muscles of the body, specifically how they communicate with each other. LEMS interferes with the nerves' ability to release an important chemical called acetylcholine (ACh). When ACh is not released properly, muscles lose the signal necessary for their full function. As a result, people with LEMS may struggle to walk or do everyday activities.

### Signs and symptoms of LEMS

The most common symptom of LEMS is muscle weakness, especially in the legs and hips. But LEMS can also weaken muscles in other areas of the body and affect a part of the nervous system that controls automatic bodily functions, such as saliva production, digestion, and arousal.



### Dealing with the detours of LEMS in daily life

Another way to recognize the symptoms that you or your loved one is experiencing is to describe how those symptoms may be disrupting daily life. Below are some examples of everyday activities and bodily functions that may be affected by LEMS.

- Walking
- Climbing or descending stairs
- Getting into or out of a car
- Raising arms or lifting objects
- Standing without getting dizzy
- Reading or focusing eyes
- Talking
- Chewing and/or swallowing
- Using the bathroom
- Getting/maintaining an erection

## WELCOME TO YOUR FIRST JOURNAL ENTRY!

This page will serve as a starting point for your journal and a reminder of how you were feeling when this journey began. Take good notes! You and your doctor may refer back to this entry to see how your symptoms have changed over time. The information you provide may help confirm a diagnosis of LEMS, point to the need for further testing, or help your doctor adjust your treatment to provide better results. Please make sure that you add all prescription, over-the-counter, and other medications you're taking every day.

### Medicines I've taken this week

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				



My overall mood/feeling is



Hopeful



Determined



Coping



Frustrated



Unhappy



Overwhelmed

Why did you choose the answer above?

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Goals for the future

By this time **next week**, I hope that \_\_\_\_\_

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**THIS WEEK'S TIP FOR THE ROAD: STAY IN YOUR LANE!**

When it comes to the treatment journey, you or your loved one should always follow the doctor's directions. **Take prescribed medicines at the same time(s) each day.** This is particularly important when starting a new medicine. At the beginning, your doctor may titrate (adjust) the dose in order to provide you or your loved one with the most symptom relief and the fewest side effects.

Questions for my doctor

Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

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## DO YOU HAVE THE RIGHT DIAGNOSIS?

### LEMS is often confused with other conditions

Because **Lambert-Eaton myasthenic syndrome (LEMS)** is a rare disorder, patients are often diagnosed with other disorders before getting to their appropriate diagnosis. This may be something that you or your loved one has experienced leading up to being diagnosed with LEMS.

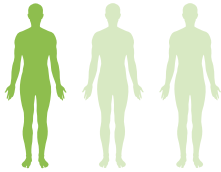


of patients with LEMS receive the **wrong diagnosis** the first time.

One of the reasons for the confusion is that there are several more common neuromuscular disorders that also cause symptoms of muscle weakness and fatigue. Some of these include:

- ✓ Myasthenia gravis (MG)
- ✓ Parkinson's disease
- ✓ Multiple sclerosis (MS)
- ✓ Amyotrophic lateral sclerosis (ALS)
- ✓ Fibromyalgia

### MG is the most common misdiagnosis of LEMS



In a study of LEMS patients, **MORE THAN ONE-THIRD** of all those misdiagnosed were told that they had MG.

**If you've already been diagnosed with another disorder**, such as MG, but are wondering if your symptoms have another cause, make a note in your journal to talk to your doctor.



#### Want a second opinion?

Go to [FindLEMSdoc.com](https://www.findlemsdoc.com) to search for experienced LEMS physicians nearest your area using only your ZIP code.



## WELCOME TO YOUR SECOND ENTRY!

Hopefully, Week 1 was easy, and you’ve gotten the hang of using the journal. As you move forward this week, pay close attention to how your symptoms are changing or not changing. Are they getting milder or more severe? If you’re receiving treatment, are you noticing any improvements? What about side effects? All of these may be clues that your doctor can use to assess treatment and make adjustments as necessary.

### Medicines I’ve taken this week

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				



## WEEK 2 | WATCHING FOR CHANGES (continued)

### My overall mood/feeling is



Hopeful



Determined



Coping



Frustrated



Unhappy



Overwhelmed

Why did you choose the answer above?

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### Goals for the future

By this time **next week**, I hope that \_\_\_\_\_

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## THIS WEEK'S TIP FOR THE ROAD: FILL YOUR TANK WITH FUEL

**Eating a healthy diet** that includes fruits, vegetables, and other nutrients and vitamins can help you or your loved one stay energized and minimize fatigue.

### Questions for my doctor

Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

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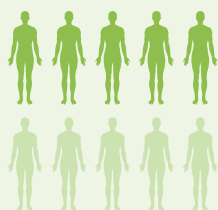
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## ARE THOSE SYMPTOMS AN EARLY WARNING SIGN?

### Some patients with LEMS may also have an underlying cancer

In about 50% of patient cases, Lambert-Eaton myasthenic syndrome (LEMS) is caused by a disorder in the immune system. But in the other half of cases, LEMS is associated with an underlying tumor—most often small-cell lung carcinoma (SCLC).



#### ABOUT 50%

of LEMS cases are associated with an underlying tumor—often SCLC.



The majority of these cases occur in people with a history of smoking.



Once a diagnosis of LEMS is confirmed, your doctor may decide to run more tests to see if cancer is present based, in part, on the symptoms that you or your loved one is reporting.



**TESTS MAY INCLUDE  
A PET SCAN OR CT SCAN**

### Another important reason to track LEMS symptoms

**Patients who have tumor-related LEMS often have symptoms that are more severe or worsen faster than patients with non-tumor LEMS.** Taking good notes every week will help the doctor get a clearer picture of how aggressive your symptoms are and how quickly they are progressing. Providing clear, detailed notes in your symptom-tracking journal will help inform whether further testing makes sense.

## WELCOME TO WEEK 3!

With 2 weeks of symptom tracking under your belt, you or your loved one should be getting a clear idea of how things are going and where you hope to be. It's time to start preparing for your office visit and a conversation with your doctor. Do you feel like you have the right diagnosis? Are you happy with your treatment results? Do you think you may need a change? Continue to track your symptoms and write down your questions so that your doctor understands exactly where you are and where you need to be.

### Medicines I've taken this week

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				



**My overall mood/feeling is**



Hopeful



Determined



Coping



Frustrated



Unhappy



Overwhelmed

Why did you choose the answer above?

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**Goals for the future**

By this time **next week**, I hope that \_\_\_\_\_

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**THIS WEEK'S TIP FOR THE ROAD: GET A FULL NIGHT'S SLEEP!**

The journey to finding renewed energy and strength requires regular periods of rest. To help you or your loved one manage fatigue and reduce stress, **getting 8 hours of sleep each night** is really important. Trouble falling asleep? Try limiting the intake of alcohol and caffeine, and turn off the TV or computer screen well before bedtime.

**Questions for my doctor**

Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

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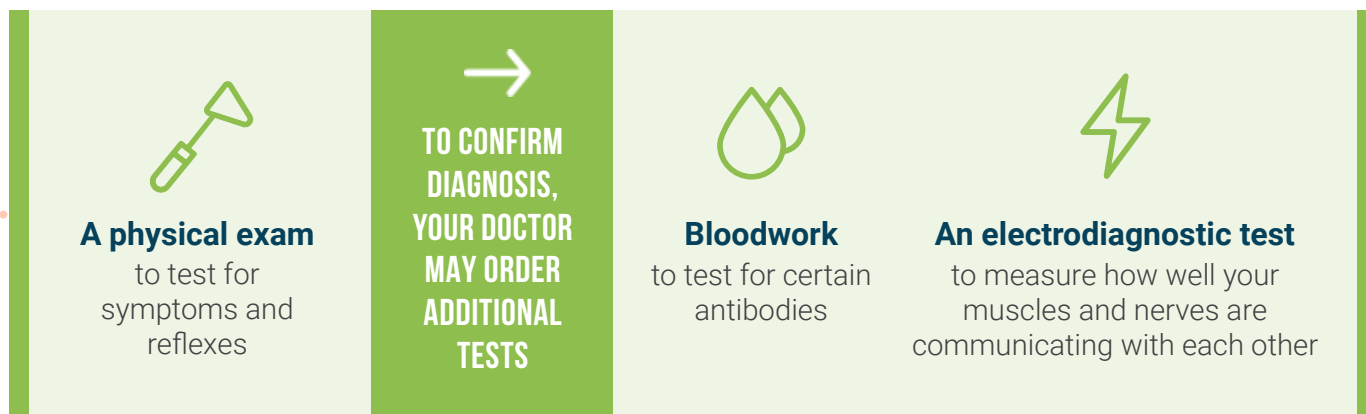
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## DIAGNOSIS AND TREATMENT OF LEMS

### Common tests for Lambert-Eaton myasthenic syndrome (LEMS)

Neurologists and neuromuscular specialists typically use 3 testing methods to diagnose the symptoms of muscle weakness and determine whether the cause is LEMS, MG, or another disorder.



### Treatment is determined by the type of LEMS



#### Cancer-related LEMS

The first step after a LEMS diagnosis is cancer testing. Tests may include a PET scan or CT scan. If a tumor is present, you or your loved one should be referred to an oncologist for treatment. In most cases, the tumor will be a small-cell lung carcinoma. Chemotherapy is usually prescribed for this type of cancer. Treating the tumor may also help improve the symptoms of LEMS. The doctor will decide if other therapies are necessary to manage LEMS symptoms.



#### Non-tumor LEMS

If LEMS is an autoimmune issue, meaning that no cancer is present, symptoms may be treated by a neurologist or neuromuscular specialist. A daily oral medicine is usually prescribed to help relieve LEMS symptoms. This medicine must be taken daily to maintain its positive effects.



## CONGRATULATIONS ON REACHING WEEK 4!

If you haven't had your office visit, keep tracking until you do. If you did see your doctor, how did it go? Did you find the answers that you were looking for? If you received a new diagnosis or started on a new treatment, it's time to set your sights on the next destination. Where do you hope to be a month from now? Write down these goals and continue using this journal to track your progress until you reach that next point.

### Medicines I've taken this week

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
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My overall mood/feeling is



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Frustrated



Unhappy



Overwhelmed

Why did you choose the answer above?

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Goals for the future

By this time **next week**, I hope that \_\_\_\_\_

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**THIS WEEK'S TIP FOR THE ROAD: KEEP YOUR ENGINE COOL!**

Symptoms of LEMS may flare or get worse when you or your loved one becomes overheated or has a fever. To keep things cool, **avoid hot baths and showers, and don't overdo exercise.** (Break a sweat, not the thermometer!) If you start noticing signs of a cold or flu, contact your doctor immediately to get guidance on what to do next.

Questions for my doctor

Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

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## FINDING SUPPORT

### You don't have to face the journey alone

Whether you're a patient or a caregiver, there are places you can go and people you can turn to for help and support with managing the challenges of Lambert-Eaton myasthenic syndrome (LEMS) or other neuromuscular conditions.



#### Reach out to family and friends

Everyone may seem too busy these days, but chances are that you have family members and friends who would jump at the chance to provide some level of assistance. Consider asking those closest to you if they'd be willing to help out with:

- A regular task, such as weekly grocery shopping or mowing the lawn
- An occasional favor, such as providing a ride to the doctor's office or pharmacy



#### Consider other life connections

You may also find other sources of support among affiliations that you or your loved one has, such as:

- Current or former work colleagues
- Religious community members
- Members of clubs or other organizations



#### Consult professional services

Most communities in the US offer support services to people aged 60 and over and their caregivers, such as providing home-delivered meals, transportation, and adult day care. To find these services in your area, visit **Care.com**.

## KEEP GOING UNTIL YOU REACH YOUR GOAL!

As you or your loved one moves forward in the search for renewed energy and strength, you may discover that you don't need to track every step of the journey. Fantastic! If you feel like you've found the right diagnosis and treatment—and have reached a good place—put down the pen. Your journal-keeping has paid off! Enjoy the rewards of your diligent work. If you're still not quite where you or your loved one wants to be, use this supplemental journal template to track your weekly journeys until you reach your desired goal.

### Medicines I've taken this week

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				



## THE WEEKS AHEAD | ROADSIDE ASSISTANCE (continued)

### My overall mood/feeling is



Hopeful



Determined



Coping



Frustrated



Unhappy



Overwhelmed

Why did you choose the answer above?

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### Goals for the future

By this time **next week**, I hope that \_\_\_\_\_

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**VISIT [LEMSAWARE.COM](https://www.lem aware.com) TO FIND MORE TIPS FOR THE ROAD.**

### Questions for my doctor

Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

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# MAKING A JOURNAL ENTRY

**WEEK 1 | GETTING STARTED** WEEK BEGINNING MONDAY \_\_\_/\_\_\_/\_\_\_

**WELCOME TO YOUR FIRST JOURNAL ENTRY!**

This page will serve as a starting point for your journal and a reminder of how you were feeling when this journey began. Take good notes! You and your doctor may refer back to this entry to see how your symptoms have changed over time. The information you provide may help confirm a diagnosis of LEMS, point to the need for further testing, or help your doctor adjust your treatment to provide better results. Please make sure that you add all prescription, over-the-counter, and other medications you're taking every day.

**Medicines I've taken this week**

	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)	Medicine (Dose and Frequency)
MON				
TUES				
WED				
THURS				
FRI				
SAT				
SUN				

5 LEMS *aware*

Enter the date for the Monday that starts the week.

Read the welcome message for a suggested area of focus during the upcoming week.

Write down all medicines each day, including the doses and frequency.

**WEEK 1 | GETTING STARTED (continued)**

**Symptoms I've noticed this week** (Fill box completely for new symptoms)

<input type="checkbox"/> Upper leg weakness	<input type="checkbox"/> Dry eyes	Other symptoms:
<input type="checkbox"/> Lower leg weakness	<input type="checkbox"/> Drooping eyelids	<input type="checkbox"/> _____
<input type="checkbox"/> Arm weakness	<input type="checkbox"/> Blurred vision	<input type="checkbox"/> _____
<input type="checkbox"/> Fatigue	<input type="checkbox"/> Erectile dysfunction	<input type="checkbox"/> _____
<input type="checkbox"/> Dry mouth	<input type="checkbox"/> Constipation	<input type="checkbox"/> _____

**Activities affected by my symptoms**

<input type="checkbox"/> Walking	<input type="checkbox"/> Talking
<input type="checkbox"/> Climbing or descending stairs	<input type="checkbox"/> Chewing and/or swallowing
<input type="checkbox"/> Getting up from a chair	<input type="checkbox"/> Getting/maintaining an erection
<input type="checkbox"/> Getting into or out of a car	<input type="checkbox"/> Having a bowel movement
<input type="checkbox"/> Raising arms or lifting objects	
<input type="checkbox"/> Reading	

Describe a specific example from the past week when your life was disrupted by your symptoms and how you felt at that moment:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

6 LEMS *aware*

Check off symptoms that you or your loved one experienced this week.

Fill the box completely for symptoms that appeared for the very first time this week.

Check off any activities that were affected by those symptoms.

Provide details about a time, event, or activity that was particularly disrupted by symptoms this week.



# MAKING A JOURNAL ENTRY (continued)



**WEEK 1 | GETTING STARTED (continued)**

**My overall mood/feeling is**

Hopeful  
 Determined  
 Coping  
 Frustrated  
 Unhappy  
 Overwhelmed

Why did you choose the answer above? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Goals for the future** \_\_\_\_\_  
 By this time **next week**, I hope that \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**THIS WEEK'S TIP FOR THE ROAD: STAY IN YOUR LANE!**

When it comes to the treatment journey, you or your loved one should always follow the doctor's directions. **Take prescribed medicines at the same time(s) each day.** This is particularly important when starting a new medicine. At the beginning, your doctor may titrate (adjust) the dose in order to provide you or your loved one with the most symptom relief and the fewest side effects.

**Questions for my doctor**  
 Write down any questions you may have about symptoms, diagnosis, or treatment. Review them with your doctor during your next office visit.

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**LEMS**  
*aware*

7

Indicate with a circle the overall feeling that you or your loved one experienced this week. The answer could be related to symptoms or other things going on in life.

Try to provide a reason for the rating.

Think about the goals that you or your loved one has for this part of the journey and record them here.

Find helpful insights for your journey by reading the weekly "tip for the road." Consider incorporating the tip into your routine during the upcoming week.

Write down any questions that arise during the week in the space provided.

*Call your doctor right away if you or your loved one has any urgent questions, such as unexpected side effects or confusion regarding doses or missed doses.*