



# Locked-in Syndrome

Locked-in Syndrome (LIS) is a rare neurological disorder resulting in widespread paralysis that severely impairs an individual's ability to communicate. Cognitive function is unaffected.

## Q: What are the symptoms of Locked-In Syndrome (LIS)?

The lower part of the face and all four limbs are paralyzed. As a result, people living with LIS experience a wide array of restrictive symptoms, including an inability to move, chew, swallow, speak and breathe. Lateral eye movement is lost, but vertical movement, such as blinking and opening and closing eyes, may be retained. In order to prevent a misdiagnosis of an unconscious state, patients presenting with these symptoms should have their comprehension tested using a coded system of vertical eye movements to respond to assessment questions.

## Q: What causes Locked-In Syndrome?

Stroke is typically the cause of LIS, but the disorder can also be the result of traumatic brain injury; infections or tumors that damage the middle section of the brain stem; opioid overdose or exposure to toxins; and diseases that destroy the myelin sheath surrounding nerve cells.

## Q: What are the three categories of Locked-In Syndrome?

Classification of LIS depends on the amount of motor control remaining after the onset of the disorder. Classic LIS is defined as quadriplegia and an inability to speak, with vertical eye movement preserved. Incomplete LIS means the individual has some voluntary movement other than eye movement, such as in a finger or toe. Total LIS is characterized by complete immobility.

## Q: How should Locked-In Syndrome be treated?

If known, begin by treating the cause of the disorder. Long term or comprehensive home care will be necessary for most cases of LIS, with a focus on preventing

secondary conditions caused by the lack of mobility. Initially a breathing aid may be needed. Good nutrition will be important and may be delivered via a feeding tube. Physical therapy can slow muscle weakness and atrophy. Medication, compression stockings, and elevating legs may prevent blood clots. Caregivers should pay close attention to skin condition and frequently reposition individuals living with LIS to prevent pressure sores. Communication training should begin as early as possible after diagnosis.

### **Q: Can assistive technology help people living with Locked-In Syndrome?**

Low and high tech supports ranging from picture and symbol communication boards that augment an eye movement communication system to eye tracking and speech generating devices can help expand the communication abilities of people living with LIS. Brain computer interface technologies are also being developed to enable people with severe motor disabilities to operate a computer using only their mind.

### **Q: Are there clinical trials for Locked-In Syndrome?**

Yes. Recent and current clinical trials have focused on improving communication for people living with LIS via the use of brain-computer interface technology. The U.S. National Library of Medicine maintains a searchable database of federally and privately supported trials around the world; information regarding current LIS-related trials, including eligibility, can be found at [ClinicalTrials.gov](https://clinicaltrials.gov).

### **Q: How many people are diagnosed with Locked-In Syndrome each year?**

Occurrences of LIS are rare; it is unknown how many people are currently living with the disorder.

*Sources: Merck Manual, National Institute of Neurological Disorders and Stroke, Johns Hopkins Medicine, The BMJ (formerly The British Medical Journal.)*

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Our Information Specialists are available to answer your questions.

Call toll-free 1-800-539-7309 Mon-Fri, 7 am-8 pm ET.

Or [schedule a call](#) or [ask a question online](#).

## **Resources for Locked in Syndrome**

### **ABC News: Trapped in Your Own Body**

<https://abcnews.go.com/Health/story?id=2835149&page=1>

This 2007 story profiles several people with locked-in syndrome.

### **Merck Manual for Health Care Professionals: Locked-in Syndrome**

<https://www.merckmanuals.com/professional/neurologic-disorders/coma-and-impaired->

[consciousness/locked-in-syndrome?qt=&sc=&alt=](#)

**National Institute of Neurological Disorders and Stroke (NINDS): Locked-In Syndrome**  
<https://www.ninds.nih.gov/Disorders/All-Disorders/Locked-Syndrome-Information-Page>

**National Organization for Rare Diseases (NORD): Locked-In Syndrome**  
<https://rarediseases.org/rare-diseases/locked-in-syndrome/>

**Wikipedia: Locked-in syndrome**  
[https://en.wikipedia.org/wiki/Locked-in\\_syndrome](https://en.wikipedia.org/wiki/Locked-in_syndrome)

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