Unlocking the secrets of locked-in syndrome

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Your patient depends on you for all of her basic needs. Help her and her family cope by providing emotional support and teaching them how to communicate.

By Rachel L. Palmieri, RN-C, ANP, MS

LOCKED-IN SYNDROME (LIS) is characterized by complete paralysis of the voluntary muscles in all parts of the body except those that control blinking and vertical eye movements. Patients with the classic form of LIS are conscious and can think and reason but can't speak or move anything except their eyes.

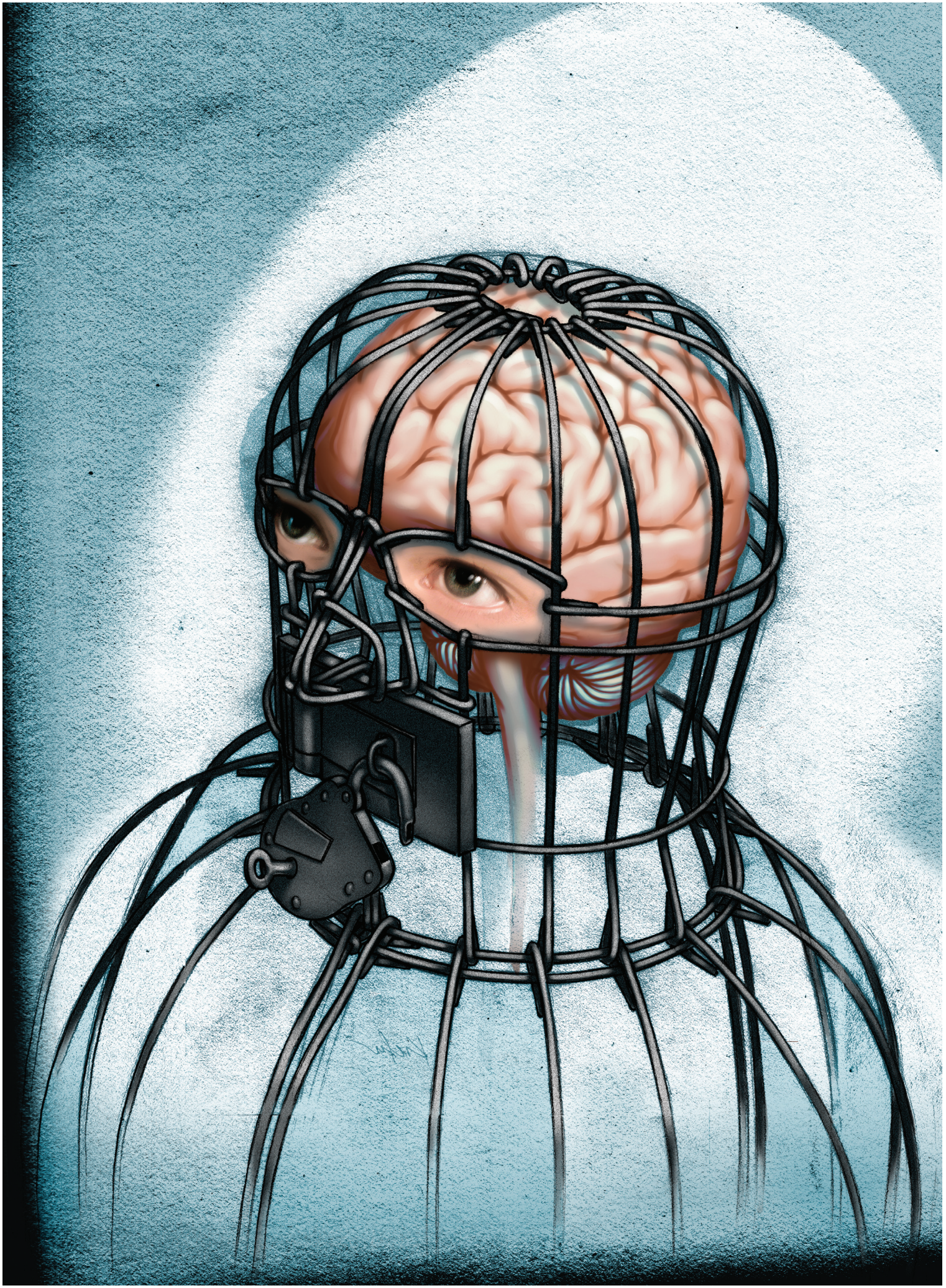
In this article, I'll tell you about this complicated disorder and how to care for a patient who's locked-in. First, let's look at how it develops.

Conscious but unmoving

A rare neurologic disorder, LIS is caused by a primary vascular or traumatic injury of the brainstem, normally corresponding to a ventral pons lesion due to an obstruction of or injury to the basilar artery.[1] Traumatic brain injury can result in a direct brainstem contusion or a vertebrobasilar axis dissection. (See *A look inside the brain*.) Other causes of LIS include:

- brain tumors that infiltrate the ventral pons
- prolonged hypoglycemia
- damage to nerve cells, particularly destruction of the myelin sheath, such as in multiple sclerosis, that affects the pons or a central pontine myelinosis secondary to rapid correction of hyponatremia[2]
- hemorrhage that originates within or infiltrates into the pons
- ischemia caused by basilar artery occlusion or hypotensive or hypoxic events
- medication overdose such as with neuromuscular blocking drugs[3]
- the end stages of amyotrophic lateral sclerosis.[4]

LIS is characterized by preserved consciousness with upper motor neuron quadriplegia. Signs and symptoms include paresis, hyperreflexia, clonus, and initial contralateral flaccid paralysis. Paralysis of cranial nerves VII, IX, X, and XII produces facial, tongue, and pharyngeal paralysis with anarthria

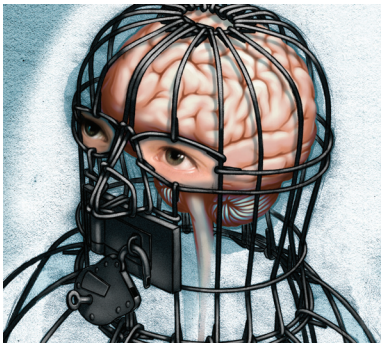


(inability to speak), causing severe difficulties in swallowing and producing sounds, and bilateral horizontal gaze paresis. However, most patients with a pontine lesion can make vertical eye movements and blink, giving them their only means of communication.[1] In patients with LIS, the spinothalamic tracts that lie dorsal to the lesion are spared, allowing for intact sensation.

Temporary LIS can be pharmacologically induced or can result from severe cases of chronic inflammatory demyelinating polyneuropathy. In this article, I'll focus on permanent LIS.

The prognosis for patients with LIS is unpredictable. In rare cases, they may regain certain neurologic functions, but the chances for motor recovery are very limited. Research shows that early, aggressive treatment offers the best chance of an improved outcome.

The incidence of LIS is difficult to determine because it's often misdiagnosed as coma, persistent vegetative state, or minimally conscious state. Association du Locked-In Syndrome, based in France, has registered 367 patients from 1997 to 2004.[4] Neurologists believe that many more cases of LIS have been undetected.



The key is to assess for voluntary vertical eye movement even when the patient appears to be unresponsive.

Categorizing LIS

Researchers have classified LIS into three categories:

- *classic*—quadriplegia and anarthria with preserved consciousness and vertical eye movement
- *incomplete*—the same features as classic but with remnants of voluntary movement other than vertical eye movement, such as a weak arm or hand movement or sometimes the ability to move facial muscles, cry, or groan
- *total*—total immobility and inability to communicate with full consciousness.[2]

Patients with *classic* or *total* LIS can sometimes improve to the *incomplete* LIS state. The chances for complete motor recovery in patients with total LIS are very limited.

Patients with LIS resulting from a stroke may have had premonitory signs and symptoms, such as headache, dizziness, vertigo, and hemiparesis. These signs and symptoms usually occur within a few days before the onset of the locked-in state, but a few patients experience premonitory signs and symptoms for days to months before LIS onset.

Difficult diagnosis

Close observation by family members, nurses, physicians, and other members of the healthcare team is required to reach the diagnosis of LIS in an apparently unresponsive patient who's experienced a stroke or traumatic brain injury. The key is to assess for voluntary vertical eye movement even when the patient appears to be unresponsive.[2]

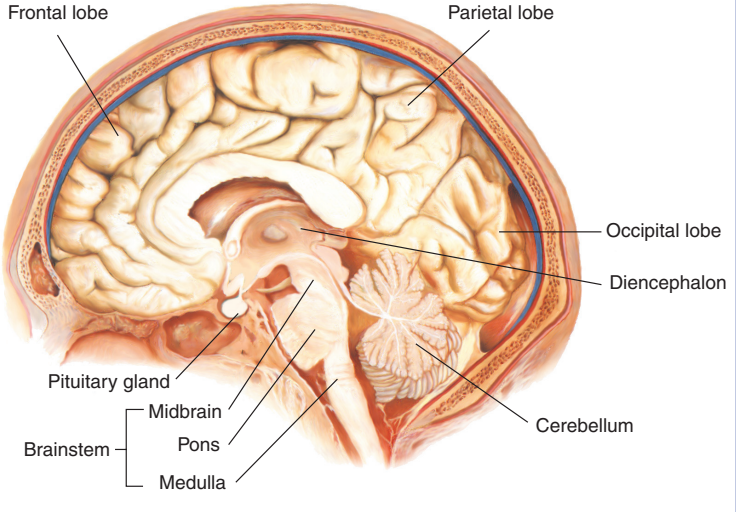
In one study of 44 patients, reaching the diagnosis of LIS took an average of about 2.5 months (78 days) after the stroke or traumatic brain injury, although several patients weren't diagnosed until 4 years later. This study also found that the first person to realize that the patient was aware was usually a family member (55%), with physicians making the discovery in 23% of cases and nurses in 18%.[1]

After beginning to consider a diagnosis of LIS, the neurologist will order magnetic resonance imaging (MRI), the preferred method for identifying ventral pontine lesions. Once a lesion is confirmed by MRI, the neurologist should reexamine the patient for vertical eye movements. He'd ask the patient questions that could be answered yes or no and look for meaningful eye movements to assess mental status.

Computed tomography (CT) isn't considered useful for diagnosing LIS because the resolution quality is compromised by bone artifact and it may be unreliable for imaging pontine infarcts.

Using an electroencephalogram (EEG) to diagnose LIS is controversial

A look inside the brain



Source: Bickley LS. *Bates' Guide to Physical Examination and History Taking*. 10th ed. Philadelphia, PA: Lippincott Williams and Wilkins; 2008.

at best. The EEG changes caused by brainstem lesions can vary from slight changes to diffuse or bilateral slowing to more striking changes such as paroxysmal discharges and sharp activity, focal abnormalities, or low-voltage fast activity.

Although evoked potential (EP) tests are of no definite diagnostic value in patients with LIS, they can provide information about the function of the cerebral cortex, brainstem, and spinal cord. In EP tests, sensory organs or peripheral nerves are noninvasively stimulated, creating tiny electrical potentials that are measured several times to get an average, which is then compared with norms.[5]

One type of EP test, brainstem auditory evoked responses (BAERs), may help localize the lesion in the brainstem in a patient with LIS.[6] In BAERs, stimuli include a series of clicks heard through a headphone. This testing, which can be done on a patient who's alert or in a coma, isn't affected by the use of I.V. sedatives, barbiturates, or general anesthesia.[5]

Scales weigh in

Using the most effective assessment tool available, carefully assess the patient and evaluate her level of consciousness. In the past, the Glasgow Coma Scale (GCS) was the gold standard for evaluating a patient with coma. (See *Scoring the GCS*.)

The Full Outline of Unresponsiveness (FOUR) Score Coma Scale was developed by researchers at the Mayo Clinic in 2005 to supplement the GCS. This scale lets the evaluator more precisely assess the extent of brainstem function, even if the patient is endotracheally intubated.[7] See *Digging deeper with the FOUR Score*.

When you have a patient with LIS, the FOUR Score Coma Scale allows you to accurately assess her eye response, motor response, brainstem reflexes, and respiration. Because a patient with LIS can move only her eyes, the eye response section of the tool is invaluable. Use it to assess whether your patient can track or blink and her response to pain. A score of E4 indicates at least three voluntary ocular excursions. If her eyes are closed, you must open them and examine her vertical tracking. Alternatively, you must document two blinks on command. This finding is key to recognizing that the patient is fully aware and has LIS. If you have any doubts about your findings, consult with another more experienced nurse who can verify your results.

What are the implications when you care for a patient with LIS? To handle this complex role, you'll need to use a multidisciplinary team approach that includes nurses, neurologists, the rehabilitation medicine team, case managers, psychologists, social workers, chaplains, speech therapists, pharmacists, and nutritionists, among others. You'll need to teach the patient and her family (or significant other) about this multifaceted condition. The treatment plan will focus on providing supportive care, medical management, and rehabilitative care while managing complicating factors such as hypertension, diabetes, pneumonia, respiratory failure, and urinary tract infections.

Finding a way to communicate

Patients with LIS are totally dependent on their nurses and other caregivers, and they can't communicate distress, fear, or helplessness verbally. Validate your patient's fear, anxiety, and pain, when appropriate.

Establish a good rapport with your patient with LIS by using a calm, reassuring voice to explain each procedure before you do it. Give your patient control over her care by establishing an eye-blinking pattern for communication. Don't ask your patient open-ended questions; instead frame questions that can be answered yes or no.

Strictly adhere to schedules for care and frequent nursing rounds. Explain any change in routine care to your patient and give her the opportunity to consent to the change whenever possible. Providing consistent sitters for a patient with LIS can reduce her fear of being abandoned.

Scoring the GCS

The GCS, developed to standardize observations of a patient's level of consciousness, provides a quick, objective, and easy way to assess central nervous system function. The GCS consists of three subscales that are scored separately, then added to give a score from 15 (best) to 3 (worst). A person with a score of 15 is fully alert and oriented and one with a score of 3 is in a deep coma. Usually a score of 8 or less indicates that the patient is unconscious.

Best eye opening response
4 Spontaneous
3 To speech
2 To pain
1 No response

Best verbal response
5 Oriented to person, place, and time
4 Conversation confused
3 Inappropriate or garbled words
2 Incomprehensible sounds
1 No response

Best motor response
6 Follows commands
5 Localizes pain
4 Nonpurposeful movement
3 Abnormal flexion
2 Abnormal extension
1 No response

Sources: Hickey JV. *The Clinical Practice of Neurological and Neurosurgical Nursing*. 6th ed. Philadelphia, PA: Lippincott Williams and Wilkins; 2009; Gusa D, Miers A, Wijdicks E. More than meets the eye: the FOUR Score scale for coma assessment. RN Web. 2007;70(12). http://rn.modernmedicine.com/rnweb.

Involve the patient's family as soon as the patient is diagnosed with LIS. The family and the patient need to work together with the multidisciplinary team to address issues to reduce stress, anxiety, and fear.

Educate hospital staff providing care to patients with LIS. Teach them about the condition and patients' needs and fears. Remind them that the patient can hear and understand everything they say. Increasing staff confidence will reduce everyone's stress and anxiety.

Digging deeper with the FOUR Score

The FOUR Score Coma Scale includes four subscales to score separately for eye response, motor response, brainstem reflexes, and respiration. Lower scores indicate more severe signs and symptoms.

Eye response (E)

Try to elicit the best level of alertness by using at least three trials, then grading the best response. If the patient's eyes are closed, open them and see if the patient tracks a finger or object. In cases of eyelid edema or facial trauma, tracking with only one open eyelid will suffice. If horizontal tracking is absent, examine the patient for vertical tracking. Alternatively, document two blinks on command, which indicates a locked-in syndrome (patient is fully aware).

E4 Eyelids open or opened, tracking, or blinking to command
E3 Eyelids open but not tracking
E2 Eyelids closed, opens to loud voice, not tracking
E1 Eyelids closed, opens to pain, not tracking
E0 Eyelids remain closed with pain

Motor response (M)

Grade the best possible response of the arms. If the patient demonstrates at least one of three hand positions with either hand, the score is M4. If the patient touches or nearly touches the examiner's hand after a painful stimulus compressing the temporomandibular joint or supraorbital nerve (localization), the score is M3. If the patient has any flexion movement of the upper limbs, including withdrawal or decorticate posturing, the score is M2.

M4 Thumbs up, fist, or peace sign to command
M3 Localizing to pain
M2 Flexion response to pain
M1 Extensor posturing
M0 No response to pain or generalized myoclonus status epilepticus

Brainstem reflexes (B)

Grade the best possible response. Examine pupillary and corneal reflexes. Preferably, test corneal reflexes by instilling a few drops of saline on the cornea from a distance of several inches to minimize corneal trauma from repeated examinations, or use cotton swabs. Test the cough reflex to tracheal suctioning only when both of these reflexes are absent. A score of B1 indicates both pupil and corneal reflexes are absent, but the cough reflex (using tracheal suctioning) is present.

B4 Pupil and corneal reflexes present
B3 One pupil wide and fixed
B2 Pupil *or* corneal reflexes absent
B1 Pupil *and* corneal reflexes absent
B0 Absent pupil, corneal, and cough reflex

Respiration (R)

For ventilated patients, use respiratory patterns shown on the ventilator monitor to identify patient-generated breaths. Don't adjust the ventilator while the patient is graded, but try to ensure that the patient has a $Paco_2$ within normal limits. To assess the breathing drive, you may need to disconnect the ventilator for 1 to 2 minutes while providing oxygenation. A standard apnea (oxygen diffusion) test may be needed when the patient is breathing at the ventilator rate.

R4 Not intubated, regular breathing pattern
R3 Not intubated, Cheyne-Stokes breathing pattern
R2 Not intubated, irregular breathing pattern
R1 Breathes above ventilator rate
R0 Breathes at ventilator rate or apnea.

Sources: Eken C, Kartal M, Bacanli A, Eray O. Comparison of the Full Outline of Unresponsiveness Score Coma Scale and the Glasgow Coma Scale in an emergency setting population. *Eur J Emerg Med*. 2009;16(1):29-36; Mayo Clinic. *FOUR Score Instruction Guide*. Rochester, MN: Mayo Clinic; 2007.

If she has active lateral head or limb movement but can't use a regular call light, provide her with one that's pressure-sensitive and teach her how to use it. This device is activated by slight pressure from any body surface. Patients with classic and total LIS won't be able to use this device.

Work closely with the speech therapist to develop a way for the patient to communicate effectively. The most common options are the yes/no eye blink (looking up for yes, closing eyes for no), Morse code (blinking to spell out her thoughts), or an alphabet board system.[8]

Although the yes/no eye blink limits the content of communication, it lets the patient respond quickly to yes/no questions. But this system has several drawbacks: The patient has no way of initiating requests, and she can't communicate complex thoughts.

Using Morse code, she can communicate more fully. However, this method requires training the patient, staff, and family members, which may not be practical in the acute hospital setting.

To use one kind of alphabet board, the assistant calls out names of blocks of colors on the board and the patient signals the one she wants by an upward eye movement. The assistant then specifically calls out the letters found within that block of color. The assistant writes down these letters to formulate the patient's statement or question.[2]

The point board system may be the best solution for communicating. The patient learns a sequence of blinks to initiate use of the board, which holds numbers, letters, and common words placed in columns. This system uses less of the patient's energy because she can blink for columns and rows. With the point board, she blinks the number of times that corresponds with the columns and then the rows for words, letters, or numbers. The assistant can write these down.

Once the patient learns to use the point board, explain the system to her family members. Don't be surprised if they're dubious at first. Help them understand that the patient can

communicate quite well with this tool. Everyone involved with this task needs to be understanding and patient.

Now let's explore the nursing care a typical patient needs.

Family education is one of the most important issues that you'll undertake. Because of the complexity of LIS, teach the family to have realistic expectations about what their loved one can achieve. Have them express their frustrations where the patient can't hear them, and then address their concerns. They'll need to accept that the only way to communicate with their loved one will be through a communication or point board, Morse code, or blink yes/no method. Support and encourage the patient and her family members.

Think about ways you could stimulate the mind of someone with LIS, such as by playing favorite music, books on tape, or uplifting TV shows or movies. Encourage family and friends to read to her, touch and massage her, and hold her hand.

Involve the social worker and psychologist to help deal with complex issues that arise. Acknowledge family members' feelings of fear, anxiety, and isolation, and offer them your support. These simple steps may help to allay their fears.

Meeting the patient

Julia McCall, 50, is transferred from the neurologic ICU to your medical unit following admission for a stroke. While Ms. McCall was in the neurologic ICU, the nursing staff observed her keenly and noted signs and symptoms suggesting LIS. Ms. McCall was unresponsive and had preserved eyelid and vertical eye movement, anarthria, quadriplegia with intact sensation, and bowel and bladder incontinence. She was hemodynamically unstable and required a tracheostomy and mechanical ventilation. The diagnosis of classic LIS was confirmed by neurologic exam and testing. Her EEG shows diffuse slowing and the MRI showed a pontine lesion. On admission to the neurologic ICU, Ms. McCall's GCS score is as follows:

- Eye response: eye opening to pain, 2
- Verbal response: no verbal response, 1
- Motor response: no motor response, 1

Her GCS total score is 4, indicating she's comatose.

The FOUR Score Coma Scale is as follows:

- Eye response: eyelids closed, open to pain, not tracking, E1
- Motor response: no response to pain or generalized myoclonus status epilepticus, M0
- Brainstem reflexes: pupil *and* corneal reflexes absent, B1
- Respiration: breathes at ventilator rate or apnea, R0

The FOUR Score Coma Scale score is E1, M0, B1, and R0. The score isn't totalled.

The FOUR Score Coma Scale was developed to address some of the limitations of the GCS. For one thing, the GCS doesn't address patients who can't speak because they're intubated. Withdrawal from pain, which can be easily misinterpreted, isn't used in the FOUR Score. Brainstem reflexes and respiratory pattern, not used in the GCS, have been added to the FOUR Score. The lowest FOUR Score is more predictive of in-hospital mortality than the lowest GCS.[7,9]

Following a plan for patient care

Use these guidelines to care for a patient with locked-in syndrome.

Respiratory function

- Place the patient in the lateral recumbent position, keeping her neck in a neutral position.
- Elevate the head of the bed 30 degrees unless contraindicated.
- Oxygenate with 100% oxygen before and after suctioning.
- Suction oropharyngeal airway or via endotracheal or tracheostomy tube every 1 to 2 hours to clear airway of drainage. Limit suctioning to 10 seconds or less and one insertion per attempt.
- Provide tracheostomy care every 4 hours.
- Frequently monitor the rate, depth, and pattern of respirations.
- Observe frequently for signs and symptoms of respiratory distress.
- Auscultate the chest every 2 hours for adventitious sounds.
- Monitor arterial blood gas values periodically and continue pulse oximetry.
- Administer supplemental oxygen as ordered.
- Provide mouth care every 2 to 4 hours and brush the patient's teeth every 8 hours.
- If the patient is mechanically ventilated, provide a "sedation vacation" with a spontaneous breathing trial as ordered.
- Institute venous thromboembolism (VTE) prophylaxis, as ordered.

Cardiovascular function

- Monitor vital signs frequently.
- Monitor the rate, rhythm, and quality of apical and peripheral pulses.
- Document any dysrhythmias.
- Don't use the foot gatch under the patient's knees or place constricting objects behind her knees.
- Position the patient so that each joint is higher than the previous joint; the distal joints will be highest.

Integumentary system

- Use lubricants, protective dressings, and proper lifting techniques to avoid skin injury from friction/shear when transferring and turning patients.
- Use pillows or other devices to keep bony prominences from direct contact with each other.
- Optimize nutrition and hydration.
- Conduct a pressure ulcer admission assessment, and reassess risk daily; inspect skin daily.

(continued)

Following a plan for patient care *(continued)*

- Provide pressure-relieving devices but not donut-type devices.
- Use protective barriers on fragile or irritated skin.
- Don't massage bony prominences.
- Perform a risk assessment with a reliable and standardized tool such as the Braden Scale.
- Clean skin at time of soiling; avoid hot water and irritating cleaning agents. Use moisturizers on dry skin.
- Keep the patient's heels off the bed at all times.
- Turn and reposition the patient at least every 2 hours.
- Protect the skin of incontinent patients from exposure to moisture.

Musculoskeletal function

- Perform passive range-of-motion exercises at least four times daily.
- Position the patient in proper body alignment, using a trochanter roll, splints, slings, pillows, and foot positioners or athletic shoes, as needed.
- Collaborate with the physical therapist.

Urologic function

- Monitor intake and output.
- Follow strict aseptic technique in the care of the patient's urinary catheter.
- Remove the urinary catheter as soon as possible.
- Consider an intermittent catheterization program.
- Provide perineal care.
- Monitor urinalysis and urine culture and sensitivity results for signs of infection.

Gastrointestinal function

- Monitor and record the character and frequency of bowel movements.
- Auscultate the patient's bowel sounds.
- Initiate a bowel program.
- Use peptic ulcer prophylaxis as ordered by the healthcare provider.

Neurologic function

- Provide sensory stimuli by talking to the patient; for instance, explain the surroundings and treatments.
- Stimulate as many of her senses as possible.
- Encourage the family to touch and talk to the patient.
- Use orientation instruments, such as a clock, a calendar, the window, favorite objects, or family photos.

Pain

- Assess for nonverbal pain indicators.
- Assess for distended bladder or fecal impaction.
- Assess for foreign object on or under the skin.
- Administer analgesics and provide alternatives to analgesics.

Nutrition and hydration

- Request a nutritional consultation.
- Maintain an accurate intake and output record; include a daily calorie count.
- Monitor skin turgor and mucous membranes for dryness.
- Monitor urine specific gravity and serum osmolality values.
- Provide hydration as ordered.
- Weigh daily.

Source: Adapted from Hickey JV. *The Clinical Practice of Neurological and Neurosurgical Nursing*. 6th ed. Philadelphia, PA: Lippincott Williams and Wilkins; 2009.

After several weeks of intense neurologic and nursing intervention, Ms. McCall's GCS and FOUR Score Coma Scale scores improve, and she's transferred to the intermediate medical unit. At this time, her GCS scores are as follows:

- Eye response: open spontaneously, 4
- Verbal response: no verbal response, 1
- Motor response: no motor response, 1

Her GCS total score is 6.

The FOUR Score Coma Scale score is as follows:

- Eye response: eyelids open or opened, tracking, or blinking to command, E4
- Motor response: no response to pain or generalized myoclonus status epilepticus, M0
- Brainstem reflexes: pupil and corneal reflexes present, B4
- Respiration: not intubated, regular breathing pattern, R4

Her FOUR Score Coma Scale score is E4, M0, B4, and R4.

Over the past weeks of neurologic ICU care, Ms. McCall's condition improved significantly. She opens her eyes spontaneously, enabling her to track and blink on command.

You note that Ms. McCall is fully alert but mute without facial expression or movement, is quadriplegic with intact sensation, and has bowel and bladder incontinence. Her eyelid and vertical eye movement are intact. She has a tracheostomy tube but has been successfully weaned off the ventilator, and has a nasogastric tube for nutrition and an indwelling urinary catheter.

See *Following a plan for patient care* for a detailed guide to nursing care. Follow the American College of Chest Physicians guidelines for VTE prevention, as ordered.[10]

After 3 weeks in the intermediate medical unit, Ms. McCall is transferred to a long-term-care facility with a rehabilitation unit.

Research holds hope

Some hope of "unlocking" LIS is on the horizon. Rehabilitation engineers and speech and language therapists are developing infrared eye movement

sensors and computer voice prosthetics. Computers are enabling patients with LIS to initiate dialog, prepare questions or messages, and use the Internet. Research has shown that when augmentative communicative devices are added to a computer, patients who can't talk may find a way to communicate effectively.[2]

Tissue plasminogen activator (t-PA) has been administered to a patient with evolving LIS. The patient had signs and symptoms of pontine ischemia caused by a vertebrobasilar dissection that suddenly deteriorated into an LIS state 32 hours after the onset of signs and symptoms. The quadriparesis was successfully reversed within 3 hours of onset with a combination of pharmacologically induced hypertension, anticoagulation, and t-PA.[11]

Leadership role

The patient diagnosed with LIS will need intense nursing care and management. Your role is to lead the multidisciplinary team in providing comprehensive medical care to the patient and emotional support to the patient and her family or significant other. ✧

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Rachel L. Palmieri is the neuroscience program coordinator at Washington Hospital Center in Washington, D.C.

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