

What's the Evidence? Locked-in Syndrome

Key findings

- Locked-in syndrome (LIS) is when a person experiences total paralysis of all the muscles in the body.
- There is no cure or standard treatment for locked-in syndrome.
- Therapy for LIS usually involves a combination of physiotherapy, speech and communication training and swallowing training which have been shown to have a positive effect on people with LIS.
- The National Institute of Neurological Disorders and Stroke [website](#) has some good background information about LIS, and some links to websites which publish information about clinical trials.

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What were we asked?

A parent wanted to know about locked-in syndrome, recovery, and what methods of rehab are available.

What did we find?

Locked-in syndrome (LIS) is when a person experiences total paralysis of all the muscles in the body. This means they are unable to speak or move. People with locked-in syndrome can usually move their eyes and are sometimes able to communicate by blinking.¹

What treatment is available?

There is no cure or standard treatment for locked-in syndrome. A therapy called functional neuromuscular stimulation, which uses electrodes to stimulate muscle reflexes, may help activate some paralyzed muscles. Therapy for LIS usually involves a

combination of physiotherapy, speech and communication training (some patients are able to make some noise) and swallowing training which have been shown to have a positive effect on people with LIS.² Long term physiotherapy is recommended for patients with LIS, with the aim of achieving long term improvements in movement ability³ Short term results may be difficult to achieve and some patients and therapists may become discouraged. It may take some time before the benefits become apparent.

What research is there on recovery from locked-in syndrome?

There is limited evidence regarding the prognosis for LIS and most academic papers are case reports, describing one or a handful of people with LIS; or narrative reviews summarising information about LIS from a range of other sources without describing a systematic search for evidence.

A narrative review of LIS from 2002 discusses the clinical features, diagnosis and prognosis of LIS⁴. In this review, a range of outcomes from individual case reports were discussed. Some patients regained some movement in their fingers and toes, some were able to communicate using a computer and use powered mobility⁵, and some recovered substantial movement ability⁶. However, one of the limitations of individual case reports is that they Locked In Syndrome only describe outcomes for a very small sample of patients. Each of these patients received different programmes of therapy and individual circumstances differ from person to person. It is not possible to say whether the treatment regimens used in each of these cases would have the same effect on the recovery of another person with LIS, particularly as the exact cause and effect of LIS may differ from person to person.

Most LIS literature focuses on adults, but a review of the literature carried out in 2009 focused on children and young people. This review found that, of the children and young people studied, 35% showed some motor recovery (11/31), 26% returned to some level of independent living, 23% died and 16% remained paralysed and unable to speak⁷.

Communicating with LIS

It may be possible for people with LIS to communicate using blinking and eye movements. For example, 'yes' may be

signalled with one blink, and 'no' signalled with two blinks. A review by León-Carrión et al summarises three ways of communicating using eye movements⁴. A computer system may also be used to aid communication in patients with LIS. A camera scans the patient's eye shape and movement and monitors where their gaze is being directed. Using a letter table, the subject can choose and select a letter by holding it in their gaze.

Social support has been identified as one of the key factors in helping people affected by LIS to adjust and cope with the condition, and establishing an effective communication method is clearly beneficial. Psychosocial adjustments and quality of life in people affected by LIS were reviewed in 2009⁸. This paper concluded that psychological treatment for depression, effective strategies for coping with the disease and support to maintain social networks are needed for people to cope with LIS.

Signposts to other information

The National Institute of Neurological Disorders and Stroke [website](#) has some good background information about Locked-In Syndrome, and some links to websites which publish information about clinical trials; there is currently one [trial recruiting people with LIS](#) at Massachusetts General Hospital in the USA. The COMA science group [website](#) has more information about LIS.

We would like to hear your feedback on this summary. Please [contact us](#) if you have any comments or questions.

References

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Note: This information is produced by PenCRU researchers and reviewed by external experts. The views expressed are those of PenCRU at the University of Exeter Medical School and do not represent the views of the Cerebra charity, or any other parties mentioned. We strongly recommend seeking medical advice before undertaking any treatments/therapies.