



Empowering Children. Supporting Families. Building Brighter Futures.

Resource 058 | Brain, spinal cord, and seizure conditions

Infantile epileptic spasms syndrome

What it means

Infantile epileptic spasms syndrome (IESS) is a serious epilepsy syndrome of infancy. Spasms are often brief and easy to mistake for startles or stomach discomfort. Development may slow or regress. Prompt recognition and specialist treatment are important; a developmental referral alone is insufficient for suspected spasms. [1]

Causes and risk factors

Possible causes include genetic conditions, differences in brain structure, brain injury, and metabolic disorders. Tuberous sclerosis complex is one associated condition. Sometimes investigations do not identify a cause. Both the underlying disorder and ongoing epileptic activity can affect development, so care addresses both. [1,2]

General family education. A concern deserves assessment, but this guide does not diagnose a child or prescribe treatment.



Signs and everyday impact

An infant may suddenly bend forward, lift or extend the arms, stiffen, or make repeated small head drops. Events often occur in clusters, particularly around waking. Families may notice reduced interaction or loss of previously acquired skills. The movements can be subtle rather than dramatic convulsions. [1,2]

Assessment and diagnosis

Suspected spasms need urgent pediatric neurology assessment and an EEG, often including sleep. Characteristic EEG abnormalities help diagnosis, but the classic pattern is not present in every case. Clinical history, video, imaging, and selected genetic or metabolic tests help determine the syndrome and underlying cause. [1,2]

Treatment and therapy

Treatment should begin promptly under specialist direction. Hormonal treatment and vigabatrin are important options; the choice or combination depends on the cause, risks, and local guidance. Selected children may need other medicines or surgery. Repeat clinical and EEG assessment checks response. Developmental therapy, communication support, and family support proceed alongside medical care. [1,2,3]

Support at home

If safe, record a short video showing the infant and repeated movements; do not delay assessment to capture one. Note when clusters occur and any change in skills. Follow the specialist's medicine, monitoring, and infection precautions. Ask caregivers to report unusual movements even when each event lasts only a moment.

When to seek help

Seek same-day urgent medical assessment for suspected spasms or repeated unexplained head drops. Use emergency services for breathing difficulty, prolonged unresponsiveness, or a prolonged seizure. Do not wait for a routine therapy appointment.

Questions for your care team

- Could these clusters be epileptic spasms?
- How soon will EEG and treatment-response checks occur?
- Which medicine monitoring and developmental supports are needed?



Podcast preparation

Use this outline to develop a later podcast script.

Suggested opening

Welcome to Mariel Early Intervention. Today we discuss infantile epileptic spasms syndrome. Infantile epileptic spasms syndrome (IESS) is a serious epilepsy syndrome of infancy. This is general education; each child needs individualized care.

Opening: Define the topic and its developmental context.

Understanding: Explain causes and signs without inviting self-diagnosis.

Assessment: Describe evaluation and distinguish screening from diagnosis.

Support: Discuss treatment, therapy, and practical family supports.

Closing: Explain urgent signs and one clear next step.

Misconception to address: Myth: brief movements cannot be seizures. Infantile spasms may last only a second or two but occur repeatedly.

Before recording: update clinical references and local service details, arrange clinical review, and use fully consented or fictional examples.

Terms in plain language

- Spasm: a brief seizure involving sudden muscle contraction.
- Regression: loss of a skill a child previously used.
- Hypsarrhythmia: an EEG pattern sometimes associated with infantile spasms.

Sources and further reading

Sources accessed 3 October 2026. Numbered references support the clinical overview. Treatment availability and referral routes vary by country.

[1] INFANTILE EPILEPTIC SPASMS SYNDROME (IESS)

<https://www.epilepsydiagnosis.org/syndrome/west-syndrome-overview>

[2] INFANTILE EPILEPTIC SPASMS SYNDROME (IESS)

<https://www.epilepsydiagnosis.org/syndrome/west-syndrome-diagcriteria.html>

[3] 6 Treating childhood-onset epilepsies

<https://www.nice.org.uk/guidance/ng217/chapter/treating-childhood-onset-epilepsies>