CONDITION

West syndrome

West syndrome is an infant seizure condition that can affect early brain development.

WHAT IT IS
Early-life epilepsy with repeated brief spasms

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Brief body crunches, repeated clusters, developmental slowing, lost skills

WHAT CAUSES IT
Brain differences, genetic changes, metabolic disorders, or unknown

HOW IT IS DIAGNOSED
Video EEG linking spasms with abnormal brain activity

MAIN TREATMENT
Hormonal therapy and anti-seizure medicine; sometimes surgery

CAN IT BE CURED?
Sometimes - spasms stop, underlying condition persists

IS IT AN EMERGENCY?
Sometimes - prolonged seizure, breathing trouble, or poor recovery

LONG-TERM OUTLOOK
Spasms often resolve; developmental and epilepsy risks may continue

Overview

West syndrome is an epilepsy condition that begins in infancy. Epilepsy means a tendency to have seizures caused by bursts of abnormal electrical activity in the brain.

The main seizure type is an epileptic spasm . These are very brief movements in which a baby's head, arms, legs, or whole body suddenly bends or stiffens. Spasms often happen repeatedly in clusters, especially after waking.

West syndrome has traditionally been defined by three features:

Not every baby has all three features when symptoms first appear. Specialists increasingly use the broader term infantile epileptic spasms syndrome , or IESS. West syndrome usually refers to IESS with the characteristic developmental and EEG findings.

An EEG, or electroencephalogram, records the brain's electrical activity. The EEG changes

associated with West syndrome can interfere with brain development even between obvious seizures. Prompt recognition and treatment matter because ongoing spasms may increase the risk of developmental difficulties.

- Epileptic spasms
- A very disorganised brain-wave pattern called hypsarrhythmia
- Development that slows, stops, or moves backwards

Symptoms

Spasms most often begin during the first year of life. Each one usually lasts only a second or two, but many may occur close together.

A spasm may look like:

Movements may affect both sides equally, or one side may be more involved. A baby may cry afterward or seem unsettled. Clusters commonly happen after waking, although they can occur at other times.

Because the movements are brief, they may be mistaken for startle reflexes, colic, reflux, or normal baby movements. Repetition in a similar pattern is an important clue.

Development may also change. A baby may stop making progress with smiling, rolling, reaching, sitting, or interacting. Some lose skills they had already gained. They may become less alert or less interested in people and surroundings. Developmental changes can be subtle and may appear before, during, or after the first visible spasms.

- A sudden head nod or body crunch
- Both arms lifting or spreading
- The legs drawing up toward the body
- Brief stiffening of the neck, trunk, or limbs
- A subtle eye movement, facial grimace, or momentary pause

Causes and risk factors

West syndrome has many possible causes. Anything that disrupts how an infant's brain forms or functions can sometimes lead to spasms.

Possible causes include:

In some children, testing does not find a cause. This does not mean that anyone caused the condition or that something was missed during pregnancy.

West syndrome is not caused by ordinary parenting, feeding choices, or a baby being startled. Most cases are not directly inherited. However, some genetic causes can be passed through families or may affect the chance of the condition occurring in another pregnancy.

- Differences in brain development or an earlier brain injury
- Genetic changes affecting brain cells
- Tuberous sclerosis complex, a genetic condition that causes non-cancerous growths
- Metabolic conditions that affect how the body processes energy or nutrients
- Brain infections
- Reduced oxygen or blood flow around birth

Diagnosis

Suspected spasms need urgent assessment by a clinician experienced in childhood seizures. A short video recorded safely on a phone can be helpful, but recording should not delay medical care.

The central test is a video EEG . This records the baby's brain waves while a video records their movements. It can show whether an event is an epileptic spasm and whether the brain's activity is severely disorganised.

The EEG should usually include both waking and sleep because the abnormal patterns can change with sleep. Hypsarrhythmia is the classic pattern, but some babies have a modified or less obvious form. A normal short EEG does not always settle the question if the movements remain concerning; longer or repeated monitoring may be needed.

Further tests look for the underlying cause. These may include:

Doctors also assess development, vision, hearing, feeding, head growth, and the baby's physical examination. Finding the cause can guide treatment and provide more information about future health, but treatment for the spasms may begin before every result is available.

- MRI scans to examine the structure of the brain
- Genetic testing
- Blood or urine tests for metabolic conditions
- Tests for infection when the history suggests one

Treatment and management

The first goal is to stop both the visible spasms and the abnormal EEG activity as quickly and safely as possible.

Established initial treatments include hormonal therapy and vigabatrin, an anti-seizure medicine. Hormonal treatment may involve a corticosteroid or adrenocorticotropic hormone, commonly called ACTH. The most suitable approach is influenced by the suspected cause, the baby's health, local specialist guidance, and the risks of each treatment.

Vigabatrin is particularly important when spasms are related to tuberous sclerosis complex. In other situations, hormonal treatment, vigabatrin, or a combination may be considered.

Close monitoring is necessary. Hormonal treatments can affect blood pressure, blood sugar, infection risk, and mood or sleep. Vigabatrin can damage peripheral vision, meaning the outer part of the visual field. Vision assessment in babies can be difficult, so specialists balance this risk against the harm caused by uncontrolled spasms.

Families are usually asked to track clusters and report whether they have stopped. A follow-up EEG is important because visible improvement does not always mean the abnormal brain activity has resolved.

If initial treatment is unsuccessful, specialists may consider another hormonal approach, a different anti-seizure medicine, or dietary therapy such as a medically supervised ketogenic diet. Brain surgery may be an option when testing identifies one abnormal area that is causing the seizures and can be removed safely.

Developmental care is also part of treatment. Physiotherapy, occupational therapy, speech and language therapy, feeding support, and early education services may help a child build skills and participate in daily life.

Medicines should not be stopped or changed suddenly without guidance from the prescribing team.

Complications

West syndrome can affect development, learning, movement, communication, and behaviour. The degree of difficulty ranges widely. Much of the long-term outlook is linked to the underlying cause, although how quickly the spasms respond to treatment may also matter.

Possible complications include:

Some children later develop another epilepsy pattern, including Lennox-Gastaut syndrome,

which involves several seizure types and learning difficulties. This does not happen to every child.

Repeated seizures can also affect sleep and family life. Caregivers may experience exhaustion, uncertainty, and stress, particularly while waiting to see whether treatment is working. Practical and emotional support are important parts of care.

- Continued developmental delay or loss of skills
- Intellectual disability
- Problems with movement, feeding, vision, or communication
- Relapse after the spasms initially stop
- Other seizure types later in childhood
- Treatment side effects

Prevention

West syndrome usually cannot be prevented. Many causes involve genetic changes, differences in early brain development, or events that could not have been predicted or avoided.

Good pregnancy and newborn care can reduce some causes of brain injury or infection, but it cannot prevent every case. There is no proven home action, diet, or supplement that prevents West syndrome.

If a genetic or metabolic cause is found, genetic counselling can explain whether it could affect relatives or a future pregnancy. Counselling provides information and testing options; it does not mean that either parent caused the condition.

Living with it and what to expect

Epileptic spasms are linked to early childhood and often disappear as a child gets older. Their disappearance does not always mean the underlying condition has gone away. Spasms can relapse, and some children develop different seizure types later.

Developmental outcomes range from development close to the expected range to substantial lifelong disability. Children whose development was typical before the spasms, who have no major structural brain difference, and whose spasms stop promptly may have a better chance of making progress. These features cannot predict one child's future with certainty.

Follow-up usually includes seizure reviews, EEGs, developmental assessments, and monitoring for treatment effects. Children with an identified genetic, structural, or metabolic condition may also see other specialists.

At home, it can help to keep a simple record of seizure clusters, sleep, medicines, and developmental changes. Families may receive a written plan explaining what to do if seizures recur or a different seizure lasts longer than expected.

Over months and years, support needs may change. Some children need help with feeding, mobility, communication, or learning. Others attend ordinary childcare or school with limited adjustments. Early support services and an individual education plan can help match assistance to the child's current needs.

Routine follow-up remains important even after spasms stop because development and other seizure types need continued observation.

When to get medical help

Seek urgent, same-day medical assessment if a baby has new, repeated movements that could be spasms. This is especially important when the movements occur in clusters after waking or are accompanied by reduced interaction or loss of skills.

Also seek urgent advice if:

Call emergency services if a seizure lasts five minutes or longer, unless the child's individual emergency plan gives different instructions. Emergency help is also needed if seizures continue without the child recovering, breathing becomes difficult, the lips or skin turn blue or grey, there is a serious injury, or the child remains unusually unresponsive.

A typical cluster contains many very brief spasms, so its total length can be confusing. Follow the child's seizure plan and seek emergency help when the cluster is unusually prolonged or recovery is poor.

Medication questions, sleep problems, feeding concerns, therapy needs, and school planning can usually be discussed during routine follow-up unless there has been a sudden change.

- Previously controlled spasms return
- Seizures become more frequent or look different
- A child becomes unusually sleepy, weak, or difficult to feed
- There are possible medicine side effects
- Development slows or previously gained skills are lost

Common questions

Is West syndrome the same as infantile spasms?

Infantile spasms describe the seizure type. West syndrome traditionally means spasms together with developmental slowing or loss and the characteristic abnormal EEG pattern. Infantile epileptic spasms syndrome is now often used as the broader name.

Will my baby grow out of West syndrome?

The spasms often stop during early childhood, either with treatment or as the seizure pattern changes with age. However, developmental difficulties or other forms of epilepsy may continue. Ongoing follow-up is needed even when no spasms are visible.

Can a child with West syndrome develop normally?

Some children make strong developmental progress, particularly when no major underlying brain condition is found and treatment controls the spasms quickly. Many children have ongoing learning, movement, communication, or behavioural needs. Early test results cannot predict the exact outcome.

Why does my baby need an EEG during sleep?

The abnormal electrical patterns linked to West syndrome may become clearer or change during sleep. Recording both sleep and waking activity gives the specialist a better chance of identifying the pattern and checking whether treatment has worked.

Can infantile spasms come back after treatment?

Yes. A relapse can happen after an initial response, and other seizure types can appear later. Contact the child's epilepsy team urgently if familiar movements return. A repeat EEG may be needed.

Are infantile spasms painful?

It is not clear that each brief spasm causes pain. Some babies cry or appear distressed during a cluster, while others do not. Crying may result from the sudden movement, tiredness, or confusion rather than pain itself.

Sources

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