
What are infantile spasms?

Infantile spasms (IS) is a rare type of epilepsy. Some disorders that cause problems with the brain can also cause IS, but sometimes the cause is unknown.

The spasms often:

- Start between 3 and 12 months of age.
- Cause the body, arms and legs to bend forward and stiffen.
- Begin soon after waking from sleep.
- Last about 1 to 5 seconds.
- Happen in clusters of 2 to 100 at a time.
- Often end by age 5 but are often replaced by other types of seizures.

What are the possible symptoms?

Your child may have 1 or more of these:

- Sudden bending forward and stiffening of arms and legs
- Fussiness during episodes
- Developmental delays (may not reach usual milestones, such as sitting, walking or talking)
- Abnormal EEG with unusual brain wave patterns

What tests could my child have?

Your child may have 1 or more of these tests:

- EEG (electroencephalogram)
- VEEG (video electroencephalogram)
- CT scan
- MRI scan
- Blood tests
- Urine and stool tests
- Spinal fluid tests

What is the treatment?

Your doctor will talk with you about specific care for your child. Some treatment guidelines include:

- Spasms can be controlled but not cured with medicines. Medicines may include:
 - Steroid medicines, such as adrenocorticotrophic hormone (ACTH) or prednisone.
 - Seizure medicines, such as vigabatrin or Topamax.
- Surgery to remove the area in the brain causing the spasm.
- Ketogenic diet.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Infantile spasms, continued

What should I look for and remember?

To help the doctor plan your child's treatment, keep a journal with these things noted about your child's spasms:

- When did the spasms start?
- How long did they last?
- What did the spasms look like? (Video is very helpful.)
- Did your child have any changes in color or breathing?
- Did your child stop breathing?
- What did your child do after the spasms stopped?

Your child may be sleepy afterwards. **DO NOT** give them any food or drink until they are awake and alert.

What should I do if my child has a spasm?

Helpful tips include:

- Keep calm, and stay with your child.
- Lay your child on a flat surface.
- Remove any hot or sharp objects from the area.
- Do not try to restrain your child.
- Do not put anything in your child's mouth. They will not choke on their tongue.

When should I call the doctor?

Call 911 **right away** if your child has any of these:

- Breathing problems or stops breathing
- Blue color of the lips, gums or nails

Also call the doctor if your child:

- Has more spasms than normal.
- Has changes in the way the spasms look.
- Has spasms that last longer than normal.
- Does not return to their normal self within 30 minutes after the spasms stop.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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