

Acute disseminated encephalomyelitis (ADEM)

What is ADEM?

ADEM is a sudden attack of inflammation (swelling) in the brain that damages myelin.

- Myelin is the protective covering of nerve fibers.
- Sometimes the inflammation also attacks the spinal cord.
- Most childhood cases happen in children younger than 10 years old.

What causes it?

ADEM is an immune reaction to an infection. The immune reaction causes the body's immune system to attack its own tissues. This includes the brain and sometimes the spinal cord.

- It often happens 1 to 2 weeks after an infection from a germ or virus.
- ADEM may also happen after a vaccine (immunization).
- Sometimes, ADEM is believed to be caused by an antibody reaction against a brain protein called MOG. When MOG antibodies are found in the blood of a child with ADEM, we call the condition MOG antibody disease (MOGAD).
- Sometimes the cause is not known.

What are the possible symptoms?

Your child may have 1 or more of the symptoms listed below. This depends how severe (bad) the brain injury is.

Mild symptoms	More severe symptoms
<ul style="list-style-type: none">• Fever (temperature of 100.4°F or higher)• Seems confused or does not play or act like normal• Fussy or sleepy all of a sudden• Sleepy all the time (fatigue)• Headache• Upset stomach or vomiting (throwing up)• Trouble thinking, concentrating or remembering• Stiff or sore neck• Weakness, numbness or tingling on 1 or both sides of the body	<ul style="list-style-type: none">• Slurred speech• Trouble seeing• Eyes move in ways that are not normal for your child• Trouble walking• Paralysis (cannot feel or move parts of the body)• Seizure• Agitated or combative (tries to fight)• Loss of bowel or bladder control• Trouble eating• Trouble breathing• Coma

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

ADEM, continued

What tests could my child have?

Your child could have:

- A physical exam.
- A focused exam of the brain and nervous system. This includes checking the eyes with a flashlight.
- Blood tests (labs), including tests for MOG antibody.
- Lumbar puncture (LP), also called a spinal tap. This involves taking a small sample of fluid from the space around the spinal cord. The fluid is checked for signs of infection or other problems.
- CT scan of the brain.
- MRI of the brain and spinal cord.
- EEG. This test checks for abnormal electrical waves in the brain. It may also show seizures, even very small seizures.

What is the treatment?

Your child's treatment depends on how bad the brain injury is. Treatment often happens in stages. Some children need inpatient or outpatient rehabilitation, also called rehab. Other children may not need rehab at all. The treatment for ADEM with or without MOG antibodies is about the same.

Acute (short-term) treatment

Your child may need 1 or more of these:

- Medicines called steroids to help decrease swelling.
- Intravenous immunoglobulin (IVIG) to help protect the body against the immune reaction. It may also help heal the damaged nerves.
- Nasogastric (NG) tube if your child cannot eat.
 - An NG tube is a small, plastic tube that goes up your child's nose, down the back of the throat and into the stomach.
 - It is used to give fluids, formula and medicines to your child.
- Oxygen to help your child breathe easier. Giving oxygen to your child helps to make sure the brain gets enough oxygen, too. In rare cases, your child may need a ventilator to help with breathing.
- Plasmapheresis to clean the blood. This helps to protect the body against the immune reaction. It removes the antibodies that are attacking the body's tissues.

Rehabilitation (rehab)

The type of rehab and how long it lasts is different for each child. It depends on how bad the brain injury is and how your child recovers. Rehab helps your child:

- Get back movement and strength.
- Improve moving, talking, eating, thinking and caring for themselves.

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The rehab team includes:

- Doctors who specialize in rehab.
- Nurses who provide basic care for your child and teach you how to care for your child at home.
- Physical (PT), occupational (OT) and speech therapists (ST).
 - PT helps your child with strengthening muscles, improving balance and walking.
 - OT helps your child with activities of daily living. This includes getting dressed, brushing teeth and bathing.
 - ST helps your child with swallowing, eating and talking.
- Neuropsychologists who assess your child's thinking skills.
- A social worker and case manager who help your child get ready to go home.
- A teacher who helps your child prepare to return to school.
- Other team members like a child life specialist, music therapist, recreational therapist and chaplain.

When will my child go home?

Talk with the doctors, nurses and therapists about when your child can go home. The inpatient rehab team will:

- Meet with you each week to talk about how your child is doing. This helps them decide when your child can go home.
- Teach you what you need to know to care for your child at home.

Your child may also need rehab after they go home. Healing and how long it takes is very specific to your child.

When should I call the doctor?

Call the doctor if your child has:

- Trouble eating or sleeping, especially if they are sleepier than normal.
- Trouble seeing or hearing.
- Little or no interest in playing.
- More or different seizures than normal.
- Changes in behavior, function or thinking (not acting normal).
- More painful headaches.

Also call the doctor if you have questions or concerns about how your child looks or feels.

When should I call 911?

Call 911 **right away** if your child has:

- Trouble breathing.
- Lips, gums or nails that turn blue or purple.

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- Trouble talking when breathing.
- A seizure for the first time.
- A longer seizure than their normal seizures.
- Choking or trouble swallowing.
- Less response to you or is harder to wake up

What is the long term outlook for my child?

The long term outlook for children with ADEM is different. It depends on how bad the disease is. Many children make a complete or almost complete recovery.

- Recovery most often begins within days but may take up to 6 months or longer.
- Some children may have leftover problems, such as blurred vision, weakness or numbness.
- Children with ADEM and positive MOG antibodies may be at risk for “relapsing” disease. This means new attacks of nerve inflammation can happen months or even years later. It is advised that children with ADEM and MOGAD get care from a doctor that specializes in autoimmune and demyelinating disorders.

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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