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# Acute Flaccid Myelitis

Acute Flaccid Myelitis is a recently discovered neurologic condition. Since the Centers for Disease Control and Prevention (CDC) began tracking it in 2014, there have been 769 confirmed cases to date, with more than 90 percent occurring in young children.

## Q: What is Acute Flaccid Myelitis (AFM)?

Acute flaccid myelitis is a rare neurologic condition affecting the gray matter of the spinal cord that causes the body's muscles and reflexes to weaken.

## Q: What are the symptoms of AFM?

The main symptoms of AFM develop suddenly and may include loss of muscle tone and reflexes, arm or leg weakness, drooping eyelids, difficulty swallowing, slurred speech, and pain in the arms, legs, back or neck.

**Life-threatening symptoms**

- Rapid and shallow breathing
- Extreme fatigue or lethargy
- Body temperature changes
- Blood pressure instability

If you or a family member develops any symptoms of AFM, it is critical to seek medical treatment immediately.

## Q: What causes AFM?

Researchers at the CDC believe that viruses play a role in causing AFM. In data gathered starting in 2014, more than 90% of patients reported a mild respiratory illness or fever before developing AFM. Most cases developed between August and October, correlating with the period each year when many viruses, including enteroviruses, circulate.

## Q: What can I do to prevent AFM?

Since viruses may trigger AFM, the following preventative actions can help decrease risk:

- Wash hands regularly with soap and water
- Avoid contact with people who are sick
- Keep up to date with recommended vaccinations

## Q: How is AFM diagnosed?

AFM is diagnosed through a combination of assessments including physical examination, magnetic resonance imagining (MRI), electromyography (nerve conduction tests that record the electrical activity of the muscle, neurological exam, and lab tests (to check the fluid around the spinal cord for inflammation.)

## Q: How is AFM treated?

There is no formal treatment protocol for AFM. Some patients have received corticosteroids (to treat inflammation), intravenous immunoglobulin (to treat immune disorders) and therapeutic plasma exchange (used to remove antibodies from blood) but it is not yet well understood whether these treatments may help some patients.

Healthcare providers will focus on managing individual symptoms of AFM. For example, physical and occupational therapy may be needed to respond to nerve damage/muscle weakness. A urologist might be needed to treat bladder issues.
If possible, work with a team of specialists including a physician that specializes in physical medicine and rehabilitation (called a physiatrist), a neurologist, and a pediatrician to coordinate care.

*Sources: Centers for Disease Control and Prevention, Cleveland Clinic*

**Need to talk to someone?**
Our Information Specialists are available to answer your questions.
Call toll-free 1-800-539-7309 Mon-Fri, 7 am-8 pm EST.
Or schedule a call or ask a question online at
https://www.ChristopherReeve.org/Ask.

## Resources for Acute Flaccid Myelitis:

**Acute Flaccid Myelitis Association**
https://www.afmanow.org/
3950 Hillcrest Lane
Sacramento, CA 95821
Email: info@afmanow.org
The Acute Flaccid Myelitis Association works to raise public awareness about AFM and advocates for increased research funding. In addition, the group offers support for family members and caregivers, providing community and financial assistance for medical equipment and treatments.

**Acute Flaccid Myelitis Working Group (AFM Working Group)**
https://acuteflaccidmyelitis.org/
AFM Working Group is a non-profit organization founded in 2018 to advance research and understanding about AFM and share knowledge with community members. Members include representatives of the patient community, neurologists, pediatricians, and specialists in infectious disease, critical care medicine, physical medicine & rehabilitation, epidemiology, genetics, virology and immunology.

**Centers for Disease Control and Prevention (CDC): Acute Flaccid Myelitis**
https://www.cdc.gov/acute-flaccid-myelitis/index.html
1600 Clifton Rd.
Atlanta, GA 30329
1-800-232-4636
The CDC is a federally funded U.S. agency dedicated to protecting the public's health.

**CDC: Helping Children Who Have AFM**
https://www.cdc.gov/acute-flaccid-myelitis/helping-children/index.html

**CDC: How to Get Involved with AFM Research**
https://www.cdc.gov/acute-flaccid-myelitis/helping-children/research.html

**Facebook Group for Parents of Children Living with Polio-Like-Syndrome/Acute Flaccid Myelitis**
https://www.facebook.com/groups/601223099978283/
This private Facebook group provides support and information to families affected by AFM.

**Siegel Rare Neuroimmune Association (SRNA) : Acute Flaccid Myelitis**
https://wearesrna.org/living-with-myelitis/disease-information/acute-flaccid-myelitis/
1787 Sutter Parkway
Powell, OH 43065-8806
Phone: 855-380-3330
SRNA is a not-for-profit international organization dedicated to the support of children, adolescents, and adults with a spectrum of rare neuroimmune disorders including AFM.



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