

What to Do When Your Child Has AFM: The Basics*

The Acute Setting (Hospital and inpatient rehab)

What does AFM mean? AFM stands for Acute Flaccid Myelitis. This is a neurological syndrome that appears to result from sudden damage to a specific region and/or group of cells in the spinal cord that control muscles. The injury to this region/group of cells causes “floppy” weakness in the corresponding muscles of the body (flaccid paralysis). Most cases of AFM only occur once in a person’s lifetime.

What caused this AFM? AFM is a known complication from many viruses, including the enterovirus family of viruses which includes poliovirus, the best-known cause of AFM. Even if a child was vaccinated against polio, they can develop AFM from another virus (such as enterovirus EV-D68 or A71). It has been shown that mice infected with types of EV-D68 can develop AFM.

What are the manifestations of AFM in the acute period (first days/weeks)? Because the virus attacks the motor neurons (nerves) in a patchy way, the muscles are weakened in an often patchy and asymmetric way (arms, legs, torso, face, talking, swallowing, breathing). Some kids can experience painful muscle spasms (treatment: valium), pain behind the knees and legs (treatment: gabapentin), blood pressure that runs high (treatment: blood pressure medications), difficulty with swallowing (needs feeding tube through the nose initially and through a hole in the belly if persists), difficulty with breathing (can need a breathing mask or tube initially, a tracheostomy if persists).

Medications to try for the AFM itself? None of these interventions has been proven definitively to be effective, because the numbers are too few to do randomized trials (the scientific ‘gold standard’). However, the following have been tried in many of the children, and it is worth asking about them in the first few days/weeks.

- ***Intravenous immunoglobulin (IVIg) is an IV medication that transfers immune molecules from other people into the blood. This treatment helped the mouse model of AFM when given very early in the infectious process.***
- Steroids reduce the immune system’s ‘angry’ response to the virus and its damage, perhaps reducing further damage caused by the immune system itself.
- Prozac has been tested for its potential to help treat some viruses, but newer studies suggest it’s not effective.
- Plasmapheresis (aka. PLEX or plasma exchange) runs blood from your child via an IV to a machine to “clean” the blood.
- Symptomatic therapies (for the symptoms like pain, blood pressure, etc).

Recovery in the acute setting? In the acute setting, it may be safest to wait until the symptoms stabilize, meaning there is no worsening in any function.

- Then, after a period of 24-48 hours of bedrest, start mobilizing your child with inpatient physical and occupational therapy (PT, OT). Even if at first you and your child’s PT do not see

any clear muscle flickers, it is possibly beneficial to starting using electrical stimulation (e-stim) starting even in the acute care setting and continuing over time, to prevent muscle shrinking (atrophy).

- To your child, you could initially explain the injury like a broken limb that needs to heal (common in child's environment) and that it will take a while.
- The positive energy from the rehabilitation team will be very important.
- It may feel hopeless while your child is sick, but some of the kids made some rapid improvements in the first few weeks and months. Some recover as time goes on. We are continuing to see some kids recover some function even 4+ years out from their illness.

Best ways for friends to help? Friends can organize a dinner drop-off schedule, and close friends can keep your child company a few hours so that you can get a nap, walk, shower or spend time with other children, who often feel scared and abandoned while the parents' focus is on the sick child.

The Post-Acute Convalescent Phase

Best places for rehab? Kennedy Krieger Institute in Baltimore and Shriners Hospital in Philadelphia are best known for AFM rehab. It's never too late to try a stay there. Try samples of letters drafted by other parents.

Nerve transfers? They may help, especially in the first year or 2 and depending on availability of healthy nerves for transfer. Talk to one of the experienced surgeons (Dr. Zlotolow and Dr. Kozin at Shriners, Dr. Mitchel Seruya at UCLA).

Best neurologist for a second opinion?

California: Keith van Haren (Stanford)

Colorado: Teri Schreiner (UC Denver; has a rehab, Denver Children's)

Maryland: Carlos Pardo (Hopkins; has a rehab, KKI/Kennedy Krieger)

Massachusetts: Leslie Benson, Mark Gorman (Boston Children's)

Pennsylvania: Sarah Hopkins (UPenn, has a rehab, Shriners)

Texas: Benjamin Greenberg (UT Southwestern) <https://myelitis.org/resources/disorder-workshop-session-acute-flaccid-myelitis/>

Managing vents and feeding tubes. Reach out to parents on the Facebook site for particulars. Parents have tried educational toys/songs to motivate kids through routines, like this: Kids Anatomy Vest, this type of Educational Toy along with a fun song written about the respiratory system and how to breathe. It's super motivational and fun. <https://youtu.be/LWWzXYWvn84>

Nutrition? There are no studies to date but many parents have increased protein intake for their children.

The Long Haul

Ongoing rehab care is essential. Rehab care nourishes hope. ***Kids continue to improve years after their illness, despite what you may have been told by their neurologist or pediatrician. We are continuing to see kids make gains 4+ years out from their illness.*** They need continuous reminders to exercise the weaker limbs that are holding them back, so continuously engaging those limbs is important. Bones need to be stimulated to grow, ideally daily through weight bearing, repeated movements, even if the limb is weak. The spine needs to grow straight, and vests/braces may be required. Orthotics can help maintain good alignment and reduce injuries. Joint stretching could help prevent spasticity (tightness in the muscles); botox injections and anti-spasticity medications can help as well.

Electrical stimulation? Applying a small electrical current to the muscles can help recovery. It is usually advised that “e-stim” happen while your child works on engaging the muscles but passive may be helpful also. Your PT can order one, or you can order directly from amazon or <http://www.valmed.com/ems.html>. If you have access through your PT, try an FES bike for electrical stimulation of entire groups of muscles. See <https://myelitis.org/resources/can-functional-electrical-stimulation-restore-function/>

Annual care. Depending on your child’s pattern of injuries, make sure you get updated x-rays of your child’s spine and limbs if these remain weak. Consider vitamin D and calcium to help the bones stay strong. Check diaphragm for weakness.

Joint health. Weakness of muscles around the hip or shoulder can predispose to dislocation or injury of the joint. You should talk to a rehab specialist or a physical/occupational therapist about strategies to help prevent this.

Bone health. Decreased pull on the bones when the muscle are weakened, can result in thinner, potentially weaker bones (arms or legs). Ensuring that your child gets good amounts of vitamin D and calcium may help keep their bones strong. Ask your pediatrician how much to include in their diet and supplements.

Vaccines. Your child needs them, to reduce the likelihood that they could be further weakened by other infectious illnesses.

Consider a talk/play therapist for your child and/or your family. Children are remarkably resilient to change, but illness and its aftermath will likely require a recalibration for children and parents. Your child may need new tools, new words and new approaches to navigate this loss of control and being ‘different’ and ‘special needs’. If they have siblings, your child may experience anger and jealousy at their ‘able’ siblings. Your child’s limitations will affect the siblings as well (style of play, guilt, loss of parent’s focus on them).

Navigating all the caregivers. Keep a list of medications, involved doctors, major concerns, and emergency numbers up to date. Insist on meeting with school leadership, support and

playground staff at the start of each year and then periodically during the year, to come up with an up to date safety plan.

Paying for all this. Be prepared to fight with insurance (get samples of letters from the fb page). Consider a GoFundMe page. Be aware of your insurance plan and limits on therapies (usually a certain number of sessions/year). Talk with your therapists and physicians about this to avoid “running out” of coverage unexpectedly.

Connecting with other families. [The transverse myelitis association](#) organizes summer camps, an annual symposium and weekend get togethers, look for one in your area.

Caring for yourself. At some point, you will have to, so that you can be your best for yourself, your child, and the rest of the family. Consider mini breaks along the way and talk therapy.

Prepared by Parents of Children with AFM fb group

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***This information is what is known as of December 1st, 2018.**