

REPORT

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WHAT TO DO IF YOU CAN'T OBTAIN MEDICAL CARE FOR ADHESIVE ARACHNOIDITIS (AA)

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Special Note: Although the medications listed in this report are non-prescription and have no known serious side effects, stop any that you feel is causing side effects or complications.

As this report is written (September 2025) AA is still a rare or uncommon disease and few physicians are familiar with it or will treat it. AA is a very serious, chronic inflammatory disease that causes severe intractable pain, paralysis, bowel and bladder dysfunction, and a number of central symptoms such as headache and vertigo. Left untreated the disease may progressively impair multiple biologic and physiologic body systems and result in a bed-bound debilitated state and premature death. This report and the suggestions herein are done as a public service to hopefully assist a person with AA control the disease until knowledgeable medical care can be obtained.

This report focusses on three components of treatment:

1. Control of inflammation
2. Pain relief
3. Retention of neurologic functions

1. Inflammation Control

We consider intermittent, low dose use of methylprednisolone, dexamethasone, and ketorolac to be the foundation of inflammation control in AA. Here are our suggestions if these potent anti-inflammatories cannot be obtained.

- a. Can't Obtain Methylprednisolone or Dexamethasone: Obtain a whole adrenal gland supplement and pregnenolone from a health food store or internet source. Follow the labeled instructions on whole adrenal. Take 200 to 300 mg of pregnenolone morning and evening. Also obtain dehydroepiandrosterone (DHEA). Take 200 mg in AM and PM.
- b. Can't Obtain Ketorolac: Take one of the following: diclofenac, KPV peptide, or thymosin. There are herbal/natural anti-inflammatory agents that various AA patients report to be effective in reducing pain, improve energy and motivation, and promote a feeling of well-being: curcumin, astragalus, ashwagandha, serrapeptase, quercetin, tart cherry extract. Select one to start and obtain it at a health food store or internet source. Take a labeled dosage in AM and PM for 3 to 5 days. Repeat this procedure with a different agent until you find one or more that provide some relief.

2. Pain Relief

Essentially all persons with AA can find a physician or nurse practitioner who will prescribe a low dose opioid, and a bioelectric transmission drug called a neuropathic agent (i.e., gabapentin, baclofen, diazepam, lorazepam, carisoprodol, alprazolam). Continue taking these prescription agents and consider taking these agents with a booster or potentiator to obtain better pain relief. (See Table) When taken with your opioid they may give you additional pain relief.

If you cannot obtain a prescription opioid or only a very deficient amount that doesn't control your pain, you will need to rely on kratom and/or marijuana for pain relief. Kratom is the only non-prescription opioid. Depending upon the state, kratom may be available in retail stores. Otherwise seek an internet source.

Measures to Reduce Your Pain Level

Here are measures that some AA patients have successfully used to lower their pain levels and lessen their need for opioids. Try using PEA as your 1st measure. Then try the others sequentially over time to see if you can significantly reduce your pain.

1. PEA (Palmitoylethanolamide) Trial: Obtain PEA in 300 or 600 mg dosage. Take one dosage in AM and PM for two weeks. If your pain level drops continue PEA on 3 to 5 days a week.
2. Ivermectin Trial: Ivermectin comes in 3, 6, and 12 mg dosages. It can be obtained without a prescription. Take a single 12 or a 3 or 6 mg dosage twice a day for 5 days. If pain is reduced, continue ivermectin on 2 to 3 days a week.
3. Descending Pain Blockage: Persons with AA usually have central and descending pain. Take St. John's wort or lions mane twice a day for 5 days. If you obtain some relief, continue the agent as long as it helps relieve your pain.
4. Peptides: Try one of these peptides for two weeks KPV, BPC-157, ARA 290. If the peptide provides pain relief, continue it on a 2 to 3 times a week basis.

TABLE

OPIOID BOOSTERS

Take one of these boosters with your opioid to get additional pain relief.

Taurine 1000 mg
 Glutamine 1000 mg
 Lion's mane mushroom
 Quercetin
 Benadryl
 St. John's wort
 White willow bark
 Aspirin
 CBD
 KAVA
 Palmitoylethanolamide (PEA) 300 to 600 mg

Retention of Neurologic Functions

There are two basic sets of exercises that are essential to stop AA disease progression and hopefully reverse some symptoms. One set (see attached) is called "Spinal Fluid Flow Exercises" and another is for "Neurologic Retention and Prevention of Paralysis." (See attached)

Diet and certain vitamins and minerals are important and can often significantly reduce pain, particularly if sugar and starches (carbohydrates) are reduced. (See attached)

The Basic AA Diet

1. Each day: eat one or more of these protein foods: beef, lamb, pork, poultry (chicken, turkey), seafood (fish, shrimp, crab), cottage cheese, eggs (See Table)
2. Each day: eat some vegetables and/or fruits that may suppress inflammation (See Table)
3. Stop drinks that contain regular sugar (carbohydrates) including fruit juices, soft drinks, coffee, and tea
4. Restrict sugars and starches known as carbohydrates (e.g., breads, pastries, pasta, pizza)
5. Low amounts of alcoholic beverages are permitted

<u>Common Protein Foods</u>	<u>Some Anti-Inflammatory Vegetables/Fruits</u>
Seafood: fish, shrimp, crab	Broccoli
Beef	Green beans
Pork	Leafy greens: spinach lettuce, kale
Lamb	Peas
Poultry: chicken, turkey	Corn
Eggs	Blueberries
	Apples
	Oranges
	Pineapple
	Grapes
	Watermelon
	Cantaloupe

At least one serving in each category is required each day.

Note: Persons may wish to supplement protein intake with an amino acid formulation.

Critical Vitamins and Minerals

There are a select number of vitamins and minerals that build a foundation for control of adhesive arachnoiditis. These specific vitamins and minerals, in our view, help pain control, suppress inflammation, and prevent progressive deterioration. Most have also been found to help prevent Epstein-Barr virus reactivation.

Vitamins

Vitamin C, 2000 mg in AM and PM

Vitamin B-12, 500 to 1000 mcg daily

Vitamin D, 500 to 800 units a day

Minerals: Magnesium, selenium, zinc, boron

A person with AA is well advised to use more than one mineral. Take one of the minerals each day. They can be rotated.

Exercises for Regeneration and Recovery

Our studies and observations of persons with adhesive arachnoiditis (AA) tell us that progressive foot and leg paralysis as well as bladder and bowel dysfunction may develop unless some specific exercises are done each day.

Leg and Arm Exercises (Stand while doing these exercises)

1. Stretch arms straight up and hold for 5-10 seconds. Repeat 3 to 4 times.
2. Raise one knee and leg at a time and hold for 5-10 seconds.
3. Flex your ankle and foot 5-10 times. Can repeat several times a day.
4. Walk with arms swinging only as far as energy will allow. Don't overdo.
5. Stand straight up with legs together. Look slightly upward for 10 seconds (military attention).
6. Stand and rock back and forth on your toes and heels several times a day. (May need to hold on to a chair or cabinet for stability.)

Walking: Walking is the physiologic cornerstone of AA nerve regeneration. Persons with AA need to take at least two short walks a day (at least 100 feet). Walking upstairs or on a treadmill is excellent.

Weightlifting: Lifting a 2-to-5-pound weight is highly recommended twice a day. Simply raising the weight to your body (curls) and raising the weight overhead done on a regular basis will strengthen muscles and other tissues around the lower spine. We believe that light weightlifting done daily will strengthen spinal ligaments and spinal canal cover as well as the arachnoid membrane.

Spinal Fluid Flow Exercises

The micro-masses of AA impede spinal fluid flow. Enhancement or acceleration of spinal fluid flow to keep it flowing at a normal rate helps prevent any infection, contaminant, or metabolic waste from retarding the healing process.

Clinical Complications of Flow Impedance by AA:

We have received numerous reports from persons with AA who have had these manifestations or complications that may be related to spinal fluid flow impedance.

Spinal fluid leaks	Nasal/eye watering	Fainting/falling
Tinnitus		
Headaches	Vertigo	Increased cranial pressure

Major Message: Exercises to enhance or accelerate spinal fluid flow are simple and some should be done at least once or twice each day by persons with AA to promote healing, and to help prevent deterioration and the complications listed above

Spinal Fluid Flow Exercises

1. Rocking chair – 5 to 10 minutes
2. Walking or gentle bouncing on a trampoline – 3 to 5 minutes
3. Porch swing, 5 to 10 minutes
4. Deep breathing – hold one minute, repeat 5 to 10 times
5. Arm swings while walking or deep breathing

Summary

AA is a rare or unusual serious, chronic inflammatory disease of the spinal cord. Untreated, it may produce intractable pain, neurologic debilitation, and premature death. To date, few physicians know how to treat the disease. The measures in this report are intended to stop progression of the disease and hopefully provide some relief and comfort until knowledgeable medical care can be obtained.