ARACHNOIDITIS HANDBOOK FOR SURVIVAL

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July, 2017

1st Edition

Published as a public service by the Tennant Foundation.

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PREFACE

My Message to Arachnoiditis Patients

I have learned one thing in treating arachnoiditis patients. You must have a survival plan. If you don't, your life can end as you have known it, or, in the worst case, you may die as the severe and catastrophic complications of arachnoiditis can take your life. Arachnoiditis has historically been considered a rare disease for which there was no hope of relief, control, or improvement. Thanks to some scientific breakthroughs and clinical experience with hundreds of patients, treatment protocols have been developed that, for the most part, can be administered and prescribed by any caring and concerned physician or nurse practitioner. Even though finding a caring and concerned physician or nurse practitioner must be part of your survival plan, there is much more. This handbook has been written to help you develop and implement your survival plan. Arachnoiditis is more often than not, a progressive, debilitating disease that can take over your life and throw you into a nightmare of misery, grief, and pain. In other words, time is not on your side, as you never know the timing or rate of progression. Don't hesitate or procrastinate. Start your plan today.

Forest Tennant M.D., Dr. P.H.

Acknowledgment

I wish to thanks Jerry Davis for his most helpful review and additions to this handbook.

TWENTY-FOUR STEPS IN DEVELOPING YOUR SURVIVAL PLAN

1. **ACCEPT YOUR DISEASE**: Realize you have an intractable, incurable condition; accept it. If you don't, you will delay developing and implementing your plan. Time is against you. You need your survival plan, and any delay may give this condition, the devil's disease, enough time to control you rather than the other way around. If you don't or won't control it, chances are you will have a progressive disease that can paralyze you, impair your bladder and bowel, leave you demented, and even leave you in a miserable dying state with adrenal failure and overwhelming infection. Don't hesitate or stall. Time is not on your side.

2. **HOW DID YOU GET THIS DISEASE?:** Review how you got this disease. Too many surgeries and medical interventions? A foolish accident? A spine condition you neglected? A greedy, incompetent health practitioner? Whatever and whoever it was, put it in the past. Don't forget your experiences because you should teach them to others. But don't let the causation drag you down. You must move on.

3. **STUDY THIS DISEASE**: Arachnoiditis means inflammation of the middle layer (arachnoid) of the spinal canal cover (known as the dura mater, theca, or meninges). Learn how it starts and the anatomy of your spinal cord. You can't will or pray arachnoiditis away. But stress and lack of prayer can make it worse.

4. **THINK CONTROL, NOT CURE**: Don't initially think about cure or beating it. Think about control. This is a major survival attitude. Why? With control two good things will happen: (1) the disease won't progress; and (2) you will keep a quality, happy, and gracious life.

5. **STALL OR STOP PROGRESSION**: You will most likely need some time to get good medical help, find some financial resources, and develop a survival network. Go to the health food store and purchase, whatever your pocket book can afford, the following: (1) pregnenolone (heals nerves); (2) glutamine (builds the body's natural pain reliever); and (3) curcumin (suppresses inflammation). Take whatever dosage is on the label for a couple of days. After this increase the dose by 50% if your pocket book can handle it and they don't cause you any side-effects. Don't expect any major pain reduction, miracle, or great psychologic boost. Just know one thing. These 3 agents will give you enough healing and protection power to keep you alive, functional, and have enough mental capacity to plan your survival. Progression of arachnoiditis can be a nightmare since it can happen very suddenly with an unpredictable rate of deterioration. There are cases in which an arachnoiditis patient could walk, think, and laugh on one day and within 24 to 48 hours be non-functional, mentally confused, and unable to walk. Also arachnoiditis can progress into an autoimmune disorder in which you suddenly develop muscle and joint aches, thyroid deficiency, and skin rashes. Don't stall any longer. Take action!

6. **CHECK IN WITH YOUR GOD**: Have a private conversation with your God and spiritual leaders. Don't ask, why me? Ask how you can overcome your suffering and serve the purpose you are here to serve.

7. **DON'T BLAME YOURSELF**: Don't even begin to believe that you are some "bad person" or inhabited by an evil spirit because you have this condition. Your talks with your God may tell you why you have this disease and what your mission happens to be. Every arachnoiditis patient I've encountered has telegraphed to me some purpose for their life. It's human nature to have these beliefs. Just don't let self-pity or blame hold you down, as these negative beliefs will sap the motivation, energy, and endurance you will need to carry out your survival plan.

8. **GET SOME PAIN RELIEF**: Get the best pain relief you can obtain in your circumstances. Too many arachnoiditis victims take the attitude they won't do anything for pain relief unless they get exactly what they want from their doctors. Your pain relief goal MUST be to have enough relief to get out of bed, take care of yourself (toilet, bathing, food, walking, etc.), and feel some of the joys of life and think clearly. Unless you are one of the very lucky people who have a doctor who will prescribe maximal pain relief, follow this plan for survival: (1) take whatever pain medication your doctor will prescribe and your insurance will cover or you can afford to buy with cash; and (2) supplement your prescription pain medication with non-prescription (over-the-counter) medications.

   In this handbook are lists of pain relief (analgesic) drugs. Some are prescription and others are not. You will need a combination of prescription and non-prescription pain relievers.

9. **KEEP EATING AND DRINKING**: Arachnoiditis will usually wipe out your appetite or cause you to only want to eat sugar, sweets, carbohydrates (e.g. bread, rolls, potatoes, pie, cake, pizza, etc.). You don't have to eat 3 meals a day, but you have to take in enough protein to help slow the progression of arachnoiditis. Protein is found in poultry, seafood, meat, eggs, and cottage cheese, and it contains the amino acids or building blocks that make your natural pain relievers like endorphin, gamma amino butyric acid, serotonin, and norepinephrine. There is a recommended diet for you in this handbook. Besides daily protein, you need some fruits and vegetables each day as they contain anti-inflammatory agents. If you can't stand to eat a protein food, you can buy energy bars, drinks, and powders that contain protein. Look at the labels to make sure the product contains protein. Drinking plenty of fluids to help keep your circulation and spinal fluid moving.

10. **MAXIMIZE CRITICAL NUTRIENTS**: The cauda equina nerve roots and the arachnoid lining of the spinal canal covering (dura mater or theca) are very sensitive and fragile anatomic structures. That is why they can be so easily diseased by inflammation, adhesions, and scarring. You must maximize your nutrition even though you may not have much of an appetite. Go to your local health food store and get some of the following of which you should take some every day: (1) multi-vitamin, mineral tab or cap; (2) brewer's yeast 2 to 4 a day; and (3) alfalfa tabs 2 to 4 a day. You can substitute algae or sea plant for brewer's yeast and alfalfa.

11. **WALK AND STRETCH**: You must keep your spinal fluid moving. The spinal canal is a closed system of fluid that does three basic functions: (1) lubricates nerves and spinal cord; (2) brings nutrients to the nerve roots and spinal cord; and (3) carries away and flushes out inflammatory waste. Spinal fluid doesn't have a pump like the heart to keep the flow going. Arachnoiditis usually causes some blockage of the flow. Upper body movement, walking, stretching, and deep breathing all help to keep the spinal fluid moving. It is critical to keep the spinal canal flushed so inflammatory waste doesn't accumulate.

    Fully stretching your arms and legs upward and outward must be done at least 6 times a day. Why? Arachnoiditis is an inflammatory and scarring disease. The adhesions and inflammation can trap and scar nerve roots and other connections to your legs and arms. Contractures or shrinkage may develop which can leave you partially paralyzed (paraparesis). Also nerves to your bladder, stomach, bowel, and sex organs can become scarred and dysfunctional. Review the sections in this handbook on spinal fluid flow and electricity control. You'll find many helpful tips.

12. **JOIN A SUPPORT GROUP**: You need to know and talk with other persons who have arachnoiditis. It's a lonely disease. Only other persons with it can appreciate your fears and tears. There are great social media support groups which you can rapidly find on the internet. My one misgiving about support groups is that some members may try to overly sell a specific, favorite treatment. You can't wholly take advice or guidance from another patient on medical treatment because every person is different. One size does not fit all.

13. **DON'T FORCE PAIIN OR FATIGUE**: You must avoid pain. Don't try to exercise, walk, lift, sit, or stand in a position or anything else that causes pain. Don't overdo any activity that causes fatigue. Some of your nerve roots are now adhered to the spinal canal arachnoid lining by adhesions. You may damage them more if you sit on them too long. Some of your nerve roots are now trapped in scars. If you lift too much or stretch too much, you may tear the scar and worsen your condition.

14. **FIND A CARING DOCTOR OR NURSE PRACTITIONER**: At this point in time (2017) very few doctors, nurse practitioners, or other health professionals know much about arachnoiditis. Until this changes (and it will), find a doctor or nurse practitioner in your community who is sympathetic and concerned. You can bring materials to them about the proper tests and treatment. This includes the new treatment protocols which are being continuously improved. The specialty of the doctor or nurse practitioner isn't as important as their willingness to help. Many of the best treatment agents for arachnoiditis are old and time-tested drugs that any doctor or nurse practitioner can prescribe. You can obtain our latest treatment protocol by looking at the last page of this handbook.

15. **STAY AWAY FRM NAY-SAYER DOCTORS AND EMERGENCY ROOMS**: You've got a tragic, misunderstood, and feared disease in the minds of many doctors and other health professionals. Some even deny its existence and will avoid making the diagnosis or discussing it with you. Stay away from these folks. You don't need the stress or humiliation. Stick with positive medical professionals. As part of your survival plan, you must have a flare treatment you can do at home and stay out of emergency rooms. At best the emergency room will give you a shot of ketorolac (Toradol®), corticosteroid (Medrol®), or opioid (Dilaudid®, Morphine, Demerol®). You can and should be prepared to do your own flare treatment in your own home. Members in your support group will have some ideas for flare treatment. Unfortunately, most arachnoiditis patients have to learn to give themselves a shot. Diabetics do, so you can too. There are also some good topical (rub-on) medications to help control flares. These include lidocaine, carisoprodol (Soma®), prednisone, and morphine, and they are particularly effective under a heating pad or infrared device.

16. **NO MORE INVASIVE PROCEDURES**: Chances are you've had spinal procedures including surgery. Once you get arachnoiditis, leave the affected area alone when it comes to more epidural or facet injections. Surgery and implanted devices are a last resort and only to be recommended to you by very trusted doctors.

17. **SUPPRESS YOUR NEUROINFLAMMATION**: Arachnoiditis is a neuroinflammatory disorder involving the arachnoid lining of the spinal canal covering and your nerve roots (lumbar-sacral) or spinal cord (cervical-thoracic). You need a blood test to help determine how much inflammation you may have. Your physician or nurse practitioner can order from your local laboratory these two standard inflammatory tests (markers): (1) C-reactive protein (CRP); and (2) erythrocyte sedimentation rate (ESR). There are some newer inflammation tests that are just now becoming available in laboratories. They are interleukins, tumor necrosis factor, myeloperoxidase, and alpha-1-antitrypsin. If any of your inflammatory markers are high in your blood, you will need a more aggressive treatment program. Be clearly advised that pain relievers merely give you symptomatic relief which allows you to function. You must, however, suppress your neuroinflammation in order to improve and obtain some recovery. In fact, if you don't suppress your neuroinflammation, pain relief medication including potent opioids like morphine, methadone, oxycodone, and fentanyl may not be very effective.

    There are 3 classes of anti-neuroinflammation drugs. Almost every arachnoiditis patient will need at least one drug from each class: (1) anti-inflammatory (ketorolac, indomethacin); and (2) microglial suppressors (acetazolamide, metformin, minocycline, pentoxifylline). In severe cases you will need

some low doses of the third class, the corticosteroids: methylprednisolone or dexamethasone. The above-listed agents are used today (2017) because they, in contrast to other anti-inflammatory and corticosteroids, cross the blood-brain barrier and enter the spinal fluid. Keep in mind the date of this handbook (July, 2017). Other agents are being investigated and tried. You can expect the above treatment agent lists to grow or even be replaced by better measures. In summary, it is the understanding of how to suppress neuroinflammation that is finally giving arachnoiditis patients some hope, relief, and recovery. Your physician and nurse practitioner can find the starting dosages for the anti-inflammatory agents in our protocol. You can obtain one and take it to them. In addition to the above, you should take some of the natural anti-inflammatory agents. Some of my favorites are curcumin, boswellia, and aloe vera.

18. **GET SOME SLEEP**: Sleep not only provides some rest to the spine and its nerve connections, many of the body's natural pain and healing biochemicals are produced during sleep. Sleep also helps spinal fluid flushing. A prescription sleep-aid such as Ambien® or Restoril® is just fine and usually quite helpful. Melatonin at a dose of 5 to 20 mg may not only help sleep but provide some next-day pain relief. While sleep is fine, too much bed-time is counter-productive. Some arachnoiditis patients spend too much time in bed. Control of arachnoiditis requires a lot of daily walking and movement.

19. **FIND SOME MEANINGFUL ACTIVITY**: You must find some meaning and mission in your life despite your handicap. Hobby, volunteering, reading, craft, or other. Your mind and body must stay active despite your pain and disability. Keep in mind that arachnoiditis is a disease INSIDE your central nervous system, and it can destroy your mind and mental abilities if you don't exercise and use your mind and mental capabilities each and every day.

20. **BUILD A STRONGER FAMILY AND FRIENDSHIPS:** You have a family of some sort. Maybe you are lucky enough to have a loving spouse, children, or parents. Whoever you have, work to build a better, stronger, more-loving relationship. Let all those around you know that your disease and handicap won't diminish your love and caring for them. Let your close friends outside your family know how much you appreciate them. You can't survive arachnoiditis without friends and family. Love and friendship simply enhance the biologic circuits that can fight the devil's own disease.

21. **ELIMINATE ELECTRICITY**: Your spinal cord, nerve roots, and peripheral nerves all function by transmitting electricity just like the wires to your toaster or refrigerator. When you develop arachnoiditis, you put a block in the conduction or transmission of your electricity. When this happens electricity accumulates and piles up. Finally it will escape and you will know this because bioelectricity, when transmitted at other than its normal rate or route will cause jerking, tremors, or funny sensations on your skin such as dripping water or bugs crawling. Also your feet may burn and you will experience heat and sweating episodes. A pain flare may also result. Inside the spinal canal around your arachnoiditis site, excess electricity will cause more inflammation. This begins a vicious cycle – more electricity begets more inflammation which causes more blockage and more electricity.

    You can help eliminate your excess electricity. Soaking in water is best. If you have a pool, Jacuzzi, or tub, you should soak at least once daily. A long shower isn't as good, but let warm water flow over your back at the same time you massage your lumbar spine area with an old-fashioned scrub brush. I'm a great believer in massage, castor oil rub downs, magnets, and copper. All of these measures may be frowned upon by many medical people, but they've been around for hundreds of years. Magnets make electricity move and copper pulls out electricity. The ancient practice of wearing a copper bracelet or anklet is wise.

22. **FIND HORMONAL CARE**: A recent scientific and most critical breakthrough for arachnoiditis patients is that the central nervous system (brain and spinal cord) make select hormones for nerve

protection and nerve regrowth if injured (neuroregeneration). To obtain significant relief and recovery you will need to be blood tested for hormone deficiencies and also thake certain hormones. The protocol which you can obtain for you and your physicians lists the hormonal blood tests that I recommend. Neuroregeneration involves hormone replenishment and administration of neurohormones such as oxytocin, pregnenolone, human chorionic gonadotropin, and human growth hormone. Once you get your survival plan in place, including pain relief and inflammation control, you should seek out hormone testing and treatment.

23. **PREPARE FOR THE LONG HAUL**: Arachnoiditis can be mild, moderate, severe, or catastrophic. Some mild cases have actually resolved. Moderate cases will need some modest pain relief and inflammation control for an extended period and possible a lifetime. The severe cases have to plan on a lifetime of medical treatment. You have a severe case if your bladder or bowel are impaired or your leg(s) are weak and you walk with a limp of drag. Severe cases also have headaches and blurred vision. Catastrophic cases are those that are rapidly progressive and cause paralysis, incontinence, and a bed-bound state. Patients may experience severe pain, adrenal failure, dementia, infections, and early death. Catastrophic cases can only be controlled by aggressive treatment. If you are typical and have a moderate to severe case, you need to prepare for a lifetime of control and treatment. In my experience moderate to severe cases are experiencing 30 to 70% improvement. A few are approaching almost a cure state. These are the patients fortunate enough to obtain maximal pain relief, inflammation control, and hormonal neuroregeneration.

    To prepare for the long haul, first try to place yourself in one of the 4 categories: mild, moderate, severe, or catastrophic. Develop an attitude of "I'm not going to let this thing ruin my life and I'm going to control it". Be prepared to spend part of everyday tending to your control and survival. One last point. Self-pity is OK as long as you don't let it inactivate you. Frankly, arachnoiditis naturally brings hostility, fears, hopelessness, and too many tears if you let it. Many victims of this devil's disease are now thriving and surviving, and you can too!!

24. **BASELINE, BAD DAY, AND FLARE PAIN:** Arachnoiditis patients, other than those in the mild category, must plan on experiencing 3 kinds of pain days: (1) baseline (usual); (2) bad days (drags you down, no energy); and (3) flare days (can't function, need couch or bed). A major part of survival is to plan AHEAD for these 3 days and not be caught unprepared. In other words, don't kid yourself. For unknown and unexpected reasons, you can have a bad day or flare day. Each person has to develop their strategy. Bad days, for example, might be controlled with extra doses of oral and topical medication along with soaking in water. Flare days may require extraordinary measures including an injection of ketorolac, methylprednisolone, or hydromorphone.

    The cause of, at least some flares, is accumulation of inflammation and electricity within the spinal canal. You can prevent some bad days and flares by implementing some of the measures to eliminate electricity and keep your spinal fluid moving. Other bad days and flares just seem to happen with no apparent relationship to excessive mental stress, over-exercising, or fatigue. But, whatever the cause, be prepared beforehand!!

DEFINITIONS USED IN THIS HANDBOOK

ARACHNOID: It is the middle layer of the covering of the spinal cord and brain which is usually referred to as the thecal sac or meninges. The inner layer is called the "Pia Mater". It is extremely thin and fragile. The outer layer is the dura which is thick and firm. The arachnoid middle layer contains blood vessels and can become inflamed if irritated or damaged.

ARACHNOIDITIS: Inflammation of the arachnoid layer which can be caused by trauma, infection, toxins, or friction between the arachnoid layer and spinal cord or nerve roots. (ICD-10, G03.9)

ADHESIVE ARACHNOIDITIS: This condition is present when there are adhesions between the arachnoid layer and the spinal cord or nerve roots in the cauda equina. Adhesions are seen on contrast magnetic resonance imaging (MRI). (ICD-10, G03.9)

CAUDA EQUINA SYNDROMES

ACUTE: Sudden compression of the nerve roots below the lumbar one vertebra (L-1). It is usually caused by severe trauma. Emergency surgery to relieve the compression is often necessary.

CHRONIC: Chronic pain, bladder and/or bowel dysfunction, and lower extremity (legs) impairment are the typical symptoms. An MRI will show nerve root inflammation, as evidenced by edema (swelling), clumping, and/or displacement, but there are no distinct adhesions which attach the nerve roots of the cauda equina to the arachnoid lining.

FIBROSIS:

EPIDURAL: Scar tissue in the epidural space which has resulted from inflammation.

INTRATHECAL: Scar tissue inside the spinal canal or thecal sac which has resulted from inflammation.

TARLOV CYSTS: A cyst or outpouching of a spinal nerve root. (ICD-10, G96.19) Often called a "perineural" cyst.

WHY A NEED FOR THIS HANDBOOK?

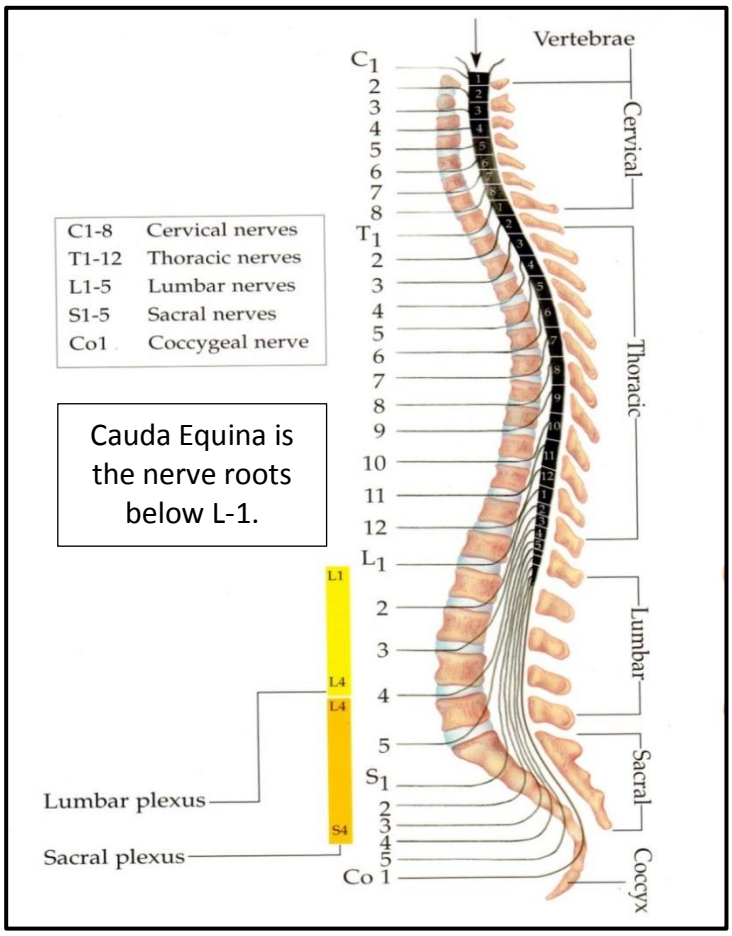
- Until now arachnoiditis (ARC) has been considered a rare disease. No more. Its incidence is up several hundred-fold this past decade. Most every community and medical practice now has cases.

- The technology of contrast MRI's has advanced so that ARC can be diagnosed in a person with typical history, symptoms, and physical exam.

- Treatment protocols have been recently developed thanks to new knowledge on neuroinflammation and neurogenesis.

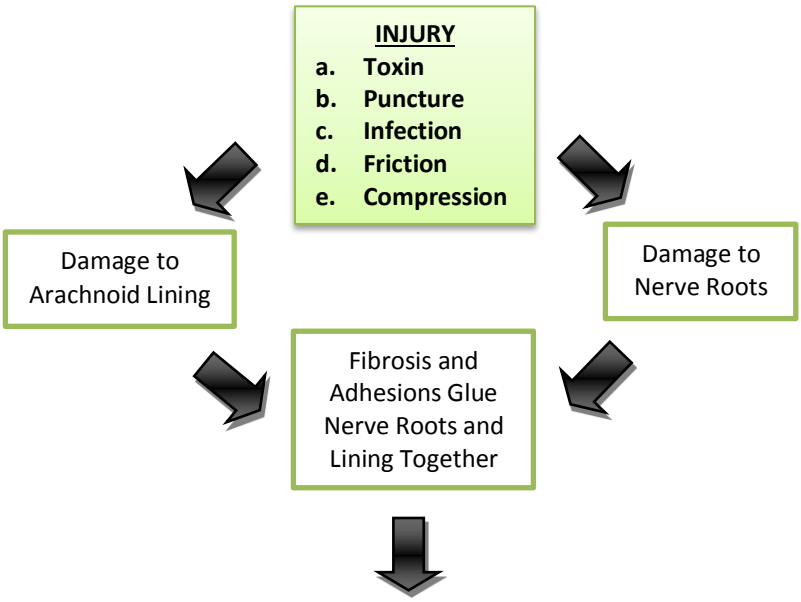
THE BOTTOM LINE

Every community and medical practice must now develop the expertise to prevent, identify, and treat the growing prevalence of this disease.



Arachnoiditis occurs when some nerve roots in the cauda equina adhere, by adhesion, to the spinal canal covering rather than float freely in spinal fluid.

TWO WAYS THAT ADHESIVE ARACHNOIDITIS MAY DEVELOP



The initial injury can be to either the nerve roots in the cauda equina or directly to the arachnoid lining.

A myth and old belief is that arachnoiditis only occurs when the spinal canal covering (arachnoid is the middle layer) is damaged by puncture or other insult.

CHRONIC SPINAL CONDITIONS THAT MAY CAUSE ADHESIVE ARACHNOIDITIS (AA)

Herniated discs
Scoliosis
Collapsed vertebrae
Degenerative osteoarthritis
Spinal stenosis
Perineural (Tarlov) cysts
Osteoporosis
Spondylolisthesis
Rheumatoid Spondylitis

If you have a severe case one of the above conditions long enough, you are at great risk to develop adhesive arachnoiditis.

Surgery, radiographic dyes, infections, and medical procedures such as an epidural corticosteroid injection may accelerate the development of adhesive arachnoiditis if a chronic spinal condition and cauda equina neuroinflammation are present. Patients with genetic, connective tissue disorders such as Ehlers-Danlos and Marfan's syndromes commonly develop AA.

NEUROINFLAMMATION: THE MISSING LINK

The reason that arachnoiditis sufferers have not been able to get much help is because medical science did not realize that the central nervous system creates an inflammation that has unique characteristics compared to the inflammation that is found in joints and muscles. Neuroinflammation of microglial cells is not suppressed by and does not respond to standard anti-inflammatory drugs or hydrocortisone.

SPINAL CORD INFLAMMATION: Arachnoiditis is inflammation of the lining of the spinal covering. In adhesive arachnoiditis, spinal nerve roots in the cauda equina or spinal cord attach to the arachnoid lining. These persistent attachments are called adhesions. MRI's of these inflamed nerve roots show swelling, enlargement, clumping, and displacement.

SYMPTOMS AND CHARACTERISTICS OF SPINAL CORD INFLAMMATION:

PAIN	FATIGUE	SUDDEN FLARES	SCARRING
SWEATING/TEMPERATURE		PROGRESSIVE CLUMPING	

INFLAMMATION ACCUMULATES: Neuroinflammation constantly builds up and then may suddenly "strike" causing a severe pain flare or nerve impairment. Worse, it continues to create more adhesions and scarring.

REASON FOR FAILURE: Arachnoiditis patients naturally want to focus on relief of pain, fatigue, and paralysis. We now realize that any medication for pain or even hormonal treatment is most effective when neuroinflammation is first controlled.

PREVENTION OF BUILD UP: Every arachnoiditis patient must have a specific medical regimen to suppress neuroinflammation and prevent it from accumulating toxic by-products. This has been the missing link to relief and recovery.

AUTOIMMUNE DISORDER: The neuroinflammation of arachnoiditis is fundamentally "biologic waste". Spinal fluid carries neuroinflammation waste to cervical lymph nodes in the neck which discharge it into the general circulation. Unfortunately, neuroinflammation waste is toxic to the body outside the spinal canal, so an autoimmune disorder may develop. Arachnoiditis patients are always amazed to find that their disease which originated in the spinal canal is now causing a variety of autoimmune manifestations which may include: (1) thyroid deficiency; (2) carpal tunnel; (3) arthritis; (4) muscle aches; and (5) skin rashes.

SELF-TEST
DO YOU HAVE EXCESSIVE NEUROINFLAMMATION?

Answer each question based on your feelings and symptoms in the past week.

1. Do you have periods of heat? ☐ Yes † ☐ No
2. Do you have periods of sweating? ☐ Yes † ☐ No
3. Do you feel like your body has too much electricity or "shock" at times? ☐ Yes † ☐ No
4. Do you have periods of burning in your feet, hands, pelvis or buttocks? ☐ Yes † ☐ No
5. Do you have periods or episodes of strong feeling on your skin like bugs crawling or pin stabbing? ☐ Yes † ☐ No
6. Are you sensitive or become nauseated and dizzy in heat such as a hot summer day? ☐ Yes † ☐ No
7. Do the areas over pain sites sometimes become red and hot? ☐ Yes † ☐ No
8. Does your temperature rise at times? ☐ Yes † ☐ No
9. Are your pain flares accompanied by sweating and heat? ☐ Yes † ☐ No
10. Do you have periods of stabbing, shooting, or jerking pains? ☐ Yes † ☐ No
11. Do you have recurrent pain flares you can't control? ☐ Yes † ☐ No

INTERPRETATION: If you answered yes to over half of the above questions, you will most likely need specific treatment for neuroinflammation.

SELF-TEST
DO YOU HAVE ADHESIVE ARACHNOIDITIS?

If you answer yes to 12 or more you most likely have adhesive arachnoiditis.

		YES	NO
1.	Does it hurt to lie flat on your back?		
2.	When you stand with your leg straight and raise it, does this cause pain in your back?		
3.	Do you lose water (bladder) or stool (colon) without warning?		
4.	Does standing too long cause so much pain you have to sit or lie down?		
5.	Do you have periods or episodes of intense sweating or heat (temperature)?		
6.	Do you sometimes have to stand to relieve your pain?		
7.	Do you sometimes have shooting pains, tremors, or jerks in your legs?		
8.	Do you have to sometimes sleep sitting up?		
9.	Do you sometimes have pain behind your eyes?		
10.	Do you have trouble starting your bladder to urinate or bowel to defecate?		
11.	Is your pain constant (always present)?		
12.	Is your vision ever blurred?		
13.	Have you ever collapsed while standing or walking?		
14.	Are your hands and/or feet cold a lot of the time?		
15.	Do you get twitching or crawling feelings over your back and spine area?		
16.	Do you get burning or electrical pains in your feet?		
17.	Do you have to sit on a pillow or cushion at times?		
18.	Do you have pain when you walk up steps?		

FOUR CATEGORIES OF ARACHNOIDITIS

WHICH ONE FITS YOU?

MILD

- ✓ **Occasional pain controlled by natural pain relievers and inflammatory agents**
- ✓ **Full extremity range of motion**
- ✓ **Normal serum CRP & ESR**
- ✓ **No spinal fluid obstruction or leakage on MRI**
- ✓ **No bladder impairment**

MODERATE

- ✓ **Pain requires intermittent, low dose opioids and other analgesics**
- ✓ **Full extremity range of motion**
- ✓ **Normal serum CRP & ESR**
- ✓ **Adhesions and spinal fluid obstruction on MRI**
- ✓ **Some bladder hesitancy or urgency**

SEVERE

- ✓ **Constant pain requiring regular opioid use**
- ✓ **Some decreased range of motion in lower extremities plus weakness and some bed-bound hours**
- ✓ **Elevation of serum CRP or ESR**
- ✓ **MRI shows adhesions, spinal fluid flow obstruction, and leakage**
- ✓ **Bladder hesitancy/urgency**
- ✓ **Burning feet**

CATASTROPHIC

- ✓ **Constant pain and flares requiring daily opioids**
- ✓ **Impairment of walking and standing, bed-bound hours**
- ✓ **Decreased range of motion in upper and lower extremities**
- ✓ **Elevation of serum CRP or ESR**
- ✓ **MRI shows adhesions, spinal fluid flow obstruction and leakage**
- ✓ **Bladder hesitancy, urgency, and some incontinence**
- ✓ **Headaches, blurred vision, mental confusion**
- ✓ **Serum hormone abnormalities**

NATURAL, NON-PRESCRIPTION PAIN RELIEVERS AND ANTI-INFLAMMATORY AGENTS

NATURAL PAIN RELIEVERS

Palmitoylethanolamide (PEA)
Cannabis (CBD) oils/extracts
Kratom
Curcumin/turmeric
Glutamine/GABA
Serrapeptase
White willow bark
Boswellia

Natural pain relievers almost all have some anti-inflammatory action.

All arachnoiditis patients need to identify at least 2 of the above which give you some pain relief. Use these in addition to prescription pain relievers that your physician or nurse practitioner may prescribe. Do NOT rely totally on prescription drugs to relieve your pain.

NATURAL ANTI-INFLAMMATORY AGENTS: Carnitine, Omega fatty acids

These will help, over time, to control your neuroinflammation, reduce pain, and promote healing.

PRESCRIPTION PAIN RELIEVERS FOR ARACHNOIDITIS

Listed here are most of the prescription pain relievers that a physician or nurse practitioner may prescribe. Best results are obtained by using agents from more than one category. Starting dosages are listed, and effective dosage may need to be higher.

A. Neuropathic Agents (Act to control electrical impulses.)

	Starting Dose		Starting Dose
1. Pregabalin (Lyrica®)	50 mg TID	5. Gabapentin (Neurontin®)	100 mg TID
2. Topirimate (Topamax®)	25 mg BID	6. Baclofen (Lioresal®)	5 mg TID
3. Diazepam (Valium®)	2 mg BID	7. Carisoprodol (Soma®)	350 mg BID
4. Duloxetine (Cymbalta®)	20 mg BID	8. Tizanidine (Zanaflex®)	2-4 mg TID

B. N-Methyl-D-Asparate Receptor Antagonist

1. Ketamine 15 to 25 mg sublingual or oral BID. Increase up to 100-150 mg/day.
2. Pregnenolone 25-100 mg daily

BID – is twice a day
TID – is 3 times a day

C. Topical Agents

1. Lidocaine/Prilocaine gel
2. Lidocaine patch
3. Morphine 30-60 mg in 1 ounce of base cream or gel
4. Any other single or multi-agent topical that has been found to provide relief

D. Adrenergic Agent for Descending Pain

	Dose
1. Methylphenidate (Ritalin®)	5-10 mg BID
2. Amphetamine/dextroamphetamine Salts (Adderal®)	5-10 mg BID
3. Dextroamphetamine	5-10 mg BID

E. Weak Opioids

1. Tramadol 50 to 100 mg-1 to 4 a day or prn pain
2. Codeine/Acetaminophen 30-60 mg 1 to 4 times a day or prn pain
3. Buprenorphine (Butrans®)

F. Intermediate Opioids

1. Hydrocodone/Acetaminophen 5 to 10 mg with 325 mg of acetaminophen 1 to 4 times a day prn pain
2. Oxycodone/Acetaminophen 5 to 10 mg with 325 mg of acetaminophen 1 to 4 times a day or prn pain

PRN = as needed

G. Potent Opioids

1. Morphine 15 to 30 mg 1 to 4 times a day
2. Hydromorphone 2 to 8 mg 1 to 4 times a day
3. Tapentadol 10 to 50 mg 1 to 4 times a day
4. Oxycodone 10 to 30 mg 1 to 4 times a day

H. Long-Acting Opioids: Reserved for arachnoiditis patients with severe, constant pain and documented adhesions, active neuroinflammation, and progressive neurologic impairments (paraparesis, bladder-bowel dysfunction, blurred vision, autoimmune symptoms). They are added to weak-intermediate opioids.

1. Methadone-5 BID, raise dosage as needed
2. Fentanyl Transdermal 50 mcg patch every 3rd day, raise dosage as needed.

SPECIAL NOTE: Injectable opioids are reserved for very active adhesive arachnoiditis patients who have uncontrolled constant pain and flares and/or poor gastrointestinal absorption of oral opioids.

HIGH PROTEIN ANTI-INFLAMMATORY DIET FOR ARACHNOIDITIS PATIENTS

PROTEIN

It provides the amino acid building blocks that are necessary for the production of neurotransmitters and tissue healing.

YOU MUST EAT SOME OF THE FOLLOWING EACH DAY

FISH	CHICKEN	TURKEY	BEEF
PORK	EGGS	COTTAGE CHEESE	

Spirulina and chlorella algae, black beans, and pumpkin seeds are much higher in protein than meat. If you can't or won't eat any of the above you must obtain protein powder drinks and/or protein bars from the health food store.

VEGETABLES AND FRUITS

Some vegetables and fruits have anti-inflammatory activity. Eat some of these each day.

CARROT	CELERY	BEETS	TOMATOES
BROCCOLI	BRUSSEL SPROUTS	SPINACH	CUCUMBERS
RADISH	ONION	LETTUCE	WATERMELON
BLUEBERRY	BLACKBERRY	RASPBERRY	STRAWBERRY
APPLE			

DRINKS (Only use dietary sugars if weight is a problem)

COFFEE TEA DIETARY SODAS WATER

Low dose, occasional alcoholic drinks are acceptable.

BANNED TO CONTROL WEIGHT

MILK REGULAR SODAS FRUIT JUICE BREAD, ROLLS, BUNS

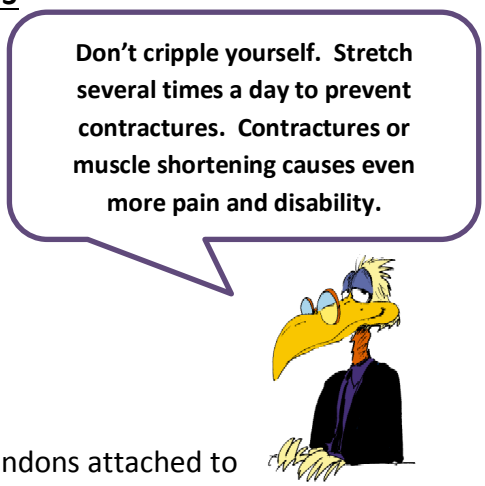
HIGHLY RESTRICTED TO CONTROL WEIGHT (Eat these very sparingly)

POTATOES including	FRENCH FRIES	CORN
CAKES/PIES	PASTA/PIZZA	

SUPPLEMENTS

Multi-vitamin/mineral cap/tab-daily
B-12 weekly
Brewer's yeast
Alfalfa
Algae

HOW TO PREVENT CONTRACTURES OF YOUR ARMS AND LEGS



Arachnoiditis is primarily in the lumbar-sacral spinal canal. You may sustain some spinal fluid leakage. Between the neuroinflammation and leakage, arachnoiditis patients frequently develop contractures that involve your arms and legs. When this happens you can't extend your arms or legs to their full length. If you develop contractures between your legs and pelvis, you will end up in a walker or wheelchair.

CONTRACTURES: A PATIENT'S WORST ENEMY

A contracture is a scarring and shrinking of the muscles and tendons attached to your joints. Muscles are attached to your spine vertebrae, hips, and knees. When pain starts to scar, shrink, and contract your muscles, you are pulled to one side and your hips and knees are pulled too tightly into their sockets. When contractures occur more pain is generated. This leads to less reach and walking ability. The reason pain patients end up in a wheelchair or need a walker or cane is contractures. Given here is the basic stretching exercise which you must do daily if you have arachnoiditis.

DO 3 OR MORE TIMES A DAY!

STEPS FOR BASIC BACK AND NECK PAIN

1. Spread fingers.
2. Reach straight up with both arms until you feel pressure on your pain site. DO NOT CAUSE PAIN!
3. Hold for a count of 15.
4. Repeat at least 3 times a day.
5. Over time – try to extend your upward reach.

STRETCHING PRINCIPALS

1. Stretch to a point you feel tugging or pulling but not pain.
2. Standing is best to stretch but sitting or lying down is OK.
3. You should do more than raise your arms. Stretch your arms and legs in positions that let you know you are tugging or pulling on a contracted area.

IMPROVING YOUR SPINAL FLUID FLOW

- ✓ Arachnoiditis commonly causes spinal fluid flow obstruction. When spinal fluid is obstructed you may get these symptoms among others:

  - Headache
  - Blurred vision
  - Inability to think or read
  - Weak legs
  - More pain
  - Poor balance
  - Ringing in ears

- ✓ Even worse—the spinal fluid cannot carry away inflammatory particles generated by the inflamed nerve roots. This retards healing. Another function of spinal fluid is to bring nutrients from your food to the nerve roots in the cauda equina. This function may also be impaired. You must do some of the following each day to keep spinal fluid flow very active.

  - Rock in a rocking chair
  - Walk on a trampoline
  - Use vibrator or massager over spine (Back scratchers and scrubbers are good)
  - Soak or wade in water
  - Walk and swing your arms ("Power Walking")
  - Rock back and forth on your feet
  - Rub your spine with copper and/or a magnet
  - Nod your head up and down
  - Scrub you back with a brush
  - Deep breathing (diaphragm) with stomach

SPINAL CORD EXERCISES

FULL-BODY STRETCH LAYING DOWN: Lay down on the floor and do a full-body stretch. Count up to 10.

FULL-BODY STRETCH STANDING: Spread hands and reach "to sky" until you feel pressure and tugging in your back. Count up to 10.

SIT AND STRETCH ARMS: Stretch your arms and spread your fingers. Count up to 10. Can do while sitting in a car or plane.

LEG RAISE WHILE LAYING DOWN: Raise leg until you feel tugging in your back. Count up to 10.

LEG RAISE WHILE STANDING: Stabilize yourself next to a table or wall. Raise your leg and flex your foot.

KNEE PULL WHILE LAYING DOWN: Pull knee back until you feel tugging in your back. Count up to 10.

HOW TO GET MORE OXYGEN

WHY OXYGEN?

Oxygen is necessary for healing, nerve functions, and medication effectiveness. Without enough, you may progressively deteriorate.

SYMPTOMS OF LOW OXYGEN

- Fatigue and Lethargy
- Slow or Forgetful Thinking
- Depression and Feeling of Hopelessness
- Tired But Can't Sleep
- Pain Medication Works Poorly

HOW DO I GET OXYGEN?

Oxygen is breathed in through your lung and enters your red blood cells to be carried throughout your body. Regardless, if your pain site is spine, brain, joint, or muscle, you must have oxygen for pain relief and healing. The more oxygen, the better.

HOW DO I GET MORE OXYGEN?

Your base oxygen intake and carrying capacity is what is in your blood when you are quietly sitting or lying down. Anytime you become active, your lungs breathe a little faster and deeper and your heart pumps a little faster, so you carry more oxygen in your blood. The healing and pain relief formula is simply to stay more active than what you are when you sit or lay down. Just increasing your breathing and heart rate due to any cause increases oxygen at your pain site.

FIRST STEPS TO MORE OXYGEN

1. Stay active! Walk every day.

2. Breathe as deeply as you can with your stomach (diaphragm) and hold it for 10 seconds. Do it sitting or standing. Do it in a car, church, or home. Do this at least 10 times a day.

TOPICAL RUBS FOR TREATMENT OF ADHESIVE ARACHNOIDITIS

Arachnoiditis patients can greatly boost their survival plan with the use of topical rubs. They induce healing of tissues around the inflamed site and help stop spinal fluid leakage. We recommend any of the following:

1. Estradiol - 2mg
2. Diazepam (Valium®) – 10mg
3. Medroxyprogesterone – 10mg
4. Morphine Sulfate – 30mg
5. Carisoprodol – 350 mg
6. Prednisone – 5 mg

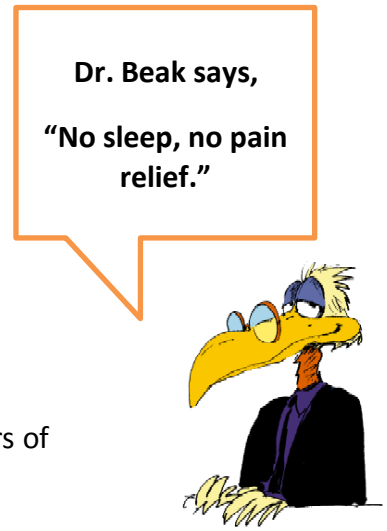
To make topical creams, crush 2 tablets and stir into 1 ounce of cold cream.

Topical creams work best under infrared, vibrator, massager, or heating pad.

SLEEP

A regular sleep pattern enhances the hormone and immunologic systems that are necessary for neurogenesis. Here are some guidelines:

- ✓ Be in bed between 10:00 and 11:30 PM.
- ✓ Do your last stretches and medication dosage 30 to 60 minutes before bedtime.
- ✓ Keep your pain medications beside your bed. Take additional dosages during the night, if necessary.
- ✓ Take your first morning pain relief medications so you can be out of bed between 6:00 and 7:00 AM.
- ✓ Goal is 4 to 8 sleeping hours. Do not expect more than four hours of consecutive sleep.



- ✓ Most popular sleep aids are zolpidem (Ambien®) and temazepam (Restoril®).
- ✓ Take melatonin 5 to 20 mg with your sleep aid to assist sleep and help regulate your hormone and immune systems.

INSOMNIA

Intractable pain (IP) patients including those with arachnoiditis who have centralized their pain will almost always have insomnia. Very few IP patients can get over 4 hours sleep at a stretch. Many only sleep for about 2 hours at a stretch. The cause of insomnia in IP patients is not just pain but the central nervous system is over-aroused or stimulated.

Follow these steps as IP patients **MUST** get some sleep each night.

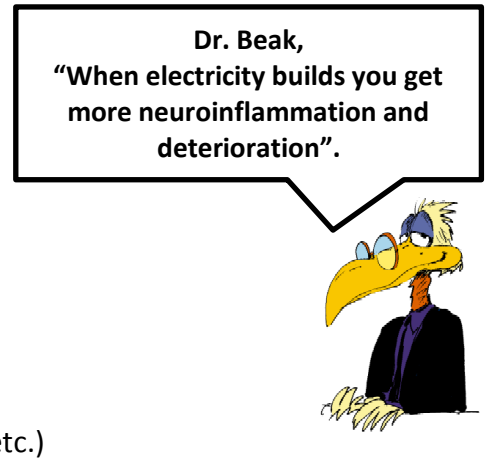
STEP ONE—Use pain medication at bedtime. Take a dose of your pain medications just before bedtime. You may need to take another dose when you awaken in the night.

STEP TWO—If you can't get enough sleep with a bedtime dose of your usual medication, take one or more of these natural, non-prescription, over-the-counter preparations.

- L Tryptophan-1000 to 2000mg
- Valerian-1000 to 2000mg
- Benadryl® (diphenhydramine) – 25 to 50 mg
- Melatonin – 5 to 20 mg

ELECTRICITY ELIMINATION

A major problem with clumped or trapped nerve roots is that electricity does not pass as it normally should. It builds up – causes increased inflammation – and then it may suddenly release itself in dysfunctional bursts. This is why patients get:



- ✓ Shooting and burning episodes of pain
- ✓ Leg jerks and tremors
- ✓ Burning feet
- ✓ Temperature rises with sweating
- ✓ Funny sensations on skin ("bugs crawling", etc.)

Here are routine measures to eliminate electricity. Do some daily.

- ✓ Rub your spine with copper or magnet 2 to 3 times a day
- ✓ Wear copper anklet or bracelet
- ✓ Use magnets in your shoes or mattress
- ✓ Wear lots of jewelry
- ✓ Hold door knobs or other metal a second longer
- ✓ Soak in water (Epsom salts help)
- ✓ Pet your dog or cat (Any fur will do)
- ✓ Walk barefoot on carpet or outside on your lawn

SHOES, LIFTING, AND BRACING

Persons with adhesive arachnoiditis (AA) should wear supportive, tie shoes such as tennis shoes unless their feet are too painful. There are also some shoes designed to include copper in them.

Bare foot is better for an arachnoiditis patient than the modern day practice of wearing thongs, sandals, flip flops, or slip-ons. These non-supportive footwear are a risk in 2 ways: (1) Falls; (2) prevents correct walking posture.

One slip, slide, or fall can set an arachnoiditis patient back to square one. A fall may tear adhesions which may cause severe pain which then re-heal with permanent nerve entrapment and even more impairments!

WALK WITH CORRECT POSTURE

An arachnoiditis patient must take walks every day to move spinal fluid and prevent adhesions.

Walk with toes pointed straight ahead. Swing your arms.

Lift your head so that your ears are directly over your shoulders. Breathe deeply.

LIFTING AND BENDING

The adhesive arachnoiditis patient must be very cautious and careful while lifting and bending over.

If you attempt to lift something that weighs more than about 10 pounds, you run the risk of tearing adhesions or scars in and around your lower spinal canal. When you bend over, raise up slowly because a jerk or rapid movement can cause a tear or rip. If this happens severe pain follows and the damaged area may be worse than ever.

THE IMPORTANCE OF SPINE BRACING

Shockingly, few arachnoiditis patients are told they need to periodically wear a brace to protect their damaged area.

WORST SITUATION: Riding in a car on plane that has bucket seats.

DANGER SITUATION: Walking in unfamiliar areas such as a shopping center, grocery store, or social event.

MOST IMPORTANT TIME TO WEAR A BACK BRACE:

PAIN FLARE

Always wear a back brace to protect yourself in the above situations.

SOME OF THE DRUGS USED TO TREAT ARACHNOIDITIS

KETOROLAC

This is usually an essential agent for treatment of neuroinflammatory disorders of the central nervous system. We have found that it is the ONLY drug that is both a: (1) potent pain reliever; (2) reducer of neuroinflammation.

It can be taken as an injection (Toradol®) or nasal spray (Sprix®). Patients can use ketorolac on a regular basis to suppress pain and neuroinflammation and/or for flares. It can be mixed with another drug such as methylprednisolone (Medrol®) for emergency purposes.

OXYTOCIN

This central nervous system hormone has 2 functions: (1) pain relief; (2) nerve protection and neuroregeneration. Patients can take it on an intermittent basis for either pain relief or on a regular basis to obtain some neuroregeneration.

HUMAN CHORIONIC GONADOTROPIN (HCG)

We consider this hormone to be an essential hormone to obtain any degree of permanent recovery from arachnoiditis. HCG has 2 basic functions: (1) nervous tissue growth or neuroregeneration; and (2) elevation of the hormones thyroid, testosterone, estrogen, and progesterone.

PREGNENOLONE

It is the most plentiful hormone in the central nervous system. It functions as a nerve protector and healer as well as a pain reliever. An adequate level is needed for treatment drugs to work. Most patients need a supplement 3 to 5 days a week. The usual supplemental dosage is 50 to 100 mg, but some patients find 100 to 300 mg to provide great pain relief.

ESTRADIOL

Research suggests that estradiol is a major hormone that regenerates nerves inside the central nervous system. It can be taken orally or topically. We often recommend estradiol cream be applied under a heating pad or infra-red over the affected spinal area.

MICROGLIAL SUPPRESSORS

There are these 4 agents that have been shown in research studies to suppress neuroinflammation by suppressing a cell called microglia: minocycline, acetazolamide, metformin, pentoxifylline. Arachnoiditis patients need to take one or more of these to prevent progression and prevent pain flares and other complications.

> **Acetazolamide**: In addition to suppressing neuroinflammation it regulates spinal fluid flow. Patients with spinal fluid flow obstruction will usually find that this drug will reduce the complications of spinal fluid flow obstruction including: blurred vision; headaches; ringing in ears; arm weakness; and poor balance.

Pentoxifylline: In addition to suppressing neuroinflammation, it is believed to increase blood flow and oxygen to the diseased area of the spine and possibly dissolve some fibrosis and adhesions.

METHYLPREDNISOLONE/DEXAMETHASONE

These are corticosteroids that cross the blood brain barrier and enter the spinal fluid. They are usually essential in patients who have progressive disease, adhesions, and active neuroinflammation. We recommend low, intermittent, afternoon dosages. They are also used with ketorolac or opioids for acute pain flares.

IS A CURE OF ARACHNOIDITIS A POSSIBILITY?

At the time of this writing, July, 2017, I will not use the term "cure". I will, however use the term "near cure". We have now treated some adhesive arachnoiditis patients for over 5 years with the full treatment protocol: (1) neuroinflammation control; (2) pain relief; (3) spinal fluid flow exercises; and (4) neuroregenesis with neurohormones. Despite initially being in the severe or catastrophic category they have resolved their disease to the point that they are fully functional and take no opioids for pain relief.

Cure or "almost cure" appears a possibility. Our clinical experience suggests that the 4 component treatment protocol may do one of 2 things: (1) dissolve adhesions and fibrosis freeing up entrapped nerve roots; or (2) walls off nerve roots into an inert scar and growing new nerve roots around the scar.

As a general rule we advise arachnoiditis patients that their disease is not hopeless and that we see a 30 to 70% improvement in our patients under the new treatment protocol. Be clearly advised that patients who do the best diligently follow a survival plan including active walking, exercises, and neurohormones. Keep in mind that the new protocol treatment for arachnoiditis has evolved over a relatively short time period of about 5 years. At this time, new and different treatment and hormonal agents are being investigated to add to the protocol.

Caution is recommended on some of the claims being made about arachnoiditis "cures". Stem cells, cannabis, and inside-the-spinal canal surgery (thecaloscopy) are being touted as superior treatments. I know of no solid clinical reports to back-up these claims. Intravenous infusions with lidocaine, Vitamin C, and ketamine, among others, may provide short-term symptomatic relief, but I don't know of any solid clinical reports of long-term effectiveness.

At this time, the arachnoiditis patients who have improved the most experienced some improvement in the first month of treatment and significant improvement after 3 to 6 months. Neuroregeneration is a slow process, but we now know it is possible which gives us enhanced hope for "near cure" and even the possibility of "cure".

To obtain a copy of the Medical Protocol for physicians and nurse practitioners, e-mail, fax, or write to:

Arachnoiditis Medical Clinic
Tennant Foundation
338 S. Glendora Ave.
West Covina, CA 91790
Fax: 626-919-0065
E-mail: veractinc@msn.com

Give us the following information:

Name
Address including City, State, Zip
E-mail
Fax

There is no charge as the handbook and protocol are given as a public service.