



ARC (ARACHNOIDITIS) NEWSLETTER

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It has been four months since the last newsletter appeared in our website. We have had several developments that may in the immediate or late term benefit patients suffering from “ARACHNOIDITIS”.

Editor.

PATIENT'S EXPERIENCES

ARACHNOIDITIS AND DEPRESSION by Sara Ann Conkling (part II)
What are the chances of getting depression with arachnoiditis? As you might imagine, there has been no study specifically geared to this topic, but there has been a study which shows that 29 percent of people with low back pain will develop depression after their injury. (Source: Polatin, et.al, p. 68). Contrary to popular myth, people with back pain do not in general become substance abusers post-injury, only about 2% of us do (Polatin, p.68), or pathologically anxious, only about 5% of us do (Polatin, p.68). But even though alcohol abuse is a relatively rare post-injury phenomenon, both smoking and pre-existing alcohol abuse have both been correlated with chronicity and severity of pain(Heliovaara, et.al, p. 608). Contrary to popular myth, there is no association between relative body weight and low back pain, with the exception that pregnancy can exacerbate low back pain (Heliovaara, p. 613). Depression is supposed to be the biggest mental health risk, and perhaps the biggest overall health risk, that can be tied to ARC.

[See “Arachnoiditis: the silent epidemic” for precise statistics.](#)

Whether or not someone has a history of depression before the injury, a lack of subsequent adequate pain control can set off depressive symptoms. The

neurochemical explanation is quite elegant; the short story is that the pain and the depression neurochemicals are related, and that untreated chronic pain steals some chemicals that we definitely need to stay cognitively balanced. It can and should be argued that whenever possible, physical pain should be reduced as much as possible, to likewise minimize the risk of depression. Otherwise the pain is like a burglar, robbing chemical substances from our brains which we need to preserve for our mental health. Once the robbery has taken place, the depression makes the experience of pain worse. Since pain and depression seem to potentiate each other, both need to be treated as unwelcome intruders into the lives of those of us living with Arachnoiditis. There is general agreement that aggressive and early treatment of both pain and depression should be pursued.

The prognosis for Arachnoiditis is depressing, as it is incurable. According to one researcher, we have a 23-percent chance of developing unpleasant urinary symptoms, the majority of us will become dependent on opioid analgesics, we have a greater-than-average suicide risk and a general shortening of our lifespans by 12 years (Guyer, et.al, p.1332). Oh, and our chance of returning to previous full-time work is markedly limited. As this statistical doom unfolds, it is difficult not to feel depressed about it.

The Upbeat Part

It is apparent that even with such a gloomy prognosis, there are things that can be done which will enhance quality of life in general, and which may also decrease the chance of our developing major depression subsequent to arachnoiditis. Here is my list of suggestions, based on my research and totally unsubstantiated personal opinion:

1. We can insist on an accurate medical diagnosis for our primary spinal injury, and disavow the "chronic pain" label which carries the derogatory stigma of being pain that exceeds what is "expected" or "normal" (as defined by someone else who isn't feeling our pain). We can insist that this accurate, descriptive, medical

diagnosis of our spinal injury be applied to all of our relevant medical records, so that we can be appropriately labeled. As the medical payment system insists that we be labeled it may as well be an accurate label which reflects our injury. Likewise, we alone, should retain the right to characterize any pain that is associated with our injuries.

2. We can insist on having our care provided by people who do not hold our suffering, or us, in contempt. This was evident to me as I combed the pain literature the existence as a thin veiled contempt among some physicians for patients whose injuries are both painful and difficult to effectively treat. There is a propensity, in this situation, among some providers to blame the sufferer, especially when a treatment trial is unsuccessful. Some have gone far enough to promote the notion of a "chronic pain syndrome" which in my view is probably the ultimate derogatory label for a person who is suffering. Patients labeled with "chronic pain syndrome" (as opposed to merely "chronic pain") may be presumed by some physicians to be hysterical, hypochondriacal, addicted, or malingering, or some combination of all of the above, when it seems more likely based on the description of their suffering that they are people with inadequately diagnosed and/or treated medical problems with or without concurrent prescription opiate dependency. It is easy to follow one's heart during a medical treatment encounter as to who has compassion and who doesn't, as to who patiently and consistently encourages us toward goals and as to who automatically blames us when something unexpected happens. In seeking medical treatment, we should be aware that the results of available medical treatments for arachnoiditis have been labeled "discouraging" (Guyer, p.1337). As patients are subjected to "discouraging" (read, non-ego-gratifying) treatments. Whether or not the provider takes that out on us by applying a derogatory label, or instead patiently and compassionately continues to attend to our suffering and encourage our healing, is of essence in choosing and maintaining our provider relationships. I believe that a good provider-patient relationship is an essential component of mental health maintenance in any patient with arachnoiditis.

3. We also obviously want to avoid providers who are unwilling to become educated about our injuries. Because of the iatrogenic etiology of many arachnoiditis cases some health care providers may be prejudiced against making a diagnosis of arachnoiditis, or unwilling to accept a diagnosis of arachnoiditis. Once the diagnosis is accurately made we need to stick with people who are not going to torture us about it. We are already plenty tortured by the injury itself.

3. We can become educated about our diagnosis, our prognosis, and our treatment options, both medical and alternative. We can then endeavor to find one primary care provider to help us sift through all the options to find the combination which works best for us. We can likewise insist that those we live with become educated, and facilitate this by providing copies of appropriate articles to them. We can then choose our everyday companions based on their positive and healing responses to what they learn about us, our suffering, and our healing.

4. We can get treatment, if we need it, for pre-existing mental health issues, substance abuse, and/or smoking cessation. We can do this to give our bodies the best possible chance to heal, but we also need to put a great deal of effort on these issues ourselves.

5. We can get vocational counseling so that we can make the most positive and thoughtful decision possible about whether we can return to work, and if so, what and how much work is possible considering the other demands of our rehabilitation.

6. We can get counseling specifically geared to increase our coping skills, increase our abilities to relax and fight stress, and increasing our self-esteem.

7. We can make our home and work environment as pleasant as possible, and buy any creature comforts that we can reasonably afford toward that goal.

8. We can do whatever we can to lessen the other stresses of our lives (financial, emotional, psychosocial), while actively advocating for more humane bureaucratic processes for those of us in need of governmental assistance. We can make the effort to stay connected to our spiritual communities. We can save some of our "good energy" for activities that are uplifting and fun.

9. We can endeavor to limit the amount of time each day which is taken up with the tedium, paperwork, etc. which is part of the process of being able to receive medical care and other needed assistance. We can likewise set aside specific time and space to grieve the myriad of losses which confront us, in the hopes that this strategy may prevent a more complicated, uncontrolled grieving process.

10. We can adopt a dog or cat or other attractive critter, or occasionally borrow whatever well-behaved two-leggeds our relatives want to lend us, assuming we don't have some already. We can do this just for joy, and to take the focus off our own needs and problems. Here seems like a good place to pay tribute to my dog:

He knows when I am feeling bad and sticks to me like glue. He is always happy to see me, and he always has a kiss for me. When I am crying he gets in my face and licks the tears away. He isn't using my disability as an opportunity to try to sell me magnets, or herbs, or anything. He doesn't preach or tell me how I should feel about what is happening. He doesn't care if my back hurts and all I can do right now is lie flat - that is fine with him, he will take a nap, too. He is available to play when I call him. He will drop what he is doing if I call him. If he notices my weight, he doesn't say anything about it. He understands why someone would want to eat a whole box of cookies, or spend a whole afternoon outdoors counting the clouds. It seems that all he wants to do is to be close by and love me. He has other things to do (chew things, chase the cat, etc.), but he puts love first.

The necessity of at least one such friend seems obvious.

Depression is a known risk of arachnoiditis - the good news is, it is often preventable. If prevention fails it is also a treatable condition. To avoid depression we must believe that it is possible to have arachnoiditis without it having US. We need to be apprised of the reality and the risks of depression but also of what we can do to make ourselves less susceptible. In doing so we need to commit ourselves to the best available appropriate treatment and the best possible quality of life. We deserve no less.

Sara Ann Conkling

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Bibliography

- Ashburn, MA, Staats, PS. "Management of Chronic Pain", *Lancet*, 1967: 353:1865-69.
- Atkinson, J. Hampton, et.al., "Prevalence, onset, and risk of psychiatric disorders in men with chronic low back pain: a controlled study", *Pain*, 1991: 45:111-21.
- Burton, CV, MD, "Adhesive Arachnoiditis", in *Neurological Surgery*, Third edition, vol. 4:3856-63.
- Carosella, AM, et.al., "Factors associated with early discharge form a multidisciplinary work rehabilitation program for chronic low back pain", *Pain*, 1994: 57:69-76.
- Cats-Baril, WL, et. al., "Identifying Patients at Risk of Becoming Disabled because of Low-Back Pain", *Spine*, 1991: 16:605-7.
- Crauford, DIO, et.al., "Life Events and Psychological Disturbance in Patients with Low-Back Pain", *Spine*, 1990: 15:490-494.
- DSM-IV, otherwise known as the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
- Florence, DW. "The Chronic Pain Syndrome", *Postgraduate Medicine*, 1981:70:5:217-9+.
- Guyer, DW, et.al. "The Long-Range Prognosis of Arachnoiditis", *Spine*, 1989: 14:12:1332-41.
- Heliovaara, Markku, MD, et.al., "Determinants of Sciatica and Low-Back Pain", *Spine*, 1991:16:6:608-14.
- National Institute of Neurological Disorders and Stroke, Arachnoiditis Web Page, http://www.ninds.nih.gov/health_and_medical/disorders/arachnoi_doc.htm.
- Polatin, PB, et.al. "Psychiatric Illness and Low Back Pain", *Spine*, 1993:18:1:66-71.
- Sanders, SH, et. al "Relationship between Psychopathology and Graduated Spinal Block Findings in Chronic Pain Patients", *Pain*, 1984:19:367-72.

LETTER FROM THE GOOD SIDE OF THE MINCH

by Mike Feehan

The Fight for Benefits

The UK's Department of Health and Social Security have not been the most forthcoming organisation I have ever had to deal with. Since I was first deemed unfit to work by my doctors I have had a long uphill struggle to get the Benefits my working

life has entitled me too. I know from the correspondence I receive that this experience is not limited to the UK and that many of you are fighting just as hard.

If that is so, I can assure you that it is not an insurmountable hill you are trying to climb. So far I have successfully appealed two negative decisions designed to save the government some expense. The first was an 18-month process for Incapacity Benefit, which we won last March – the back pay came in real handy.

This Benefit had been stopped after a cursory examination by one of their doctors who may me sound like Superman on Steroids. During the time it took to get to the appeal stage they had tried to get me to drop the appeal on two occasions. Both times they claimed that I had not responded to one of their communications, both times I proved them wrong.

The latest Appeal, in January this year, was for Disability Living Allowance. Once more we won hands down after producing a folder for each member of the Appeal Panel which contained a full record of events and a complete rebuttal of another of their doctors examinations.

It has been a hard road and many times I felt like giving up, without Jude I might have. I hope this experience goes to show you that, with a supportive partner and a determination to win your rights, that hill is not so high as it originally seemed.

Legal Procedure

In the fight to gain my benefit rights I employed a solicitor (attorney) on the mainland. He applied and got Legal Aid for me, which has paid for a High Resolution MRI Scan, done in January. We are awaiting the results.

There is a commonality with sufferers, which is indicative of the way they have been treated because it leads to a kind of paranoia that is normally only found in conspiracy

theorists. On more than one occasion in the past I have been told by sufferers that they have some documentary evidence which “could blow this whole thing apart”. However, they will not share that documentation because their lawyers have convinced them that to do so would jeopardize their case in the courts.

A few months ago I was sent a package of information by a high profile ARC charity in the UK. I was horrified to find that it included a warning to sufferers that their local Post Office employees had been suborned by the DHSS to report on how healthy they appeared when collecting their benefits. The message was on black paper with white lettering and obviously had been designed to put the fear of God into folk who are mainly in their pension years.

Protection of information and examples of such actions as described above help nobody except those who’s best interests are served by ensuring that the issue of ARC is kept at a very low profile. If you have any information which could help us raise the level of that profile then please make it available in the public domain.

It has long been my contention that we all need to involve the public in this issue. If we win the public to our side then we have a chance to get our politicians involved. Currently they cannot or will not.

Western Isles Disability Sports(WIDS). When I left the West Country for this windy and storm driven lump of rock in a tempestuous sea I determined that I would not get involved in public life again. I had previously been an active member of the British Legion, a worker for the Social Democrats and an American Football Coach. Now I reasoned that I had enough on my plate and that my energies would be wholly dedicated to the ARC issue. There is an awful flaw in that argument. When you concentrate your energies in one cause to the exception of all others you can become a one dimensional, boring person. I mean who wants to hear you prattle on incessantly about your disease? How does that make you appear to others?

Having answered those questions about myself I decided to do something about it. The opportunity came last summer when I was told of a new organisation, which needed help. There were no facilities or groups that aimed to help the disabled reach their sporting goals in life, and, thanks to the Paralympics many disabled adults and children now have sporting aspirations.

It started out as a weekly commitment to help members of their Committee run an afternoon session for disabled youngsters at the Sports Centre Gym in Stornoway. Since then I have become more involved having been voted onto their Governing Body. It has been a roller coaster ride because all new organisations are learning as they go, and we, like many others, have made our mistakes. Be that as it may, I have been repaid for my time over and over again by the smiles on the faces of our members as they have gained new skills through sports or enhanced existing ones. Last week that repayment was doubled when we took a trip to Barra – an island at the southern tip of our archipelago. This was our second visit, the first being an exploratory one in December of last year, which was a great success. This time we fulfilled one of our stated aims by supplying them with equipment and commissioning a sub-branch, which we hope, will grow and develop independently. It also filled another gaping hole by giving our members here some opposition.

The point in bringing this to your attention is not only to point out that we all need to concentrate on other activities, but also to bring you an example of how this problem can be solved. Families and friends get desperately fed up of our tales of woe and we ourselves become so wrapped up in them to the point that we cannot see that the world is full of opportunities to expand our lives and make them worthwhile. It certainly makes me humble and proud in turns when I see many young people overcome their physical limitations. It goes without saying that such experiences remind me that I am not the only one who has battles to win.

Conclusion

I hope that I have brought a smile to your face or persuaded you that life, even for ARC sufferers, still holds the same magic. We all have difficult and pain filled days

but sometimes we need reminding that they don't have to dominate our whole lives. ARC is devastating but it does not need to be an ending, I don't always manage to do so, but I intend to make it the starting point of a new life and, moreover, one that is positive and with a sense of achievement as a reward.

I wish you all well and, if you are ready for another slice of island life in a month or so, I will be more than glad to keep you updated.

Regards,

Mike Feehan

RESEARCH

One is the finding of the apparent beneficial effects that propanolol produces by reducing the production of cerebrospinal fluid, therefore reducing the pressure sensation and the spinal pain. The other is acetazolamide, the old time diuretic, by inhibiting the enzyme carbonic anhydrase it appears to affect the dense net of receptors and transmitters located in the posterior horn of the spinal cord that is essential in the transmission and the perception of the type of pain usually present in ARC. It "tames" this pain.

In addition observations have been made in the pursuit of developing an experimental model of arachnoiditis. It has been noted that when certain neurolytics (medications that suppose to damage nerves) actually produce clotting within the vessels of nerve roots so an element of ischemia (not enough blood supply) may be involved in producing the type of permanent damage seen in ARC. The importance of finding an experimental model is that we can confirm what substances produce ARC, but most importantly we can then identify what can be used to treat it.

INFORMATION FRONT

Both of these studies will be presented at the American Society of Anesthesiologists Annual Meeting scheduled to take place from October 10 to 15 in Orlando, Florida. In addition the Arachnoiditis Foundation, Inc. will sponsor a Scientific Exhibit for three days on the various causes of arachnoiditis and how to prevent most of the cases.

Since there is no definite treatment at this time, it seems that major efforts need to be directed to inform the medical profession that certain invasive procedures performed on the spine may have by far greater risk than perceived.

On this matter we have identified several warning events that when present, in these cases, should serve as “red flags” to not proceed as planned, stop what is being done and cancel the procedure. We realize that this new cautious attitude may face some resistance, but since almost all of the over 400 examined patients, in whom ARC has been confirmed radiologically, one or more of these red flags have been found. They are:

Previous history of neurological disease.

Paraesthesia (sensation of electric shock-like) during the procedure.

Incidental (not intended) dural puncture(s).

Blood in the cerebrospinal fluid.

In the last four months 22 lectures or presentations on this very subject have been given to various medical groups in four different countries.

REGULATION

Medicare recognition of Arachnoiditis

Early this year, in conjunction with other interested parties, we were instrumental in having Medicare assign a disease code which would allow it to be recognized as a diagnosis requiring diagnostic tests and treatment.

Usually other insurance companies follow and most likely they will also recognize it likewise.

A paper entitled “Clinical symptoms in patients with arachnoiditis” was published in the Romanian Journal of Anaesthesia and Intensive Care. This research paper identified the most frequently noted symptoms in patients with lumbar arachnoiditis. We studied 70 adult patients (40 men, 30 women) with radiologically confirmed ARC by either MRI or myelogram followed by CAT scan. In these patients we noted the location, characteristics and type of pain, sensory abnormality and frequency of muscle spasms, as well as, other symptoms such as headache, profuse diaphoresis, insomnia, bladder, bowel, and sexual dysfunction. The personal habits, work status, disability, physical activities and participation in litigation procedures were also recorded. We found that severe burning and low back pain were present in 96%, radiating toward the lower extremities in 70% of them; segmental numbness, tingling, hypoesthesia and dysesthesia were common. 98% complained of muscle spasms. Low grade fever, headaches, fatigue, heat intolerance and diaphoresis occurred in more than 65% of the patients. Bladder dysfunction was present mostly in women. Sexual dysfunction, such as loss of libido, impotence, pain during and after intercourse was present frequently.

Certain skepticism has been expressed concerning the distribution of pain and sensory alteration reported by patients with ARC. This is probably due to the type and location of the lesions involving nerve roots, dural sac and some times spinal cord with profound disarray of the nociceptive pathways and receptor hypersensitivity that appears to be present in ARC. The symptoms herein described, when present in a patient that may have an injurious event to the spine, should alert physicians as to the presence of ARC, which needs to have diagnostic imaging confirmation.

REFLECTIONS:

Tonight's Mirage, Tomorrow's Reality

In the midst of a morning dawn
the very bright sun reminds you soon
that what went on past eves,
was just a game; last nights debts,
are due at noon.

If a mirage is a nocturnal day,
what then is sure to last.
And what you think is yours today
tomorrow is gone and lost away.

Empty dreams built in vain
of what was here today.
There may not be a remain
after the bottle is finally drained.

Should you not enjoy today?
After all, illusions are the soul's prey.
Tomorrow, may be better than today,
but while it comes, adore living today.

J.A. Aldrete

CAUSES OF ARACHNOIDITIS

PRACTICAL TIPS

CALL FOR LETTERS, ARTICLES, POEMS, DEBATES, etc.

Readers are invited to write short, but meaningful, articles on any subject related to Arachnoiditis. They may be submitted with the author's name or anonymously, however, with the understanding that:

- a. The Editorial Board reserves the right to modify them or alter them to conform with the style and the "Objectives" of the ARC Newsletter.
- b. The copyrights will be waived with the assurances that the Editorial Board will not derive any profit from any of these publications.
- c. They are simple, constructive and civil.

Thank you.

The Editorial Board

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