

Does Arachnoiditis Get Better

Posted by suespoems - 26 Jul 2010 10:12

I have recieved a letter today off a neurologist I was seeing to say arahnoiditis is an inflammatory condition (which I know)and may leave the body and show no signs but some symptoms.(Wow magic fairies that heal I wish) I honestly think he is trying to hide the fact I have Adhesive Arachnoditis and trying to make out my recent scan didn't show this condition.Funny how they said that about the first scan yet when Dr sarah had them read by a neuroradiologist it clearly showed.I know full well this scan I had a few months ago can't possible hide the AA as I know this condition is with you for life but when a neurologist is telling me different I need someone else to confirm if he is right or an I right?

I am very annoyed at the moment and going to try and get a copy of this scan, although I think the answer will be no but worth trying.Maybe Doc Sarah can advise.

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Re: Does Arachnoiditis Get Better

Posted by suespoems - 01 Aug 2010 20:19

Hi Helen

Thanks,Yes I am in the uk.Are you i the uk too?I don't know how to delet messages here so I just edited them to blank pages on some messages I posted as they build up.I run my own website but know one has Arach most have spinal problems,arthritis etc there isn't any support groups in my part of england even for back pain etc so I set up an online group and have made lots of lovely friends.No I wouldn't name names.Its just ashame none even has an interest to learn about the condition and thats what annoys me most.Hope you have a good week ahead.

Take care!

Sue

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Re: Does Arachnoiditis Get Better

Posted by kev - 06 Aug 2010 01:41

helen wrote:

Hi Sue

Good to see you're still using the Forum. Can you let me know if you are in the UK (assume you are). I've deleted some of my previous messages on the Forum too - I know exactly how you feel !! **I would love to name names, but know it's not allowed.**

Take care Helen

Same here! These people should be named and shamed for what they have done. I am starting to check back all the treatment i have had - and i'm intent on seeing my records - and already i'm angered by what has and has not been done to me.

At the moment they are trying to wash their hands of me but i will not go quietly!

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Re: Does Arachnoiditis Get Better

Posted by helen - 06 Aug 2010 12:43

Hi Kev

You may be surprised by what you read in your medical records! I've learnt that what is said in consultation rarely gets into print to my GP - all it does is make me angry and frustrated - good luck

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Re: Does Arachnoiditis Get Better -So confused

Posted by ellijaygal - 17 Oct 2010 17:24

Every single thing I have been told and seen is that AA is NOT a condition/disease that will ever be cured. It does not get better. It is progressive (gets worse) or some remain stable for many years before it gets worse.

I am curious as to how AA can "disappear" and symptoms remain. AA is an inflammatory (and so I have read an autoimmune) disease that causes your spinal nerves to stick together and adhere to each other or to scar tissue or basically anything because they become so sticky and cysts to form in your dura. How can the results of a MRI show that your nerves are bundling, or cysts exist and that reverse itself? If the nerves truly can separate or cysts can disappear and leave only symptoms behind I am confused about every thing I have ever read, been told and lived through regarding AA. I would NOT trust a doctor that states clinical findings supporting a diagnosis of AA have disappeared. They don't.

I am beginning to see a lot of people that have failed back syndrome or other issues being stuck with a diagnosis of arachnoiditis with no proof whatsoever. Previously people had to fight to figure out what was wrong with them who live with this horrid disease because the majority of cases are caused by physicians or contrast materials. Now it is going to the other extreme and seems when a neuro or ortho tire of trying to figure out where your pain is coming from they merely diagnose you with arachnoiditis and send you to a pain therapist. I would not trust ANY physician that diagnosed me with AA without there being proof on a MRI. (Just my humble opinion)

I feel it is an injustice to the patient and the millions of people who have true AA. The pain of AA does not compare to the pain of a bulging disk, herniated disk, scoliosis, constant sciatica syringomelia, RA or anything else. I say this because I dealt with all of these issues prior to acquiring adhesive arachnoiditis. I hurt like crazy with the other things, but AA is a totally different indescribable pain. Until physicians make true diagnosis of AA based on clinical findings the sufferers of AA will never be taken seriously and a cure will never be sought.

Barb

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Re: Does Arachnoiditis Get Better

Posted by Juva - 17 Oct 2010 21:10

Hi Sue,

Where do you live? It seems that there are very few doctors in the U.S. who now much about this. I'm in SW Oklahoma & have a hard time even seeing a specialis, let alone one who knows how to diagnose or treat arach.

I'm wondering about trining hospital. It seems to me that they would be more familiar with the not-so-familiar ailments. I have an appt with a neurologist on Tue & depending on how that goes, I may get in touch with a dr at a teaching hospital.

I hope things improve for you very soon.

Juva

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Re: Does Arachnoiditis Get Better

Posted by Juva - 17 Oct 2010 21:20

Oooops,

I'm sorry, I went back & noticed that you are in the UK.

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