

New Articles from today

Posted by Kim - 11 May 2005 18:15

Hi All

Now I haven't quite got the hang on the Newsflash programme yet so I am going to post here until I can get it right.

New posts today are in The Adhesive Arachnoiditis Syndrome on the menu

www.theaword.org/index.php?option=com_co...69&Itemid=51

The term is a descriptive one, comprising erythros (red), melos (extremity) and algos (pain). This denotes the triad of redness, increased temperature and pain usually in the extremities.

www.theaword.org/index.php?option=com_co...70&Itemid=51

The syndrome of low-pressure CSF headaches was first recognized following diagnostic lumbar puncture.

www.theaword.org/index.php?option=com_co...71&Itemid=48

Pain is a provocative word. What causes it, how it develops in each individual person is a complex interaction between physical, genetic, psychological and mental state. It depends upon experience and perception.- A rare NON DocSarah article but relevant to a post put up on the Forum.

Think will have to do a disclaimer for the site now as we do not recommend any form of treatment or medication - just information.

Good quality, I hope.

This site is going to be as good as we can make it with information and support.

Would you like a Carer's section? Terry, as a carer seems to think we should, as their needs are quite different from ours. I refuse to use the words 'sufferers'. I am living with it, coping with it, but it is not my master.

Bye for now



Kim

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Re:New Articles from today

Posted by macandmaur - 12 May 2005 05:43

I will always use the word sufferers because I am suffering from something that is not my doing and my family suffer watching me in pain.

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Re:New Articles from today

Posted by Kim - 13 May 2005 15:35

Ok

We will agree to differ on that one. It's a good thing we are not all alike isn't it? Suffering to me implies pity and I want action not pity.

No doubt we will cross swords again. Luck forward to it.

Kim

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Re:New Articles from today

Posted by macandmaur - 14 May 2005 03:25

Anyone that knows me certainly knows that I do not pity myself, I stayed at my Job for 18yrs until I was collapsing so much the pain specialist put his foot down and said leave! I still hung on another 2 months and the week I was leaving I was too sick to go the last 3 days. I am too pigheaded and have never thought about being pitied. I too want the disease recognised and that is why we are in the process of setting up our own Association for Arachnoidits Sufferers and I am secretary! So Action not pity!!!!!!!

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Re:New Articles from today

Posted by Kim - 17 May 2005 18:42

And if there is anything I or we can do please ask. It is only by sharing information and experiences we can get to the bigger picture.

What sort of Action do you recommend?

Nationally in the Arachnoiditis Trust, we spoke to politicians, we lobbied for many years.

Locally as I am now, I wonder sometimes whether I am making a difference. Lots of people can now say the 'word' arachnoiditis. Lots of people understand arachnoiditis is chronic pain!

Funds weren't available for the national pressure group but local groups could get funds for community groups.

At the moment, as a group, I am helping individuals. The website is just a spin off. Lots of people don't have access to the Internet so I mail out information or take it down to them.

Many people are housebound, so can't get to the local library or internet cafe for access.

I have tried for over three years to have the needs of housebound people recognised to no avail. There is no political capital in housebound people, that's the problem.

I could go on but tonight I am just too tired - and that's allowed

Bye

Kim

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Re:New Articles from today

Posted by macandmaur - 21 May 2005 11:48

Hi Kim,

Sorry to take so long to answer. I have been down and out.

Your question about homebound, I worked in a public library for 18 yrs and all public libraries in Australia and NZ have a home bound service, my daughter does it at a public library where she goes to nursing homes and private homes and the council also has a service where they bring the elderly in for their shopping once a week in the council bus. I had thought of some way of using this service to let these people know what is happening in the world of Arachnoiditis but how do you know who has it and some of them don't even know they have it themselves. The trouble is that Council consider libraries a loss and don't like putting extra money into them, no matter what the cause.

I spoke to a girl whose mother was in hospital having about her 4th op and when she talked to me she gave me all the systems of Arachnoiditis and I asked her if her mother had ever had a myelogram and she said yes! She just thinks she has a bad back.

We have formed a really good little group and become really good friends as the OLD friends don't understand because they don't see you at your worst and think you look ok.

As a friend's husband said who has it, we are beautiful on the outside and rotten on the inside.

I also mail out what I can to those not on the net, I have found a lot of heads are better than one!!!! and we learn so much from each other.

Chronic pain, I went to the dr and he wasn't on that night so went to another and he said what is the walking stick for and I told him I had Adhesive Arachnoiditis and he 'said my god that is a terrible disease.

I had to have a brain scan last week and the Radoligist said he used to give Myleograms and he was always worried about them because he never felt they were right. He said about 10% of people got Arachnoiditis from them.

Well I to am falling asleep at the computer and am going down to give a colleague computer lessons tomorrow so I am off to bed.

take care!!!!

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