

Need Doc Sarah's advise

Posted by Subur - 10 Mar 2007 08:15

Hi,

I posted a question a few months ago but did not receive a reply so I thought I'd try again. I have been diagnosed with Cauda Equina Syndrome, chronic spinal stenosis, chronic nerve compression, DDD, and have had 4 spinal surgeries in the last 3 years. I had a myelogram after my first surgery and the Dr. had a hard time getting the needle in place because it kept veering off all the scar tissue around my spine. I had a second myelogram the day after having an ant/post fusion which contained both RBC and WBC and I'm not sure if it was the result of a traumatic tap or because an artery (and who knows what else) was nicked during surgery when they were trying to cut through all the scar tissue which caused a hematoma that required another surgery. My problem is that I have EVERY symptom of Arachnoiditis and have for a few years now. I asked my Dr. if I had it and he said he didn't think so but that my nerves may be stuck together. Huh?!

I had a few things listed on previous MRI's and myelograms and I wasn't sure what they meant. What does it mean when you have enhancing scar within disectomy defect which is entirely contained within the anterior epidural fat?

Or enhancing scar encasing the nerve roots?

Also, what would cause reduced filling of the nerve roots on a myelogram?

Do you know of anyone who is familiar with A. that could review my films?

My Dr. cannot explain why I still have pain all the time.

Thank you,

Sue

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Re:Need Doc Sarah's advise

Posted by helen - 20 Mar 2007 04:40

Hi Sue

I am sure you have Arachnoiditis. You don't need to see another doctor - just telephone your local radiology department and ask for your scans to be reviewed by a consultant neural radiologist. I did this some time ago and it only cost me about ?50. It was well worth it as he telephoned me to discuss my case! You don't normally get that one-to-one contact with the person actually reading your scans. In my experience the Neurologist only wanted to hide the facts about my condition and I really had to badger him to commit my diagnosis to paper for my GP.

Hope this is helpful! Best wishes, Helen 🍌

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Re:Need Doc Sarah's advise

Posted by DocSarah - 29 Mar 2007 16:50

Dear Sue,

from what you've said, you have a number of causative factors for arachnoiditis and scan results to match. In essence I would presume a working diagnosis of adhesive arachnoiditis. You also have some epidural (extradural= outside the dural sac vs. subarachnoid inside the dural sac) as well which is often the case.

In any event, exact precise diagnosis is not going to make a difference to how your problems are managed. I imagine it will cost you money or at least time and effort to chase the diagnosis; this would be better spent on establishing a workable management plan which is likely to include pain relief (medication) physiotherapy (gentle) to ensure continued mobility and reduce deconditioning, and probably some psychologically based approach to help you tackle the impact pain is having on your emotional wellbeing.

I hope this is of some help.

Sorry for the delay in replying. I am having some difficult domestic circumstances which seem to have been ongoing for a long time!!

Take care,

all the best,

DocSarah

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Update - 1 year later

Posted by Subur - 07 Jun 2008 18:47

Just thought I would post an update a year after my last post. I went to see a Urologist for my bladder problems (e.i. neurogenic bladder) and after the Urologist reviewed my lumbar MRI from 2 years ago he

noted I had arachnoiditis. Funny thing is that I had asked my Ortho (who did my 4 spinal surgeries) TWICE if I had A. and he would only say my nerves were stuck/scarred together. I guess he didn't want to admit that he had caused more damage to my back. It doesn't change things but it sure is nice to be validated and have it down in black and white.

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Re:Update - 1 year later

Posted by Kim - 08 Jun 2008 21:10

Oh dear, what a suprise. Welcome to the club of people never been told directly by those who should know better.

Kim

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