

Need advise with "A" diagnosis

Posted by Mummy3 - 15 Jun 2010 20:11

Well, I will keep this short and will not go into all the problems in my back - but had surgery 2 years ago and it's been heck ever since. I have been a mess ever since. Last month had MRI and radiologist mentioned he saw nerve clumping within the thecal sac suggestive of arachnoid scarring at L4-L5. (in addition to some herniations again). The picture on the MRI is textbook arachnoiditis. The nerves are one large mass inside the thecal sac. Went to a neurosurgeon who said, "yes, you have all the symptoms of arachnoiditis.. and maaybeee (sing songy) I can see it and say you have mild arachnoiditis (he was looking at the MRI and saw the clumping on the lit up MRI) but your sysmptoms could also be from other things"; he then tells me I need fusion in the lumbar and neck(7mm herniation) areas. My pain dr is also hesitant to diagnose arachnoiditis.. it's like he doesn't want to talk about it. I am currently hoping my pain dr can convince my insurance company to approve Lyrica for me(they denied it). have been taking it for 4 days (free sample) and already notice the difference in the nerve pain! I even asked the nurse, who is helping with the Lyrica problem, about the arachnoiditis - although she acknowleged it is on my MRI report, she said she would have to speak with the dr about the diagnosis. Should I care what they diagnose me with if I can get the meds to help with the pain? They are even thinking of adding fibromyalgia to my diagnosis to get the Lyrica approved... why not the arachnoiditis? Is it possible I do not have arachnoiditis and the nerve clumping is from something else? Thanks for your help and thoughts on this in advance!!!

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Re: Need advise with "A" diagnosis

Posted by Kim - 20 Jun 2010 01:35

Don't give up yet, please.

The Doc will answer tomorrow.

Kim

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Re: Need advise with "A" diagnosis

Posted by kev - 20 Jun 2010 01:41

Mummy3, i can empathise with your situation, i too have A but my surgeon is very shy when it comes to mentioning the word 'A'. My MRI states the same as yours, nerve clumping, i have all the symptoms but all he said last time i asked about it was "Well yes all your symptoms suggest A but ...hmmm....,yes A is suspected. He hasn't committed it to paper and this infuriates me.

Don't give up, fight to get Lyrica, it made a huge difference to my feet pain but my brain is a bit foggy and forgetful and i've put on weight.

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Re: Need advise with "A" diagnosis

Posted by Mummy3 - 23 Jun 2010 23:09

Well, I went to see a neurosurgeon and orthopedic spine dr. The neurosurgeon said I did have the symptoms and considered the clumping as mild on the MRI - the orthopedic said EVERYONE had some form of arachnoid scarring after surgery... How is this possible?

The orthopedic dr also found all my nerve pain symptoms as unusual since they are sporadic, and all over the place (i.e. - sharp pains come and go, burning pain comes and goes in my calves, feet, thighs, numbness comes and goes and varies from leg to leg)... he said he didn't know what to make of it.

How about making an arachnoiditis diagnosis out of it...LOL

But alas, no - since he says it's common to have my nerve clumping...

common, huh?

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