

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 - 16 Jun 2010 23:10

WOW what a good post Mummy3

Being UK too late to respond tonight. I watch every day and will post tomorrow

Kim

DocSarah has new 'blogs' coming up and the online questionnaire should be up by the weekend.

Watch this space!

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Re: Need advise with "A" diagnosis

Posted by Mummy3 - 16 Jun 2010 23:44

Hi Kim,

And thank you. I will await your reply tomorrow. How frustrating to have doctors see a problem with an obvious diagnosis and ignore it like it's magically not there. To add insult to injury, offer to diagnose me

with something I don't even have.

Thanks again.

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Re: Need advise with "A" diagnosis

Posted by Kim - 17 Jun 2010 22:48

From what you've said, given the nerve root clumping on MRI scan, you have a diagnosis of arachnoiditis. That said, what really matters is how the problems it causes are managed. I suspect Lyrica can be used under licence for fibromyalgia, but I would suggest you ask for that to be listed as a secondary diagnosis i.e. due to the arachnoiditis. I hope you manage to get the Lyrica prescribed and please let me know how you get on.

Best of luck!

Regards

DocSarah

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Re: Need advise with "A" diagnosis

Posted by Mummy3 - 17 Jun 2010 23:23

Thank you. I did ask the doctor to diagnose the arachnoiditis and fibro secondary - and even explained that many people with arachnoiditis are dually diagnosed with fibro. I don't think he agreed. He still shy's away from the "A" diagnosis. Why is that? Is it just my doctor or are many reluctant to make the diagnosis. It just couldn't be more plain that I have it. It's documented on 2 MRI's, it's in the radiologists report, and my symptoms mirror those of "A". Your insight would be appreciated. Thank you again so very much. I feel I need the right diagnosis to receive the correct treatment. Knowing there is no cure for this, I do not want to be labled as someone who is complaining for no reason or worse drug seeking. As you already know - the pain is very real and debilitating. One last question, is it safe to have further spine surgery with "A"?

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Re: Need advise with "A" diagnosis

Posted by Kim - 20 Jun 2010 00:02

Hi,

sadly you are by no means alone in finding that doctors shy away from diagnosing arachnoiditis: mostly because it tends to be iatrogenic i.e. caused by medical procedures and there is fear of litigation.

It is helpful to have a diagnosis but not essential: basically the important thing is to find a doctor to help you manage your symptoms.

Re: surgery: in general, it's best to avoid it unless you have a situation where you are deteriorating to the degree that not operating is a bigger risk than operating : broadly speaking, surgery carries a significant risk of increasing arachnoiditis because of the risk of blood entering the subarachnoid space; blood is highly irritant and causes/exacerbates inflammation.

Hope this helps

Regards

DocSarah

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