

spinal Fluid answer ASAP

Posted by Becky - 09 Sep 2006 00:50

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Hi Doc Sarah,

I hope you are moving along on getting your new home set up? I know this can be a very stressing and tiresome job.

I wrote you an email back in July or Aug, it must have gotten missed. I will start over.

June 27th, I had a pump trial done, had it put in on tues and taken out on thurs. I had a horrible pain that shot up from stepping on my foot to my back. I called Dr Whitworth at 4 am (LOL). He told me to head straight to his office as soon as they open to take out the catheter. Since then I have been going down hill with new symptoms and more pain.

When I went back for my visit in July they set me up with one of his new helpers in there, another Dr. I did not think much of her, plus she could not give me any answers why all this happened with the pump trial. My Aug visit I saw the NP, told her everything, and she was very upset. ☺

She immediately tried to get me to see the dr and of course he was too busy. The soonest appt I could get was on Sept 6th. I typed up everything, that was causing me pain and where it was exactly. it went like this:

Since pump trial, I have been experiencing new pain. I have constant throbbing and aching in both legs, and burning. Burning is down the back of both legs, right ankle, left inside of calf, down buttocks to foot on outside of rt leg. Behind rt knee on the inside of my leg.

I have swelling in both legs. When I try to bend down on both legs, they feel like they are going to explode, and it is hard to get up from that position. Cannot stretch legs without pain from a bent position. Having nerve pain behind the rt knee on the inside of my leg when trying to straighten out leg. Toes on rt foot are numb and my feet feel like I am walking on gravel when barefoot.

Back pain feels like someone is taking my spine and twisting it with both their hands and the lower back feels like it has a knife in it all the time.

Drove to Franklin on Fri Aug 24th, later that night my spine felt like it was getting twisted. This is very painful.

If I am standing in one spot, my legs burn more and get numb the longer I am standing there, almost like I can't feel them. This usually happens in about 2-3 min.

During pump trial, I could not walk on my left leg without having stabbing pains running up to my back, every time I stood on that foot. When she took out catheter it was very painful, my back is so sensitive to the touch, without having something being pulled out.

For the last week I have been waking up in pain every night. I find it hard to fall asleep b/c of the pain.

My legs are sore to the touch, more in some spots than others.

When I am having a lot of pain in my back. I get an sm headache and nausea. I also am having pain in my hip joints to the point I can hardly walk on that particular leg. This is not constant, but very painful when it does come on.

He went over all his records and told me for some reason I was not getting spinal fluid into my lumbar area. I am not sure if he saw it when he was putting the catheter in or what. I am scheduled for an MRI on monday and hopefully we can get s

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Re:spinal Fluid answer ASAP

Posted by DocSarah - 15 Sep 2006 08:51

Hi Becky,

sorry not to have answered sooner. The end of your message got cut off but I'm guessing your query relates to why your spinal fluid isn't circulating properly and why you have worse symptoms since the pump trial.

CSF (spinal fluid) circulation can be impaired or completely absent in areas with arachnoiditis scarring because the clumped nerve roots can obliterate the subarachnoid space.

The pump trial may unfortunately triggered an exacerbation of the inflammatory aspect of arachnoiditis. Some of the symptoms you describe (leg swelling) can occur as side effects of the pump.

The pump trial may have failed because of the CSF flow being impeded.

Hope this is sort of what you wanted to know.

Regards,

DocSarah

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Re:spinal Fluid answer ASAP

Posted by Becky - 02 Nov 2006 20:20



Hi Doc,

I had my MRI , which showed 3 bulging disc's, and L5-S1 is degenerating like the one above it. My Pain has not let up, and have not worked since July 28. I have applied for disability, I called them today and they said a decision has been made and I should receive a letter within a few days. She wouldn't tell me over the phone, whether they approved it or not.

Dr. W will not let me go back to work, if they deny me I do not know what I am going to do.

He is changing my meds next month b/c of my insurance. I will be going from Oxycontin 80 mg 3/day, and roxicodone 30 mg 3/day. I have been on these meds for a yr and they don't even work anymore. He is planning on giving me Methadone and oxycodone for bt. What are your thoughts on the methadone? I had to do an EKG because of QT something. Could you explain what this is? My GP did it and said I was on the borderline of having this. Dr Whitworth said that if I had this problem, the methadone would kill me. What are your thoughts?

I am so over all this pain, the stress from trying to come up with money to pay bills. I just do not want to live anymore. I am single and do not know what to do.

Hugs,

Becky

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Re:spinal Fluid answer ASAP

Posted by helen - 03 Nov 2006 12:15

Hi Becky

Sorry to see how bad you are feeling right now. There are lots of us who sympathise with you, but feel very frustrated because we don't have the answers. The symptoms of pulling, strangulation, pressure etc., along with the pain are very distressing. I hope the Doc can give you the advice you seek soon - hang in there.

Best wishes, Helen

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Re:spinal Fluid answer ASAP

Posted by helen - 03 Nov 2006 12:17

Hi Becky

Sorry to see how bad you are feeling right now. There are lots of us who sympathise with you, but feel very frustrated because we don't have the answers. The symptoms of pulling, strangulation, pressure etc., along with the pain are very distressing. I hope the Doc can give you the advice you seek soon - hang in there.

Best wishes, Helen

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Re:spinal Fluid answer ASAP

Posted by Becky - 03 Nov 2006 18:11

Hi Helen,

Thanks for writing to me, this disease is just so awful. I see more and more ppl getting it. I belong to COFWA and they add new members all the time. It makes me sick.

I tell everyone about the epidurals, and the other ways of getting this disease. I am trying to get the word out. I even told my credit card person, I was talking with on the phone. LOL

His wife has had 3 for childbirth. He said that she will be going natural this time. I gave him this website to read up on the disease. How did you get this?

Hugs,

Becky

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