

## MRI imaging help - need a diagnosis -

Posted by Kia Kaha - 10 Feb 2013 21:50

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Hi forum members.

I am female, 43, live in the South Island of New Zealand.

4 years ago I was fit, healthy an active surfer, two jobs a home business and environmental campaigner with a loving partner and 3 adult children.

Then in 2009 everything started going down hill. Started around the time I had a surfing accident, hard jolt to pelvis lower back jumping off board into shallows. (Found out 20 months later I had actually sprained my sacro-iliac joint and my sacrum had twisted), I didn't see doc at the time.

over 5 months from this I got symptoms of bladder pain, constipation and pain during sex, lower back sacrum pain, then numbness over saddle and feet.

This began a pile of medical investigations into organ etiology.

So summary:

I have had chronic lower back pelvic and leg to feet pain, burning for 3+ years, problems with bladder, bowel and sexual function, sensory deficits, numbness etc etc.

I haven't been able to sit for 18 months, I can't stand for more than 5 mins, bend, squat, walk more than 20 metres, spend 23/7 on my back lying down, most movements exacerbate pain. I've lost my job, business, most friends, partner of 7 years, two of my children not supporting me, lost my house, and now living alone, been dumped by public hospital and 2 failed accident claims denied.

So thats a picture of my situation.

I have had a number of investigations, and a few MRI's.

Pain clinic tells me I just have neuropathic pain and/or its psychosomatic, and offer me drugs, which I have had several bad reactions to. They have now denied me any support and treatment, my GP is refusing to make any new referrals.

Have had a MRI brain scan looking for MS.

A number of surgeries looking for endometriosis, interstitial Cystitis, Adenomyosis, all come up ok.

I have had a pudendal nerve block that was positive downstream from the isial spine.

A private Gyne specialist says I have Pudendal Neuralgia and a compressed Ilioinguinal nerve. I also get 'play ups' from my genito-femoral nerve.

I am in a situation here where I am unable to get any disability recognition because I do not have an acceptable diagnosis other than chronic pain.

I cannot get any new referrals to see a neurologist (even though I did see one 2 years ago, he said I did not have MS, and if there was something wrong neurologically, it would show up in my brain MRI, which was clear).

I recently educated myself as much as I can about the interpretation of MRI imaging when Arachnoiditis is present, and went back to my two MRI's to see if there was anything similar. Even though each radiologist said they found nothing, (they were looking for spinal tumors or slipped discs etc).

I have attached two images from my 3T MRI june last year, one a cross section at L5-S1, kinda looks to me like stage 2 Adhesive Arachnoiditis, nerves pressed peripherally towards the disc with empty dural sac.

The other one looks like clumped nerves over S1-S2 to S3

What does anyone think?

Please help I am desperate for a diagnosis.

If I go pleading to my GP again with another possible cause/etiology of my pain and sensory issues she is definitely going to put me in the psychosomatic/hypochondriac bin.

I am asking if I can get some help here to see if Arachnoidosis is a possibility before I present the idea to her.

I am sure most of you understand the desperate need/search for a cause against failures to diagnose via medical profession.

Kia Kaha (be strong)

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## Re: MRI imaging help - need a diagnosis -

Posted by Kia Kaha - 11 Feb 2013 23:32

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29 views, and no replies..

Anyone??

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## Re: MRI imaging help - need a diagnosis -

Posted by helen - 13 Feb 2013 22:13

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Hi Kia Kaha

Sorry you've had little response and very sad to read what has happened to you.

I've looked at your MRI scans and, from my own experience, can only comment on the cross section one. A normal spinal cord should show all the nerves laying in the bottom of the sack, yours appear to be clumped/adhered to the upper wall.

I have pudendal nerve damage and sympathise with you, and can relate to your experience with the medical profession. Nerves within the pelvis can be severely damaged and only specific tests can reveal this. You mentioned a pudendal block - was that a pelvic block by injection or epidural?

It's taken me years to find consultants who are trustworthy.

Best wishes Helen (London)

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## Re: MRI imaging help - need a diagnosis -

Posted by Kia Kaha - 13 Feb 2013 22:47

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Hi Helen, thanks so much for your reply.

Yes I too thought the cross section (axial?) mri screen shot looks like they are clumped and adhering to peripheral with empty sac.

I just need to find someone to re-read my MRI who is experienced in Arachnoiditis to confirm.

But as I said my GP is refusing to make any new referrals.

So I am assuming if it is Arachnoiditis is it typical to have Pudendal neuralgia symptoms?

I had a pelvic exam by the gyne who said I have pudendal neuralgia, and he said the nerve was very sensitive along the entire course both sides. But apparantly the MRI shows no structures that would cause compression or entrapment within the pelvis.

The Pudendal Nerve block I did have was bilaterally (unguided) at the ishial spine.

I have attached a pic of the effects and also the areas where the pain was still present.

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## Re: MRI imaging help - need a diagnosis -

Posted by helen - 14 Feb 2013 10:18

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Hi Kia

There are no typical arachnoiditis symptoms, everyone has a different story.

I was offered a 'guided' pelvic block, but refused as it was invasive. My arachnoiditis was likely caused by an unguided epidural which probably hit one of my numerous Tarlov cysts in the sacral canal. My diagnosis of arachnoiditis came some years after the initial bowel/nerve damage was assessed correctly.

I was going to suggest you send your images to Dr Charles Burton, but have just found out that his website "The Burton Report" was shut down in 2010. You may be able to track him down. I sent him an e-mail some years ago, to which he replied personally. (I can't find him in my address book but will also try to locate him)

Helen

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**Re: MRI imaging help - need a diagnosis -**

Posted by Kia Kaha - 14 Feb 2013 22:39

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Thank you again Helen,

I found Dr Buntons email address, and have emailed an outline, and received a reply from him within the hour requesting to view some of the images of the MRI, which i have sent, just waiting to hear back!!

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