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-illiac 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 ishial 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 - 16 Feb 2013 00:04

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I got a reply!!!!

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Ms. Reeves:

Your MRI study does indeed suggest that you have Class II adhesive Arachnoiditis.

I trust that this information will be of value to you and expedite appropriate therapy.

Charles V. Burton, M.D.

Sentinel Medical Associates

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so now opens a whole new chapter:

what do I do now?

How can I manage this?

What are the treatment options?

Thanks so much Helen, if it wasn't for you suggesting Dr Burton, I would still be floundering today trying to get it considered.

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Re: MRI imaging help - need a diagnosis -

Posted by helen - 16 Feb 2013 13:37

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So pleased for you!! Hopefully your GP will accept the diagnosis and get clued-up on Arachnoiditis.

Where to go from here is a difficult question.... I would strongly advise you to avoid anything invasive. I took the route of pain relief with as few side effects as possible. My body is extremely sensitive to drugs so any that I've tried have always been at the lowest dose to start off with.

There's lots of info about treatments, written by Doc Sara, on this website.

I've only been on two - Amytriptaline (sorry can't spell) which stopped my bladder from working after a while. Then Kev told me about Pregabalin which is specifically for pain generated by the central nervous system. It has proved helpful, but I'm on a low dose 75mg 3 times a day.

I've tried a couple of "non-medical" things too!!

Helen

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Re: MRI imaging help - need a diagnosis -

Posted by Kia Kaha - 16 Feb 2013 14:27

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I known about drug reactions I'm allergic to penicillin, maxalon. And intollerant to oxycontin, methadone, zoplicone, and especially gabapentin for which I became a suicidal freak out. My pain Dr accused me of Googling the side effects and faking them. That was the start of being labeled as psychosomatic.

That, after 2 years of trying to vet a diagnosis I was dumped by the public health system!

Its been a nightmare, I so hope now I can get the treatment needed.

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Re: MRI imaging help - need a diagnosis -

Posted by helen - 16 Feb 2013 16:14

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Hi Kia

I've had arachnoiditis for 14 years and about 4 years ago was advised (by the same Neurologist who diagnosed A) that all my new symptoms were psychosomatic too. He prescribed 2 very strong antipsychotic drugs, which my family urged me to try. Like a fool I took them for a short while, then did some digging and discovered the Neurologist had been withholding test results, thereby deceiving me and my GP. Even with proof, my GP still stated that she did not believe "in the concept of Arachnoiditis".

You mentioned constipation - I follow a very low gluten diet and ensure to get fibre from salads and vegetables (not cereals) because they're water soluable. My gastric specialist is a Professor & Researcher on the effects of spinal cord injuries to gastric track and bowel.

Let us know how you get on - Helen

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Re: MRI imaging help - need a diagnosis -

Posted by Kia Kaha - 24 Feb 2013 20:33

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helen wrote:

> You mentioned constipation - I follow a very low gluten diet and ensure to get fibre from salads and vegetables (not cereals) because they're water soluable. My gastric specialist is a Professor & Researcher on the effects of spinal cord injuries to gastric track and bowel.
>
> Let us know how you get on - Helen

I looked up a grain free diet and found the Paleo system of eating, which I have been doing for over a week now.

thepaleodiet.com/

see how that goes.

On the other front, the new GP sent a referal to a neurologist, who did not want me as a patient, so now a new referral to a neurosurgeon, and I havent heard back yet.

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Re: MRI imaging help - need a diagnosis -

Posted by helen - 25 Feb 2013 16:23

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Haven't heard of that diet before. Based on the advise I was given you should avoid nuts as they cause bulk! Also if you are tolerant of milk include it in your diet as it lines the intestines.

Pleased that your GP has accepted your diagnosis, but sorry to hear about the neurologist, hope you find a sympathetic consultant soon.

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