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 - 25 Feb 2013 20:19

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thanks, I've probably had half a kilo of cashews in the last week! lol, will cut down.

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Re: MRI imaging help - need a diagnosis -

Posted by Kellett - 18 Jun 2013 12:47

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Hallo Kia

I'm in the UK, found your posting about arachnoiditis by accident. I'd like to think that my experience may give you a new view.

I have had arachnoiditis for more than 20 years, knew about arachnoiditis long before I learned about the trauma (spinal fractures and brain damage) that in my case caused arachnoiditis. Whilst investigating the cause of my arachnoiditis, a radiologist gave me the following information(1) and a doctor involved in a cluster of cases where myodil spinal injections prior to X-ray gave me informations (2) and (3).

1 - Check your MRI scans. These come with a variety of white lines, maybe labelled a-b, c-d, 1-2, 3-4. You get the idea? I haven't looked at your scans because I'm not a medical professional. If you look at the white lines, look for another matching scan - ie an MRI cross section of the spine showing various white lines such as a - b, c - d, e - f etc will have a different view of each of the same areas, so by counting the white lines and the notes on the lines, you can find out if you have all your MRI scans or if there are some missing. (When my spine was MRI'd there was a pile of scans at least 4 inches thick).

2 - Arachnoiditis (an inflammation of nerve roots where they exit the spine) will show on the MRI as "little white dots" at the spinal cord. (Understand this is the most basic of descriptions as I am not a medical person) so know what you are looking for. The "little white dots" are essentially the scar tissue caused by the inflammation. I think you mentioned disc compression? Were the nerve roots compressed where they exited the spinal cord? Do an internet search for the nerves you mentioned. The right search will identify what part of the spine the nerve come from. Did you have X-rays of those particular areas? Did you have spine X-ray with a myodil dye injection? Myodil is not now used because it was a known causal factor re arachnoiditis.

3 - Understand that arachnoiditis is an iatrogenic disease, which means it was caused either by doctors or their treatment. I was reliably informed that the reason it is so difficult to get a diagnosis is because it

is proof of clinical negligence. I'm surprised you are having such difficulty in New Zealand as I thought in your country they had a "no fault" med neg culture, unlike here in UK.

It sounds as though you have been very sick. What put me back on track and made my condition liveable is that I was sent for exercise in a hydrotherapy pool. At first the exercise programme was a nightmare because my bones and nerves were so badly damaged but it took about nine months for my body to start to work a bit better. I have heard a lot of people with arachnoiditis say "oh, I can't do that" and the words everyone with arachnoiditis uses is that the more they do, the worse they get. Well, you can push past this, it takes real determination and a lot of hard work but if you persevere, you can get there. What I'm saying is that if your legs stop working, walk a little bit further (it will hurt but just do a bit more than you think you can do). If your head hurts, instead of taking pills and resting, read a few more pages of a book (you might have to read them again another time but do it anyway). You need to stop thinking of what you can't do and try to do a little bit more and eventually it will be less of a problem. My health is by no means good and I haven't been able to work for over 20 years since my accidents but I do have a quality of life that I would never have expected possible when I first found out about arachnoiditis.

Best wishes

Roz

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Re: MRI imaging help - need a diagnosis -
Posted by gmak - 30 Jun 2013 16:13

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Thank you roz! I am thrilled to hear that someone is better! I have a question, if adhesive arach is on MRI's from 1988-2012 & says it is peripherally clumping of nerve roots, axial view shows all spinal nerves adhered to dura from L3- tailbone, tethered cord stretched from L1 to L3 but im ok, sorts. What i mean is i have severe constant pain & many other symptoms but there has been no visible signs of progression. Im the exact same as i was 5 years ago. Does anyone think that i may just stay at this level & arach not progress to wheelchair etc or is this a pipedream?

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Re: MRI imaging help - need a diagnosis -
Posted by janette whalan - 03 Jul 2013 02:43

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It sounds like a nightmare !   Look more into arachnoiditis with the strength of magnetic waves they use for the scan, I've read it needs to be a certain strength to give a better picture. The only other thing I can suggest is, it could be sacro iliac joint

If your pelvis and spine was effected then it is possible to have damaged your sacro iliac joint which is the joint along side of the sacrum which joins the pelvis, if it is damaged it can effect all the areas you mention, it also gives hip,pelvic,leg and back pain. If you can imagine that joint not being stabile any more. It can be hard to diagnose because it does have movement. I'm sure there are special tests. Try to find information regarding S.I joints. Learn about it then try to find someone. Orthopaedic doctors should be able to help. If it is diagnosed, it can be fused to make it more stabile.

Hope it helps.......thinking of you

Jan w

Re: MRI imaging help - need a diagnosis -

Posted by janette whalan - 03 Jul 2013 02:46

Hi kia

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Hope it helps.......thinking of you

Jan w

Re: MRI imaging help - need a diagnosis -

Posted by KayLondon - 26 Nov 2021 03:29

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.

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