

Am I different? My story

Posted by youngdavey - 08 Apr 2007 18:42

My Myelogram was given in 1980. I reacted very badly and spent two weeks in bed with crushing headaches.

A few years later I awoke one morning and could hardly walk for pain in the feet. This lasted for about 8 weeks after which time I gradually improved to the point where I can walk a short distance, say 100 yds or so, when the pain will kick in to the point where I have to stop and rest. I also feel very ill - like flue. If I continue walking beyond this point I can ultimately reach a level of pain where I am literally speechless. At times, if stressed, I can catch fire completely and the whole upper body painfully burns. I have even found myself banging my head against the wall to take my mind off the burning pain.

To deal with this last symptom I have made-up an ice pack for the back. I have also read some books on CBT

After many specialists and many MRI scans it seemed I had Arachnoiditis (my GP had read Dr Sarah's paper and most of my symptoms - muscle weakness, periods of foot drop, twitching, electric shocks, bladder problems etc, etc, matched).

I take Gabapentin, Co-proximal (now switching to Co-Dydramol), Lofepamine, Lactulose, Tamsulosin, Coracten, Bendroflumethiazide and Omeprazole. I rattle quite loudly when moving around.

Where I seem to be different to other sufferers - if I have read other sufferers stories correctly - is that I suffer little discomfort/pain when laying down.

This has a twofold impact. When at rest I feel guilty at not doing more. When I try to walk say, around John Lewis, I am overcome with symptoms and wish I had not made the effort. I make bad purchasing decisions and invariable have to return items for exchange later.

I have a collapsible scooter for 'long' distances and to get to the local shops, if I don't wish to take the car. But a scooter is not always convenient and getting it into the car is not easy even with my wife's help. I have therefore for sometime been considering a wheelchair but fight with the psychological barriers of making such a decision. Is this defeatist? Will I stop making the effort to walk and get even weaker as a result? What will people think - will I be thought a fraud when I get up and walk into the shop say? Stupid maybe I know but that's the way I feel.

I would love to hear of any similar struggles and how folk have come to terms with such a decision.

Do other sufferers get relief when resting? I seem to get the impression that most, if not all, suffer continuous unremitting pain.

Hope I have not bored with this longer than intended post.

David

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Re:Am I different? My story

Posted by helen - 09 Apr 2007 00:35

Hi David

You are not alone, I can assure you. I have days of such excruciating pain that I stay in bed all day and its all I can do to get to the bathroom, or make myself a drink. Another day I can do quite a lot, some cleaning and shopping and people say "are you ok now - you look well!". It's such a frustrating illness to deal with and very hard on family too. I feel like Jekyll and Hyde, not knowing from one day to the next what will happen. Not being alone with this illness doesn't make it any easier - I am finally going to get some psycho-therapy to try and help me cope.

Kind regards, Helen

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Re:Am I different? My story

Posted by kev - 09 Apr 2007 04:54

Hi Davey,

Like Helen I also have days of such excruciating pain that I stay in bed all day but others i can do quite a bit. Usually though lying down gives me quite a bit of relief from the aching pain or sharp pains in my back but does nothing for the burning pain. I think Arac affects us all in different ways and there is no 'standard' pain picture.

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