

major flare up

Posted by Harlton - 14 Mar 2014 23:58

Hi all,

This is my first post, I looking for advice if there's much I can expect to do about this. I have had all the usual symptoms, following my first and second surgeries in 91 & 92. Told that I have this following the 2nd surgery, but I wasn't told it's progressive. Symptoms have never stopped, but been managed with the help of the meds and exercise.

Until 3 or 4yrs ago when I got over involved in my professional interests, and it resulted in what I thought was a heart attack.

Following this event I have been unable to do much of anything. I'm very short of breath and without the inderal and now a doubling of my dosage of dilaudid, I would only be able to stay in bed all day and sleep. At least this allows me to get about a bit.

I've had cardiac stress tests and they've ruled out any problems, even though they got strange results. I was fairly fit before, this, so it's seemed out of the blue for me. I now even have problems brushing my teeth, with bicept spasming, breathing is hard and I have to live a very sedentary life style, I tire very quickly.

Recent MRI's, CT's and X-rays of my spine, have found an increase of scar tissue and lesions in the lumbar area, plus many cysts and lesions covering my cord and nerve roots, thru the thoracic and cervical regions, these are all new. They have put this down as the cause of my current problems, which started at 54 following that attack. I'm now 58 and the problems have only increased.

My GP wants me to have injections into my cord, and look into the possibility of more surgery, but I've refused. An MRI which was done when I was 52+ showed up as clear, and I was fairly symptom free then, so this is fairly sudden to me.

I could do with an opinion, on what's best to do next, how to go on from here, would be really appreciated.

my life now, is just constant pain and disability, and there seems little chance of regaining anything.

My Doctor and others seem to have very little knowledge or interest in this condition, and I've starting butting heads again, which doesn't work out well for me, but letting them do whatever they want is usually worse. I was told by the last surgeons I saw no more surgery, but when I bring this up, I get blank stare or passive comments. Any help or advice on what to do next would be welcome. Sorry for the length of this.

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