

Hello everyone!

I can't believe another year has whizzed by...it must be true what they say about life going quicker as you get older!!!

And once again I need to say 'Sorry' for not being around more reliably on the Forum. I have been quietly popping in from time to time but I will try to be more involved this year.

Every year I try to write a little something for TheAWord sort of as a present to Kim in particular and of course Ann, Vera and everyone 'behind the scenes' who keep the website up and running. They are a really great bunch who give so much of themselves. So I have put together a short piece on sleep.

Firstly, some news:

Professor Antonio Aldrete's new edition of 'The Silent Epidemic' should be published soon and will contain a chapter I wrote on Prognosis.

I met with Professor Jan Warnke, a German neurosurgeon, not long ago. He has been doing thecaloscopy (telescopic division of adhesions) on arachnoiditis patients and is very interested in the condition. We had an interesting meeting and he and his associate are going to take the Cochrane Review of treatment of Adhesive Arachnoiditis forward (it was simply too much work for me alone).

I have been contacted by a group in Australia who are taking up to 80 cases to lawyers, against Glaxo. I've been asked to help and will certainly do what I can from a distance.

I am still working on the Database. I urge everyone to get involved, especially with the new questionnaires. And many thanks to those of you who have already sent me your details. Every piece of information helps. We now have 56 people on the database.

Pregabalin: does it work? I'd be interested in peoples' experiences with this 'son of Gabapentin'. In my clinical work I have found that it fails to meet expectations, and seems (for some unknown reason) not to be effective in people with arachnoiditis. Either that or it is not tolerated well. This is rather a shame as it can be quite useful in other chronic pain patients, particularly in relieving anxiety related to pain and also in promoting better sleep.

That said, I have yet to find a medication that has lasting benefits in relieving pain. All too often meds become part of the problem rather than part of the solution. More on that another time perhaps...

Now, on a more personal note:

People sometimes ask me how I cope with living with arachnoiditis, especially now I am working. The answer is, 'with difficulty, but I get by'. Sometimes by the skin of my teeth, sometimes slightly more easily, but life is never smooth. Nothing new there then, I can hear you say! I also get asked what is the best way to manage...and to be frank, despite nearly 30 years' experience of chronic pain of my own, 5 years' training to be a doctor, 10 years' research into arachnoiditis and 5 years working in pain clinic/pain management, I am no nearer an answer to that billion \$ question.

Currently I work in two jobs. One is Pain Management. Here I see the flotsam and jetsam of patients cast adrift by medicine. They range in age from 11 to 80. But all have similar experiences...they have gone to the 'experts' (often many and from far and wide) and come away empty handed. By the time I see them, they are losing hope, patience, and sometimes, their last few shreds of sanity. However, they all seem to benefit from the Pain Management Programme approach. One remarked to me recently she wished she could live at the Min (where the programmes run) as it's the only time her life made sense! But the aim is to give people a toolkit to help them out in the real world and most take home some new ways of dealing with old problems.

What about my other job: I work with older adults with mental health problems, mostly those with depression, anxiety and some with dementia. I am now being asked to see a lot of people with depression and pain or pain and anxiety. So you can see that my two jobs are not too dissimilar. Despite the best drug treatment, some patients never get full relief from their depression or anxiety. So again we are in the same situation as with chronic pain. And of course, dementia has no cure. As author Terry Pratchett, who has Alzheimer's himself, has been saying in the press, we are heading for an epidemic of Alzheimer's in the future.

You might by now be wondering a couple of things such as 'Why is she waffling on about all this depressing stuff?' and 'Isn't doing those jobs depressing?'.

Let me answer the second first. No, strangely enough I don't find my jobs depressing. Sure, there are times when I get upset for people, but there's no harm in being upset from time to time, it's a part of being in the human race and being alive. I don't lose hope either, except occasionally for brief moments. That's because everywhere I look I see examples of quiet courage, dignity, and care. I see a lot of humanity and that's very humbling. It certainly diminishes my personal suffering and puts it into perspective.

Bear with me, I am working towards the thrust of my message. For a variety of reasons, I've had a few low points recently. Then a couple of unexpected turns of events happened and I think now I won't be needing the antidepressants after all....

I've just been on holiday and was hoping it would give me a morale boost. Unfortunately, Egypt gave us Pharaoh's Revenge in a big way so the holiday didn't go too well, nor did the few days after our return!

However, something surprising came out of the experience for me: I find I really appreciate the chilliness, the bare trees, the quintessential Englishness of being home. And now that my nausea is starting to settle, being able to eat just simple foods is a real pleasure.

The second thing happened only this morning. I was on the phone to a distraught patient. To be frank, a part of me dreaded talking to her because I know there is nothing I can do to change her situation. But as we talked, or rather, she talked (tearfully) and I listened, I stopped feeling useless and started really listening. It became clear to me that despite major obstacles, this

courageous lady had taken some really positive steps. I pointed this out to her and by the end of the phone call we had changed the whole tone of the conversation from one of hopelessness to one of possibility for the future. We both knew the future is going to be tough for this lady, but we also acknowledged that she has come a long way and done some incredible things that show how strong she really is (even though she often doesn't feel it).

It helped me to realise that I have a lot in life to celebrate and that sometimes in the midst of our weakness, we find our hidden strengths.

I have to confess, I tend to find Christmas a difficult time. I was talking to a friend about this and we agreed that we'd like (a couple of Scrooges!) to cancel Christmas as it causes as much unhappiness as happiness. In fact we thought maybe if it is put to the public vote, a surprising number of people would vote with us! However, since this morning, I find myself having a bit of a change of heart. Sure, Christmas is never quite what it's cracked up to be, but warts and all, the year wouldn't be complete without it.

And then after Christmas, the best bit of the year, opening the new diary and the new calendar and seeing all those days and all those future opportunities...that's my favourite gift at this time...the promise of the year to come.

My warmest wishes to you all for a hopeful New Year.

Dr Sarah Fox (DocSarah)