

I do have a little news about upcoming events: I have been invited to speak at a conference in France in July next year: it is a conference about Tarlov cysts and arachnoiditis. It will be a great opportunity to raise awareness and also network.

Professor Jan Warnke is hoping to be there too. He is applying for funding for 3 research centres in Europe and has asked me to be involved with one in the UK. So keep your fingers crossed: this would be a major step forward.

Although Prof Warnke is a neurosurgeon and I remain sceptical of the benefits of surgical intervention, he is a very down to earth and approachable man and for that reason I believe he is genuine in trying to help people with arachnoiditis in a broader sense than simply furthering research into his surgical procedure (thecaloscopy). It is also well worth keeping an eye on his results because it would be foolish to overlook a possible treatment avenue.

I have had a warning from Maureen in Australia, about an allegedly highly unscrupulous individual who is offering a €~cure€™, which is not only financially costly, but also carries a significant health risk.

Please everyone be very wary about any such offers: please be assured if there is a cure out there, I am not aware of it (and I do keep my nose to the ground on this). If you find someone €~peddling their wares€™ please contact the website and let us know: and please, *please don€™t* get sucked into trying anything out without running it past your own doctor first.

On a more personal note, this year I€™ve reached the 30th Anniversary of having chronic pain (what do you reckon that is: pearl, like in wedding anniversaries??): shall I break out the champers? Maybe not...

Funny thing is, looking back, I thought by now I pretty much understood pain and all its bedfellows: depression, anxiety, sleepless nights etc. etc.

Strangely enough, it seems I was wrong (which seems to be a rather more common occurrence than I like to admit!). Over the past year I have experienced new facets of pain, not new to other folk with chronic pain, but new to me.

In September 2008, I took on a second permanent part time job, partly for financial reasons, but largely because I love working with people with chronic pain. By October, I was already needing time off work, as my chronic abdominal pain was flaring up. I had to go to A&E but as always, no-one could really help. I saw a very pleasant and thorough junior doctor who was rather alarmed at my long list of problems and perplexed at my extensive medical history. But of course, no-one had any answers.

In November 2008, I was running steadily downhill into depression that really set in, strangely, whilst I was on holiday (perhaps partly because I was physically more unwell than usual on holiday).

Throughout the first half of this year I battled with a bout of depression deeper and more ferocious than any I™ve had before. Somehow I managed to keep working, but each day was like wading through treacle. Probably the worst aspect was the early morning waking (3-4am): not from pain (as usual) but from panic, repetitive depressive thoughts and snippets of songs embedded in my brain playing in an endless loop. I found I was no longer able to listen to music, or enjoy watching films.

Everything seemed bleak.

I tried using techniques I™ve used in the past (cognitive behavioural therapy: see my article on depression) but to no avail. I realised I needed help and saw my GP. She prescribed Citalopram. I™d had it™s cousin, Escitalopram, a few years ago, and done well on it.

But this Citalopram was terrible stuff, it just ramped up all my symptoms. I found myself looking

at chat rooms and forums for people on it and they all recounted similar stories: the first 2 weeks were meant to be the worst.

I stuck it out for the 2 weeks, through literally gritted teeth but still felt awful. So I went back to my GP and was put on Mirtazapine which I asked for because I knew it is good for sleep.

It helped within quite a short space of time. I stayed on it for about 6 months in all. It bumped me off the bottom of the depression ditch, but I still felt low and my anxiety levels were high.

I was trying to stay off valium and sleeping tablets, but occasionally giving in just so that I could go to work.

In March I was invited to give a talk and a workshop on AA at a conference in Canada. It wasn't an ideal forum because the conference was about rare disorders and we know AA isn't rare.

But I felt that it was a worthwhile endeavour. I agreed to go and prepared my talk and workshop. I then attended a conference on Pain with some of my colleagues. It wasn't physically or mentally challenging, but I caught some sort of virus and ended up with a chest infection and exacerbation of my asthma.

After lengthy talks with my hubby, we agreed I simply wasn't up to transatlantic travel so I reluctantly had to cancel my trip to Canada.

In May I decided my bowel troubles needed more proactive management and arranged to start daily colonic irrigation with a new system: which in fact I finally started in July: with some considerable teething troubles, so to speak. I have an atonic neuropathic bowel and periodically

run into subacute bowel obstruction which is painful and unpleasant.

I also realised that the strain of two part-time jobs was too much, so I gave up the one which paid less: sadly that was the pain job. I've never had to give up a job I love before because of my health: it has been quite a loss and certainly a lesson in what other people have had to go through: the loss of a fulfilling occupation and of course the financial ramifications.

My GP very sensibly suggested some counselling and despite my initial reservations about it, I must admit it has been very helpful, and has got me through some extremely turbulent domestic problems that have blighted the past few months.

Through all this, I began to realise too that my pelvic pain, which I have sort of mentally filed under 'Another arach Pain' had in fact been getting worse over the last few months. Hubby pointed out that me and the sofa cushions had become inseparable each evening, as I tended to hug it ever tighter in an effort to reduce the pain.

I went off to see one of the pain clinic doctors which was a little strange, being the other side of the consulting table! I know the doctor as a colleague, although we had never actually worked together as such. I was reassured by his thoroughness and agreed that I have visceral hyperpathia (hyper-sensitive abdominal organs basically).

In one of my routine check kidney scans (because of my neuropathic bladder) a large fibroid had been seen. So off I trotted to the Gynaecologist. A very nice, and rather attractive consultant went through my various options but between us we decided overall a subtotal hysterectomy was most likely to be helpful.

Opinions (Gynae vs Urologist) vary on how much the fibroid is affecting my bladder problem but I (as the patient having the problems) am convinced they are worse as the fibroid has got bigger and caused more pain.

Of course, there are risks attached, not least that my visceral hyperpathia might flare up, but I

worked out what I hope will be an effective regimen to counter that (more below).

In amongst all this, we have had (largely for financial reasons) to move house. In fact it is a little more complex because we did have 2 houses: having been unable to sell up last year due to the dead housing market, my husband's two daughters were living in his house just down the road from my house.

So initially we had to sell his house, then mine and all move into another house. We are almost there, moving date some time in December (fingers crossed!). As they say, moving house is the third most stressful life event (after death and divorce). So it's not been easy, to say the least. I am typing this surrounded by boxes!

Reluctantly, I have had to revisit the land of pain medication...having carefully (and proudly) come off everything over the last couple of years...back into Catch 22 situation.

If I don't take the meds, the pain interferes with my ability to think which is far from ideal trying to work..if I take them, I feel somewhat out of sync with the world.

Some of you may be aware that a while ago I posted a request for people's experiences with Pregabalin (I admit with some shame I haven't collated people's responses as yet): my own are overall quite positive.

I have slowly increased from 75mg at night to 75mg morning and 150mg at night. I can't increase further as per the pain doctor's suggestion of 150mg twice a day as I would be too zombified but I plan to do so just before my op as part of my pre-emptive strike on the ramping up of my pain (more about my op in a mo). I do feel that my pain is better and I also sleep better and am less anxious.

But..rather oddly, I find I am more irritable, and I do strange things like leave the back door unlocked all day after going out, or even better, leaving it locked with the keys outside still in it (really helpful for any would-be burglars!). I am having to work hard on concentrating.

So it does have a considerable down-side and I do plan to reduce right back and probably stop altogether if I can after my op: but I will do so very slowly do reduce the rebound anxiety and insomnia I am expecting may occur (as per my experience coming off its predecessor Gabapentin).

I am on a BuTrans patch, initially 5micrograms but now 10mcg. It lasts 7 days and is really pretty easy to use. Again, I think it has helped. It's a medication I have prescribed a lot to my elderly patients who can't tolerate other medication and I've only had a couple who have had problems, mostly with a rash from the patch adhesive.

BuTrans is Buprenorphine, a morphine type of drug, about as strong as Cocodamol or Tramadol. It is less constipating. You can still take Paracetamol and anti-inflammatory drugs (Brufen etc.) as well. So I would certainly recommend it as an option.

While I'm mentioning medication, there is a new one available called Targinact.

I am not taking it, but you might be interested to know about it. It is Oxycodone + Naloxone. Naloxone is actually a morphine antagonist, i.e. it counteracts the effects of morphine, but when taken orally, it only affects the morphine receptors in the gut, not those in the central nervous system, so it counters the effects of the Oxycodone on the gut (constipation) without blocking its pain relieving effects.

So it is good for people who are struggling with chronic constipation related to taking painkillers. The usual start dose is equivalent to 200mg Tramadol a day (half the maximum daily dose).

Incidentally, for those who are using a Fentanyl patch, there are two helpful developments you might find interesting.

The 12microgram patch can be used to titrate up the dose so you don't have to have a big jump of 25mcg. By the way, 25mcg Fentanyl is equivalent to 100mg Morphine a day, so Fentanyl is a very strong drug.

If you are having a lot of breakthrough pain, there are new formulations of Fentanyl: buccal tabs for instance, and a spray, that are a lot faster acting than Actiq lozenges which you have to keep in your mouth for 15 minutes.

That said, in my experience with people with chronic pain, despite hefty doses of multiple painkillers, pain tends to persist. I've seen people on what other doctors have described as "industrial doses" of medication and still be in high levels of pain. I tend to advise gentle very gradual reduction and despite people's reservations, in general I am proved right in that their pain doesn't get worse (as they expect) but they do feel much better overall not being drugged up to the eyeballs.

So my plan for my own medications is to hopefully reduce after my op. Which brings me back from my little diversion... they say God laughs at those who make plans.

Well the NHS must be in stitches (pardon the pun) over people who plan their lives around their scheduled operation date. My op (meant to be on 26th October) was cancelled on the day, as were 2 other ladies, we were all at the hospital: I had signed the consent form with the consultant.

Then we got hit with the news: no beds available!! Of course I gather this is the norm rather than an aberration. I hear some people have been cancelled several times. I spoke to one lady (a volunteer at the hospital) who said her open heart surgery was cancelled 3 times: the last time

she was on the gurney, had had her pre-med and drifted off in a snooze, only to be told when she woke up that she hadn't had the op, it had been cancelled.

Quite rightly, she refused to go home until she was operated on...they operated the next day! What a terrible indictment of the NHS.

Anyway, I am now hoping to get it done on 4th December, hence I am writing this message ahead of time (partly because our house moving date might also be on the 4th...and I may not get around to writing after that...)

I've been off work for some weeks now, having built up my meds to the point where work became impossible. What with the op and my other problems, it is not a dead cert I will be going back..we shall see.

I am now due to see the colorectal surgeon about my atonic bowel and may be headed for an ACE (anterograde colonic enema) procedure (sort of like a mini-stoma) or a full ileostomy. I wouldn't agree with the song title, "The best is yet to come" !!

So in some ways, I feel like I have come full circle.

This time in 2003, I was about to start work after 14 years out (which were mostly related to health problems). I've spent 6 years being more a doctor than a patient. Now I am back being a patient. I'm not at all sure I like it!!

So what's the point in telling you all this? Well I guess I want to share it with you. You should know that "DocSarah" really is just like you... and what have I learnt over the past year since my last Xmas message?



Firstly, feeling low, down, upset, bereft (I've had some losses this year that I won't go into) is NOT the same as depression. Depression IS like Churchill's "black dog", it completely takes over. I needed tablets and counselling to get me out of it, as well as my own strength.

Depression doesn't necessarily come on when you expect it. It doesn't correlate neatly with your pain or even necessarily with what's going on in your life- sometimes it just descends out of the blue. And mental (emotional) pain seems to me to be far harder to cope with than physical pain.

Personally, I'd take physical pain any day of the week rather than depression. Some doctors think people "somatise" their emotional distress, i.e. turn it into physical symptoms. I think those "experts" are unlikely to have experienced chronic illness or indeed depression. I wouldn't wish depression on anyone, but I sure do wish "experts" could understand what it's really like then maybe they'd have a different viewpoint.

Whilst working, without realising it, I think I became someone who wanted to control life, mould it to what I wanted. I forgot that that is a pointless endeavour: any control we think we have is an illusion. I got myself SO organised for 26th October, assumed that this would go smoothly..since my op was cancelled I've had to learn to let go of all that and get back to the reality of life.

My horizons keep trying to shrink...but I'm still trying to widen them again bit by bit. What does next year hold? If I had a "flashforward" (as in the TV series) what might I see? And what might I do about it? Who knows? For now I'm taking life a day at a time. Next year can take care of itself.

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

Sarah Fox

## Christmas Message 2009

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