

# My story of my struggle with Pelvic Chronic Pain (since March 2007) Artwork© Soula Mantalvanos 2012

[www.pudendalnerve.com.au](http://www.pudendalnerve.com.au)



*June 8 2007 Self Portrait With Brace & my new, (lightweight) Lacoste shoes*

Hello, my name is Soula Mantalvanos and I am a 42 year old Australian (parents from Cyprus) living in Victoria. Thank you for entering my site, I hope my experience can be of great help to you or anyone you may know suffering from chronic pelvic pain, particularly related to Pudendal Neuralgia caused by injury or trauma. My intention for this website is to raise awareness for Pudendal Neuralgia so that it is addressed and treated appropriately, and disperse current descriptions of 'myth', 'syndrome' and 'psychological condition'.

As mentioned in the disclaimer, my website will document my injury, my treatment (appropriate and not), relevant resources I have found online and also material kindly provided to me, by my treating practitioners, specialists in Australia and Internationally.

Readers will also find me writing extensively about my frustrations, disappointment and the unnecessary and unhelpful obstacles I've had to endure as a 'long term' injured worker of the Work Cover system. My intention to document this information is to create a resource for our Minister to draw upon, have a place for injured workers to have a say. But please, if you are an injured worker, stay calm when you're posting, I will not approve inappropriate posts (everyone will know what you really want to say, we're all in the same boat!).

So...

- Do you have pelvic chronic pain?
- Have you had this pain since injury, pregnancy, birth, or some other trauma to your pelvic area?
- Does it feel like a toothache, does it itch and gnaw, do you feel like you're on fire?
- Do you feel spasms, fluttering and glitchy?
- Are your toilet signals irregular?

- Is there no obvious issue on your x-rays and MRIs?
- Do you find distraction can often work incredibly but afterwards the pain becomes excruciating?
- Is the pain often worse after activity rather than during?
- Do you feel no one quite understands you, your explanations, and your pain descriptions?
- Have you been told you have a Psychological Condition, that you sound like you're crazy?
- Do you associate your pain with ringing in your ears and feel you can't quite pinpoint where it is?
- Have you had endless appointments with no relief?
- Do vibrations, a fright, or bumps send a surge through your spine?
- Do your legs go weak?
- Do you find sitting unbearable?
- Have you fallen on your coccyx and after years, does it still feel like it happened yesterday?
- Are you part of the Work Cover system and feel you are being treated poorly and that the whole system is like a circus?
- Do you feel the Work Cover system can't help with return to work because the WorkSafe Agent treats you poorly?

Hopefully you'll find a road to relief here or at the very least a place to release your frustrations. And don't write to me about it if you do, go out and start living life (just don't forget to spread the word)!!

P.s. Pain hasn't killed my sense of humour, look out for it as you read along!!



## My pre pain life...

...was bliss.... filled with endless activity and huge lists of ideas and tasks that were always completed. Who had time for a book or television (actually I still don't make time for television)? I was active, I had capacity, boundless energy to execute my creative thoughts (and meet the expectations of a full social calendar!). I worked veeeeery long and wonderful days, I walked everywhere, lunching, dining, starting every day at a local cafe, picking up art materials, walking the dog, running the dog, to Carlton, the city, Fitzroy, I skipped through the streets of the great arrondissements of Paris when on annual holidays, and swore by my four day a week yoga routine that unravelled my body and had me feeling like Gumby warm to the ends of my extremities... There was no 'tired', 'sore', 'fatigued', 'have to rest', there was no 'pain'. Like I said, life was bliss.

Our (husband Theo's and my) small graphic design company, Orign of Image was in its 8th year and running beautifully, I had already had two solo exhibitions and completed most of the works for two more shows, I worked hard and we entertained a great social life (not to mention a very pricey art hobby). In fact, my beautiful printing press was delivered

the day of my accident. I've been drooling over it ever since, only having snippets of capacity to 'play'... (but Theo's had great fun with it and kept my prints and art going).

These are examples of my art work. See more on my websites [soula.com.au](http://soula.com.au) and [soula.com.au/blog](http://soula.com.au/blog).

## The big bang injury

It wasn't enough that I kept active by walking the dog every morning, practicing yoga 4 x 45 mins a week, occasionally running the dog a little at the park in the afternoon to break up the day, walking to Fitzroy, Richmond, the City, Carlton, local cafes, dinners, outings, long drives and worked by day and was in the studio by night (whenever we weren't socialising), I thought I sat too long... so I bought a fitball to make sure my chore stability was being cared for while I was sitting. Hmmm. All was going well until my (antiburst) fitball burst! I fell to concrete flooring in a split second (or as my husband, Theo says, I seemed to hover for a split second before going down).

This was the 'major' event that changed my life and 5 years later led me to putting this site together. Still to this day, I can't believe that 'bang' was severe enough to have actually stopped me. I seemed to think

I was a little invincible, well I never had any issues before, not one sick day, I was convinced I'd be fine in 8 weeks after having an x-ray that even though looked awfully cloudy to me, came back with fractureless results. But that's all that was checked. No MRI, no pelvic scan, no SI Joints... after all, it didn't seem like such a bad accident.

I went back to my Doctor when the 8 weeks were up still complaining of pain and that I could feel something about 2 inches behind me into the right buttock, as if someone had put a thick needle in there and my doctor thought I should be checked out by a rectal surgeon. All clear again, nothing wrong with the coccyx but mind you, hellish pain when I got home and for the next 24 hours. The examination sent me into, what I recognise now, is a flare up. I was confused... how can 'nothing' be causing so much pain.

I continued trying to work, deteriorating while my pain increased and even though my aids were building around me. I stood on towels to minimise the sensitivity that was getting worse every month, I lay down more, The flare ups were increasing, I tried Massage, Acupuncture, Feldenkrais, Hydrotherapy, a Chiropractor, Pain Management Centres, Psychology, I found an Orthopaedic Surgeon who did extensive x-rays finally and they came back pretty perfect (minor disc bulge)... I was at my

witts end. All I was stuck with was a tremendously impressive medical CV!!!

I reached the point where I could no longer stand bare foot, could not lay on my back, had to sleep every day for 1-3 hours to calm the nervous system which was the only way to lower the pain, everything hurt. I stopped working.

In May 2009 I had a follow-up MRI that showed I had a retroverted uterus. This doesn't mean much more than *I have a retroverted uterus*, apparently women have either retro or antiverted and actually both as it should move with our motion, but I remembered that I had an antiverted uterus and thought to check it out. My brilliant gynecologist, Professor Michael Quinn (Lifesaver: Ovarian Cancer Testing) who felt things were just a little too tender, whipped me in for a laparoscopy the following Monday.

Of course I thought I was going to be cured. Had to be something simple...

*Findings: A very thickened rectovaginal septum and a thickened left uterosacral ligament also. The septum was resected.*

I woke up on my back. And strangely extremely relieved to hear that there was something wrong and it was dealt with. The laparoscopic procedure had me in re-

covery mode for about 5 weeks but I lost the feeling that a 2 inch needle was inside me, I was sitting, I had very little pain, still tender when I sat, but my heel sensitivity was gone and by 7 weeks I could shake myself and it felt wonderful. I went back to Professor Michael Quinn, I told him he cured me to which he obviously replied, *I couldn't have cured your back pain.*

I had 3 blissful months before some serious pain began again. Seemed as I increased my capacity another onion layer surfaced. By January 2011 I didn't know what to do with myself again.

## The way relief started

In 2010 I visited a pain specialist who was treating me with acupuncture and this specialist suggested I have an epidural injection in my lower spine to see if I might have pain relief and if so continue with one or two more consecutively.

I went to visit my Orthopedic Surgeon, Mr Roy Carey for an update (and dreamt he was going to say, 'we found the cure for chronic back pain' which he didn't of course), but also to discuss the injection idea and he recommended to aim the injection more specifically into the coccyx. I had that done and my pain relief was

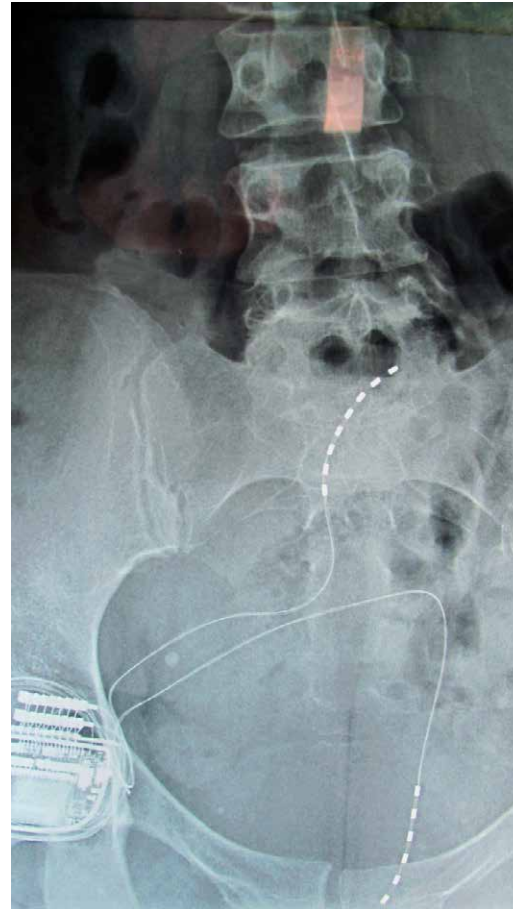
only from day two to about day four. But this was enough for Mr Carey to understand my pain issue was not mechanical but rather neuropathic. He referred me to Professor Peter Teddy (professorial fellow in Neurosurgery in the Department of Surgery at Melbourne University) at Precision Neurosurgery.

Prof Teddy listened (and heard!), asked for one more scan, then took my scans, and presented my case to an international conference of surgeons, and also back home to the Department of Surgery at Melbourne University. The suggestion was, rather than take drastic action (which I was willing to take at that point I was so desperate) and remove my coccyx, that we first try a Peripheral Nerve Stimulation device?

In my case, the procedure was much less complicated as I didn't need the leads to go through the spinal canal but rather along the right side of my sacrum and coccyx. There is a trial period in which the unit sits outside and is 'plugged in' via the leads that, yes, are sticking half out/half in your body. Look I know that might sound gruesome to some but please... we're talking about chronic pain here... it was nothing. A cinch... it worked, it's in now and giving me great pain relief.

But that's my experience. This is an operation, infections are a serious consideration here (so is the anesthetic effect, weeeeeee!).

**This x-ray is me now!! )**



## The way relief continued...

A few months into my implant and I felt like I was human again... my senses were back and it was incredible!! That thick pain fog was lifted and I could taste, smell, see, concentrate, focus, remember, listen, think, plan, dream, enjoy, laugh, read, oh what bliss!!!!

So, clearly it was time for research. Here I was for almost four years thinking my issue must have been motor/mechanical but still considering Regional Pain Syndrome, Pain loops etc along the way. I picked up a book my massage therapist, Pam Frost recommended: Norman Doidge, MD | *The Brain That Changes Itself*. The book referenced Dr Lorimer Moseley and mentioned something along the lines of him extending the 'mirror box' experiment and stated he was Australian!

So I googled... I found an ABC interview with Margaret Throsby that I had actually heard before but not remembered, and many many email addresses for a point of contact. So I wrote... I thought either I can help myself, I can help Lorimer (yes, we're on first name basis now!) or both! Lorimer's reply was simple: '*...tell me roughly where you are and i can link you up with someone good*'. And boy did he!! It felt like a miracle and took all of about 15 minutes for the physiotherapist (at the chronic pelvic pain clinic at the Women's

here in Melbourne Australia) to give me her French infused explanation that my pain was most probably coming from my Pudendal Nerve (yes, a name, I had a name!). It took another 15mins for her to put me in on my back (I never lay on my back as it was too painful) and apply a pressure/postural technique that switched my pain off! (Yes, OFF... calm, silence, stillness, roar gone, no spasm, quiet, peace)... unbelievable but this is true.

I won't go into much detail about how I felt, there really isn't any way of explaining the relief of having a roaring pain that's been halting your soul for 4.5 years, identified, clarified, acknowledged, manipulated with a single finger's pressure point. I can't explain how it felt to finally know (not hope or dream) that I will eventually become the best I can and that I finally found a practitioner and therapy that was going to help me. I could almost see my issue in the palm of my hand (before I was in limbo and had to come up with my own names, I won't write them here!!).

What I will describe though, is the language, empathy, understanding and thorough explanations that I have had during my appointments so that anyone else in the same situation will know exactly where they need to go (Actually I'd be surprised if you were still reading! *Taxi!! Physiotherapy Department, 1st floor Grattan Street & Flemington Road Parkville VIC*).

**My conversations have gone something like this:**

**Me:** *I haven't told anyone this but there's this short denim skirt I have and whenever I wear it I have a less painful day...*

Physiotherapist leaves and comes back with a pregnancy/baby pressure belt that is adjustable either side. *Et voila, a support for the pelvis adjustable to my requirements which was not so tight over my implant and uninjured side.*

**Me:** *In winter, I'm sure it hurts more to walk because my boots are heavier than shoes and I'm wearing a heavy coat.*

**Physiotherapist:** *Yes, weight is pressure for the nerve.*

**Me:** *I'm on fire today, I have all this burning, like fireworks going on.*

**Physiotherapist:** *lies me prone, applies pressure to a pressure point, fire put out instantly. This is a flare up.*

**Me:** *I feel like I have my finger stuck in a power point, I have a surge up my spine, the rattle of a tram or car drives me crazy, and don't scare me or I'll drop, my legs get weak and I can't move...*

**Physiotherapist:** *Sensory pain.*

**Physiotherapist:** *How is your pain now?*

**Me:** *My pain is good now.*

**Physiotherapist:** *Laughs... but doesn't really find this funny. Pain is never good.*

So now when I have a physiotherapy appointment, instead of blank stares when I attempt to describe the fine details of my pain and activities I get clear descriptions for every point I make, in fact I even get a diagram and descriptive explanation, drawings referencing my insides, url links, and best of all, solutions in the form of techniques to release my pain, positions to release my entrapped nerve, even my husband gets attention, empathy for the difficulty he endures, he is shown the pressure points and techniques so he can help as accurately as possible (therefore finally finding peace for himself!!). I even had an explanation about my extracted ligament and septum, she'd seen it happen with trauma (pregnancy or birth) to the hips.

Finding this wonderful therapist leaves me in a very positive position too. I never had options before, I was told: *go home and make yourself comfortable*, but now I can calm my pain and I still have further treatments to explore depending on how I progress and this is thanks to the few specialists that have insisted on researching and learning about peripheral neuralgia and not ignored it leaving it a *psychological condition* or the more general *we don't know with back pain*.

(Documentation ends for now, on January 31, 2012)