

My Back Story by Barbara Ford-Hammond

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Introduction

My Back Story is the story of my back.

If you feel so inclined you are invited to join me on my journey where we will go to some dark places and maybe some light but no promises.

It contains swears where appropriate, bodily functions and the present time is March 2016. I time jump as you'll see.

All doctors, consultants and surgeons are represented by their initials.

Everything here is my personal experience and findings. Nothing is medical advice.

October 2012

You may or may not know that in times of yore I was a poorly dollop and needed surgery to mend my back. Quite a lot of surgery. More than once. The last one, in 1991, was a Transpedicular Fixation of the spine at L4, L5, S1 – I am sharing this information for those who want nitty gritty.

This is a magical operation whereby the surgeon, DH, put screws into my spine and attached rods in-between them. Mostly all was good in the lower back department. Twinges, niggles and random spasms occurred but were manageable. My husband and smalls are marvellous and helped whenever it was needed. About 13 years ago I had an 'episode' whereby the disc above the operation prolapsed. But, after various interventions by AQ, I managed to avoid further surgery and was back to it. Until now.

Just over a week ago, in the blink of an eye, a spasm occurred and instead of easing away it got worse. Then worse still. By the weekend I was unable to move normally and moved around slowly with words falling from my mouth that I didn't know I knew! I was reminded of the pleasure a growl can bring about.

My tummy knotted into a nauseous ball when my lovely doctor, HB, said, "I think you have a prolapsed disc or discs in amongst your metalwork. I will get in touch with the hospital where you had the operation and we'll take it from there."

Time

After my visit to the doctor, which was in itself a challenge because to move at all took psyching up and much planning. Sometimes I moved my legs and winced, other times it's not so bad. Part of the added stress is the not knowing. Will I or won't I need to growl? Will I get stuck?

The doctor was most sympathetic and insisted I would be seen within the week at the hospital where I had the previous operations carried out.

Tick tock tock tock. Managed to wait until Thursday before calling the hospital to discover that the referral letter had been faxed that morning. Faxed...

Through creative questioning I discovered who was the best person to call at the hospital only to learn of the many steps before a patient gets within a sniff of an appointment.

From the first contact the steps are: receive letter, review to check secret code of urgency, best consultant for the job is picked, consultant's secretary receives letter, it is reviewed, secret code of urgency is discussed, best consultant for the job agreed or changed, if changed throw a six and start again – do not pass go, if agreed code again discussed and when the planets align the letter is sent to the patient for patient to call to book appointment.

At any stage the notes can be lost in translation. In between each stage everything floats about in a limbo world where space and time become dark matter. We know it's there but can't actually get hold of it.

Average wait from initial contact is 12 weeks, 6 if special, fewer if deemed really urgent. If patient hasn't heard within 2/3 weeks they are welcome to get in touch. 18 weeks is the magic number to have started in a process. Average time to begin to 'be in midst of being sorted' in one-way or another is 4/5 months.

It is hard to be cross with anyone as everyone is charming, honest and as helpful as they can be. The system however, sucks. Advice given, often – if really in a pickle go to A and E.

Or, phone private clinic and book an appointment to be seen in a week. It comes down to how much is the value of time?

I arranged and saw AQ, yes, the same one as before. He suggested injections into facet and sacroiliac joints under sedation. While sedated the patient is with it enough for the surgeon to know they've hit the spot/s but patient has no memory. Some refer to this as having twilight meds. Duly done as a day patient I hobbled home to recover. Some bits felt much better but others didn't. When I

saw AQ after and explained this he bizarrely asked me how brave I was and then said, "You're a hypnotist aren't you? Remove your clothes that are covering your lower back, lie prone on couch and I'll be back in a minute."

True to his word he returned armed with some loaded syringes and proceeded to inject my tender bits. Ouch, is all I have to say about that. He kindly repeated this twice more with the last being on Christmas Eve. My back was healed to a point of management and life returned to some semblance of normality and I was well enough to swim to the 'Rock' in Skala Eressos in the summer of 2013.

Giddy Up

I left you in the summer of 2013 and we shall now jump to almost two years after first seeing AQ, to September 2014. The twinges had been flaring on and off through the summer but bearable until the moment when deep inside you know you're fucked. Those old familiar pains and a deep gnawing ache accompanied by spasms and the inability to sit, stand or function normally.

After waiting to see if it would abate, while knowing it wouldn't, I saw doctor HB. He was concerned and said we should maybe get organised and refer directly to an orthopaedic surgeon. He phoned the following week to check on me and continued to call to gauge my ... not sure what; pain levels, rage, murder capabilities. All the while things were deteriorating in a scary manner.

Personal alert - you have been warned - I developed dribble incontinence. This is when you have a wee but you cannot empty your bladder until you stand and then out it flows. Seems you cannot have a front problem without the back joining in and I started to have soiling from my bowels. This is embarrassing and scary.

Doctor HB called as usual and when I told him he said, "You must go immediately to hospital in case you have Cauda Equina. I shall organise an ambulance."

Cauda Equina Syndrome is a serious condition whereby untreated it can cause permanent paralysis. I told doctor HB these issues hadn't got worse and his thoughts were that at least I'd be there getting treated. I was frightened and said I didn't want to go by ambulance. He replied was that he was on his way. When he arrived he tried to insist but graciously gave in and said I could be taken by Mick and he would phone to ensure they were ready. He called the hospital immediately and spoke to several people. I heard him because he was next to me on the sofa.

I thought about nut-shelling here but decided to share my experience in full technical detail. You probably won't be surprised to learn that no-one was expecting me but I was duly put in a cubicle and after a bladder scan and 2 different doctors examining me and putting their fingers up my bottom - not at the same time - they decided I probably didn't have the dreaded horse-tail condition (cauda equina literal meaning) but they would admit me after I'd had x-rays and I'd get an MRI the following day.

One of the perks of being in hospital is that they happily pump in the drugs. Princess Morphine soon became my favourite and they plied me with an array of other meds. I was too high to remember now what they were. I just said yes please to everything on offer. This was a blessing as I was in a 6-bed ward with 5 very old ladies with an average age of 90. Old ladies do not sleep and the nights are as noisy as the days. One lady kept asking how to escape and seemed to think I'd help her.

Anyway, moving on, in the morning, and after no sleep despite all the meds, I met a grumpy abrupt consultant; again, too high, too scared to remember his name. He said, "And what brings you here today dear?" You want me to say I slapped him don't you but I reigned in my anger (morphine definitely helps with that) but before I could speak he said, "It's a mechanical issue but I will check with an MRI."

Lying completely flat in a tube of metal is not something I would ever choose to do if given the option and by the time it was finished I was in tears with pain but the radiologist, nurse and porter helped ease me into a wheelchair and back up to the ward. Escape lady was thrilled as she was sure I'd returned with a cunning plan and knotted sheets.

As you may remember I have the lumbar fusion and nothing could be seen on the scan because of the interference in the magnetic resonance and I had to go for another MRI with a higher calibration. All I could think to say was "Give me drugs." They did.

Okay, back in the tube and I felt a sensation of warmth. Now, I know they can get warm but I got hotter and hotter and I pressed the help get me out of here alarm. I told them it was too hot and the radiologist did that voice. You know the one - patronising because I'm too dense to know heat when I feel it. We agreed, after they assured me I wasn't being cooked from the inside shish-like, that they were almost done and I'd let them finish. Clearly, he too was scared of Grumpy.

In the evening a scary nurse appeared and said I could go home and doc Grump had said he would see me in his clinic as soon as possible to make a plan. That was not going to happen. Happy at the prospect of home I got out my phone to call Mick. Scary nurse was not impressed and said she meant in the morning. That also was not going to happen.

This time my voice found its way out and I insisted that if I was being discharged it would be immediately and at home I'd be able to sleep. She huffed and puffed muttering away to herself that she'd have to locate a doctor to sign the form. I smiled sweetly and said, "okay."

I felt sad to leave escape lady and hope she found a new partner quickly.

PS. Mick did some research and discovered that back in the early 90's stainless steel was used for my fixation and that an MRI at a high magnetic calibration could heat up the thinner wires...

The CS experience

Part One

This time I called the GP surgery and spoke to PW. I made it clear I had no intention of seeing that consultant again and perhaps I should try some pain management. Where we live we have the 'Choose and Book' system and I chose and he booked CS at the nearby private hospital.

CS was charming and I was admitted at the beginning of December for some magical SI injections under sedation. Their magic was short-lived and because I wanted to visit Charlie and family (a whole other story that involves 4 grandsons and RAF posting to Cyprus) doctor HB injected local anaesthetic into some trigger points to keep me going. He did this for 2 weeks running. I managed to go away and went back into hospital mid-January for more injections under sedation. These were repeated in February.

Again, not enough relief and with pain developing more and more and an added problem of my right leg giving way CS suggested sacroiliac nerve denervation. We decided that although I was not 100% I could go to Cyprus beforehand and we planned a visit to Cyprus followed by a few days in Crete to arrive back the day before the treatment. While in Cyprus I felt a flare-up coming on. Knowing that if I let it get full-blown I'd a) end up in bed, which is no fun and b) we'd have to cancel going to Crete and go home if I could even manage to get on a plane.

Being a brave girl I told Mick I needed to go to the private Polyclinic in Limassol to try and get some trigger point injections to stop it developing. He knew I wouldn't inflict the embarrassment of saying that unless I was a mess.

When we arrived I asked if there was an orthopaedic surgeon who could do the injections. After a short wait a wonderful surgeon, SC, appeared - the hospital had called him and he came to the hospital just for me. He examined and then while lying on my back he pulled my left foot towards my thigh and pushed down on my knee. Well, talk about seeing stars it was excruciating. He then did it on the other side. He then gently said, "You have sacroiliac joint dysfunction."

You what? I have to go all the way to Cyprus to get a diagnosis? WTF! No, really, wtf. In an instant he said what we'd thought was a possibility.

He organised some strong painkillers and said he'd contact an anaesthetist, MJ, who could help me as he didn't do the injections. While we waited a nurse appeared with the painkillers. Not pills, oh no, a huge dose of liquid Tramadol was injected into my bum cheek. I went very Alice in Wonderland; the ceiling was moving while I watched giant bugs floating about - it was awesome.

The stunningly beautiful MJ appeared and said she could help and that as there was no-one waiting for operations (she'd just finished and was expecting to go home) we could use the recovery room to save the cost of a theatre.

She found about 10 trigger points and with drip in and painkillers flowing into my bloodstream, yes more, she proceeded to inject local anaesthetic. She added some steroid to the last few and went in a bit deeper when all was numb to help calm the SI joints. Total cost for afternoon in hospital, all meds, her fee plus her assistant came to €90. What a bargain. Her magic kept me comfortable for the rest of our stay and the few days in Crete.

Back home, then to the hospital and under sedation (the magic words) an instrument that resembles a crochet hook is inserted into the nerve, shish-like and it is microwaved. Be careful, not only for what you wish for but also with your words.

For a few days after I thought a miracle had happened. Although a bit tender I felt so much better. Then the anaesthetic wore off and I was in a desperate state with the problems I'd had before the procedure but now 2-sausage size and shaped burns inside my lower back. I know this helps some people but for me it was hideous and I felt assaulted. The pain was so intense and I was a wrecked. One evening, about a week after, I felt nauseous with pain. I left the sitting room to go upstairs but when I got to the bottom of the stairs everything became so intense that I didn't know which foot to move to get going up. Mick appeared and I tried to explain through my tears of pain, frustration, anger and fear and then I fainted. The time after this is a blur and during the months that followed I fainted a few more times. One time I was sitting on the sofa and then woke up on the floor sporting a carpet burn on my cheek (not in a good way).

Now, pain faints are odd. Sometimes you get a warning whereby everything goes a bit whooshy and distant. If you are aware of this you might be able to get down quickly and raise your feet. At other times there is no warning and the first you know is the waking up stage. Coming round is always scary and confusing.

The review after nerve denervation is 12 weeks and when I hobbled in for it I was wrecked. By now I had to use a walking stick and was physically and emotionally drained. I had nothing left. I was then furious with myself because I cried when explaining to CS how poorly I was and in that moment I knew he had labelled me as a neurotic.

CS decided he'd emptied his toolbox and suggested I talk with a psychologist. Sigh. As I left his office to head towards the door I felt a stab of pain and the feeling of swimmy. I have a vague recollection of a nurse asking in a far-away voice if I was alright. Apparently I was not and I found myself waking up on the floor of the hospital corridor with a crash team and medical staff totalling 12 people. Even lying down I could feel myself coming and going and my head was

cradled by a wonderful nurse who kept reassuring me while she stroked my hair. Someone tried to get a cannula in my arm but the blood was pumping and then I heard a male nurse ordering everyone about and he managed to put one in my hand.

As luck would have it he was on secondment from a hospital with a busy A and E department and took charge in a manly yet slightly camp way. He was theatrical and funny and I felt safe in his care. He was furious that the blood pressure machine was broken when he checked the reading so called for a cuff so he could do it the old-fashioned way.

The machine wasn't broken and my blood pressure had gone to 230/110 from the pain. Well, that is dodgy and I was taken up to the ward for all sorts of tests. They put painkillers and bring down the BP meds into the cannula. Nurse Camp was fantastic and I am so grateful he was there. He was multi-skilled and even got a pot of tea for us.

When BP was low - usually too low - really I'm all over the show and when the meds ensured the pain had reduced enough I went home.

This sorry episode had used up another year.

The CS experience

Part Two

I received a copy of the letter that CS sent to my GP. He covered all his bases and I am sharing the letter I sent to Doctors HB and PW and expect you can work out what his had said.

Although I had intended to not discuss Doctor CS's letter I have decided to address a few of points.

When I went to see him I did not take any medication to ensure I was quite lucid; hence the severe pain by the time I got to see him.

He said he had reached the end of what he could do and that he would be happy to refer me for a second opinion to discuss surgical intervention. His words. Not mine. He mentioned firstly a spinal cord stimulator but I reminded him, again, that I do not get sciatica type pains in my legs. He then suggested psychological help but, as he pointed out, for me I did not think that was the answer.

When I called his secretary to ask if he had sent a referral for another opinion she knew nothing and said it had to be by the GP. However, I received a letter for another appointment with him, which I cancelled.

He was witheringly dismissive about the medications prescribed by doctors who have known me for years (you and yours). Repeatedly saying they did nothing and were of no use.

The faint was from pain, has happened before and he knows this. To imply my state caused it is misleading. I keeled over in the corridor from pain and the next thing I knew, when I opened my eyes, I was lying on the floor with about 12 people standing around. At that point, yes, I was very upset. Who wouldn't be?

For someone unsupported who doesn't have the wherewithal to seek further help or have understanding local doctors his words could be devastating. I am not dismissing his work (just his opining) - I had some relief from the earlier injections.

I am in the fortunate position of not having to put up with his dismissal as the final word. It is not my fault that he has reached the bottom of his tool box. I take full responsibility because I requested him and asked you to refer me.

I returned to the GP and saw lovely lady doc PW. She understood me and said she would start the process of a referral. I was back in the waiting game to end up at a place where I might or might not get help. It was a touch deja-vu.

By now I had researched to the nth degree everything to do with the sacroiliac joints and found answers to many questions. Some of the questions I didn't even know I had. Too much research was often terrifying but generally people are most helpful when sharing their own experiences.

Historically my left side has always been worse and often felt like the bones were grinding. When the right side flared up I assumed it was in sympathy - seems not so. If one side moves too much or not enough it affects the other. My right side would feel as though everything was separating and then, as I mentioned before, my leg started to give way. Hence the walking stick.

Even with all the injections I still had the bladder and bowel issues. Mick and I talked and talked and talked some more about what to do. Together we decided to get an expert opinion and we independently researched. When we shared our findings we had come up with the same place, team and consultant.

I phoned GJ who is SJ's secretary and she said I could go the following day and that SJ would begin his afternoon clinic a bit earlier. All we had to do was work out how to get me to Wales. Yes, Wales...

Wales

Off we went with many meds, many pillows and many miles later we arrived at a rather splendid hospital. I was nervous about what SJ would say but had decided that I would abide by whatever he suggested. I had x-ray and MRI images and when he saw them he told me what was wrong. This invoked relief coupled with a rather lovely feeling of trust. He knew his stuff and he 'got' me.

He said, "We always have 3 options - ignore, stab or cut." Despite my unhappy ending with CS he had provided me with diagnostic injections or stabs in this context. As I had ran out of managing I couldn't ignore so we went with option 3. He did a rather fantastic visual explanation of the procedure that would involve using screws to secure the bones and demonstrated using a model of a spine.

I did not technically have SIJD - it was called Failed Back Surgery Syndrome or failed back. My lumbar fusion screws and rods extend down into the sacrum and this prevents the natural pelvic movement.

The fusion had been in place for 25 years but it's very action or non-action had caused my problems. SJ's preferred method is one side followed by the other after about 6 weeks. He said which side I had done first was my choice and I could make the decision on the day.

I went home to talk and talk and talk some more about which side to do first. Historically, the left had always been worse but it was my right leg that gave way. I could make a case for either side - I can with most things but I chose the left to be done. A couple of weeks before the surgery I had a thorough pre-op assessment and on the day before I went for bloods referred to as 'Group and Save.' I put a lot of tension into things and this was one. Not the actual blood being taken: no issues there I am a blood donor and can watch needles going in without reacting, it was my mind association of the operation being referred to as 'major'. Since previous op every procedure had been as a day case - minor.

Anyway, on the morning of the Monday 26th October 2015, I was ready. By then my state of mind was irrelevant it was about being smooth-skinned and having nicely shaped nails!? I know, it's a girl thing. However, the compression socks do go on a bit easier on smooth legs.

Your social diary is chock a block when you go into hospital. You are taken to your room and shown the bathroom and pull cords in case of need followed by the nurse who admits you, the host/hostess with the menu, the anaesthetist who drugs you and the surgeon who cuts you. By now the butterflies were hysterical, flapping about in disarray with no hope for calm. Eyes on the clock, trips to the loo, trundling trollies and a little voice reminding me I could leave and then in floated the theatre nurse to collect me.

Lying in the little room next to the theatre everything happens at once. Sheet over to protect modesty and for theatre staff to not laugh in front of the patient at

the paper pants and bra (yes) I had to slip my arms out of my gown to get ready for easy flippage. The anaesthetist put on a tourniquet and slapped my hand a bit before slipping in a cannula. I felt nothing and that is the moment of surrender. To say, "Stop, I'm going home" would be silly. And then it was sleepy-time - I felt myself drifting and when I opened my eyes it was all done and I was in the recovery room.

I realised immediately that I couldn't move my left leg and it felt like a dead weight and did so for about 48 hours. For the first 24 hours I was confined to bed along with all the fun a bedpan entails when you can't move much and with a non-working leg.

As the feeling returned in my leg the top of my foot began to feel strange but when you consider what had been done it's reasonable that the nerves would complain. Something briefly commented on before my first ever operation and never talked about since (even I had forgotten) is that I have an extra bit of bone on the top-left of my sacrum which made my pelvis even more uneven. SJ explained that he had put in 3 screws to accommodate this. I stayed in the hospital for 5 nights and was treated like royalty. There was a steady supply of painkillers, delicious food and hot drinks whenever desired.

It's a strange phenomenon when you're in hospital in that you don't know you're hungry until you hear the trolley coming and then you aren't sure if it is food or pills rattling your way. Either was welcome - I think it's because as a patient all you have to do is heal. Everything else is done for or to you. I was on crutches and would be for 6 weeks and had to wear the sexy socks for the duration. Every day a nurse washed my feet and legs followed with a massage and I felt well cared for.

Pain meds turn into a cork that plugs up your bum and despite laxatives there was no movement and I had the threat of a suppository on Friday. Luckily at 4am that morning we had action and I'm sure I heard the Hallelujah chorus singing. My reward, apart from the relief, was tea and biscuits. Travelling home was a bit of a challenge and I had to lie flat in the front with pillows aplenty but we made it and Mick took on all nursing care including sock duties.

The skin sensation on the top of my left foot became more painful and I developed stabbing pains in my foot and the outside of my lower leg. I thought it was part of the healing and put up with it until it felt like raw burnt skin and became unbearable. Back to Wales for 2 MRIs: pelvis and lumbar spine. This meant head first and then feet first. The news wasn't good. The top screw was pressing on my L5 nerve root and had to be removed urgently so back in I went on the 19th November for SJ to remove the screw and squirt in donor bone graft. Firstly; I am grateful to the person who carried a donor card so I might make use of harvested bone. Secondly; I never saw this experience as a fail. SJ and I

discussed all eventualities beforehand and he felt it was important to add a top screw to help where my sacrum had the extra bone. The result was a win because he had a perfectly shaped hole ready for the bone graft.

Pleasingly I was allowed home the following day to heal and recover and started again on the 6 weeks crutches and socks regime.

The healing process continued but all the while my right side became more painful. SJ had said I should get in touch when I was ready to have that side done and I made the call in the New Year. 18th January 2016 was the day and by now I was an old hand. This time it was a whirl of activity as I was first on the operating list. Gulp, no clock-watching. I'd just donned my gown, paper pants and bra when it was time and off I went for the 3rd operation in 12 weeks. You can imagine my joy when, expecting to be in for 5 nights as before, SJ told me I could leave the next day. He said I knew what to expect and he knew I'd prefer to heal at home.

Here I am 6 weeks later. Driving, down to one crutch and practising without and... drum roll... no back-pains. No aches. No burning. No spasms. Nada, zilch, sans misery.

The result is better than I ever hoped for. After so many years of sometimes coping, mostly not and several fails I am constantly smiling to myself.

Pain

Sacroiliac joint dysfunction/syndrome/problems or any word you wish is ghastly. For many years I had deep, heavy aches in my lower back. I would get spasms that took my breath away and made me want to fall to my knees. I had one particular pain that I called the claw. It was as if a bony skeletal hand was pressing on the right side of my back gripping my side with sharp claws attempting to pierce my skin at the front. After the first op this never returned and the incontinence and soiling issue was also resolved.

Asking to describe the pains I would say - well - they can be metallic, wooden, electrical, sharp, stingy, blunt, burning, raw, forceful. They could be in any combination. It hurt to sit, stand, walk or lie and every time I moved when in bed I awoke.

Chronic pain is a challenge for everyone because life revolves around it and it defines who you are. Would I or wouldn't I be alright? Would we have to leave wherever we might be? Despite having hypnotic tools at my fingertips I still needed bucket loads of pills to cope. However, if I didn't have the hypnosis knowledge I know I'd be, at the very least, an opiate addict.

I have never been suicidal but chronic pain, when there is no respite on the horizon, takes you to very dark places as it's hard to foresee a future. You become an expert liar rather than honestly report how things are when asked and avoid contact with everyone outside of the home in case someone asks. The tiredness hurts every cell and moods can swing from rage to tears and back in an instant. I have the love and support of my family and friends. Fuck knows how anyone copes without such support.

Bowels

I discovered that when you start to 'go' after a few days (or more for some unfortunates) it becomes easier if you can raise one or both knees towards your chest without twisting your pelvis. It doesn't matter what you look like, no-one can see you. The position we adopt on toilets is not really the best for emptying. Squatting is the best and lifting knees helps shift everything. This is not medical advice, just shit I learnt - ha do you get it?

Trigger Points

Myofascial **trigger points**, also known as **trigger points**, are described as hyperirritable spots in the fascia surrounding skeletal muscle. They are associated with palpable nodules in taut bands of muscle fibers.

https://en.wikipedia.org/wiki/Myofascial_trigger_point

Highly Recommend

<http://www.nuffieldcardiffandvale.com/>

This is my beautiful pelvis.

