

I had Harrington rods fitted in 2010 after surgery for a spinal cord compression injury at T10-T12 worsened an underlying scoliosis. The minute I had the Harrington Rods fitted I was in constant pain. I went back several times to the surgeon that year and was given loads of reasons as to why. You are too thin (I could actually feel the heads of the screws through the skin between my shoulder blades). You are imagining it. You are doing too much. You name it, he gave it! I put up with it for 4 years and then finally revisited my surgeon for the last time. He literally laughed at me (yes he really did!) and told me my memory was "playing tricks on me" and I was in worse pain before! He said if he removed the metal work, my spine would collapse straight away. So, after a somewhat (4years) protracted "recovery" from the surgery I had to admit defeat and take early medical ill health retirement from teaching and because I retired very early was left poor, in constant pain with a very limited life. I rarely went out as each day was a herculean task just to get up and manage basic tasks. By 2pm, my day was done and all I could do was take more pain relief, lie down and rest. I was in constant pain and felt drained all the time. A teacher's charity donated an electric chair but the area where I live is so bad for wheelchairs that it was a dangerous experience using it outdoors! I got a Canine Partner in 2011 who changed my life. She helped me with daily tasks but most of all she encouraged me to try walking again so I could take her out. Among many tasks she would get my phone, bring her lead and dog coat, empty the washing machine and press the Lifeline button if needed. At the end of the day she would take off my jumper and socks when needed and generally let me know she was there for me! We managed some really bad times together.

In 2014 through my incessant research I stumbled across the name Rebecca Dutton. www.melisa.org She proved to be an inspirational drive towards getting my needs finally met. She kept in touch with my progress and encouraged me to check my metal levels through the Melisa foundation. That was a real eye opener as the blood results showed that I had become highly allergic to Nickel and had very high levels of certain metals in my blood including cobalt and chromium. The pieces of the puzzle finally began to fit together. Earlier that year, I had experienced some very frightening yet, up until now, unexplained health

difficulties. On one particular day a few months ago I had visited my GP after a bout of very unpleasant symptoms beyond my existent obdurate pain. Much to my horror, after a quick exam, she immediately called for an ambulance. My heart rate was extremely rapid and along with my other symptoms she could not rule out an aortic aneurysm. Once at the hospital I was seen urgently. An aneurysm was excluded but I was sent for an urgent liver scan. The result showed cysts on my liver, the detox centre of the body, and significantly enlarged ducts in my pancreas. I spent the next few weeks on a treadmill of specialists, ruling out all sorts of nasty and frightening differential diagnoses. Finally I was deemed clear of cancer or heart issues yet my symptoms and scans remained unexplained. Had they seen these blood results I'm pretty certain an answer would have been more forthcoming. At that point I noted on the Melisa website that so many people were suffering with the same symptoms as me (burning in groin, leg pain, numbness, etc.) after having Harrington rod implants. After a lot more research I found a very open minded and skilled orthopaedic surgeon at the Spire Hospital in Bristol called Mr Harding. For the first time in 8 years a surgeon actually asked *me* "What do you want to happen?" I told him and he said there was a 10% chance of my spine bending again. Ten per cent! That's a 90% chance it won't! So two weeks ago I finally had the Harrington rods removed. (from T2 -L2) The intervertebral cages were non- removable but most of the metal work has finally gone!

It's very early days but already the burning in my groin has mostly gone and my legs don't burn and fizz any more. Its true, its painful to walk right now but its only 2 weeks post op and there's a lot of bruising internally no doubt (my backside was literally blue for a while!). If I can overcome my naturally impatient nature I know that I am heading for a better future. Living in constant unremitting pain is a real @@@@. It affects not just you but your family too. My son was 14 when I was first injured. By default he became my carer and our active lives ended overnight. Gone were all the sports and adventure holidays and a happy chilled mum. Much to my shame pain made me snappy at times. He was a scholarship child but ended up pretty much studying from home instead of going to school as his role was so exhausting. He then became ill himself - the

stress triggering an underlying genetic problem. It was just too much for him to see his active mum so disabled and in so much pain. It took him several years to get fit and well again and catch up on a missed education, enabling him to get the qualifications he needed to pursue his dream. He is now finally starting a new career with the police. Constant pain can affect your psyche too and can drive you to dark places on a bad day. Unless you've been there it's hard to explain. Add an unsympathetic surgeon into the mix and it's intolerable. I still have some pain (my cervical discs were damaged by the metal work) but on a scale of 1-10 it's now about 3 (it used to be about 50).

Mr Harding made a cut top and bottom rather than along the whole spine and the wounds have been painful but its post -op pain and I can bear it as I know it's limited. Even now in these early days I don't feel so constantly exhausted and unrefreshed after sleep like I used to. For the first time in 5 years I was able to sleep on my side! I'm glad I made the decision. I was terrified as I hate hospitals now (I've had six spinal ops in my life). However it was without a doubt the best decision that I've ever made.

My advice would be if, like me a few weeks ago, you look ahead in your life and only see pain, be as proactive as you can. Don't take no for an answer. Be a tigress and fight back. Best of all find a stronger tigress like Rebecca Dutton to help you through. Julia Glendinning of The Melisa Foundation is another tigress that is out there for you. I was openly laughed at when I wanted it removed. I accepted it for 4 years and then fought back and thanks to Becky's encouragement, found a more skilled orthopaedic surgeon. The Melisa Foundation is full of stories just like ours. Do have the Melisa test. Your blood results may well shock you into action (like mine did). The surgical implant field appears years behind in terms of **recognising** and **understanding** the **implications** of metal allergies on individual health and well-being. It is my firm belief that **everyone** should be tested before surgery. Goodness me if I want highlights applied **externally** at the hairdressers they insist on a patch test **a week before** going ahead! Yet some of us have to accept as much as several feet of metal work fitted **internally** and can only cross our fingers and hope we don't

have any allergic responses! My first surgeon didn't have at his fingertips, the necessary knowledge of or immediate access to, the exact constituents of what he was implanting into my body! It was only after considerable pressure from me and an educational email from Julia Glendinning that he finally agreed to check with the manufacturers' on my behalf. (manufacturers don't appear to respond well to patients' requests) Interestingly, Mr Harding checked straight away for me before he removed them and ensured that I was not exposed to nickel during surgery. I still have some metal work (cages) in my lower intervertebral discs but again I was assured that they were not nickel based. I was advised that the Harrington rods were titanium alloy based and no nickel was apparently present (other than possible cross contamination in the factory) What cannot be explained is why I went on to develop a severe allergy to nickel (before the implants, I was able to wear nickel – based jewellery with no ill affect) and why the levels of cobalt and chromium in my blood were so high. It remains a mystery (I sadly wasn't able to keep the removed rod for testing which may have provided some illumination). However I'm going along with my printed blood results. They speak for themselves. I clearly have been exposed at some point. My liver, heart and pancreatic symptoms likewise, clearly suggested something was off key in my body. I am also going along with my pain levels and degree of neuropathy now that the Harrington rods have been removed. I'm finally able to begin to plan for a future that isn't deluged in pain.

I wish you all the greatest of .. not luck, no ... I'd like to say .. tigress power. Believe in yourself and what your body is trying to tell you. Don't be fobbed off like I was for years. If you, like me, have had to deal with unbearable pain then the chances are something isn't right and may be fixable but you will need to find the right surgeon for you-most importantly one who **actively** listens! Best of all know that there are several tigresses already out there, willing to fight your corner. I owe a great deal to Rebecca Dutton and Julia Glendinning, as does my son who now has a user-friendly mum!

God bless to you all. I really do understand what you are going through and my heartfelt prayers are with you.

Mandy