

Creativity and Pain Relief

A few years ago I underwent bilateral hip replacement to correct a condition called congenital dysplasia of the hips. Whilst leading up to the operations (or what is known in patient terms as 'waiting time') I bought a book called *The Artist Way* by Julia Cameron – a course in discovering and rediscovering your creative self. I did this mainly to take my mind off sitting with my pain. I am also dyslexic which is a different kind of pain in a sense – the pain of written communication problems.

The Artist Way course included writing journal pages for three months and taking on various tasks. Looking back now, I see it was a way of changing my behaviour patterns and broadening my experiences.

A strange thing happened, I began to enjoy writing and found that I was able to off load my emotions and have written disclosure of how I felt. I firmly believe that this had an impact on my later recovery and possibly helped me to heal physically and emotionally.

After going through traumatic surgery I suffered nerve damage and a resultant left drop foot. I was immobilised after the operation and had to lie flat on my back for two weeks. I remember waking up one morning and feeling as if my left lower leg and foot had disappeared! My foot felt like it belonged to someone else but at the same time I could still feel pain in it. In fact, it was the worst pain I have ever experienced and would not fit on any measurement scale.

My foot didn't feel part of me. The pain was intense and strange in that I wasn't able to recognise it within me. At first the doctors told me that this sensation would disappear as I became mobile and I despaired because I wasn't able to make them understand that I felt as if my foot had disappeared. I was later diagnosed with complex regional pain syndrome (CRPS) – you only need to insert an A into CRPS to understand how I felt. I had undergone traumatic surgery in order to correct a congenital disability I'd lived with for 37 years only to discover I'd developed another, more sinister, 'incurable' condition. This was devastating news and I felt guilty because I'd reassured my children and friends that I'd be OK after the hip operations. Now it was intensely painful even if they came near my leg. I was angry, but after feeling sorry for myself for a while I became determined that I would find a way to recover.

I realised I had to quite literally pull myself together to re-establish the connection between my brain and foot. I believe developing my creativity helped me do this.

I continued my daily diary writing but after my second hip replacement (when the CRPS and drop foot developed) I also began to do little drawings mainly to try and show what my foot felt like internally. I needed the medical staff to believe me and I needed them to know

exactly how my foot felt to me. Looking back on these drawings, I can see that they are not very well formed and that I was expressing the feeling and sensations that were occurring. In other words, my foot drawings did not LOOK like my foot but were an artistic description of what my foot FELT like to me.

I felt I needed get to know my foot from the inside as well as the outside, so I bought a 'colouring in' anatomy book. I used this new knowledge to help me focus on the damaged nerve. I would imagine moving my foot and feel it moving in my mind. I can remember having a nerve conduction test which showed no activity at all in the nerve, so I tried imagining moving my foot and the machine used to measure activity buzzed which surprised the doctor doing the test. He told me that whatever I was doing seemed to be having an effect, so I carried on visualising and imagining movement.

As part of getting to know my foot and becoming re-attached to it I needed to learn to love it again. I stroked it, massaged it and treated it with aromatherapy foot baths until it no longer felt like a detached spare part I hated.

I began to introduce more form into the drawings so that they resembled more what my 'missing' foot actually looked like. These drawings helped me to 'see' my foot as MY foot, as BELONGING TO ME. I also discovered the Rosie Flo children's colouring books by Roz Streeton (www.rosieflo.co.uk). These consist of outlined drawings which require the 'colourer in' to add heads, legs and arms to the characters. I believe this all helped me to 'normalise' my body awareness.

Taking photographs of my lower leg and foot played a big part in this 'attachment and feedback' programme I developed. These photographs gave me more normal, visual feedback. Linked to this I placed a mirror beside my bed and would look at my feet in this mirror first thing in the morning and last thing at night. I felt that the connection between my brain and leg needed to be re-established and that repeating these tasks was the best way to do this.

I also read and researched through many books building up a map of knowledge and understanding of my body and it's anatomy. The book which stands out is one entitled *The Feeling of What Happens* by Antonio Demasio – it struck many a chord in my mind and I was able to make connections with my own situation and gain a better understanding (see *The Mapping of Body Signals* on p149 of the book.).

As a result, I tried out various ideas which included following my own programme of exercises. I concentrated on bilateral, automatic, rhythmic movements in which my foot activity was part of a larger, pattern of movement.

I began with crawling which was difficult for me, because at the age of 38 I didn't know how! As a result of my congenital hip problems I had never crawled as a child so was guided by my then six-year-old son who helped me learn how to crawl properly. Once I got

going it was strange because my spatial and body awareness improved. I then moved on to cross over movement in water with a float around my body to keep me upright.

I had various spatial and body awareness problems to deal with on top of my drop foot, CRPS and pain. My two new hips meant I was two inches taller so I occupied a different place in space. My environment had shrunk and I could see things on a different level.

I had to learn to walk again – before the operations it was more of an ‘as best as I could manage waddle’. A quote by Keith Harrison in *The Fish that Evolved* puts it so well: ‘walking on two legs is just a controlled way of repeatedly not quite falling on your face’. At the start, when friends saw me walking to school they told me that I was walking like I did on a cross trainer so I had to teach myself how to walk properly again. The way I projected myself in space was different and I believe these bilateral, automatic exercises I set myself helped me ‘normalise’ again.

I did a lot of walking with floats in water being constantly mindful that my foot needed to feel connected. Then I moved on to swimming, using a cross trainer and cycling. Interestingly when I first started cycling I was unable to turn left because it didn’t feel as if I had an intact left side and my brain just couldn’t make an attachment to this.

I felt that my brain needed to become ‘attached’ to my left lower leg and foot once more. This was a difficult process because my left foot was causing me so much intense pain. The natural, instinctive thing to do was to detach from it, to try to ignore it. However, my background reading helped me to understand that I had to make my brain attach to this limb and to the pain once more if I was to make a recovery. Plus, I was determined that, having made the decision to undergo surgery to ‘put right’ my previous disability, I wasn’t going to be saddled with another! In fact having never experienced life without pain, my previous experience of managing and living with it helped me through this process.

I built a 3D map of my body in my thought process and strangely as I did this I could actually feel the ice cold, blue pain in my head at the same time as experiencing the same sensation in my affected left foot. Making a *connection* was painful to begin with, but this changed over time.

Using colours in my drawings also helped me to express and distract from this pain as well as track my small, positive steps forward. I believe being creative is pain relieving because it takes the focus away from pain and at the same time fires off new neurones giving the brain a new focus of attention. Writing and drawing also gave me something productive to do at night when the pain kept me awake, although writing poetry had a negative effect so I gave that up.

Today, I have recovered completely from my foot drop and have received the official ‘all clear’ from CRPS. My drawings record my recovery in visual, colourful detail. *The Chronic Illness Journal* has published my story entitled *Moving Out of Pain*. I am working with other patients pre- and post-operatively and am in demand to counsel patients with CRPS. I

cycle everywhere and can even turn left! I can swim a mile outdoors and am on target to be part of a relay team to swim the English Channel before I am 45. Life looks rosy.

Interestingly, doctors who initially didn't listen to my developing CRPS symptoms are now telling me that I can't be cured from CRPS. They tell me it's an incurable illness and that my symptoms are only in remission, that I should expect it to return. In my mind there's no more certain way of ensuring it does return than to believe this..... so I don't!

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