

From one of our new Gold Coast members, Ros



Once upon a time there was a happy-go-lucky little girl who lived in Clifton, a small country town on the Darling Downs in Queensland, and she got polio; acute anterior poliomyelitis they later said. Christmas had gone and it was now late January, 1955 and she was 7 ½ years old.

It was hot and dusty. Flies hovered over the dung on the ground where a few animals were tethered further up the street, but there was excitement because the circus had come to town. That excitement didn't last long for her family though, as she quickly became very ill and was rushed to the Toowoomba Base Hospital about an hour to the north.

Two significant things occurred that final January day. The first concerned horror crashes on the Toowoomba Range with heavy loss

of life and injuries. In fact, six adults and children died and seventeen others were injured that day. There were long delays as many of the damaged and dying were rushed to the same hospital as this very sick child, destined for the isolation wing.

Credit here to the Local History and Robinson Collections, Toowoomba City Library, for promptly locating newspaper articles, (i) reporting the tragedy, thus confirming January 31, 1955 as the date the child was hospitalised. This information will also assist in the retrieval of hospital records, if they still exist. (ii) A further Toowoomba Chronicle article of February 22, 1955 reporting that Toowoomba Hospital authorities acknowledged 8 polio cases for February with a total of 16 notified during the summer period. The child was one of the 16.

Secondly, on its way to Toowoomba, the ambulance passed through the tiny town of Nobby, synonymous with Sister Kenny, but the child was asleep and too young to realise that detail had any significance to her until many years later. In fact, it's logistically possible that, as the ambulance sped on its way through Nobby, it probably passed close to Sister Kenny's final resting place as she died 26 months, to the day, beforehand. In 1911, Sister Kenny opened St Canice's Cottage Hospital in Clifton where she successfully treated a number of polio victims. In 1955, the year the child fell ill, her final book, 'My Battle and Victory: History of the Discovery of Poliomyelitis as a Systemic Disease' was published posthumously in London, UK.

Coincidences, definitely, but these coincidences make me feel a wee bit warm and fuzzy and with health issues predominating much of my life, there has not been a lot of that stuff about the place for a long time so I'll take what I can get.

The child's father was a very experienced and informed ambulance superintendent so diagnosis would have been swift. She cried and cried when the doctor told her parents that she had to go without delay to a hospital so far from her family. Distressed, she screamed that her mother also had to go to hospital and stay with her. To comfort the child, her wonderful mother did, indeed, carry one additional port (suitcase), no doubt empty but effective.

There was never a memory of being admitted only of waking up alone, no mother, no port, just herself in a bed pushed into the corner of a dingy room. There was a large, dark box shape on four legs standing just off to the left which was scary. They came and asked her to get out of bed and walk for them; a strange request she thought but, when she tried to walk, she couldn't feel her legs as they gave out from under her and she collapsed.

Her next memory was of being in a different bed, in a different room with a couple of other patients but only one was in her line of vision. An older, sad-eyed girl who, when their eyes connected, never spoke to the child. In fact the child thought she must be angry at her. Undressed, the older girl was very pale and thin. When the child did risk a look, her eyes could not help but focus on the poor girl's sunken tummy with two pale hip bones, like fins rising up above her body and sort of curving in a bit at the top. Poor girl.

The child's new bed was beside a window that had a type of cage covered with chicken-wire effectively stopping outsiders from getting too close. Might have had her loving dad in mind? I understand they reprimanded him some weeks later because, encouraged by her progress, he had asked if she could try to stand for him to show how well she had improved. And I think she did show him. Mind you, this was the man who years later saved her paralysed old dog, by using his skills over months to get him walking again. The vet had wanted to put him down when he saw him after he had been hit by a car and left to die beside the roadway. Some people, like my late father, are skilled, natural healers.

There are memories of hot, wet grey blankets being wrapped around her body and of people moving her limbs. There was a lot of this. It was almost like Christmas in another sense with presents in her line of vision waiting for her to be able to play with them. Great encouragement to get better for children! There were colouring books and crayons, picture books to be read and there was this rather pretty pink toothbrush with 'things' on it. All these new treasures could not be taken when she left isolation.

The day came when they moved the child to a small room at the end of a ward in the main hospital. A twelve year old girl was in the only other bed and she told the child that each day doctors would come around for her with a really long needle. She had already had a big long needle in her back when she first got sick so she was terrified. Heart pounding, she spent much of each day hiding under the sheets and it was so hot under there.

The wireless was in the main ward and one day she heard for the very first time the most beautiful music that years later she identified as *The Dying Swan* by Tchaikovsky. Each day when it played, she took that music to her heart for comfort and it stayed with her for many, many years.

Lots of times they came for the child, not with long needles, but to take her to a small glass enclosed room in the middle of a main ward. Inside that glass room was a bench and a mushroom shaped pool of warm water and, under the water, was a type of stretcher where she lay down while someone moved her limbs. Even at that age she felt awkward when, naked as the day she was born, she was stood on the bench to be examined further. The glass wall offered no protection.

After the child returned home, she couldn't sleep without the light on for a long time. If she awoke in the middle of the night to find her room in darkness, she screamed and screamed terrified of the night. One day she told her mother that she found a way to go to sleep with the lights off. 'Come and see', she said. There was a bookshelf in the headboard of her bed and there, within the confines of that structure stood one tall white candle glowing for the world. There also was one black, sooty, smoking mark above the candle where the flame had eaten into the woodwork. That didn't work but the child has always been an 'ideas' person even to this day and no homes have burnt down as a consequence.

The child thought fondly of her teacher, as little girls often do, and that teacher wrote her a letter after she transferred to the main hospital. Something to treasure. On returning to school, no matter how much she tried to catch up she was sadly always aware that she fell short of the teacher's expectations. Year 3 was repeated.

Growing up, the child's memory was that she spent three weeks in isolation, one week in the main hospital and at least three months out of school, much of it bedridden. Her mother said, though, that it was much longer. Strong lace-up boots were the norm for a long time but she had a full recovery. She eventually did well at sports day athletics, rode her bike, climbed trees and walked for miles. A miracle, they said. However, when she got to high school her athletic prowess took a massive nose dive. Either she was running slower or the other girls were just running faster. Much later, as an adult, she became conscious that she struck the floor heavier with her left foot when she walked so she worked to balance her footsteps.

As you've no doubt guessed, I was the child and this was my story, written in the third person because, up until five weeks ago, it belonged in the past, seemingly having little relevance to today. I'd even thought that the course of three vaccinations (April 1957 to June 1958) were the reason why I had never progressed to Post Polio or Late Effects of Polio (LEoP). In fact, I've always had a strong belief in my own ability to heal and I'm positive that belief has its origins in my recovery that year. That belief has also not been a bad thing when enduring later health episodes but now it's being tested.

NOW BACK TO FIVE WEEKS AGO

I don't sleep well at night. In fact, I haven't slept well for many, many years due to pain anywhere between my head and my heels, generally over much of the 5 foot 3 ½ inches of me. Used to be 5 foot 4 ½ inches but I lost a little bit along the way ... as some of us do. Now, up until about five weeks ago, I accepted this pain was due to any or all of the health issues which I have mentioned towards the end of this story. I don't want to bore anyone too early in the piece but, as they are relevant, I feel they should be included somewhere.

Years ago I learnt that it was harder to get to sleep at night by quietening my thoughts and trying to relax. My stimulated brain and constant and varied thoughts through the day helped me keep the edge off my pain. I knew it was there, it still hurt, but, in effect, by keeping my thoughts moving I could keep it controllable. Without that brain clutter, the savage strength of the pain would rush in to fill every core of my being. It got to be that I was scared to go to bed at night and I was already sleep deprived because of a life-altering overuse injury that occurred late 1999.

Anyway, for some time now, I've kept a small radio beside my bed and listened to a talk-back show through the night. I've found a whole new world out there; a world full of people like myself who don't sleep so well. The volume is kept low enough so it doesn't intrude but high enough so my 'good' ear hears most of what's being said. Eyes shut, just listening until that blessed moment where my conscious mind is no longer aware and I've drifted off. Sometimes it takes a while. Sometimes, I come awake and it's incredible that I woke up in the middle of the night about five weeks ago to a particular conversation.

The announcer was talking to a woman about polio. I recall she mentioned it was Polio Awareness Month which I no longer thought had any direct relevance to me but the caller was articulate, inspiring, she had a message and that message got my attention.

You could have knocked me over with a feather, as they say. I was hearing possible answers to questions that my GP and I had been chasing for some time. That was good but it was also bad and I had a few down moments over the next few weeks until I took this on board. In fact, if I'm honest, I'm sure I will have more of these moments, I believe the key is in educating myself via the resources that are now available to me and contact with like-afflicted people, though I am humbled when I hear what others have had to deal with, many for most of their lives.

Anyway, I didn't hear the caller's name but, in the morning, I tried to track her down. I was born on the Darling Downs, she said she lived on the Downs so I Googled 'Post-Polio, Darling Downs'. There was a group photo, an editorial and a name and phone number at the end. I rang that number and Deborah Khan of Toowoomba answered. Deborah said she was the person I heard on the radio. We spoke for ages and have had a number of conversations since.

She encouraged me there and then to contact Spinal Injuries Association (SIA) in Brisbane, to include my name on Polio Australia's register and also to liaise with Lyn Glover, facilitator, of The Gold Coast Post Polio Network, fortunately less than a thirty minute drive from my home.

I made the calls, a couple of days later I was going through the kit promptly provided by SIA and soon after that I was meeting members of my new Post Polio Network. In fact, at the time of writing, I have attended two local meetings very capably run by Lyn. It's a new world for me again and I'm keen to learn as much as I can while contributing, where I capably can.

I appreciate the value of support groups. Thirty years ago my bowel was badly perforated during major surgery because endometriosis had not earlier been diagnosed. I lived in Queensland but my support group consisted of one ex-nurse 1400 klm away in Melbourne (as the crow flies), who, herself, was living with endometriosis. It was she who provided valuable information about a disease I'd never even heard of before, had trouble pronouncing for days after the surgery, and who, some years later, provided me with the name of a surgeon recently US trained who, at a hospital only an hour's drive away, undertook 4 laser abdominal operations in a fifteen month period. I've referenced this period and its outcomes under the section below entitled Pain, Pain and More Pain.

MY GENERAL PRACTITIONER

My GP is a generous soul. He listens to what I have to say, gives me credit for having a good understanding of my body and its changes and still laughs at my often-repeated parting words, 'geez, and I haven't yet lived!'. Although I've been with this medical centre for the past thirty years, he has only been my doctor for the past three or four.

A couple of weeks ago I said to him, 'It's possible you're not aware that I had polio', as I handed him a copy of the recently acquired paper produced by Polio Australia, *The Late Effects of Polio : Introduction to Clinical Practice*. And no, he wasn't aware. 'Look, I'm in here', I said as I rattled off symptom after symptom.

One of my new-found Post Polio friends, Shirley, shared this knowledgeable, yet catchy, comment. Her doctor's receptionist said to her, 'you are probably our only patient who has had polio', to which Shirley replied, 'no, I'm probably the only one that you KNOW about!' Never a truer word said, as they say.

By his own admission, my doctor was unaware of much of the recent polio information, which does not detract from his abilities but reinforces what the contributors to the resource materials have found. Polio has been off the radar in this country for many years. Once the true numbers are assessed, plus add to that number the thousands upon thousands who will move here from various other countries, it's going to be a major, major problem for decades to come. In the short-term, so much will rely on empowering ourselves as best we can by widespread education and further R & D, (these are new times hopefully with new scientific possibilities in this area), so that we can assist in the management of our own degenerative condition.

Although I don't have high cholesterol, I'm told that I will need to take a cholesterol pill for the rest of my life. A brain MRI identified that I have small vessel disease. Although my cholesterol is low, a pill I was taking for small vessel disease was Crestor. I've since become aware from the resource material that Crestor is a statin and that statins should be avoided or taken with caution. Accordingly, my doctor recently altered my prescription to 1 x **Lipidil 145mg** slow release tablet per day.

About four and a half months ago I committed myself to one capsule a day of (BioCeuticals) **CoQ10 Excel 150 mg** and it appears it's taken the edge off the monumentally overwhelming fatigue I had endured for some time, the type that sucked the life-force out of my body and that my once controlling brain was ineffective against. That type of fatigue. Some days I might still nanny nap up to half a dozen times from lunchtime to bedtime but, while I'm going to be working on managing that issue better, the edge has definitely been taken off. As of writing, it's my intention to enquire about taking a second CoQ10 pill per day.

Dreadful leg cramps led me to (BioCeuticals) **Ultra Muscleze Advanced Magnesium Blend** and that was pretty effective almost from the outset. No cramps for a month, then a few less painful ones and I've just increased the dose slightly, as advised, and it appears to be ok again. I've also increased my water intake.

Three years ago, prior to undergoing the brain scan, the neurologist recommended that I start taking a mixture of Folic Acid, B12 and B6. Migraines and extreme pain throughout my head, neck and upper torso and limbs were some of my symptoms. It was painful to even lightly touch any part of my chest, shoulders and upper back. A month or so of one daily capsule of (BioCeuticals) **Methyl-Max** settled that down and my shoulders are more relaxed. Part of the early diagnosis in 1999 was costochondritis (inflammation of the cartilage connecting my ribs to my breastbone) and of course, chronic long term pain over years had taken its toll and stress was a regular part of my life. That type of pain settled, ie lightly pressing on the area elicited no painful 'aaahs'. I was advised to continue with this supplement for the rest of my life.

Apart from that, I take Caltrate Plus for my bones, Atacand and Noten for my high blood pressure, Somac for my stomach and one Plavix every second day (I bruised with one daily). There are also pain medications which are more effective with my lower back than with the head pain. I feel like I rattle and am a bit resistant to adding to the list, though I am reading up on L-Carnitine. Nothing is added without my doctor's awareness and approval. Prior to my injury in 1999, I was taking none of the above. Noten is a beta-blocker, another of those medications it's suggested should be avoided or taken with caution. I have yet to discuss this with my GP but, little steps. I'll do so in the New Year after I've adjusted to the change in my cholesterol meds.

With the pain, my first choice is either a hot or cold pack. I actually half fill a rubber water bottle, the type we used to take to bed to warm our feet, and cool it down in the bottom of the frig. I've found it to be really effective against my lower back while I'm sitting. It's a good size, the moving water is very supportive, the ribs on the outside of the bottle keep the really chilled part off the skin while allowing a cool temperature to do its work. The ribs also delay warming of the contents by direct body contact.

PAIN, PAIN AND MORE PAIN

Now, to understand the health issues I was dealing with is to understand why the Late Effects of Polio or Post Polio were never put on the table for consideration. These issues had taken my focus for many years and, as it was, a lot of the symptoms outlined in Polio Australia's aforementioned paper were a full or partial fit for any of the following.

To put it plainly, if I was an otherwise healthy, fit person for all those years and LEOp symptoms presented, then, as long as I was able to readily access someone knowledgeable of all things polio, it would have been a different story. From what I'm reading in the resource materials however, access to 'someone knowledgeable' would have been a difficult thing as polio and its later effects have not been required study during the training of our medicos for a very long time.

The increasing depth of the dreaded fatigue this past year, however, was worrying and blood tests didn't provide any answers.. Also, and for a long time, I've been distressed by the erratic and often excruciating nerve pain. In this chapter, I debated what to leave out against what to include and, after three or four re-writes and umpteen pages, decided my story was getting way, way too long and much, much too serious.

I don't really recall a time since my mid-thirties when I didn't have pain. Half a dozen abdominal surgeries, ovarian cysts, endometriosis and a severely perforated bowel brought their own challenges. Endometriosis is a debilitating condition that remains with you forever. It also brought constant backache, abdominal pain and helplessness into my life. As it had not been diagnosed pre-surgery, my bowel, which was abnormally attached to my uterus, was cut so badly that another surgeon later wrote, *'when I have looked with the laparoscope it has been daunting in that the pelvis has virtually been filled with bowel and adhesions'*.

Then, in 1999, I suffered a really bad occupational overuse injury that eventually put paid to my working life. Even with hundreds of physical treatments, I was in the pits for a long time, emotionally and physically spent, and those years have been costly in more ways than one. They were synonymous with joint, muscular and nerve pain, introduced me to intense migraines, neck, shoulder and limb pain plus weight gain, high blood pressure and sleep deprivation. Added to that were the also extreme tsunami-like heat surges scrolling up my back, over my head and down my chest only to re-gather at my waist and start all over again. A vicious cycle. I also found what head sweats were like as any sign of stress (and these were highly stressful years) opened up the floodgates in my head and perspiration dripped down my face, in fact all over my head. Not a good look at all.

Loss of economic certainty, loss of confidence and gradual social withdrawal; these were my new realities.

Often when I am fanning myself, which is still most of the time, I get knowing looks from other women of my age and the comment, *"I know how you feel, awful isn't it"*. I just nod and return that knowing look and keep waving my fan. In the early days I tried to explain it had nothing to do with menopause, more to do with stress as my doctors advised, but quickly found that the latter, as with depression, didn't always engender comfortable conversation.

Some years ago a health practitioner told me that *sleep helps regulate your body's temperature* and I had been sleep deprived for years, at that time getting about three hours a night. Eight and a half years ago I started sleeping, all seasons, under a very effective ceiling fan (often with the odd hot water bottle easing my aching bits beneath the bedclothes) and commenced a regime of half a sleeping pill at night, which continues to this day.

I felt that the breeze on my face also gave me the impression that I was breathing better as well. Mind you, the sleeping pill I take is Stillnox, the one receiving so much interest these past years on the television, but apart from maybe one strange bit of behaviour (or so my younger son said) and the loss overnight of a few biscuits from the cupboard that no one else claimed to have taken, I don't believe I've gone walking out the door in my pj's at all, touch wood!

When I was first diagnosed with Endometriosis, I managed by 'living in my head' above the pain centres in my body. I recall at the time drawing a simple cartoon with one round shape at the top (my mind) dragging a bloated, teardrop shape along the ground. That was me for some years. With this more recent overuse injury, my head and neck were also in pain so there was no similar method of escape, even for a short time.

At last, a few years back, a brain scan brought both good and bad news . Good, because it finally showed me reasons for my head pain and short-term memory impairment that I'm sure my then medico attributed greatly to my emotional state: a not un-common assessment so I've been told by many others these past several years. Like, who wouldn't be emotional living a life embraced by pain and loss for so many years, while caring for and losing a much loved mother but don't ignore the possibility of physical pain. And 'bad' because it showed me something I didn't want to see, trigeminal neuralgia plus a similar pressure on the auditory nerve. Possible pressure on the occipital nerve and C2 in my neck. Not to forget all those white spots on the computer screen, blockages I think?

So, as I didn't tolerate the medications so well, I was then a candidate for surgical insertion of bi-focal lenses in both eyes. Contacts were not suitable. My light-weight multi-focal glasses had for a long time worried the trigger points on my face and head where they touched and pain was drilling into these sites, aggressively. Some months later, sans spectacles, that part of my pain had greatly reduced so I consider that an extremely successful, though radical, procedure for this conservative type of person.

Into the above mix I had confirmation that there's a broad-based disc bulge at L4/5 with possible left L5 compression in the lateral recess. There's degenerative disc bulge at L5/S1 with right S1 neural compression. Sciatic nerve pain, though relatively quiet these past several days, has its own set of challenges. Fortunately, I have a very good osteopath who helps manage my pain

I often sit for hours each day with either a hot or cold pack on my lower back. I no longer use gel packs but opt for the good old rubber water bottle. Half filled I keep it cool in the bottom of the frig; it's big enough to cover a larger area, the movement of the water is positive, the ribs on the outer skin keep the coldest part away from my back while delaying the eventual warming from my body heat. Though simple, one of my best ideas I think, and I've gone through quite a few water bottles over the years.

Back to the aforementioned paper from Polio Australia and Bladder Dysfunction. For the past couple of years I've had bladder problems with voiding. Sometimes it works fine, other times it's recalcitrant requiring a bit of mind-speak and practical gymnastics. I'm working on it. Apart from some weakness and occasional balance issues, I'm also on page 17 in the paragraph on Bisphosphonates.

However, an Oral Maxillofacial Surgeon that I met with post-infusion, told me that I now have a 10% chance of developing osteonecrosis of the jaw (ONJ) if I had an extraction. Recent root canal re-treatments, performed by a very good Endodontist, though pain free during the procedure brought about intense head and facial pain a week or so later. It seems that my nervous system is revolting against any invasive procedure and I'm naturally concerned. After so many years of intense pain I don't know how much endurance is left in the tank to cope with more. And I am due to return to complete the process at the end of January.

A week either side of my brain scan, I had my first angiogram which showed that I had a couple of minor irregularities with my heart but the procedure was the problem. I screamed when the nerve was struck, not once but three or four times, and did my best to be understanding when they later came to me and explained that was unusual. Up until recently, I thought the doctor was at fault; now I've had a re-think and believe my highly sensitive nervous system caused the pain. So many diverse though painful experiences lead me to this conclusion and I really don't want to be awake if they have to give me another one of these things, or any invasive procedure.

Though not so often, I still get the odd feeling of pressure on my upper chest even with minimal exertion. There was a time some years ago where I had difficulty swallowing, where I couldn't then take a breath until I sat up or drank some water. I read on a counsellor's questionnaire that that might have more to do with the psychological rather than the physical so treated it as such and it eventually went. Now I'm wondering if these two issues might well have something to do with LEOp?

2007 and 2008 were awful years. My dear mum, who lived with me, had most of her stomach removed January 2007 and later died at home February 2008 of gastro-oesophageal cancer, wasting away to thirty something kgs. With the assistance of Blue Care visits, I cared for her at home and was with her when she passed. Totally traumatic time for a long time.

A month before she died, she spent two weeks in the hospital's palliative care ward and they were outstanding in their care and support of both of us. I was with her for hours each day, my head pain was rampant and she was concerned for me. One day her nurse told me, 'sit down, your mother's worried about you and I'll just check you out'. Later he remarked, 'you've got less oxygen going to your brain than your mother has!'

Anyway, she wanted to come home to die and the resident counsellor asked me how I felt about that as I was her carer. My mother had never talked with counsellors so he often spoke with me. He knew my health problems and wondered if I could cope. I told him that if it was good for her then it was good for me. He said 'I think you're pretty impressive'. I'm a hugger, I gave him a quick hug and, extremely tired, emotionally and physically hurting, I left him to rejoin my mother with a bit of a smile on my face. Mum wouldn't cry and didn't need me to cry in front of her .. until that one time a couple of days before she died when we cried and hugged together. In those last few days, exhausted and struggling to hold on, I tried to remember the counsellor's parting comment. I was virtually running about the house like a chook without its head, as they say, asking of myself, *that 'I' word, what's that 'I' word again?* I for Impressive; as if the memory of my last words with the counsellor would come back when I needed them. Pretty silly image if I wasn't so desperate.

Once remembered, I wrote I THINK YOU'RE PRETTY IMPRESSIVE in big letters and every time I thought it was all too much to bear and felt I couldn't cope, I looked at that note and it helped me to keep going. I'm one of those people who believe that a problem shared is a problem halved and if I verbalise something then it's negative energy is much reduced. Luckily it works for me. When I was working injured, I used whatever motivational tool I could to keep going, when one wore out, I found another. One of my favourites came from text shared with me by a colleague. It read, *I used to have so much stress in my life but once I started calling it excitement, I felt so much better.* There are some clever people about.

I wondered if I would tell this particular part of my story but then, the emotional and physical pain brought on by caring for and eventual loss of my mother stayed with me for a long time. It factored so strongly into my general health so has a part in this story, unfortunately.

AND SO, IN CONCLUSION

Collectively, the above health issues have taken my focus for a long time so I was a wee bit shattered when I finally understood the import of the message I was hearing five weeks ago. Suffice to say, so much of my story is written on most pages of Polio Australia's recent paper, *The Late Effects of Polio: Introduction to Clinical Practice*. Importantly, I've come across this now rather than further down the track. That's a positive.

With sufficient lead time for this article, I have been able to pace myself, writing a bit each day, generally starting about four o'clock each morning. I have a lot of trouble with my shoulders and neck and, as typing is a manual repetitive activity which I rarely do nowadays, it's been necessary for me to manage this exercise, bit by bit, piece at a time. In fact, I only have access to emails and the internet via my small Android phone. The computer is my son's old uni laptop.

Importantly, if I hadn't agreed to Mary-ann's request for my story, I would have remained unhappily in ignorance believing that my once hard-working brain could no longer string a few intelligent sentences together. I had high standards of myself when working and there've been times these past couple of years when I'd tell my friends that I was finding it hard to think up a few good adjectives. So, I hope you enjoy or otherwise benefit from this story as much as I feel I will benefit from writing it, because thoughts have been flowing thick and fast. It's been stimulating. A bit of proof reading will, hopefully, pick up the odd word I've inadvertently used but this has been so very good for me. Thank you Mary-ann.

I'm not someone who talks about regrets, feels sorry for themselves or says life's not fair. Suppose I shouldn't say it but, being what they call *a cup half full person*, I do sometimes believe that miracles can happen, not all the time mind you, just sometimes, and now I'm putting out there that the first miracle I want is a healthier, less painful nervous system. Big ask. But, five weeks ago, when I had digested this new information, I did look to the heavens and say to myself, *'I've lost so much, how much more do I have to give up?'* Thank you for taking the time to read my story.