

# My mystery illness

We all know the feeling of when we are getting the flu. Our body aches, our limbs and head feel heavy with every part of our body feeling like it has been trampled and is in need of rest. That is how my illness started.

I had a brief bout of diarrhea and then the aches and pains set in. For weeks I felt like I was getting a severe case of the flu. I hadn't been sick all winter and was fit and exercising regularly. I was happy and healthy, loved my life and had not a care in the world. I accepted I was getting some sort of bug and had a relaxing week. I went to bed early and started having long baths to ease the pain and fatigue that I was starting to feel.

Within a few days, the feeling of tired limbs became much worse. I felt exhausted all the time; I was even waking up exhausted. I was pulling myself out of bed in the morning and retiring to my lounge room sofa chair for a forty-five minute rest while mentally willing myself to walk the extra ten paces to my bathroom to have my morning shower. The fatigue was severe right from the start, but I pushed myself to function as I usually did. I was taking lots of rest, which included naps during the day and going to bed early, just waiting for my flu to pass.

Within days of the onset, I was experiencing disturbing pins and needles in my back. They started in my upper back and shoulder blade region and then progressed to include my lower

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back and pelvic region. Massage, rest, heat packs and topical ointments did nothing to alleviate the pins and needles I was feeling deep in my torso. Some of them actually made the pain and the pins and needles worse. I resigned myself that I had caught the flu and that I would just have to take it easy for the next couple of weeks until I was feeling better.

I drove myself to work on Monday morning after sleeping through most of the weekend. A friend had stayed for the weekend and I drove her to her workplace. In the car she exclaimed in shock at my lower abdomen which was swelling like a balloon as I drove. It was an amazing sight to literally see my belly grow as if I were watching a time-lapse photography video of a pregnancy. My friend was very worried about me. I told her I didn't feel well and was very tired and sore. The pins and needles in my back turned into stabbing pain as I drove towards the office. The pain sensations I was feeling were so severe and different from anything I had ever experienced before that I stopped my car to halt any unnecessary movement. I just felt so sick and knew that something was very wrong. The nerve-tingling sensations of the pins and needles were so unnatural that holding the steering wheel caused pain that was like someone pushing knives into my upper back.

My first thought was that maybe the reason I was having these nerve sensations was because my back was misaligned and I was having pressure on some part of my spinal cord. I rang my masseuse and explained my symptoms and she responsibly suggested I see a doctor rather than have a massage. I agreed and made an appointment at the sports clinic I frequented for any sporting medical problems and then booked a physiotherapy session directly afterwards. I attended both appointments at the end of the workday and the doctor ordered blood tests to cover any possible infections caused by my recent trip to Africa. I then went home to bed physically exhausted. I slept solidly through the night.

The exhaustion and fatigue I suffered during the rest of the week was like nothing I had experienced before. I forced myself to work on the Tuesday and crashed into bed the moment I arrived home and once again slept solidly through to the next morning. Rest, rest, I kept telling myself but it wasn't helping. I couldn't even manage a simple day at work. I was waking up exhausted and the pain in my back and limbs was awful.

I was waking up stiff as a board feeling like I was going to snap if I stretched or breathed in too deeply. I was moving around in slow motion trying to minimize the pain, pins and needles and fatigue I was experiencing. My hips and back were hurting like never before. There was no relief; sitting, standing and walking were all agonizing. It hurt if I lay down and tried to get comfortable. Every motion caused severe pain and the fatigue became its own entity: as great as the pain symptoms. By midweek I had made more appointments for massage and physiotherapy and I could hardly wait for these sessions, hoping they would afford me some relief. But no treatments I undertook offered me the relief I was hoping for. The painkillers I took were not having any effect and I was slowly getting weaker and sicker as each day progressed.

I visited a natural therapist and he warmed my back with heat packs and then massaged and manipulated the painful regions in my back and torso. I went home after the session and collapsed into bed exhausted and slept deeply. I awoke the next morning in agony. The areas of my back that the therapist had massaged and worked on were very tender and painful. I called work and told them I would be at home resting. I couldn't manage getting dressed and driving to work.

My health was rapidly deteriorating and I was terribly exhausted. I slept all day. I dragged myself out to bed to go to my massage appointment that evening. After getting off the massage table, I breathed in deeply and arched my back but I still felt like I was going to snap from the deep aching and tightness.

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My masseuse was concerned and stated that she had applied barely any pressure during the massage. I returned home more exhausted than when I left and felt no benefit for having the massage.

At the end of the week I forced myself to go to the office as I felt guilty that I had barely functioned in a work capacity and had taken days off during the week. When I was at work I could barely concentrate because of the fatigue, pain, and headache that I was beginning to experience whenever I was up and moving about. The headache was piercing and intense, worsening when I moved about the office. I could barely concentrate on any work tasks. I went to a physiotherapy appointment during my lunch break. The physiotherapist concentrated on my right upper back where I was experiencing constant pins and needles. After she applied a heat pack treatment, her physical manipulation of the area was too painful for me to let her continue. I asked her to stop. I was severely exhausted and my condition was worsening and had not improved since I last saw her at the beginning of that week. She suggested I see the doctor again and get some more blood tests. And that is what I did. I waited to hear news of some diagnosis after the doctor ordered an extensive battery of blood tests. The results all came back normal. It made no sense, my symptoms were worsening and there was no indication of what was causing me such ill-health.

My job was in sales, working for a distributor of medical equipment used in laboratories and research facilities around Australia. My position required me to travel interstate frequently. I had an interstate trip booked for the following week and I decided not to cancel the trip as I felt an obligation to my employer and the large expense that had already been paid weeks in advance. I felt truly terrible, but I had always been a hard-working and reliable employee so I did not want to let my boss down by canceling my work activities at the last minute. Thus far no doctor or health professional was able to tell me what was wrong, so I tried to

function to the best of my ability. I hoped that this 'terrible flu' would finish soon.

I flew interstate for the weekend and relaxed at my accommodation sleeping the whole weekend away trying to recoup my energy for the week ahead. The only physical activity I undertook was to walk out of my apartment and across the road to the beach for some fresh air on Sunday afternoon. I retired back to the apartment exhausted by the small effort of walking the one hundred paces each way to and from the beach.

The pain of wheeling and lifting my suitcase from the airport into the car and into my apartment left my right side sorer than my left. My back was constantly aching so I ran a hot bath and soaked in it to try and get some relief. I awoke Monday morning and rolled over in bed. The pain startled me. I felt as though someone had crept into the apartment during the night and beaten me with a baseball bat. I was in agony. I was utterly exhausted and my headache was bordering on severe. It had been building in intensity over the past days and the pain in my whole body had increased because I was moving about. It seemed that the pain was bearable if I did not move at all.

I dragged myself out of bed that Monday morning and took some strong painkillers and anti-inflammatory drugs. Neither had any noticeable effect on improving the physical pain I was feeling. I awoke in so much pain and so exhausted that when I stood in front of the mirror in the bathroom I could not lift my arms to brush my hair. Getting dressed took almost an hour, rather than the five minutes it usually did. I sat on the edge of my bed at 7.30am dressed for work but wishing I could just crawl back into bed and sleep. Everything was such a huge effort. I made it through my workday by making calls sitting in my car: forcing myself to do these because I had insisted on flying interstate to perform my work duties rather than accepting I was very ill and needing more medical attention. I reclined my car seat and slept with the sun beaming in onto me. I did not see one client that

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day and felt guilty, but the effort of just getting in and out of the car was exhausting me. I just couldn't manage sitting attentively in front of a customer and doing my job as I had done for so many years. The effort of just driving to a customer site was too daunting for the level of pain and fatigue I was feeling.

I came back to the apartment by early afternoon and tried to do some emails and paperwork. I couldn't manage either, and just fell asleep in my work clothes on top of the bed. I awoke later thinking I had just dropped off for a few hours of sleep when I noticed that the alarm clock read 11.30pm. I had just slept over seven hours but still woke unrefreshed. I was shocked and concerned. I was hungry but all the takeaway food outlets were already closed for the night. Even the local supermarket was shut. I went back to bed without dinner. I awoke the next morning in pain.

I am a very positive person and I have always been disciplined and mentally strong. I like to work hard and I push myself in my natural course of daily events more than the expected norm. Although I was physically very, very tired and experiencing constant pain, I pushed myself to function because I had an obligation to my job. I was successful at work and wanted to keep it that way. I was willing myself more than anything in these early stages of my disease. I didn't want to acknowledge that these bizarre symptoms could put a halt to my familiar and successful world.

That morning I struggled to walk to my car in the basement car park. I was pausing and resting at every opportunity – at the apartment door, at the lift and at the stairs to the basement. My breathing was labored and I was gasping for breath after a few short paces. It was ridiculous as I couldn't walk twenty paces without needing to stop and rest. Mentally I was pushing myself to function; however, by the next day I realized that physically I was in dire straits. My body could no longer function with these symptoms that were escalating and not getting better.

I came back to the apartment and collapsed into bed feeling exhaustion like I never knew was possible. By mid-afternoon I awoke and knowing I was interstate to work rather than sleep, I drove myself to the state office so that at least I showed my face. I tried to function in a work capacity but I was experiencing escalating pain caused by the physical movement I had to undertake. I asked my interstate work colleague to drive me to the nearest pharmacy so that I could get some more pain killers as I had finished the supply I flew over with. These over-the-counter drugs were not helping but I was taking them every few hours trying to quell the onslaught of pain I was feeling throughout my body whenever I moved.

My colleague took me to dinner nearby, and I drank alcohol to try and numb the pain. After an hour of sitting I was in complete agony, my whole body aching, with the painkillers having no effect. I could no longer sit because I was losing feeling in my legs. I could not help but cry because this new symptom scared me and made me realize that nothing was getting better. My work colleague drove me back to my car even though I knew I was incapable of driving the vehicle safely to my apartment.

As my colleague had been a nurse for fourteen years working in a major city hospital, I asked him his opinion on whether an emergency department would give me anything stronger that would help alleviate my pain. He said it would be unlikely, so I went back to the apartment in pained exhaustion. I was very worried because I was so far away from home and so physically sick. I awoke the next morning unable to get out of bed. My hips were in agony and my legs, back and head ached from all the activity of the day before. How could so little movement cause such gross and unrelenting pain, I wondered?

After resting for hours, I went to a local doctor's clinic near the apartment and explained my symptoms to the treating doctor. I told him I had already had two sets of blood tests – basic and more thorough – in the weeks prior. He suggested I get a

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flight back home and undertake a more extensive series of blood tests immediately. He stated that my age and sex were typical of autoimmune disease onset and that my condition could be inflammatory in nature and suggested I needed immediate further medical investigation.

I arranged to fly home the next day as I had no energy to pack and go to the airport later that same day. I was just too tired to drive the hire car back to the airport.

I got home from the work trip with no work accomplished and my physical state falling apart. I needed to find out what was causing my severe and worsening symptoms. The blood tests I had the week before had all shown normal results. What was going on I wondered?

Physical pain is an awful experience that we all fear and dread. Unfortunately though for some, pain is a constant and recurring part of everyday life. This type of pain is termed chronic pain. For those not suffering chronic pain, hearing the constant drone and whining of those in pain is an experience everyone would rather do without. Having jumped the fence from healthy carefree individual to whining pain-infested human was a tough pill to swallow. Recurring daily pain causes you to vent in anger and frustration, which has long-lasting effects on those on the receiving end.

The year was 1999 and I was 29, living in an inner city home. I was physically fit and taking part in many team sporting events, some at state level. I also loved my individual sporting activities such as running long-distance. I was healthy and active, had a great job and excelled in most of my chosen ventures. I was living with a male friend and we shared the ground floor of a large Tudor-style house in a fashionable and trendy inner city suburb. I was successful at work and in my private life, and was discussing the option of buying into a manufacturing company when I was struck ill.

Several weeks into my illness, I crossed the road one morning to take a slow walk along the riverside adjacent to my home. I

woke with gritted determination to have a normal Sunday after countless weeks of bed rest with innumerable hours of sleeping. I was determined to join other locals on a picturesque walk along the beautiful riverside that weaved through my city home. I slowly traversed the river's path for about five minutes when I was overcome with a lack of energy to even take another step. I looked around me and the joggers and cyclists were busily whizzing past me. It all felt surreal.

It was a normal sunny Sunday morning and the world around me was getting on with its day, yet I was trapped in this void of inability. I couldn't walk or take another step. I looked down at my legs, pleading with them to summon the energy to keep walking. I sat myself down on the grass beside the walking path. I sat there paralyzed at the track's edge, close enough to still be in view of my home, but so far that I was trapped seemingly worlds away from the safety of my home and bed. This was a frightening realization.

Suddenly, and for no apparent reason, this weird flu that wasn't getting better was stripping me of my ability to even walk a hundred steps. It didn't matter that I had rested in bed for weeks and slept countless hours to try and recuperate from my mystery illness. I sat perplexed and deeply concerned as the discovery of the new-found limitations of this illness made me realize the barriers that this was to generate in all other areas of my life. I couldn't walk for more than five minutes after spending countless weeks resting in bed asleep.

What was happening to my body? I was forced to sit there on that lush green slope for nearly an hour. I wondered if I would be able to get home at all. I didn't have my mobile phone with me, and although I was almost a stone's throw away from the house it seemed miles away. My safety was compromised, and I was unable to care for myself in a way that most people never have to consider.

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Eventually I mustered myself into standing upright again. I took slow and steady steps and made my way back to my home. I felt elation when I was crossing the road and realized that I would have enough energy to get inside my front door. I left my clothes on and lay down into the comfort of my bed, a place of refuge for the past weeks. I was relieved beyond words to be home safe again. I drifted into exhausted slumber, and woke hours later, hungry and sore from my minimal activity of the morning. What was happening to me, I wondered? Why were the doctors repeatedly telling me there was nothing wrong? How could they not acknowledge these massively debilitating symptoms?

Something that astounded me was that on many days I would not even dress as it was too much effort to even change out of my sleepwear. This was something I had never done. I was not someone who came home from work and slipped into my sleepwear. I woke early each morning, showered, dressed for work and then changed in the evening when I came home from work. So it astounded me that I couldn't physically do a ritual that was previously a daily part of my life, like blinking or breathing. I now often went days before I would change out of my sleepwear as I couldn't physically manage it, and the days slipped away quicker than I could even care to notice because of my constant cycle of chronic fatigue and unrelenting pain with hours lost in sleep.

Before getting ill I had just entered into negotiations to buy into a manufacturing business. The nature of my health concerns caused my business partners to pull out of our fifty-fifty deal of ownership at the eleventh hour. They left me holding the bundle so to speak, so I was left with the decision to buy the lot or not. Reading this you would assume that because of the state of my health, the answer would be unequivocally 'no'. But it wasn't. We were so far into contractual negotiations when my mystery symptoms started, that I had already decided I wanted to be a part of it. I had also spent months looking for a suitable

factory lease as the business needed a new location to house the manufacturing activities.

I did not realize that this illness was not going to get better. Everyone recovers from the flu I thought, why wouldn't I be the same? How wrong that assumption was in those early months of my illness. I didn't recover from the mystifying symptoms that seemed to get worse and more complex as time progressed. My journey of this chronic illness had just begun.