

My name is Leanne. I am 42 years old and I have been sick for 6 years with autoimmune vasculitis (Small Vessel). It affects my blood vessels and in turn affects my brain (nervous system) and my organs, including my eyes, skin, liver and bowel.

My journey with autoimmune disease started in 2009. I was 37 years old, happily married with four wonderful children the oldest aged 9, and a successful town planning consultancy job, which I loved. My youngest child was 6 months old when I realised I was having trouble walking.

In time that progressed to trouble holding things (my hands just wouldn't work and I had weakness in my arms and legs) and trouble with my vision. I got worse and whatever it was, started affecting every facet of my life. I put on a lot of weight, despite dieting and exercise. Something was very wrong, but the doctors were clueless. They did X rays of my feet and knees, numerous blood tests and even scans of my thyroid and brain. Everything came back normal and I was sent on my way. They thought I was exaggerating, making it all up, even. I was totally and utterly lost and felt abandoned.

Over a course of three years I went from a fully functioning, successful person, to laying down for most of the day. I couldn't exercise, go shopping, clean the house or work without becoming dysfunctional. My hands would start to tremor, I would start limping and I would lose my balance and co-ordination. On my worst days I wasn't able to count to twenty. Even the simplest of tasks left me exhausted. The worse I felt, the more frustrated I became. Worst of all - why didn't anybody believe me?

I saw numerous Drs - at least 8 different GP's and even more specialists. Each time I was sent away, and told that they could not find anything obviously wrong with me. Eventually in 2013, after pushing for more testing, an MRI indicated widespread inflammation in the major vessels/lining of my brain. I was referred to a neurologist who said they didn't know why I was sick or why my brain was inflamed. They thought I may have had MS, but all the tests for this were negative. They then said that either way, there was most likely nothing they could do for me. Again, I found myself lost, and feeling abandoned.

My health continued to decline and I spent most of my days lying down. I wasn't satisfied however that the doctors had considered every possibility. Each Dr I saw - after the first few tests came back normal - seemed to lose interest in me. Except I was still sick - very sick. Some doctors were even mean to me - telling me to stop wasting their time and get a life. It was horrible. I was 40 years old and I knew 80 year olds getting around better than I was.

After the initial disappointment was over, I started to get angry. I demanded answers. I decided that until the doctors could actually provide me a reason for what was happening to me, I refused to give up or give in. I wouldn't accept there was no name or treatment for my condition and, if I was to eventually find there wasn't any treatment and the disease was incurable, then I needed to know that for certain. My children and husband were relying on me.

I started reading about possible causes and soon realised that my numerical test results were only part of the picture. I also realised that most doctors are only trained to concentrate on their particular part of the human body - they do not seem to take a holistic approach to medicine. For

example the knee specialist didn't really care that my foot and hip were also sore - he just did knees. The brain surgeon told me there was nothing for him to cut out of my brain (he actually said that).

It was now late 2013. I had been sick for 4 years. The doctors wanted empirical proof - my word wasn't enough - they needed to see test results, the numbers, facts and figures that proved that my body wasn't working properly. I didn't find that particularly helpful as most of my standard tests were within normal ranges. The more I read, the more I realised that this is a common finding in autoimmune disease. This was quite a revelation.

In all that time, other than MS, none of my doctors had ever mentioned possible explanations like Lupus, Sjogren's or RA as being the cause of my problems.

I had non-specific signs of inflammation (A raised C reactive protein (CRP)) and the brain MRI findings, along with an enlarged thyroid, inflammation of the pituitary gland and raised liver function tests. I also was suffering from widespread pain, fatigue and nervous system dysfunction. I sought help from several more doctors and finally convinced one that I needed to be checked for an autoimmune condition. I had no idea which one, but I felt it was worth checking out. Fortunately for me, he agreed.

I was referred to an Immunologist and while I waited the 6 months to see him, I read as much as I could about autoimmune disease and decided to take action. I felt it couldn't hurt and that I had nothing to lose. I learnt that an autoimmune disease is the result of the body attacking itself and that rest, diet and reducing stress can all help the body get back on track. I stopped fighting and embraced my illness. I started listening to my body. When it told me it wanted (NEEDED), to lie down, I did. When I had too much trouble using my hands - I stopped. I gave my body a chance to heal. I saw a physiotherapist who helped me with my co-ordination problems, started wearing orthotic shoes to help with my balance and had regular massage which helped with my pain and stiffness. I told my husband and children I needed their help around the house and lucky for me they stepped up. I slept and rested and slept some more. The garden was full of weeds, I would ask my mother or the kids to help carry the shopping and while the house got dustier, slowly, I started to get better. We made the difficult decision to move to a smaller, easier to care for - single level, house and garden where I could focus mainly on my health. I designed my new bathroom with room for a shower chair. I started saying 'No' to people and life became easier.

By the time I saw the Immunologist in 2014 I had greatly improved. I was still unwell and limited in my physicality but a follow up MRI of my brain indicated that the inflammation had resolved. I would still get sick when I overdid things (shopping, cooking and cleaning) so I still desperate for answers.

The first visit with the Immunologist was wonderful. When he heard my story, none of it seemed to faze him and better yet, he actually believed me! I was overjoyed. After extensive testing he advised that I had salivary and lachrymal gland dysfunction (dry eyes and mouth) and in his opinion was suffering from some systemic autoimmune disease - similar to, but not Sjogren's in his opinion - and that whatever it is, had attacked my central nervous system. I found out that in Autoimmune Neuropathy's it is common for standard nerve testing to be normal and that my blood tests were seronegative for the standard disease markers like those found in Lupus, RA and Sjogren's, making diagnosis difficult. Still, I finally felt like I was getting somewhere. I was stable, meaning the worst of my symptoms had subsided, and I was so happy in the knowledge that I finally had a doctor who

could help me if I relapsed. It was agreed that I continue to manage my disease and he would monitor my condition in the meantime. I started using eye drops and mouth gels, which increased my comfort levels and I joined some Sjogren's Syndrome support groups, discovering that a new whole world where Autoimmune Disease is no longer invisible.

Life went on as best it could and I was relatively stable for several more months, when seemingly out of the blue I suffered a huge flare - the worst yet. It affected every part of me. I broke out in a rash, couldn't see properly, started bleeding from the bowel and was in intense pain all over. My neurological symptoms (tremor, numbness, loss of balance, shortness of breath and muscle weakness) returned with a vengeance.

After more testing including a colonoscopy, an OCT scan of my eyes - a very simple and quick but sensitive test, indicated bilateral optic neuropathy - damage to my optic nerves. This scan was a turning point for me - after having seen three different Eye Specialists over the years. The fact it was bilateral (both sides) supported the theory that I was suffering from a systemic process, and given my history and symptoms, most likely autoimmune vasculitis which causes inflammation of the blood vessels and where damage to the organs occurs due to lack of an adequate blood supply. The fact I was leaking clear fluid out of my nose and eyes and ears also supported a vasculitis diagnosis. Finally, the Immunologist had the proof he needed to start treatment. I was started on Low Dose Methotrexate, which is only one of many medications used to treat autoimmune conditions. Methotrexate is one of the DMARD'S (which stands for Disease Modifying Anti Rheumatic Drug). I was to take 10mg - a tiny pill, once a week (with folate a day either side). The medication acts as a folate inhibitor which halts new cell growth and I like to think it is the medication equivalent of 'slapping my immune system across the head', to get it to wake up to itself and get back on track to fight viruses and diseases, but leave my healthy tissue/blood vessels alone. The possible side effects were numerous - hair loss, high blood pressure and liver damage, but the damage to my body from the disease was a more significant consideration for me at this point.

Over the next few months, I was monitored for damage to my system by the drug with regular blood tests. My condition improved. The medication was working. I found I could stay up past 8pm, shop, cook and clean again without getting sick. I still had to rest, but everyday tasks were no longer such a struggle.

I now have a full complement of specialists; Ophthalmologist, Gastroenterologist, Neurologist and Rheumatologist. I am being treated for autoimmune vasculitis, but it is important to note that these diseases, including my diagnosis, are prone to change. There is extra testing they could do to confirm the suspected diagnosis like brain biopsies, but the risks far outweigh the benefits. The fact I am responding so well to the medication, supports the hypothesis and for now, close enough is good enough. It is also important to remember that where there is one autoimmune disease, there are often several. There is a significant overlap between the autoimmune diseases. While it sounds frightening, it shouldn't be. Knowledge is power and when you understand what you are battling, things often get easier. Being prepared also helps.

These diseases are chronic and progressive however and every day brings with it new challenges. Just when I think I'm on top of things, something new happens to my body. It took me a while to realise that sometimes even the Drs don't know what to do to help, as they are still learning too. So, I like to hope we can learn together. I have found that it helps to be flexible and realistic about my

future health. I try to be as proactive as I can, but sometimes no matter what I do, I need to accept that sometimes I will still have bad days and that's O.K. That's just how life works sometimes.

As a family, my disease has had a profound impact on all our lives. It hasn't always been easy, but overall we have dealt with it together, as a team, as best we can. I have lost people who I thought were good friends, but on the upside I have made new ones. I found being open and honest firstly with myself about my limitations, then with others, helped a lot. There is no shame in being sick, all you can do is your best with what you are given. Emotionally, I've found this journey has made me stronger. I've learnt a lot about myself - my strengths and my weaknesses. Being sick has meant that my priorities in life had to change. Work and material things became less important and feeling good, became more important than looking good. Being happy is everything. I celebrate each and every day with my family, because I'm still here and even when sitting on the lounge I still count. You can live a great life with an autoimmune disease.

Being referred to the Immunologist and my eventual suspected diagnosis was a huge turning point for me - it enabled me to get in touch with others suffering from similar diseases and opened up a whole new world for me. Through online support Groups and the Autoimmune Resource and Research Centre (via their cafe conversations) I quickly learnt that I was no longer alone. I now know that there are so many others out there, suffering from autoimmune disease, just like me. Our individual diseases and symptoms may differ, but in many ways we are all the same. Grieving our old lives and embracing our new ones. They are among the bravest and most inspirational people I know. Some are doing it really tough, but you'd never know it from their attitudes. Our lives have been forever changed by autoimmune disease and the best part is that we help each other through.

I thought my diagnosis would be the end of my journey, but it turns out it was only the beginning. These diseases are chronic and progressive and while there may not be a cure, there ARE treatments available. If you are lucky enough to have a Dr or Drs who are willing to help you and understand Autoimmune Disease, then you are half way there.

I have now been on Methotrexate for a year and a half and I have continued to improve. I have since found out that I am one of the lucky ones as it doesn't always work well this well for everyone. Treatment has given me most of my life back, I can now function at 85% my previous capacity which means I can look after the family once again and drive a car. I can no longer work full time though as my disease is too unpredictable but I have started gardening again. I meet friends for coffee, watch movies or read and my life is full of joy. In fact I was so well I was able to go on a two week holiday with the family to the United States in 2015. We took the kids to Disneyland, San Francisco and the Grand Canyon. It was a dream come true as only a year before, such a trip would have been impossible for me. I did have to rest and pace myself, but I managed to keep up with everyone and more importantly create some magical memories with my gorgeous family.

The highlight of the trip for me personally was a Night Tour of San Francisco and Bay area. The city lights were twinkling and as we crossed the Bay Bridge, the tour guide played 'Don't Stop Believing' by the band Journey. In that moment, I felt everything was perfect and just how it should be. I love that song so much and it has a special meaning for as I first heard the remake at the height of my illness. There were so many times over the past six years that I have sung along to that song and cried, wanting so badly to believe there would come a time when I felt better and could live my life the way I wanted again. I HAVE had to just adjust to life with an autoimmune disease - but I am still

living and life is still wonderful - just different to how I planned. So, if I have any advice at all, it is to listen to your body - you know it better than anyone and to never give up, never stop believing.