



LYME DISEASE
ASSOCIATION OF AUSTRALIA

For Lyme Disease Awareness & Action



Carlie's Story

An Alternative Path to Wellness

"at first I just fought the fatigue until it got to the point that I could no longer function"

Tell us about your Lyme story:

Officially it began in 2010 but honestly, I believe it began much earlier.

I just fought the fatigue and early symptoms but I felt over 100 years old by the time I realized this was more than just life making me feel this way.

One day I got home from teaching a simple dance class and I could not walk up a flight of stairs to get to my apartment. I lay there for about 2 hours before I crawled up them and went to bed for about 2 weeks. From here began the confusion and searching that most Lyme patients go through. I was diagnosed as having Chronic Fatigue, which basically means "we don't know why your system is in dysfunction and thus making you exhausted, why your blood pressure is so low you're closer to being in a coma than "normal" "Basically I ended up unable to function: work, drive, maintain daily tasks. All were beyond my capacity, though I was lucky to never experience further symptoms like seizures or being wheelchair bound. For me pain, fatigue, brain fog etc were prevalent, immense and relentless.

After working for many months (through Skype) with the ME/CFS clinic in England to address my ME/CFS diagnosis, my symptoms were getting worse. A friend of mine, who had already received a diagnosis of Lyme disease, urged me to get tested. She was seeing a specialist in Adelaide whose "books were full" but I managed to get in on a cancellation.

Still, we did a bunch of other tests and I was quite resistant to getting tested. Basically, I didn't want it to be Lyme. Furthermore, the outrageous cost of sending bloods to America made me slow to get the test done. Australian Medicare tests for Lyme, at this time (I was told), were essentially useless and often misleading. Eventually, I realized I had no other options left so I did get tested and it showed positive on nearly every band.

When I received a positive IGenex result for Lyme one and a half years later, the mix of relief of recognition and terror came when I researched what this diagnosis meant and what the prognosis was. By this time I had researched a lot about Lyme and the various treatments and realized there really was very little help in Australia. So I booked into a 10 week intensive treatment program overseas. I had decided that no matter what the results showed



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I either had Lyme or something very much like it and the program would address bacteria, parasites and low immune function no matter what form they took. I thought this treatment may “cure” me, but it was only the beginning. It saved my life for sure and it gave me some relief for a while but I really had no idea of the ongoing battle ahead.

My experience has been, relatively (and I mean relative to some other people’s Lyme experience) positive. I think this is largely because I stubbornly stayed away from hospitals and western medicine protocols and “line ups”, and put myself on a track that focused on alternative treatments with people who, at least, acknowledged the existence of Lyme, acknowledged the reality of my symptoms and confirmed the lack of knowledge in the medical industry to support Lyme suffering.

Tell us about your treatment protocol:

I’d like to include here a list of some of the main things I can remember that I have tried from when I received a diagnosis of ME/CFS to now (currently symptom free and living an actively healthy life)-

- 1) ME clinic in England, combination of meditation, looking at beliefs, trying to calm down the stress response and diet/supplements.
- 2) -Chronic fatigue specialist: thyroid medication, many blood tests, high dose vitamin IV etc. This specialist urged me to send bloods to America as testing at that lab was more reliable (though not wholly reliable) than Australian Medicare testing.
- 3) 3-10 week treatment in Bali; included, EBOO (ozone) Infra-red sauna, magnetic therapy, RIFE, Oxygen therapy (with exercise) Colonics, including with ozone and pro biotics, Human Growth Hormone injections, Lazer therapy, many other injections, Glutathione IV, Magnesium, Vit C IV, Supplements, bentonite clay, salt and C, etc. etc.
- 4) MMS, chlorine dioxide (arguably quite effective but so incredibly disgusting and wearing)
See: en.wikipedia.org/wiki/Miracle_Mineral_Supplement
- 5) Liquid crystals
- 6) Homeopathies, plant tinctures, Byron White formulas and the like.
- 7) Bio resonance
- 8) Ayurvedic intensive detox and diet
- 9) Kambo and Amazonian plant medicines (incredibly and distinctly helpful)



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- 11) endless vitamins/supplements of course
- 12) The list goes on but these are the main protocols I tried and combined to varying degrees of success.

What was the impact on your life?:

It's almost like I had my 30th birthday, went into some traumatizing lucid dream and woke up with a headache at 36!

This question summons before me the immense, ineffable experience that this illness insists upon and I struggle to hold onto anything that is definite about its impact. To be honest, I have spent so long looking at the gifts that lie wrapped so deep amid the "shit" that all I ask myself normally is, "How do I grow, how do I move forward, how do I survive, how do I make this ok enough to live with it?" The answer is, it has had an immense, often constructive impact on my life. It slapped me down nearly to death and forced me look at how I was living my life; what I eat, what I think, what I feel, what I believe, how I spend and manage and build or disperse my energy, and I chose to continually focus on these aspects because it helps. But, it also totally devastated me. At one point I did try to take my life, I took a bunch of pills. All this did was give my poor body more to try and get rid of after I woke up in hospital! Another impact was the removal of friends, relationships, the ability to look after myself and my career of course. I was a professional contemporary dancer and dance teacher before, obviously lyme meant this was not an option, in fact, getting from my bed to the toilet was often the biggest dance of my day!

Now I am back to doing and teaching some dance classes and have just completed training as a Kambo practitioner with the IAKP. I am also studying to be a life coach for health and wellness along side running a small business that integrates these elements and aims to help others find health. I have energy to feel, to smile, to throw the ball for my dogs, to have a relationship and to engage in life....and there are moments i am so grateful I want to cry.

What I would like for Lyme patients:

Primarily, would like society and the medical profession to acknowledge that our foundation, structure and whole paradigm of medicine and health care is faulty and dysfunctional. There are so many illnesses that are dismissed or, labelled with names that basically mean "we don't know so we will call it...blahwe will list the symptoms and try throwing drugs at you but basically what we have in our kit just isn't up to date" (or is so buried beneath patents and investments and economy and "red-tape" its unavailable) I would like for there to be recognition of the illness, whatever name they want to give it, and education of doctors and general communities so there is more compassion and understanding I'd love to say...and funding for research, but from my viewpoint now, I



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believe that, very often, money going to research in this way is so often funnelled into all the “erroneous” streams, dragging out the illusion that we/“they” are searching for a cure when it is often not the true motivator for the insurance, pharmaceutical and “health” industry. There is a HUGE vested interest within this industry for their customers to be “sustainably sick”...unlike the old Chinese structure in which the doctor was fired if the patient got sick! I hope we can come to understand it is the conditions within the body that lead to illness, not just the bacteria and infections (that are, essentially, opportunists)! I hope the plight of Lyme sufferers can impact this system, can highlight its faults and corruption and bring more awareness and consciousness to our health industry as a whole. Individually I would like this awareness to bring more compassion, support and avenues for healing for each person with Lyme and “lyme-like” illness. Goodness knows trying to research and navigate and create your own treatment plan whilst so sick is an unearthly task. I want to see people share how they have healed and create a database that can make the process of research and seeking treatment less of a maze and can provide tangible solutions for people. Each person, each body, is unique and we find healing in a unique combination of treatments and practices. I think the hardest thing is not knowing what this may be, having to spend so much time, energy, money, hope etc trying to find it. Personally, in an odd way, this has empowered me, as I have learnt and carved my own path of healing that feels deeply important to me. However, it has been a minefield and I wish for each patient that they did not have to traverse this minefield in search of the health we all deserve.

What would you like the Lyme patients who are researching getting better to know:

I would like Lyme patients to know there are ways to heal this and urge them not to buy into the “death sentence” but to keep going with knowledge that health is possible.