

Scott Chant

Age 32

I don't mind if my submission is made public



Just a bit of background; I'm a 32 year old male, I am not married nor do I have children, but I would like to one day. I was born in Cairns, had a very happy, average, upper-middle class upbringing, great family, great friends, and never had any major health problems. I have travelled to the US, Canada, and New Zealand. I have a degree in psychological science, and am a self-confessed "science nerd". I'm addicted to science magazines, articles, journals, and documentaries, and did very well in all my science subjects at school. I enjoy(ed) surfing, camping, hiking, cycling, fishing, hanging out with friends and family, trying different craft beers, and going to music festivals and concerts. I'm a bit shy, so hate having any focus or attention on me, and prefer to do my own thing and am happy to sit back and observe in many situations, and keep to myself. As a logical, scientifically minded, proponent of evidence based medicine, I am an inherent sceptic of all things "alternative", yet I have found myself being labelled as someone who believes in "snake oil" and "pseudo-science" because I have tick-borne infections. This misconception seems to stem from the viscous cycle we have found ourselves in; it starts with the lack of adequate research, which in turn leads to the denial and the labelling by most medical professionals, which then leaves sufferers high and dry, with no other option but to seek alternative treatments out of desperation, which in turn feeds the stereotype of this being a "kooky" made up disease that attention seeking hippies use to explain any health woes.

My Story:

I was doing yard work on a property in Myocum, NSW, in August 2012. I got home, had a shower, and noticed a tiny black tick on my upper left leg, so I got the tweezers, squeezed it and pulled it out, and thought nothing of it, I'd had plenty of ticks in the past (the big grey paralysis ticks), and I thought tiny black ones were harmless compared to the big ones.

The next day there was a small round rash, about the size of a 50¢ piece, at the bite site, I'd never had a rash from a tick bite before, but still thought nothing of it (the rash persisted for a month or so).

About a week after the tick removal, I started to get flu-like symptoms such as swollen neck glands, nausea, dizziness, drenching night sweats, headache, and feeling run down. I just thought it was a cold/flu so did what I always do in that situation and took a few cold and flu tablets and waited for it to resolve itself.

Over the next few days/week, the symptoms continued to worsen, with more appearing; joint pain, spine pain, knuckle pain, diarrhea, severe insomnia, difficulty thinking/concentrating, disorientation, short term memory loss, numb/tingling fingers, irregular heartbeat/murmur, and uncontrollable outbursts of rage (which was very strange and completely out of character for me).

I decided to "doctor Google" my symptoms, because they weren't consistent with any cold/flu I'd had before, and they were becoming quite debilitating. I know doctors hate it when patients do this because there is so much room for error. confirmation bias. and

knew only to look up reputable sources and published, peer-reviewed research and journal articles.

Many things came up, but one thing that kept cropping up was lyme/borreliosis. I spent a few more days searching and finally clicked on a few lyme/borreliosis articles and saw that almost all of my symptoms matched, including the order and time of onset, then I saw that it was transmitted by ticks; that's when I recalled the tick bite a couple of weeks earlier, and thought it would not be unreasonable to investigate the possibility of lyme/borreliosis, or other tick-borne diseases.

I finally went to a GP and mentioned everything I have stated above, but as soon as I said the "L" word, his expression changed, he became quite hostile, thought I was wasting his time, and started treating me like a hypochondriac, even though I am anything but (I broke my lower leg and ankle years ago and tried to sleep it off as I thought it was just a bad sprain, I rarely go to the doctor, I always think I can just handle it, I am so far from being a hypochondriac). He sent me away with no referrals or tests, and feeling even worse than I already was.

I saw another GP and he agreed that it was probably tick related, so gave me 2 weeks doxycycline. After a couple of days on the antibiotics, all the symptoms abated and disappeared. It felt so good to feel normal again. I was glad to put it all behind me.

After the two weeks of doxycycline all the symptoms gradually started to return, it was devastating. That's when I knew I had to find a doctor who was familiar with lyme/borreliosis and other tick-borne infections. The new doctor listened to everything I said, and ordered blood tests for many different tick-borne diseases. One came back positive for borrelia from Australian Biologics. And the doctor said I also had a few symptoms he had seen regularly in patients with bartonella, especially uncontrollable outburst of rage, so made a clinical diagnosis.

I began three months of Doxycycline, Rifampicin, and Plaquenil. Again all my symptoms began to disappear, I was normal again, and could once again put this all behind me. After I completed treatment, I was good for about four months, but then all the symptoms gradually started to return again, this was really starting to take a physical and emotional toll. I then did six months of the same treatment, again, complete resolution of symptoms, however this time upon completing treatment all the symptoms returned in about a week.

So once again I went back on the same antibiotics, but they were less effective this time, and I continued to have many of my old symptoms. Now I knew I had to get even more serious about this, so I radically altered my diet. I cut out all fast food, sugar (even most fruit), carbs, and most meat, especially red meat. After about three days of this I started getting diarrhea and began vomiting uncontrollably multiple times a day, I couldn't keep any food down. So I went to my GP and got some anti-nausea tablets, these did nothing. Then got some of the wafers they give chemotherapy patients to stop them vomiting, but even these weren't enough. I continued to vomit up everything I ate for a week and lost close to 10kg. Then the mental symptoms started.

I'm still not sure exactly what caused it, and it's difficult to describe, but the only words I can think of that come even close to describing it is 'suicidal terror'. I'd had a couple of panic attacks years ago, and they were horrible, but they paled in comparison to this. It was the most horrific feeling I have ever felt, I didn't know it was humanly possible to feel like this, and it was getting worse and worse with each passing day, and I continued vomiting up everything I ate, and still wasn't sleeping because of the severe insomnia.

I called my lyme doctor and he said to stop my antibiotics because it was probably a Jarisch-Herxheimer (die-off) reaction, and to get to the hospital straight away. I felt I couldn't go to the hospital because I knew they probably wouldn't believe the whole lyme/borreliosis thing, and this suicidal terror feeling was getting worse with each passing day, and becoming completely intolerable, and I thought they would lock me in a psych ward with no way to make this extremely unbearable feeling stop. It's difficult thinking back to this now, but had I have been locked in a psych ward, I would have smashed my head against the wall until I knocked myself unconscious, just to get some relief.

I felt I had no options left, I thought about cutting my wrists but the thought of that made me feel even worse. I recalled in my research that Endep (for sleep), and Avelox (antibiotic I was going to replace rifampicin with) were contraindicated and can cause fatal heart arrhythmia, so I took handfuls of each in the hope that my heart would stop. After about half an hour, my heart felt like it was going to rupture it was beating so fast, but it was still taking too long, so I snuck out the back door so my sister (who was there to keep an eye on me) wouldn't hear me.

I went down the street, at about 10pm, to a house that had an accessible third floor rooftop area, where I was going to jump off onto my head to break my neck. It all seems so completely insane and incomprehensible thinking back to it now, but that's how desperate I was to make it stop. When I jumped the retaining wall of the property, there was a guy there putting rubbish in the bin. It starts getting blurry here but I think he said, "What are you doing?", and I replied something like, "I need to get my ball off your roof". He stopped me from going any further, so as a last resort I climbed his 2m retaining wall and the last thing I remember was seeing the ground coming up fast.

It's all a blur but I remember faint parts of what happened after that. I can remember seeing people all around me as I was lying on a stretcher bed (this is a position you never want to be in). I remember the doctor arguing with me saying I didn't have lyme or borrelia or a tick-borne disease (I must have mentioned it), while he was sticking a tube in my lung to re-inflate it, I still felt like I wanted to die, and I would have thought it was a bad dream if I didn't see that doctor a few days later walking down the hall. I would like to thank him for saving my life, but also tell him there was a reason I did what I did.

I woke up a day or two later with about 8 broken ribs, multiple pelvic fractures, fractured coccyx, and a broken collarbone. Despite this, I felt surprisingly good; the suicidal terror feeling had finally gone. I spent about a week in hospital, kept taking my antibiotics and was feeling fine. I was now taking the Avelox instead of the Rifampicin.

It took a while to recover; I had to get around in a wheelchair for a month or so. I kept taking the Doxycycline, Avelox, and Plaquenil, and was doing pretty well, friends and family visited, the nausea and sleep improved markedly, until the Avelox caused tendon pain (it's known to occasionally cause tendon rupture) and the lyme doctor took me off it and put me back on Rifampicin. I was ok for a couple of weeks but then the nausea, vomiting, and insomnia gradually returned, and so did the suicidal feeling, but not as intense.

I steadily declined over the next few weeks and months, with all the past symptoms waxing and waning, but gradually getting worse until it became unbearable again. I was suicidal everyday, looking up painless ways to kill myself, I was so incredibly mentally and physically exhausted and fragile that all I could do was lay there and stare at the fan on the ceiling, and struggle to get through each minute, day after day, week after week, month after month. If you have never felt like this, then it is impossible to convey just how horrible it was, if you had one day in my body at that time you would instantly understand, and would become suicidal too. It always felt like that really severe suicidal terror episode was just around the corner

My family was keeping a close eye on me, so I was always looking for any opportunity to take my life if it became too unbearable; like hanging myself with my belt in the bathroom, running out the door with a plastic bag I would take to a spot behind a fence and suffocate myself, or convincing my brothers or sister to take me for a drive so I could jump out of the car and run into the Brisbane River, or a creek, or a puddle to drown myself in.

I was at breaking point again due to the constant vomiting, severe insomnia, and psychiatric symptoms, so early one morning I quietly filled up a pillowcase with a few things and my antibiotics, and took my brother's car without waking him. I drove to Bunnings, bought a generator, some ventilation pipe, and some petrol. I was going to drive out to the bush for a few days, try increasing the dose of Rifampicin, and if that didn't help I was going to gas myself with the generator. Using the car exhaust is less effective these days due to catalytic converters reducing much of the noxious gases.

I called my sister because I didn't want to be alone, but I also didn't want them to stop me. The ideal situation, to me at that time, would have been to have my family there holding my hand while I breathed my last breath. I know it sounds crazy that I would even consider that an option, or that they would ever let it happen that way, but I honestly thought they knew how bad this torturous existence felt, and I thought if they understood and they loved me they would see that putting me out of my misery was the kindest option. But I'm glad they were there at that time, and the many agonizing months before and after this, because they kept me alive, they kept fighting for me when I had lost all hope.

On the phone, my sister knew what was happening, and it was one of the hardest conversations I've ever had. The other hardest ones were with my brothers shortly after. Trying to say goodbye to those you love, when all you want to do is see them, but you know they will do everything they can to stop you, while at the same time trying to negotiate the terms of your death. I cry every time I think about this, and all the pain I caused my family and friends.

My brother kept me on the phone while his partner called the police. I saw them arrive, I was in a shopping centre car park, and my heart sank and panic set in. I thought they would send me to a psych ward and my only option would be smashing my head. So I quickly took the extra dose of Rifampicin like I had planned, and the police came up and asked questions and put me in the back of their car to take me to the hospital. I don't know how I did it but I managed to keep my cool, if they really knew how suicidal I was they would have cuffed my ankles.

We got to the hospital and they said I had to stay for a few hours, I didn't know how I was going to make it that long. My brothers and sister arrived, it was hard. The nurse or psychiatrist (I think he was), came over and reviewed everything and asked me a few things, and I said I've got Lyme/borrelia, he said he had some infectious disease training and there was no possible way I could have that. I stayed calm and was eventually discharged with a follow up for a psychiatrist there in a couple of days. So I saw the psychiatrist, he read my forms, asked me a couple of questions and after about 5 minutes, he said "you're not going to want to hear this but you've got OCD", I said "so it's all in my head?", and he just shrugged. I left feeling awful.

Over the next few weeks and months I kept taking the extra dose of Rifampicin, and gradually the constant nausea, vomiting, insomnia, joint pain, drenching night sweats, dizziness, chronic fatigue, brain fog, short term memory loss, etc. all started to improve but not completely resolve. I had good and bad days over the year, but seemed to plateau at about 70% and could never quite get back to 100%. I started seeing a new Lyme doctor

hypoperfusion, various deficiencies, and other compounding issues. Now we've changed Doxycycline to Clarithromycin, and this gave me about a 10% improvement, then changed Rifampicin to Mycobutin which gave me another 10% improvement, but it is very expensive at \$700 a month, plus the other antibiotics, antidepressants, and supplements to support my system and repair some damage.

I knew I was clearly still infected with something but I didn't know exactly what, I just wanted someone to look at my blood under a microscope and see what was there, I was sick of hearing about all the false positives, false negatives, and cross-reactions, I just wanted some clear answers. So I found out the National Institute of Integrative Medicine in Melbourne specialised tick-borne infections and testing, including DNA/PCR, and blood filtration, staining, and microscopy, but only for research purposes; it was better than nothing. I tried going off antibiotics for the tests but declined so much within a few days that it wasn't an option.

Got the results back and microscopy showed what looked like a lot of rickettsia bacteria, and the PCR came up positive for rickettsia also. So we ordered Medicare covered tests through Melbourne Pathology. It came back positive for Rickettsia Honei, Rickettsia Rickettsii, and Rickettsia Typhi. This was a shock as rickettsia had been ruled out long ago since I had gone far above and beyond the standard treatment of two weeks Doxycycline; I had been on Doxy for over six months straight at one point.

So now with the help of two excellent doctors, we are trying to figure out exactly what is going on, and why these usually easily treatable diseases are so resilient in my case. We are trying different approaches, working on my immune system, and going to try different antibiotics. I am gradually getting better, it has been a long hard road, but I can finally see a light at the end of the tunnel. I would be dead without the antibiotics, support from my family and friends, and the brave doctors who are risking everything to treat people like me.

This has all been an extremely traumatic, emotional, and expensive experience. I'd hate to think what things would be like without the love and support of my family and friends, and the huge financial assistance from my parents. If I didn't have access to enough money for all of this, I wouldn't be here today to share my story and I hate to think how many people out there have "mystery" illnesses that are actually tick-borne infections, ruining them and their family in every conceivable way. I'm just one case, I know for a fact there are many others with very similar stories because I have met and talked to them. I know why suicide is common with these diseases, especially those who have been misdiagnosed or undiagnosed for years or even decades, because the symptoms become absolutely unbearable, and access to treatment and support is so expensive and difficult to find.

We need to educate the public, because this can happen to anyone. We need to educate GPs and infectious disease doctors to better recognize the symptoms of tick-borne infections, because they are often the first line of defense, and could potentially prevent years of heart ache, suffering, and use of resources. And we need to study patients, vectors, and hosts to determine exactly what we are dealing with here, how many pathogens can infect humans, and why some people remain ill with active infections while others get better.

I could harbor much resentment toward those doctors who have treated me as though I was a hypochondriac and an unnecessary burden on their profession, but that would just be wasted energy. This is a much bigger problem than any individual doctor, they are just doing what they are trained to do and have enough on their plate already without worrying about every possible medical controversy; rather, this is a system failure. From the top down, there are flaws, massive room for improvement and it all stems from the lack of adequate, extensive research

Until the results of research become available, the best we can do for these patients is to treat them as though they have a chronic tick-borne infection, if all other possibilities have been ruled out, and ESPECIALLY if they gradually become much worse when treated with immunosuppressive drugs such as steroids, and ESPECIALLY if they respond to antibiotics, or other tick-borne infection treatments, which almost always includes the Jarisch-Herxheimer reaction.

This is a clear pattern among these patients (myself included), as whenever I start an effective treatment I immediately feel worse as the bacteria die off and release endotoxins and then I gradually start to improve. I have been admitted to hospital twice due to severe Jarisch-Herxheimer reactions after beginning new treatments, the symptoms of which include uncontrollable vomiting, diarrhea, migraines, shaking, very rapid heart rate, severe anxiety, and everything else you would expect from a form of sepsis. Each time I've been admitted, I had to explain to the doctor what a Jarisch-Herxheimer reaction was, even though it is in the medical literature, but they have been very understanding.

Inflammation also seems to be a big part of this, so I'm not sure if tests could be developed to identify the specific inflammatory markers, cytokines or endotoxins of these diseases? We also need to protect the doctors who are doing everything they can to help these people, because they are the only thing that stands between us and more suffering, death or suicide.

There is enough evidence to justify further investigation and enough evidence to indicate this is a growing problem. Do we want to wait another 20 years until it is so bad and costly to fix that it will take us by "surprise"? Or do we want to do something about it now, before it becomes a public health crisis? Australia could be leading the way in tick-borne disease research, as we are so familiar with ticks and so many of us have been bitten or are in situations where we could get bitten. We have so many ticks here that if we had the population size of the US, we would probably be number 1 in the world for tick-borne disease cases.

Here are some excerpts from a recent article in my favourite science magazine, Scientific American, about the spread of lyme disease in North America:

*"One of the clearest signs of health risks in a warming world has emerged in one of the world's most advanced economies, as Canada belatedly struggles to cope with Lyme disease's migration in North America"*¹

Do we want to see that headline in our own country in 10 years time? But I think it will read something like: "Spread of endemic borreliosis and other tick-borne diseases take Australian health authorities by surprise"

Pathogens, by their very nature, spread. From the same article:

*"The messaging [has an] over-emphasis on high-endemic areas and low-endemic areas," Wilson said. "That's all nonsense when you have a disease that is randomly transplanted by migratory birds."*¹

Another recent article about the difficulty in diagnosing, detecting and treating borreliosis/lyme, due to the tenacious nature of the bacteria, and their survival mechanisms:

"... the tests used by the public health service do not detect it... two experienced biologists [studying bacteria for over 50 years] at Oslo University... believe, contrary to the official stance, that the antibody reaction wanes in people who have been sick for a long time, and that only a small minority of those with chronic borreliosis test positive. The Danish infection

reasons that it is difficult to give a definite diagnosis... Through intensive studies over many years, the two biologists have formed a picture of the life cycle of the Borrelia bacterium and all the different forms that it takes... The Norwegian health service believes that a four-week course of antibiotics should be enough to kill all Borrelia bacteria in the body, but it is not that simple, according to the two biologists... As soon as the highly motile and active bacteria experience a deterioration in their living conditions, they form cysts, which are the dormant stage of the life cycle. Bacteria may also aggregate in colonies in a slime called a biofilm. This protects them from external threats such as antibiotics, disinfectants and the body's own immune system. When the environment is favourable once more, the Borrelia bacteria revert to their usual spiral form..."²

Perhaps we could implement the techniques these scientists have developed, as they would be much more reliable than current tests:

"Because the bacteria go through many stages in their life cycle, as cysts, "pearls" and various thread forms, it is easy to confuse them with parts of disintegrating cells or with other bacteria. Moreover, Borrelia bacteria are gram negative, i.e. they have thin cell walls and are therefore difficult to stain. This also makes them difficult to detect in cells and tissue. When, for example, a blood preparation is made at a clinic, the bacterial culture is smeared on a slide and dried. Light refraction is then identical inside and outside the bacteria, not making them visible. Often there are only a few bacteria in each preparation, and they are therefore easy to overlook. By developing some smart microscopy techniques, researchers have now succeeded in making the Borrelia bacteria stand out clearly - including in the blood of individuals who have no symptoms of disease."² - they go into detail about the technique they have developed in the article.

Another interesting comment from the researchers:

"We know that Borrelia can infect any part of the body. If the blood tests used by the public health service do not detect the bacteria effectively, it makes one wonder how many people have had their lives destroyed by a single blood transfusion. Borrelia is closely related to the deadly bacterium which causes syphilis, and we cannot exclude the possibility that Borrelia is also transmitted by sexual intercourse"²

A final thought from one of the researchers:

"I have pointed out a problem that nobody has taken very seriously, in my view - at least not many doctors."²

Another article highlighting the high costs and misconceptions surrounding this disease, even in the U.S. where it was once considered (and still is by some) to be a simple infection in every case:

"Lyme disease, transmitted by a bite from a tick infected by the Borrelia burgdorferi bacteria, had long been considered easy to treat, usually requiring a single doctor's visit and a few weeks of antibiotics for most people. But new research from the Johns Hopkins Bloomberg School of Public Health suggests that a prolonged illness associated with the disease is more widespread and serious in some patients than previously understood. With an estimated 240,000 to 440,000 new cases of the tick-borne illness diagnosed every year, the researchers found that Lyme disease costs the U.S. health care system between \$712 million and \$1.3 billion a year."³

From the same article; calls for a compassionate approach to dealing with sufferers of this

"Some doctors call those persistent symptoms post-treatment Lyme disease syndrome (PTLDS); others call it chronic Lyme disease... "Our study looks at the actual costs of treating patients in the year following their Lyme diagnosis," says study author Emily Adrion, MSc, a PhD candidate in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. "Regardless of what you call it, our data show that many people who have been diagnosed with Lyme disease are in fact going back to the doctor complaining of persistent symptoms, getting multiple tests and being retreated. They cost the health care system about \$1 billion a year and it is clear that we need effective, cost-effective and compassionate management of these patients to improve their outcomes even if we don't know what to call the disease."".³

What these articles show is that there is much we still do not know about tick-borne infections, specifically borrelia. I'm sure our local science and medical media would have the exact same articles if more time and money were dedicated to researching vector-borne diseases in this country. It would be an investment into the future health of Australians, rather than sitting back and waiting until it is an even bigger problem, with an even bigger price tag.

The following two links also highlight what little we know about tick-borne pathogens in Australia:

<https://www.mja.com.au/journal/2012/196/5/first-report-human-babesiosis-australia>
(Many people testing positive to borrelia in Australia are also testing positive to babesia; another tick-borne infection.)

<http://media.murdoch.edu.au/researchers-closer-to-ending-debate-around-lyme-disease-and-ticks-in-australia>

There is also a false belief that anyone with this illness is just suffering from Chronic Fatigue Syndrome (CFS). CFS, in many cases, is just a blanket diagnosis for when they don't know exactly what is wrong with you. CFS is a symptom of the problem, not the problem itself. Every time I have been treated, the CFS gradually clears up, along with all the other symptoms. And it wasn't that long ago that most doctors (and many still do) thought that CFS was a made up ailment; they thought it was purely behavioral and psychological in origin. It was the same with ADHD and autism; when we don't understand something, the fallback position tends to be to blame the person with the disease or disorder. And why choose to focus just on the chronic fatigue side of it; there is also chronic pain, chronic insomnia (this combined with CFS is torture), chronic gastrointestinal issues, and a whole host of other chronic symptoms, most of which are consistent with bacterial infections, and respond to antibiotics.

It seems like those who deny there is a problem in Australia start with the idea of CFS (or a psychological disorder), then cherry pick information thereafter to fit in with this false diagnosis, with very little evidence to back up their position, which is exactly what they accuse us of in the first place! (I tried to avoid using exclamation marks, as I wanted to keep this purely factual, but it just gets beyond the point of frustration. Many, many people are suffering, and many are committing suicide while we wait and constantly fight for help and answers; answers that only research on vectors, reservoirs, and patients can provide)

Thank you for taking the time to read this. I would like to leave you with one of my favourite quotes:

"All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident." ~ Arthur Schopenhauer

How many times have we seen this occur in science and medicine when something doesn't fit the mould or the textbook definition, yet we somehow think it couldn't happen in this day and age... at least that's what I thought, until this happened to me.

Warm regards

Scott Chant

References:

1. <http://www.scientificamerican.com/article/lyme-disease-surges-north/>
2. <http://phys.org/news/2013-06-classic-microscopy-reveals-borrelia-bacteria.html>
3. <http://www.sciencedaily.com/releases/2015/02/150205095049.htm>