

To whom it may concern;

I would like to share the complex chronic health issues that I have endured and cite them as being the reason that I am making a submission for there to be action taken for people like myself to access serious detailed testing, diagnosis and treatment of the variety of tick borne diseases that have been proven to be evident in Australia. This would provide a huge relief to myself specifically, with regards knowing IF my symptoms were a result of the multiple occasions I had been bitten by ticks.

In any other country my symptoms and health history would be investigated for Lyme disease or other tick borne illnesses and yet when we ask medical professionals in Australia to consider this as a possible cause we are rebuked.

My personal experiences began 20 years ago when I moved from Sydney to Byron Bay.

I was living in an area where ticks were rife and I was continuously finding tick craters in my skin. Many were nymph ticks that left black craters.

In 2006 I had a sudden attack of foot drop which lasted a week, extreme pain and following that gradual loss of feeling in the soles of my feet. Numbness and burning pain, pain like hot needles.

At the time three doctors at the same surgery suggested I may have MS, which was terrifying.

I was sent for a brain MRI, which did not show anything significant. I still had no answers.

In the years following this, I continued to lose feeling, experience strange nerve issues and burning pain.

I never regained the loss of feeling in my feet. I also had issues with my stomach and was treated for *Helicobacter pylori*. I was only 42 at the time.

In 2013 I left Byron Bay and moved to Melbourne, partly to access better medical care as I still had no idea what was wrong with me and I felt that being in a city would be safer. I stopped driving a car as the numbness in my feet became a problem.

After my first year in Melbourne I experienced extreme pain in my hips and spine, it was excruciating.

For a whole year I saw my doctor with continual unexplained pain and was eventually sent to the infectious disease clinic at RMH.

This doctor was the only doctor I spoke to who did not shut me down when I asked about the possibility of Lyme like illness and we discussed biofilms and Lyme disease but there was no testing available and it was not investigated.

The pain and symptoms got worse which culminated with visits alone by tram, to the emergency dept a few times as the pain was so extreme.

On one visit there, I overheard the doctor saying "she is clearly mad and needs to go home" I gave him a piece of my mind and then I made an official complaint.

By the end of 2014 I could not swallow solid food or eventually swallow my own

saliva.

It was discovered I had osteomyelitis of the spine at T2-T3 I was immediately brought into hospital as an emergency patient.

It was too dangerous to operate at the site so I was put on a six month course of antibiotics.

None of the specialists knew what or how this had happened to me and it was unusual for someone my age to have this.

In the last twenty years I have had continuous periodontal issues, regular swollen glands, aching bones, joint pain, reynauds disease, lichen sclerosis, hashimotos thyroiditis, hair loss and depression. My ankles and feet swell up and it has become harder and harder to walk.

At night the pain migrates around my body, my hands go numb and on one occasion I woke up to find that my whole left arm was dead, I had to physically lift it up and massage it to regain feeling.

If I stub my toe I get an immediate electrical shock in my head.

When I stand up my legs feel they are not attached to my body and I have blood pumping through my ears.

I have been diagnosed with fibromyalgia which in itself is controversial and sometimes having that diagnosis means that GP's do not take my symptoms seriously.

Even with nerve conduction studies that prove there are issues. I have been gaslit more than once.

Every day is different but there is always something to create havoc. I have trouble sleeping and anxiety, I suffer from exhaustion.

Last year I had an auto immune attack that gave me burning pain all over my body and scalp, like being bitten by fire ants. Along with that came pulsatile tinnitus that lasted a week and then disappeared.

I had my hearing checked but it was fine and then I started losing my hair.

The effect on my emotional state has been a long term battle, I live alone and I am single and so there is not one else to support me or care for me if I am struggling. I have enormous anxiety around my mortality as for so long I have just been told "you might never know what is wrong" and yet, to me there are stones that have been left unturned.

Every time I read a story about Lyme I think of my own symptoms and the fact that just mentioning this disease to a doctor can get a reaction that can only be described as aggressive or defensive.

There is NO acknowledgement of this illness being a possibility.

If one person in this country has been diagnosed with Lyme disease, then Lyme disease exists here.

It is not hard to check whether people have been overseas.

I wish that doctors were more aware of how deflating and depressing it is to be told continuously that one might never know what is wrong with them.

In never knowing what is wrong, we can never know how to treat ourselves.

Another point I would like to make is that I have been unable to work or find work and I do not know how to adequately explain my health issues to a potential employer, a Government department, Centrelink. A job network provider, a new doctor or any health professional. What I have has no name and no diagnosis. This is possibly one of the most distressing aspects of this chronic health issue. Every time you see a new doctor you have to spend half an hour explaining it all and you leave feeling wretched.

There is quite a lot of talk about 'Invisible diseases' and how distressing they are, this is a good example of the psychological effect of struggling with an infectious disease.

Trying to explain symptoms and give names to something that has not been named. The cost involved in managing multiple health issues and the stigma, the emotional impact and mental health issues that crop up in tandem.

The lack of knowledge amongst GP's with regards auto immune issues.

The lack of affordable mental health care as this takes its toll and friends and family have listened and still have to live their own lives one can not continually bombard them.

Thankyou for considering my story and please view it as honest lived feedback and a plea to research more into these isolating issues.

Please fund centres here within Australia to provide testing for Lyme and tick borne illnesses that we know are present in animals and have shown up in humans.

Australia is the perfect terrain for ticks and more research needs to be done into the connection between tick borne disease and many other chronic health issues.

Regards