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Medically abandoned in Australia

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Lyme Disease Association of Australia

Introduction

An increasing number of Australians are becoming chronically ill after a tick bite. The situation for many, is dire. For nearly a decade, the Lyme Disease Association of Australia (LDAA) has been working to highlight the plight of thousands of people who have been diagnosed with an illness that resembles Lyme disease; which the Australian Government elusively labels Debilitating Symptom Complexes Attributed to Ticks (DSCATT).

Patients find themselves in an uncertain medical situation, which is complicated by a lack of acceptable and definitive diagnostic and specialist practitioners. Many patients arrive at a diagnosis through a process of exclusion. Often, years of unexplained illness and debilitating symptoms have led them down the path of multiple diagnoses and associated medical tests resulting in piles of empirical evidence that charts their decline into chronic illness that impacts their lives in ways that are incomprehensible to most people.

For many patients the day of diagnosis is bittersweet. They are relieved to have a name for the illness that has plagued their lives, but they are also anxious because no one understands their illness and doctors are ill equipped to support them. There is little assurance or evidence to show that their illness can be brought under control; there are so many unanswered questions. This is the uncertainty that patients with a Lyme-like illness in Australia face.

The uncertainty for patients is compounded by the international controversies that surround Lyme disease. The controversy emerges with a diagnosis because the disease often mimics other chronic diseases and continues with the nomenclature used to describe the illness. Diagnostic processes are widely debated, and testing protocols designed for surveillance are used as clinical determinants. There are two opposing views on the length and type of treatment and research can support either side of the argument. Australian authorities have imported this controversy.

Prevalence

There is no official data that may help to quantify the size of the 'Lyme' problem in Australia. There has been no epidemiological study or surveillance mechanism established. Some evidence of the prevalence and geographic distribution of emerging Lyme-like illness is reported in scientific literature (525 cases). Despite the reports of people suffering serious illness following tick bite, many of the case reports are dismissed.¹

The LDAA has been collecting information from patients identifying with a Lyme-like illness for the past six years. The data indicates that Lyme-like illness is non-discriminatory. It can affect anyone in major cities, urban, regional, rural and remote locations. Using the Australian Statistical Geography Standard (ASGS) Volume 5—Remoteness Structure classifications, the data shows that 33 per cent of patients with a Lyme-like illness live in regional, and remote areas of Australia as presented in Table 1.

Table 1 Location of Australians reporting a Lyme-like illness

	Location of Australian patients by Remoteness Area Classification											
	Major Cities		Inner Regional		Outer Regional		Remote Australia		Very Remote Australia		Total	% of Total
ACT	40	2%		0%		0%		0%		0%		
NSW	555	22%	241	9%	51	2%	2	0%		0%	849	33%
NT		0%		0%	26	1%	8	0%		0%	34	1%
QLD	359	14%	128	5%	61	2%	8	0%	3	0%	559	22%
SA	78	3%	12	0%	8	0%		0%		0%	98	4%
TAS		0%	29	1%	12	0%		0%		0%	41	2%
VIC	383	15%	143	6%	12	0%		0%		0%	538	21%
WA	312	12%	34	1%	61	2%	12	0%	3	0%	422	16%
Total	1727	67%	587	23%	231	9%	30	1%	6	0%	2581	100%

N = 2581 number of Australians reporting a Lyme-like illness to the LDAA as at December 2017

Internationally, the incidence of Lyme disease is on the rise. The US recently updated its surveillance figures by 900% estimating more than 300,000 new cases per year.² The LDAA also tracks and reports on prevalence rates from 39 other countries; this data shows a mean global prevalence of 5.8 per cent.³ As such, it seems highly implausible that Australia is the only continent without this disease.

If Australia were to use a similar prevalence rate to that reported in the US, over the past 20 years there may be up to 496,153¹ Australians who've acquired a Lyme-like illness. In 2019, that equates to almost 24,000 cases annually. This is more cases than breast cancer and 20 times more than the reported cases of HIV/AIDS and multiple sclerosis (MS). These numbers likely underestimate the true incidence of Lyme-like illness in Australia given a lack of appropriately trained medical practitioners, and unreliable diagnostics. Australia could be looking at a large-scale undiagnosed epidemic which echoes the rising prevalence rates in other parts of the world. An official study of the prevalence and incidence of Lyme-like illness in Australia is well overdue.

Australian challenges

Isolating the pathogen[s]

The presence of *Borrelia*, the causative agent of Lyme disease, was established in Australian fauna in 1959 and human cases of Lyme disease have been reported since the 1980s. Australian authorities ignore this evidence. No investment into research on Lyme disease, its causative agent or its aetiology has occurred in Australia for twenty years. In that time there has been seven new *Borrelia* genospecies isolated internationally, bringing the known genera to 53 in total.³ Of those, 15 *Borrelia*'s are proven to cause Lyme Borreliosis and 28 cause relapsing fever. Recent investments into research in Australia isolated several novel pathogens and an indigenous species of *Borrelia*.^{4,5,6} These studies demonstrate that Australian ticks are full of pathogens; many that are known to cause disease in other parts of the world. Until a government announcement⁷ in 2019, there had been no investment in, or priority placed upon, the clinical study of patients.

Diagnostic protocols and testing

The recommended diagnostic protocols, processes and tests used in Australia are inappropriate. The pathology tests required in Australia follow a two-tier protocol that was never intended for diagnostic purposes in the US or Australia; it was devised for US surveillance. The criteria used to determine a positive test result under the US two-tier regime is neither defined nor consistently used to interpret Australian samples.

Australian laboratories produce discordant test results.⁸ As a result, patients routinely send their blood overseas for testing in specialist laboratories at significant expense. International laboratories commonly used by patients meet the highest international standards and are, under our international agreements, eligible for reciprocal recognition through the National Association of Testing Authorities (NATA), yet their results are dismissed. The responsible authority for pathology testing influences this sentiment by using an eminence-based argument⁹ suggesting overseas tests are not validated, despite a National Serology Reference Laboratory study¹⁰ demonstrating that tests performed by overseas laboratories are more reliable.

Beyond the symptoms: the stigmatisation and discrimination of living with this illness

The controversy of being diagnosed with Lyme disease, or Lyme-like illness, creates stigma. The stigma is broadly underpinned by the language used to define, discuss and deny the illness. Much of the language in Australia is derogatory. Simply, the word 'Lyme' carries with it a construct of dogma and controversy, which is further exacerbated by the elusive labelling of the illness as DSCATT.

Patients are told that Lyme is a 'fashionable organism' and that they are 'disillusioned with doctors' because they seek answers to their increasingly debilitating health problems. Some doctors refuse to have anything to do with patients who have a Lyme-like illness because of this stigma and the associated medico-legal threat.¹¹

Rather than solving a problem intelligently, the use of derogatory language in association with Lyme-like illness influences others and further polarises the debate. Much of the stigma evolves from ignorance and it is significantly detrimental to patients as it carries with it the implication that there is something discreditable about the patient.

Lack of education

The Australian medical community is undereducated on emerging illnesses that can follow a tick bite. They are reliant on official information that is inadequate and outdated. They need better support, contemporary and translational research and unambiguous guidelines that keep pace with emerging research. They also need support to manage their patients through practices that recognise the clinical burden these patients present. A sensible dialogue that captures the emerging clinical situation and helps identify the gaps in our collective knowledge is desperately needed.

"All of us, including health professionals, perceive certain conditions and disabilities as particularly stigmatising, an obvious example of this being HIV/AIDS. When a disease label is attached to a person, in our instance Lyme disease, the very label itself has the power to 'spoil the sufferer's identity'; both personal and social.... Therefore the ripple effect of health stigma is vast and can severely impact a patient's ability to source appropriate treatment, testing and essentially recovery."

<https://www.healthknowledge.org.uk/public-health-textbook/medical-sociology-policy-economics/4a-concepts-health-illness/section3>

According to the World Health Organisation, vector-borne disease, including Lyme disease, is entirely preventable through the development of informed protective measures.² The Australian community is undereducated about the risks associated with tick bites. Information and education about the prevention of tick-borne disease with advice on protection strategies is urgently needed.

The patients

The LDAA compiles data from patients about their experiences in several fora. Online surveys provide insights into patient experiences, web-based reporting underpins a geographical analysis of people who have become sick after a tick bite and the location of the tick bite, if known. Qualitative research provides a rich and detailed picture of patient experiences and gives insights into the burdens they endure.

Lyme-like illness is indiscriminatory; it's everywhere and can affect anyone. An overview of the types of patients presenting in Australia is provided at Figure 1.

Figure 1 Australian patient presentations



The patient experiences we examined tell a very disturbing story. Patients report they are regularly denied treatment by local doctors, specialists, emergency departments and allied health professionals, entirely because they have a Lyme-like illness—this level of discrimination, and inability to get adequate treatment echoes the treatment of HIV & AIDS sufferers in the 1980s.

Most patients know the location of where they were bitten and can subsequently plot the onset of their illness. There are cohorts of Australian Lyme patients who have never left the country and many patients who have acquired Lyme disease from endemic areas overseas. For most patients, reaching a correct diagnosis is tedious and expensive. On average patients see more than 13 doctors, taking ten years from the original tick bite to obtain a diagnosis.³ This means that patients are likely to progress to a chronic debilitating stage before they are properly diagnosed.

The burden of illness, measured by quality of life impacts, is substantial. Nearly 30 per cent of patients rely on a carer (generally a family member becomes the 'carer'); a quarter of patients can't drive or leave their home unaided, and some are totally isolated, unable to leave their homes at all.³

Patients report difficulty in finding a non-discriminatory doctor who is able and prepared to treat them. Nearly ten per cent of patients go overseas for treatment. Those that can't afford overseas treatments are left to travel, sometimes distances of more than 500km (25 per cent of patients), to an urban practitioner with experience in treating tick borne illness.

"I was an active and healthy man. I had a full time job and did lots of extra shifts. Until, at 45, I started to feel unusually tired. I couldn't function. I had numbness and tingling in my arms and legs. After a few investigations with no sensible explanation, I was told I was crazy and my symptoms were all in my head"

- Bob, 52

For the 33 per cent of Australia patients who are in regional or remote areas, access to health care compounds their burden of illness and impedes their chances of recovery.

Most patients report they took extended time off work, school or study; with 64 per cent of patients reporting they had to leave their jobs, school or exit their study.

Financially patients are in a dire situation with 65 per cent spending their entire savings on health care and 11 per cent report selling their family home. The LDAA's analysis of patient submissions to a Senate Inquiry found that the out of pocket medical costs were \$42,561 per patient, with a combined total of \$2,725,881.¹² Patients who reported their loss of income gave a combined value of \$1,768,031; with the average loss of income per patient being \$43,122. Some patients report multiple family members are affected by a

Lyme-like illness, compounding their burdens significantly.

The burden of treatment is unmanageable for many. Patients facing a loss of employment income; financial hardship and relationship breakdowns are poorly positioned to manage their declining health. They are particularly vulnerable. When faced with discrimination, they lose their dignity and become depressed. Patient submissions recount appalling stories of the disrespectful and discriminatory treatment experienced in medical consultations especially with infectious disease specialists.

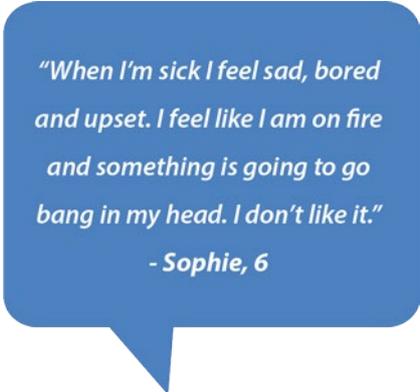
Access to health care, diagnostic investigations, therapeutic regimens and mobility aids all contribute to the burden of illness. As Lyme-like illness is not properly defined in Australia, many of

"I got a tick bite and felt really sick after it. I had a bull's eye rash but didn't understand its significance then. My health gradually deteriorated. I couldn't walk unaided and couldn't drive. I suffered in pain every day. I was severely depressed"

- Lee, 58

the internationally accepted treatments rely on 'off label' prescribing where patients bear the burden of cost, which is further exacerbated by the abolition of out-of-pocket medical expense tax rebates.

Children lose their childhood. Some suffer daily seizures that prevent their schooling, they have no social contact and their lives are defined by a series of treatment events. Around the world children are significantly unrepresented in Lyme disease statistics and Australia is no exception. The LDAA data reports on 87 children, many who do not attend school due to their illness. The long-term impacts upon these are unknown and a longitudinal study of their progress would be welcomed. Some young people live in the residential aged care system as they are unable to care for themselves independently.



"When I'm sick I feel sad, bored and upset. I feel like I am on fire and something is going to go bang in my head. I don't like it."

- Sophie, 6

There are over six hundred patient stories published as submissions to the 2016 Senate Inquiry *Growing Evidence of an Emerging Tick-borne Disease that causes a Lyme-like Illness for many Australian Patients*. The following is a brief glimpse of the impact that a tick bite has had on five Australians. They are five out of thousands of patients who have been medically abandoned in Australia.

Mandi

Mandi is 31 years old and now lives permanently in an aged care facility, after living her early life in regional NSW. She is mother to an 8-year-old she cannot physically care for. Mandi suffers bouts of paralysis of various body parts, including her arms, and her speech is frequently unintelligible. Socially isolated, she is frightened. She's been ill since her teenage years—almost half her life. She says: "I haven't finished the education I planned, embarked upon the career about which I dreamed, saved money for a rainy day or for my son's education and healthcare, or been able to access adequate or timely care to restore me to health ... I have signed Do Not Resuscitate documents". Clinical evidence aside, Mandi has multiple positive results from NATA accredited laboratories, including for *Borrelia burgdorferi*, and *B. afzelii* as well as *Bartonella*, *Brucellosis*, *Leptospirosis*, four strains of *Rickettsia*. She has SPECT scans that explain her cerebral symptoms. The NATA accredited laboratories claim that her positive results are "false positive".

Karen and René

Karen lives in outer regional Victoria, has never left Australia and has a history of multiple tick bites. Blood tests reveal a 9-year history of elevated white blood cell count, an indication of infection. Analysis of her blood by a NATA accredited laboratory reports multiple strains of *Rickettsia*, however three separate tests, on her single blood sample, returned conflicting results. Some of the symptoms Karen suffers are pain like "ripping muscles off bone", insomnia, night sweats, brain fog, uncontrollable shaking of her right arm, and she relies on a walking stick for mobility. Karen was clinically diagnosed with Lyme-like illness and co-infections by a GP experienced in tick-borne infections. The GP reported damage to her myelin sheath, a sign often attributed to Multiple Sclerosis or ALS. Before Karen could start treatment, the Australian Health Practitioner Regulation Agency placed conditions on her GP's license specifically preventing the treatment of Lyme-like illness. Karen is unable to find another treating doctor that is accessible.

In 2016, her husband and carer, René also became ill, with severe muscle spasms, night sweats, nausea and fatigue. His muscles began to deteriorate, and he has been diagnosed with the

neurodegenerative disease ALS. Like Lyme-like illness, this condition is clinically diagnosed; there are no definitive laboratory tests. Karen says:

We haven't begun to have a proper life together, I was supposed to get better, we were supposed to press ahead with our hopes and dreams, and I'm being told it is never going to happen, that the man who has been my tower of strength, my rock for the past ten years is going to be taken away from me. That we only have 6 months to 2 years left together ... When René passes away, I will have nothing ... I'm too unwell to live alone. We have no life; every day is Groundhog Day. No hope for the future, our dreams have turned to dust. There is no longer any justice or compassion in this country.

René is now in palliative care.

Natalie

Natalie is a 44-year-old woman living in outer regional NSW. While working for National Parks & Wildlife on the Northern NSW Coast in 2002, Natalie found 110 nymph ticks on her body. Over the next seven years her health deteriorated. Within one week of another tick bite in 2009, she was bedridden and no longer able to function, too unwell to care for her young daughter who is now out of her care. Over the years Natalie pursued treatment in Australia without success, so she used her life savings to travel overseas for treatment. She responded well, indicating that with continued treatment, her condition would improve and stabilise. Sadly, Natalie couldn't afford to continue treatment and over time, she lost the gains she had made. She is now facing a life-threatening decline. Natalie's cartilage is now so badly damaged by Lyme disease she can no longer lift her head and suffers severe pain, loss of arm function, brain inflammation and meningitis, breathing difficulties and impaired sight. Partial seizures and paralysis leave Natalie isolated and unable to communicate. As well as testing positive to Lyme disease in multiple laboratories in Australia and overseas, Natalie tests positive to nine other infections and viruses, indicating a non-functioning immune system.

Rebecca

At 32-years old, Rebecca is permanently hospitalised, unable to eat or drink or walk. Rebecca's eight-year-old son and two daughters, aged 10 and 12, are cared for by relatives. In 2014, the year she was bitten, she was "working two days a week, studying three days a week, plus looking after my kids ... I had no medical issues, no mental health issues, nothing like that. I was happy, healthy." she says. Within 24 hours of finding a tick on her stomach while holidaying in Kalbarri in outer regional WA, she was hospitalised: "It started with my leg getting a bit sore. Then I thought it was gastro ... then I lost control of my bladder." After being hospitalised three times during her holiday, she was transferred to Geraldton, then Armadale. Rebecca was eventually sent home with an "unknown virus", no one looked at her tick-bite or the associated bull's eye rash. Rebecca suffers violent painful seizures, that sometimes result in temporary paralysis. Rebecca has positive results for Lyme disease from two NATA accredited laboratories and one German laboratory. Rebecca has never travelled outside Australia.

All patients suffer the effects of stigma and some tragically take their own lives. There exists a serious gap between the medical community's acknowledgement of Lyme-like illness and the reality of the Australian patient situation.

Conclusions

Thousands of patients are becoming increasingly debilitated as our medical and scientific community ruminate on a causative agent[s], appropriate diagnostic tools, case definitions, and treatment guidelines. Legacy thinking and cognitive dissonance underpin widespread ambivalence in the medical community and reinforces the apathy of policy makers who fail to properly investigate the issue, increasing the risks for Australians.

A progressive and contemporary approach to this problem is urgently overdue. Recent developments in molecular technologies and next generation sequencing provide for new frontiers in discovery. Fully informed and proactive medical professionals, medical colleges, state, territory and commonwealth health organisations can stem the flow of every day Australians declining into sickness, disability and death.

On behalf of all patients with Lyme-like illness, we implore the National Rural Health Alliance to take a leadership position on this issue and make recommendations that prioritise immediate action for patients. By working together, we can acknowledge the warning signs, leapfrog old thinking, apply innovative medical technology and design solutions for what is being described as the first epidemic of climate change.¹³

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Presenter

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