

## Bad Blood by Fenella Souter

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Tick-borne Lyme disease is curable, but left untreated can become crippling. The government insists it doesn't exist here, yet a growing number of Australians are convinced they have it, and some experts are prepared to back them up. Fenella Souter investigates.

If grief and loss crush some people into mute acceptance, Mualla Akinci McManus isn't one of them. Small and rather fierce, Akinci McManus is like a fast-talking, low-slung avenging angel, and what she lacks in height she makes up for in blunt determination.



Karl McManus

Since her husband, Karl McManus, died in July last year, she has been on a mission to prove that Lyme disease, or a Lyme-like disease, passed to humans by infected ticks, exists in Australia and led to her husband's death. Hundreds, perhaps thousands, of Australians suffering from a constellation of mysterious, painful and debilitating symptoms following tick bites agree with her and say they're being denied treatment because doctors tell them they can't have the disease. Early treatment with antibiotics can generally stop the illness in its tracks, while delay can allow it to progress, invading, in severe cases, every organ in the body. Health authorities insist there is no "conclusive evidence" that Lyme disease occurs in Australia: few

people have tested positive in government-approved labs, and our ticks haven't been found to carry the *Borrelia* bacteria that cause Lyme (which is more correctly known as Lyme borreliosis). Still, the last government-funded research that looked for *Borrelia* in Australian ticks, and failed to find it, was undertaken 17 years ago.

Nothing about Lyme disease is simple. As one US Lyme website argues, there isn't a disease in the past 100 years that has polarised the medical community more than this one - and that's in a country where its existence has been officially recognised for decades. For a start, Lyme can be a notoriously difficult disease to diagnose accurately. The bacteria, or its antibodies, often fail to show up in blood tests, depending on the stage of the disease; it can hide in other parts of the body; false negatives or false positives are common, especially in places where the disease is rare.

In known Lyme areas, controversy rages about whether it's being over- or under-diagnosed. There are warring schools of thought about the best treatment. There's division over whether there's such a thing as "chronic Lyme disease": some say the illness from this slow-reproducing bacteria can continue for years, and require years of sophisticated antibiotic treatment; others argue there's no such thing as chronic Lyme and that taking antibiotics long-term is dangerous.



Mualla Akinci  
McManus

The first reported case in Australia, based on clinical symptoms, was reported from the Hunter Valley in NSW in 1982, and there have been a number of anecdotal cases since, mostly from eastern coastal Australia, where ticks are rife.

Is it here? The NSW Health Department acknowledges that occasionally tests here for Lyme have been positive, but claims those people were found to have picked up the infection overseas.

Anyone who has merely visited an overseas country where Lyme exists - from Japan to the UK - will have trouble proving they caught Lyme here. Indeed, the McManus case is complicated by the fact that the couple went to Italy and Germany a few weeks after Karl was bitten here by a tick, although his widow says they were never anywhere forested or even vaguely green - McManus was a car nut and they spent their time on autobahns, in high-rise hotels and car museums, she says. "It was all metal and concrete." On the other hand, one researcher said Lyme disease is so prevalent in Europe "you could catch it sitting in a Munich beer garden".

Good Weekend spoke to several people who have never left Australia but believe they are suffering from Lyme, or a version of it, following bites. A Sydney couple, Jodie and Brett Donnelly, believe Brett contracted the disease (and perhaps a parasite infection as well) after coming into daily contact with birds carrying infected ticks and mites at his workplace. Severe rashes and weird skin conditions were followed by extreme fatigue, pain, an atrophying leg, difficulty walking and, recently, cognitive decline and pains in his heart and spine. When Good Weekend met with the couple, it was obvious he was having great difficulty with recall and gathering his thoughts. Jodie says she has suffered a less severe version of many of the symptoms as well.



Jodie & Brett Donnelly

Brett was given diagnoses that included scabies, eczema, delusional parasitosis (a psychosis) and terminal cancer. The couple had to battle to have him tested for *Borrelia*. "And even then, it's been a nightmare trying to get the results," Jodie says. Brett has tested positive for *Borrelia*, but through a lab that lacks the accreditation the government recommends. Another recent preliminary test, at an accredited lab, appeared to return a positive result for two strains, but was not later confirmed. As one expert noted, "*Borrelia* testing can be hellishly complicated, and a negative test doesn't necessarily mean you haven't got the disease. It just means you can't confirm the diagnosis."

The Donnellys insist they have since heard of dozens of cases of other people with similar symptoms - including fatigue, rashes, shooting head pains, extremely sore soles of the feet - after some sort of contact with birds. Are these people suffering Lyme, or something else again? And why are they meeting with such resistance?

## Deadly little bite

It's impossible to tell how many Australians are experiencing Lyme-like symptoms. The lab at Sydney's Westmead Hospital conducts about 30 tests a week, and Royal North Shore Hospital about 16 a month, but there's no way of knowing how many people go to doctors with symptoms but are never suspected of having borreliosis. Many people who believe they suffer from Lyme told Good Weekend their doctor never asked if they'd been bitten by a tick or been in Lyme-endemic areas.

Mualla Akinci McManus is convinced that Lyme, or something like it, is what her husband Karl contracted after being bitten by a tick in 2007, while working on the set of *Home and Away* in bushland in Sydney's Terrey Hills. He didn't remove it until he came home, and used kerosene to do so, which is not recommended (see *The Enemy*, document end). A week or so later McManus had flu-like symptoms. In ensuing months, he developed rashes, a stiff neck, sweats, facial discolouration, mood changes and neurological complications. Three years later, the once healthy 44-year-old had a paralysed tongue, paralysed arms, was wheelchair-bound and being fed through a tube in his stomach. Had he received the proper treatment early enough and for long enough, his widow believes, he'd be alive today.

She refuses to accept the specialists' diagnosis of multifocal neuropathy or, possibly, motor neurone disease - "diagnosed after five minutes, with no history-taking, and ignoring so many of his symptoms", she says. (There are no diagnostic tests for these other illnesses, either.) Tests for *Borrelia* done by government-approved labs here came back negative, while tests the couple had done by labs in Germany and America showed positive, she says. "I know he didn't have motor neurone or multifocal neuropathy because he had three periods of improvement when he was getting the right treatment," she says, referring to his time in a German clinic. "You don't improve when you've got motor neurone. I took him out of hospital because they weren't helping him at all and I managed to get him to put on 15 kilos and build up muscle. That's unheard of with the diseases they said he had."

In the end, it was apparently a respiratory infection that killed him. Akinci McManus was awarded a Supreme Court injunction last year to have her late husband's body tested for Lyme. She won't release the postmortem report done here but says it was "inconclusive". She's awaiting results from labs in the US and Austria on postmortem tissue.

Meanwhile, she has set up the Lyme Disease Association of Australia and the Karl McManus Foundation to raise research funds. She's also planning to take a class action against the NSW Health Department, joined by more than 100 other Australians, she says, who believe they have Lyme and have not been treated for it. However, the action could take years to get going. First, they have to find a bacterium here that could be the culprit.

Akinci McManus is not one to give up. There's only one point in our interview where this tough-talking, recently bereaved woman allows herself to break down. "Karl trusted me and I failed him," she says through tears. "I must not fail him in this ... Nothing in science is black and white, so why can't they just consider it?"

## Ticks and disease

Dr Bernie Hudson, an infectious disease specialist at Royal North Shore Hospital, is one of several



Dr Bernie Hudson

doctors who treated Karl McManus. He can't state categorically whether or not McManus had Lyme, however, Hudson does believe there is Lyme, or an indigenous similar illness, in Australia, carried by ticks or perhaps some other blood-sucking insect, although he's not sure how common it is.

Illness following a tick bite is "probably massively under-diagnosed", he suggests. "As to what that illness is, that's more difficult ... For instance, there's a thing called red meat allergy, related to tick bites. People have been known to develop life-threatening allergic reactions to red meat,

triggered by tick bite. The tick saliva has got a lot of stuff in it that changes your immune response, because the tick has to be able to stick on you to get a blood meal. It can change what the cells are doing locally and those cells don't stay there - they go to other parts of your body."

Tick-borne bacteria can lie dormant in the body and severe symptoms may not appear for months or even years, by which time people have forgotten about a tick bite, assuming they were aware of it to begin with. Akinci McManus, who is also a pharmacist with an honours degree in immunology, a master's in haematology, a PhD in neuropharmacology, and was a postdoctoral fellow at the Garvan Institute, believes tick-borne bacteria could be involved in many more diseases than we realise, because the symptoms mimic so many other conditions. "Say you're diagnosed with Parkinson's. The doctor will say it's an auto-immune disease. You're not going to think, 'Oh, remember that time I was working in the garden and got bitten by a tick?'"

On the other hand, a tick bite might have nothing to do with such an illness; the causes of many of these diseases, like Parkinson's, multiple sclerosis and motor neurone disease, are still unknown. Her point is, has it been ruled out in diagnosis?

In America and Europe, where Lyme disease is common, the erythema migrans (EM) or bullseye rash, which can be an early symptom of Lyme but shows up in only 60 to 80 per cent of cases, usually sets off alarm bells. Here, it's more likely to be met with well-meaning ignorance. One Sydney woman, who wants to be known only as Kate, told Good Weekend she developed a textbook rash, taking up half her thigh, soon after lunching on Sydney's northern beaches, anecdotally a notorious spot for infected ticks. (Rickettsia, or spotted fever, a less-serious bacterial tick-borne illness, is common in the area, according to Hudson, as well as being found in northern NSW, Tasmania, Queensland and eastern Victoria.)

Kate didn't realise it was a tick that had bitten her. When she showed the rash to her local chemist, the staff had no idea what it was and gave her steroid cream. "It went down, almost overnight, and I forgot about it," Kate says. "That was in February. By July, I had some weird things happening in my head - a kind of 'eeeh, eeeh' noise like my brain was stopping and starting. Every time I got a breeze

on my hands it felt so freezing. I started feeling exhausted and confused. I was attending a class and couldn't understand what the teacher was telling me."

Her symptoms grew worse. Her hand wouldn't work properly, she started to drag her left leg. Her skin burned. It wasn't until she heard a radio report about McManus that it occurred to her it might be Lyme. When she Googled it, there was her rash. The first doctor she spoke to told her the idea was "rubbish". "He said Lyme doesn't exist here and that I'd been spending too much time on the internet." She had to beg and plead to be referred to Bernie Hudson. She says he confirmed she had Lyme disease, or a Lyme-like disease, and is now treating her with courses of antibiotics.

Says Kate, "In any country that recognises it, a person presenting with a tick bite and the bullseye rash would have a good chance of early treatment - a few weeks of very cheap antibiotics. Here, a patient has to get really sick, eventually work out themselves what's wrong, rally all their resources at a time when they're largely dysfunctional, and fight for treatment, not just against disinterest but against outright opposition coming from people who should be sympathetic." Many doctors are reluctant to prescribe antibiotics for a disease that isn't supposed to be here and that may show up negative in blood tests. But early treatment is key and Hudson, among others, believes it's better not to risk letting the disease get a grip. "Whether you believe it exists here or not, if you give someone 14 days of antibiotics [tetracyclines] the first time they appear with what looks like Lyme disease, you'll probably save them a lot of grief," he says. "I've been saying that for years. I think that's why on the northern beaches, even if the doctors don't agree, they will sometimes relent and give the patient the antibiotics."

Perhaps jolted by the McManus case, and more reports of patients with Lyme-like symptoms, the NSW Health Department is now undertaking an epidemiological study of reported cases. The results will be presented to a panel of experts "to try to figure out what's going on", says Jeremy McAnulty, director of the department's Centre for Health Protection. Does he believe it's here?

"The evidence so far doesn't point to the fact that Lyme disease is in Australia, but I can't say categorically that it's not. If it is here, it's not affecting a lot of people. The people who report symptoms, of course, have something. The challenge is to diagnose accurately what they have."

## Sick or crazy?

Lyme disease is rife in America, with a conservative estimate of 16,000 to 20,000 new cases a year, and is also common in Europe, Russia, parts of Asia and, increasingly, the UK - almost every continent, in fact, except Australia, according to health officials here. Some estimates claim it's one of the fastest-growing infectious diseases in the world, although that may be due to more widespread diagnosis.

As a condition, it was known about early in the 20th century but it wasn't named Lyme disease until the 1970s, after a group of US children from the town of Lyme, Connecticut, and neighbouring districts, developed strange arthritic symptoms. They were diagnosed with juvenile rheumatoid arthritis. However, two concerned mothers thought the cluster - eight times the national average rate for the incidence of juvenile arthritis - must be related to environmental factors and, through

hard slog, managed to get an official investigation under way. The common factor was that all the children lived and played in wooded areas, where ticks were rife in spring. Many had developed a rash after being bitten. Eventually, the illness was traced to *Borrelia* bacteria carried by ticks.

*Borrelia* is a spirochete, a corkscrew-shaped bacterium from the same family as syphilis. It's passed to humans by ticks that have picked it up from infected mammals, commonly deer, rodents or birds. Those who believe it's in Australia have proposed bandicoots, dogs, wallabies and kangaroos as possible carriers.

Like syphilis, Lyme is called "the great imitator" because it mimics many other illnesses and produces a dazzling, painful array of vague but very real symptoms that zoom erratically around the body, coming and going as the immune system wages an internal war on the bacteria. It can lie dormant for years and then appear or reappear. Not everyone bitten by an infected tick will become ill or very ill. It depends on genetic make-up.

Although it's rarely fatal, Lyme can cause changes in the brain, produce mild or severe skin conditions and blight almost every organ in the body, from the brain to the heart. Different species of the bacteria produce different symptoms, some more arthritic, some neurological.

Early symptoms can include flu-like symptoms, joint swelling, headaches, dizziness, fatigue, depression and the distinctive erythema migrans rash, characteristically circular but not always. The rash can appear anywhere from three to 30 days after a bite, but a rash can also just indicate an allergic reaction to a tick bite.

Left untreated, the bacteria can spread through the bloodstream to joints, the heart, the nervous system and other parts of the skin. Depending on the stage, the neurological form can cause facial palsy, meningitis, shooting pains, memory loss and mood swings. Just to complicate matters, people can suffer co-infections from other parasites or bacteria carried by the same tick. This may explain why some people continue to be ill even after receiving treatment to kill off *Borrelia*.

Because it can look like so many other illnesses, people with Lyme often complain of having been misdiagnosed, sometimes for years, with other conditions. One of the dangers of misdiagnosis, of failing to recognise the problem is bacterial, is that patients may find themselves on drugs like immunosuppressants or steroid treatments like cortisone that can worsen bacterial infections. (Conversely, it's argued that people can be misdiagnosed with Lyme and thus not treated for the illness they actually have.)

Some Lyme advocacy groups estimate there are about 350 other illnesses it can be mistaken for, but the common ones are depression, fibromyalgia, multiple sclerosis, rheumatoid arthritis, scleroderma, motor neurone disease, Parkinson's disease, lupus and chronic fatigue syndrome - as well as flights of fancy and neurosis.

Victorian woman Rosemary Trudeau, who runs the internet site LymeOz, believes she has had Lyme for the past 22 years, 16 of them without knowing what it was. She says she ended up in a wheelchair, barely able to swallow or breathe, weighing 41 kilograms and close to death. She was variously told she had glandular fever, chronic fatigue, MS, depression. At one point she thought it might be lupus. "So I went to the GP and said, 'Can I have a test for



Rosemary Trudeau



that?' I was in my 20s and I couldn't even hold my head up. I had to rest it on his desk. But instead of doing a test for lupus, he thought I was nuts and put me in a psychiatric ward for a week. After a while I said, 'Look, I'm not crazy, I'm just sick', and they agreed and sent me home." (Trudeau believes she contracted Lyme through an ex-partner, who had developed the EM rash after a visit to Queensland. However, there's debate about whether, like syphilis, it can be transmitted sexually, or via the placenta.)

Even conditions like ADHD and autism have been linked to *Borrelia*, although that research is hypothetical. Some Lyme sites tell stories of children undergoing sudden personality changes, or experiencing learning difficulties months after, for example, returning from a camping trip.

It's easy to see why a patient would rather think they had a treatable disease like Lyme than, say, an incurable one like motor neurone; everyone wants hope. But it's also possible they actually do have Lyme, or some local version. Could it be that we just haven't pinpointed the right strain of the micro-organism? Could it be that the tests we are using don't suit Australian conditions?

## Mixed opinions

In medical and scientific circles it's not uncommon for opinions to differ about diagnoses depending on various research studies. In Australia, a scientific study carried out 17 years ago forms the backbone of our public-health policy on Lyme disease. That study, led by Richard Russell and Stephen Doggett, two entomologists at Westmead Hospital, the hospital now responsible for much of the diagnostic testing for borreliosis, looked at 12,000 ticks at the time and found "no conclusive evidence" Australian ticks carried spirochetes. Interviewed by The Sydney Morning Herald last year, Doggett maintained that position. "There's not one piece of scientific evidence to say Lyme occurs in Australia. There are reputations built on the existence of Lyme disease in Australia. People are embarrassed ... to admit it's not here."

However, several other reputable scientists Good Weekend spoke to had criticisms about some aspects of that mid-1990s paper. For that matter, while its conclusions were firm and the two scientists are experts in their field, the paper itself contained some provisos. Isolating the bacteria is complex and the absence of evidence is not evidence of absence.

Around that same time, a PhD student, Michelle Wills, undertook work with University of Newcastle virologist Professor Richard Barry. They found at very least "presumptive evidence", Barry says, of spirochetes in Australian ticks, as had earlier work in the 1950s. Later, in conjunction with Bernie Hudson, they carried out serological tests on more than 2000 symptomatic patients suspected of Lyme and found what appeared to be some positive results. Lack of funding meant they couldn't try to put those two pieces together: it wasn't enough to find a spirochete or find sick people - they needed to show that a spirochete caused that illness.

Barry says their findings were overshadowed by the Westmead work, which, funded by the National Health and Medical Research Council, "became the orthodoxy". And medical orthodoxy is slow to shift, notes Professor Tim Roberts, a microbiologist at the University of Newcastle who also believes Lyme exists here, persuaded by clinical evidence and the Wills/Barry work. "New discoveries in

science take a long, long time to be accepted, particularly in clinical medicine. Look at the history of gastric ulcers. It took 17 years before the Royal Australasian College of GPs actually acknowledged that one should test for [the bacterium] *Helicobacter pylori* if someone's got an ulcer. Seventeen years!"

Researchers like Barry, Wills and Hudson think it's plausible we have an unknown strain or species of *Borrelia* here, which may not show up in existing tests, and even Russell and Doggett have acknowledged that possibility, although there's no hard evidence so far and, as their paper pointed out, Australia doesn't have the species of Lyme ticks found in the northern hemisphere. But given that so many strains of *Borrelia* have found their way around the world, is it so unlikely it has also found its way here? Migratory birds carrying ticks are an obvious source, says Richard Barry. He points out that a common northern European strain of *Borrelia*, called *garinii*, is found in ticks carried by birds like shearwaters. "Where do shearwaters migrate in the world?" he asks rhetorically. "They come down from the northern hemisphere and, occasionally, they do a lot of dying off the east coast of NSW. They're also called muttonbirds.

"They nest in the sandhills and then prepare to fly back. If *garinii* occurs in the tick that infests these birds, and these birds nest along the NSW coast, and our tick population is located largely in the eastern coastal region, what if these ticks get into, say, bandicoots and set up a new ecological cycle?" When other ticks bite the infected bandicoot, they pick up the bacteria. From there, it can be passed to humans. "That scenario is more than possible. It's highly possible."

Researchers have found at least 18 varieties of *Borrelia* that can cause Lyme disease, and more may turn up. Different types can cause different symptoms. The US species *Borrelia burgdorferi* causes mainly arthritic symptoms. *Borrelia garinii*, one of two major strains in Europe, causes neurological symptoms, from twitching to muscle fatigue, memory loss and panic attacks. Another, *afzelii*, is thought to cause a severe skin condition called *acrodermatitis chronica atrophicans* (see *Ticked Off*, below).

For now, in the absence of further research, the mysteries remain. Is Lyme disease in Australia? And if so, how widespread is it? Bernie Hudson remembers being at a conference some years ago and presenting his findings of 12 or 15 positive results for *Borrelia* out of 150 skin biopsies he had taken from Lyme suspects. Another researcher at the conference said dismissively, "Well, that's not many." Did that comment worry him?

"It starts like this. First they say, 'No it doesn't occur.' Then they say, 'Oh, you've got some positives. All right, there's a few there.' Then they go, 'Jeez, it's more common than we thought.' And then the last thing is, 'Shit, everyone's got it.'

"No need to panic, however. It's not swine flu. Says Michelle Wills, "You've got to keep it in perspective. You don't want people to be phobic about ticks. It's like mosquitoes: you get bitten but you're not going to end up with Ross River fever unless you're very unlucky, and it's the same with Lyme. Some people are unlucky. It's just a matter of making sure there's appropriate treatment available for the unlucky ones."

The first step, however, is agreeing there's something that needs to be treated.



## Ticked off



Wayne Bowen

Ask Wayne Bowen, a NSW farmer, to describe his symptoms and he sighs. The list includes fatigue, stiffness, muscle twitches, pins and needles, sudden headaches and crushing pain, aching eyeballs, and "feeling like razor blades are slashing my heels". "I sound like a whinger, don't I?" he says.

Like many of the people Good Weekend spoke to, Bowen also suffers "brain fog" and memory loss and is highly sensitive to noise and light. A test through Australian Biologics, a private laboratory, found "something similar to" *Borrelia valaisiana* (a species of bacteria found in Russia and China) and Bowen believes he is also suffering from acrodermatitis chronica atrophicans (ACA), a painful skin condition associated with European Lyme disease.

Bowen has never been out of Australia, but he has been bitten often by ticks and three times developed the telltale bullseye EM rash.

The diagnosis of ACA, and of Lyme, was made by Laurieton dermatologist Peter Mayne, but Bowen says he has yet to convince his specialists. They've dismissed the positive test as unreliable. Instead, Bowen has been told he has sarcoidosis.

He says, "Sarcoidosis seems to be a last-resort diagnosis when they can't find anything else. But I've also read that it can be Lyme-related. The lady who used to live next door also had it. Sarcoidosis is a one in 20,000 disease in Australia, maybe one in 10,000. What are the odds of the woman next door having it? If you Google 'sarcoidosis and rural areas', you find it's much more prominent there. You have to wonder, well, what's out in the bush?" Ticks, for one thing.



Lyme bull's-eye rash

## The enemy

Ticks are most active in spring or summer. They like humidity and can't survive very dry conditions. Prompt removal is important. Use blunt forceps or fine tweezers, grasping the tick behind its head as close to the skin as possible, without twisting. If head or mouth parts are left, don't try to dig them out; they will drop off later. With infestations of tiny ticks (ticks at larval stage - often called, incorrectly, "grass ticks"), try a 30-minute bath with a cup of bicarbonate of soda added.