

Chapter 3

Treating the illness

My father taught me to swim with the rip, and that is how my children and I have survived. I am treading water, holding up two children. The medical system is stuck on the rocks. Way before Lyme I learnt that the medical profession does the best it can, but they are swamped and they do not know everything. I see the responses from authorities added to the inquiry. They are debating if the rip exists, how they can test if it is a true rip and who has the accreditation required to tell if it is a rip. I am so relieved to see people on the beach now, but I need to know that you are not just going to write a report about what you see. I need decisions to be made that will save my children from sinking. I want my children and I to please receive the critical, effective and timely treatment that we need.¹

3.1 It will be some time before scientists are able to conclusively identify the pathogen, or pathogens, responsible for tick-borne illness in Australia. This is a critical step in the evolution of our understanding and response to tick-borne illness in Australia. For this reason, in the previous chapter the committee recommended that funding for research into tick-borne disease be prioritised. But the answers that research will bring may be years away, and people need action now.

3.2 Despite continued disagreement around the science, two important facts have emerged over the course of this inquiry: there is considerable evidence indicating that the illness we are looking at is tick-borne, and almost unanimous agreement that people with this illness must be helped.

3.3 The experiences patients have described are of great concern to the committee. Many report being dismissed by general practitioners and infectious disease specialists. Some report being turned away from hospitals and denied treatment upon mentioning the words 'Lyme disease'. Others report being shuttled from misdiagnosis to misdiagnosis over a number of years, eventually only to be told 'it's all in your head'.

3.4 This inquiry shows that there are too many people presenting with tangible symptoms for this assessment to be accurate. While the committee cannot independently verify patients' accounts, it has no reason to doubt their veracity. Put simply, this many people cannot be making themselves this sick.

3.5 Throughout this inquiry, the committee has sought to place patients who are unwell and in need of treatment front and centre.

1 Ms Julianne Hansen, *Committee Hansard*, 15 April 2016, p. 42.

Existing treatment pathways

Exactly seven years ago today I was in a hospital bed with my daughters at my side. Under my pillow was a letter telling them how much I love them and what good girls they were in case I died. Six months earlier I had over 20 nymph tick bites. I had fevers and sweats all night, and the next day the doctor gave one course of antibiotics. One week later, with heart symptoms, I was sent home from the hospital, told I had anxiety and given Valium, which I refused. After seeing every doctor and natural therapist I could for six months, barely able to walk, sleep or eat, I spent one week in hospital. Again, I was told I had anxiety and was sent home with Xanax. It was living hell.²

3.6 In its interim report the committee described treatment pathways available for people who acquired Lyme disease overseas, and treatment pathways for illness acquired in Australia. The committee recognised that many people, like the witness quoted above, felt let down by the health system, and that more should be done to educate the public and medical professionals about the risk of tick bites and tick-related illness.³

3.7 The committee also noted that Australia's health care system could be improved to better meet the needs of people with chronic illness, and that the illness in question would benefit from greater attention from the medical authorities.

3.8 The committee heard that a lack of treatment options and the resulting desperation was driving many Australian sufferers to seek treatment for Lyme-like illness overseas. On top of this, treatment locally and abroad is often expensive, and may leave vulnerable patients open to financial exploitation.⁴

3.9 Given the number of people suffering the chronic, debilitating symptoms associated with Lyme-like illness, it is clear that more must be done.

3.10 The following section of this report will look at evidence presented on treatment recommended by doctors who have diagnosed patients with Lyme-like illness, and who are at the frontline in the management of this disease.

First do no harm

3.11 As with most aspects of this inquiry, appropriate treatment for patients with Lyme-like illness was a contentious issue.

3.12 The Australian Medical Association (AMA), the nation's foremost membership organisation representing medical practitioners, explained that doctors

2 Ms Dianne Ellis, *Committee Hansard*, 2 November 2016, p. 34.

3 Chapter 2, Senate Community Affairs References Committee, *Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients*, Interim report, May 2016.

4 Chapter 2, Senate Community Affairs References Committee, *Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients*, Interim report, May 2016.

have a responsibility to rely on evidence to determine a diagnosis and treatment plan. The AMA set out its position in a submission to the committee:

Medical practitioners do their utmost to accurately diagnose the cause of an illness and provide an appropriate treatment. Doctors support the patient in understanding their condition and what they might expect, define circumstances when patients' symptoms could have several causes, identify and advise on appropriate treatment or preventive options. A doctor's duty of care is to make an accurate diagnosis or state that there is insufficient evidence for a specific diagnosis...

...To date there has been no evidence to support the existence of *Borrelia burgdorferi* (*Borrelia*) in Australia...In the absence of a conclusive aetiology of an indigenous vector for Lyme disease or a Lyme-like disease, diagnosis remains difficult and patients are frustrated when their illness is not easily diagnosed or treated. The AMA understands that this sentiment is genuine and that a failure to reach a conclusive diagnosis can be stressful, however the medical profession's role is to make clinically appropriate treatment recommendations based on the best available evidence. It is ethically and legally appropriate for doctors to refuse demands by patients, patients' family members or other third parties for tests, treatments or procedures that are not clinically appropriate.⁵

3.13 The committee did not receive any submissions disputing the call for medical treatment to be ethical and safe. The question of what constitutes clinically appropriate treatment for an illness with an undefined causative agent, however, can be seen from a number of perspectives. On one hand, there is a risk of misdiagnosis, as there is with any illness. On the other, denial of treatment in the absence of certainty around the diagnosis may arguably also contribute to an adverse outcome.

The risk of misdiagnosis

3.14 As seen above, the AMA highlights the responsibility of doctors to make evidence-based diagnoses. This is echoed by other organisations, such as the Medical Council of New South Wales (MCNSW). The MCNSW expressed concern about the harm caused by misdiagnosis and drew the committee's attention to complaints from the public and medical professionals about the performance of some doctors who have diagnosed Lyme-like illness in the absence of confirmation from an accredited laboratory:

Additionally, in those patients with serious underlying diseases, including cancers, misdiagnosed as "Lyme-like illness" and treated for long periods with repeated courses of antibiotics there has been progression of the underlying disease in the absence of the patient receiving timely and appropriate therapy.⁶

3.15 A submission from the Medical Board of Australia (MBA) and the Australian Health Practitioner Regulation Agency (AHPRA) similarly indicated that medical

5 Australian Medical Association, *Submission 456*, p. 1.

6 Medical Council of New South Wales, *Submission 935*, p. 2.

authorities are aware of concerns about treatment being administered for Lyme-like illness. Specifically, there is a concern that the diagnosis might be premature and as such may preclude more appropriate treatment for other conditions:

There is a concern that patients may be deprived of the opportunity to have more appropriate treatment for another condition because the alternative condition is not considered once Lyme-like illness has been diagnosed. Treating Lyme-like illness with long-term antibiotic treatment, in the absence of an identified infection, is of concern. This management is at odds with advice from public health authorities regarding the dangers of antibiotic resistance. We understand that some practitioners are prescribing and administering antibiotics for years (whereas the treatment of Lyme disease is for weeks).⁷

3.16 A submission from the Infectious Diseases Department at Austin Health, Melbourne, describes work and treatment undertaken with a cohort of patients who believe they have Lyme-like illness and who were referred to Austin Health for assessment. It was determined that, of these patients:

- 30-50% have potentially serious medical conditions that have either been previously undiagnosed, diagnosed but inappropriately treated, or diagnosed but denied by the patient such that no treatment was sought.
- 10-20% have a serious defined psychiatric illness that requires specialist care
- 80-90% have undergone substantial financial hardship paying for investigations from unaccredited laboratories and, in some cases, prolonged antibiotic treatment that has had no (or minimal) objective evidence of benefit.
- The current specialty-based medical approach to managing these patients is inappropriate. Instead, a multi-disciplinary approach is required to better assess these patients, including specialist physicians (e.g. infectious diseases, rheumatology and oncology), psychiatrists (with a special expertise in so-called conversion disorders) and primary care physicians (GPs) with an interest in the long-term care of patients with chronic disease. A specific funding model should be considered since the current system is inhibitory to this approach.⁸

3.17 It is unclear how the sample of patients referred to Austin Health was selected; however, the conclusions infer a considerable instance of inappropriate diagnosis and treatment.

3.18 The committee's interim report discussed the stigma feared by doctors who treat tick-borne disease in Australia, citing numerous reports of threats and

7 Medical Board of Australia and Australian Health Practitioner Regulation Agency, *Submission 533*, p. 3.

8 Infectious Disease Department, Austin Health, *Submission 820*, p. 2.

intimidation by the medical authorities. Patients reported feeling anxious that their doctors would have complaints made against them or be sanctioned for attempting to treat the illness.

3.19 The committee discussed complaints against practitioners who treat Lyme disease or Lyme-like illness with AHPRA and the MBA, and was informed that the vast majority of complaints do not result in regulatory action. Only three doctors currently 'have conditions on their practice relating to Lyme or Lyme-like illness.'⁹

3.20 The committee notes that despite these statistics, there are claims of intimidation by AHPRA.¹⁰

The risk of inaction

3.21 A number of medical practitioners with experience in treating the tick-borne illness in question discussed the risk of medical inaction and over-reliance on pathology tests. They argued that chronically ill patients need safe, appropriate treatment even when a definitive pathological cause is elusive. Medicine, as pointed out by the Karl McManus Foundation, 'is not static but constantly changing':¹¹

In a situation where the causative agent is not well characterised treatment protocols are not likely to be within the realm of mainstream medicine.¹²

3.22 Dr Richard Schloeffel, chairperson of the Australian Chronic Infectious and Inflammatory Diseases Society (ACIIDS), argued that diagnosis should begin with observation, which in this case is that Australian ticks are making people sick:

We have to recognise there are things in our ticks that we have not fully identified yet. When you make an observation, what happens is the evidence will follow the observation. But chance favours only the prepared mind. If the mind is not prepared, you will not make that A equals B equals Z. You cannot join the dots if you are not able to make that transition. That is why it has not moved forward with the doctors. I do not think they are hearing the patient. This is a clinical diagnosis before anything else.¹³

3.23 Dr Schloeffel highlighted the importance of clinical diagnosis, making the point that pathology should be used to verify, not guide a doctor's clinical diagnosis:

A pathology test should only confirm your thought process, not the other way around. We are clinicians. Doctors are properly trained, hard thinking and intelligent people who make a decision clinically, and then the test verifies our thought process. The tests are inadequate because the patient is immunosuppressed. The tests are not good enough. The bugs are varied.

9 Associate Professor Stephen Bradshaw, Practitioner Member, Medical Board of Australia, *Committee Hansard*, 2 November 2016, p. 60.

10 Karl McManus Foundation, answer to question on notice, received 18 November 2016, p. 4.

11 Karl McManus Foundation, answer to question on notice, received 18 November 2016, p. 1.

12 Karl McManus Foundation, answer to question on notice, received 18 November 2016, p. 1.

13 Dr Richard Schloeffel, Chairperson, Australian Chronic Infectious and Inflammatory Diseases Society, *Committee Hansard*, 2 November 2016, p. 50.

There are viruses, parasites and bacteria. Pathology is very secondary. Sure, do no harm, but do not lie to your patient that they are not sick because the test was negative. It is not helpful; it is not good medicine.¹⁴

The most important thing when you have patients who are sick is to listen to the patient. If you do not listen to the patient you will not make a diagnosis. Forget about ELISA test versus Western Blot and all these other things. These patients come to me, referred to me by other specialists, other doctors. I have 800 people on a waiting list. I have letters like this one from people telling me their child is going to die if they do not have treatment.¹⁵

3.24 Dr Schloeffel described the magnitude of the situation and the urgent need for action, estimating that 40 000 to 50 000 Australians may have this illness.¹⁶ He explained that diagnosis is neither quick, nor simple, and is evidence-based:

I started looking at this disease 20 years ago. I have become very interested in it of late because we seem to have more and more patients with this. People are coming forward with motor neurone disease, chronic fatigue syndrome, fibromyalgia, autism spectrum disorder, dementia, multiple sclerosis, Parkinson's disease. I have seen all of those patients multiple times. I have had 17 of my patients die and I have three of them dying at the moment. They will die from this illness. They got a tick bite and they are going to die. Most of them talked to 20 or 30 doctors before they got to us. We diagnosed them with Australian testing and overseas testing and developed what we called levels of evidence. But it was in the clinical diagnosis and the absence of other disease that we decided this was this disease.¹⁷

3.25 Dr Richard Horowitz discussed tick-borne illness in Australia in a wider, international context, describing Lyme disease as a worldwide epidemic:

The National Science Foundation and the World Health Organization consider Lyme disease to be one of the pandemic diseases that is spreading worldwide right now.¹⁸

3.26 Dr Christopher Walker, representing the Karl McManus Foundation, a charity funding research into tick-borne diseases, suggested that medical authorities' lack of focus on tick-borne illness and debates around terminology in the absence of an agreed causative agent were having an adverse effect on progress in terms of diagnosis and treatment for patients. This inaction and dearth of support from medical authorities in some cases leaves patients looking for a diagnosis themselves, making them vulnerable to misinformation and exploitation:

14 Dr Richard Schloeffel, *Committee Hansard*, 2 November 2016, p. 55.

15 Dr Richard Schloeffel, *Committee Hansard*, 2 November 2016, p. 48.

16 Dr Richard Schloeffel, *Committee Hansard*, 2 November 2016, p. 49.

17 Dr Richard Schloeffel, *Committee Hansard*, 2 November 2016, p. 48.

18 Dr Richard Horowitz, *Committee Hansard*, 2 November 2016, p. 1.

Currently health practitioners are being discouraged from diagnosis and treatment of tick-borne diseases. This appears to be linked to the Lyme disease terminology and has seen a significant reduction in treating doctors. This reduction of available medical practitioners is forcing desperate people to turn to the likes of 'Dr Google' for answers. It must be said that 'Dr Google' presents one of the most disruptive and destructive forces in diagnosis and treatment of any tick-borne disease. There exists a plethora of individuals and organisations who are quick to reproduce and repost advice without any qualification or validation. One of the most extreme, misguided 'Dr Google' discourses identified is the claim that Lyme disease can be contracted from eating too much kale. A claim of nonsense in the extreme, but nonetheless published in a women's health magazine, readily available on 'Dr Google' and easily believed by those who know no better. We need our medical profession to be actively involved in the diagnosis and treatment of these diseases, even at this confounding juncture, and put paid to such subterfuge ignorance and outright incompetence.¹⁹

3.27 Mr Mike Pym, Director of the Karl McManus Foundation, called for action based on current best practice, telling the committee that waiting for research to be conclusive would cause harm:

[W]e have to have a treatment protocol for this 'new name' set of symptoms now. We cannot wait for more science. We have to work out what is best practice now, draw a line in the sand, acknowledge that that is what is good enough and then move on—but get all of the doctors using best practice now. We all know that it will not be perfect, but it is better than watching people die. Simply doing nothing is not doing no harm; it is letting people suffer and die on your watch.²⁰

Committee view

3.28 The committee notes concerns expressed by medical authorities about the potential for misdiagnosis and inappropriate treatment in a situation where the cause of illness is not entirely clear. The committee shares these concerns.

3.29 At the same time, however, the committee recognises that complex, emerging diseases require treatment even in the absence of definitive research. As put by Dr Schloeffel, 'the science has not caught up, but the compassion needs to be there.'²¹

3.30 Recognising that it is not a medical body, the committee agrees in principle that in situations where other causes have been appropriately considered and ruled out, doctors should have access to the best available treatment guidelines for Lyme-like, tick-borne disease.

19 Dr Christopher Walker, Acting Chief Executive Officer, Karl McManus Foundation, *Committee Hansard*, 2 November 2016, p. 46.

20 Mr Mike Pym, Director, Karl McManus Foundation, *Committee Hansard*, 2 November 2016, p. 47.

21 Dr Richard Schloeffel, *Committee Hansard*, 15 April 2016, p. 23.

3.31 The committee acknowledges the work and experience of medical professionals treating this illness, and supports calls for the treatment options they have developed to be trialled more broadly in consultation with medical authorities.

Establishing a treatment protocol

3.32 Aware of the need for medical professionals to balance the risks involved in addressing an unknown or emerging disease, the committee sought evidence on how patients can receive treatment in a safe environment.

3.33 To this end, the committee held an additional hearing on 2 November 2016, at which treatment was discussed with a number of witnesses. To establish what is current best practice, the committee consulted representatives from the Karl McManus Foundation, Dr Schloeffel representing ACIIDS, and Dr Horowitz, a US-based practitioner specialising in the treatment of Lyme disease and related infections. The evidence they presented was discussed with the department, the MBA and AHPRA.

3.34 The committee invited the AMA and Royal Australian College of General Practitioners to participate in this discussion, however representatives were not available at the time of the hearing.

Effective treatment

3.35 The Karl McManus Foundation described the lack of agreement in the medical community on how best to address tick-borne disease:

Generally doctors in Australia are also split into two groups, the mainstream who will consider acute treatment and offer palliative care for chronic TBDs (ie: post Lyme syndrome). While holistic doctors are aware that when pathogens have disseminated into other tissues a broad approach may be needed which may require not only prolonged treatment of disseminated infections but also supporting the immune system and providing the right nutrients for patient recovery.²²

3.36 Holistic doctors treat what they refer to as chronic illness. This, the committee heard, is because tick-borne disease is complex and often involves more than just one single, acute infection:

The patients that I see with Lyme disease do not just have *Borrelia burgdorferi* sensu lato. What they end up having is many other species of bacteria, viruses and parasites because the ticks are now containing many of these different species and are rapidly spreading.²³

3.37 In Australia, doctors treating the disease frequently see patients presenting with symptoms consistent with relapsing fever. Dr Schloeffel postulated that research would ultimately confirm this to be the case:

Borreliosis is from a spirochete organism. It can cause all sorts of symptoms. It can go anywhere. There are multiple species. There is one in America called Lyme disease, but what we have here—I am sure a lot of

22 Karl McManus Foundation, answer to question on notice, received 18 November 2016, p. 4.

23 Dr Richard Horowitz, *Committee Hansard*, 2 November 2016, p. 1.

the patients I see have a relapsing fever type of *Borrelia*. That would be consistent with what Peter Irwin is finding in those ticks. We just have to join the dots between what he finds in echidna ticks and what I see in my patients.²⁴

3.38 The committee heard that the co-infections Dr Horowitz and Dr Schloeffel describe can in some cases lead to death if not adequately treated.²⁵ Treatment, however, is not simple, and involves more than fighting infection with antibiotics. Patients first of all need to be stabilised before antibiotics can be used to fight infection:

Treatment is not throwing antibiotics at people. I totally agree with my colleagues about the overuse or the difficulty of giving just antibiotics. You have to resuscitate the patient. These people are sick. They get brain fog, fits and seizures. Some of them are psychotic and some of them are depressed. They get pounding, vice-like headaches, seizures, twitches, body pain and POTS [postural orthostatic tachycardia syndrome²⁶]. Their blood pressure is really low and they cannot do anything—they stand up and they collapse. Their bowels do not work and they have racking pain in their body. Their body temperature is often 34—three degrees below normal—because their thyroids are failing and they get adrenal failure. If you give someone like that antibiotics to start with, they are just going to get much sicker. So we have to resuscitate the patients.²⁷

3.39 The committee understands that Dr Schloeffel, together with colleagues Dr Peter Dobie and Dr Hugh Durham, is in the process of drafting new evidence-based guidelines for diagnosis and treatment of tick-borne illness in Australia:

It will have no authority except we will try and get some backing from infectious disease specialists. I will show it to the chief medical officer and Gary Lum, because it is important that they have a look at it. But it will go out irrespective of how they think about it. It is not a dangerous document. It is a factual document based on evidence that we will present. It will be a guideline and it will be up to the individual doctors to make a decision but at least it is a guideline. If we start treating patients who get a tick bite, or something that bites, in the first instance they may not end up like this lot of people who have suffered.²⁸

3.40 The committee understands that the guidelines will move away from the term 'Lyme' and refer instead to tick-borne illness as 'Multiple Systemic Infectious Disease

24 Dr Richard Schloeffel, *Committee Hansard*, 15 April 2016, p. 49.

25 Dr Richard Schloeffel, *Committee Hansard*, 15 April 2016, p. 49.

26 Postural orthostatic tachycardia syndrome (POTS) is a condition in which sufferers experience an abnormal heart rate increase when they change from a supine to an upright position.

27 Dr Richard Schloeffel, *Committee Hansard*, 15 April 2016, p. 49.

28 Dr Richard Schloeffel, *Committee Hansard*, 15 April 2016, p. 50.

Syndrome, as suggested by Dr Horowitz.²⁹ They will be peer reviewed by two infectious disease specialists, then forwarded to the department.³⁰

3.41 The committee discussed these guidelines with the department, and was advised the department was aware of the draft and engaging with Dr Schloeffel on the content:

In discussion with Dr Schloeffel, the department provided information on how he can modify the ACIIDS guidelines which he is currently writing to be included in the National Health and Medical Research Council's clinical guidelines portal. The department will also continue to encourage Dr Schloeffel, along with his ACIIDS members, to work with academic units in medical schools to develop NH&MRC grant applications for patient based research.³¹

3.42 The committee understands the new treatment guidelines will be complete and ready for dissemination by the end of 2016 or early 2017.³²

3.43 The committee also approached the Karl McManus Foundation on the topic of treatment guidelines, and was informed that the Foundation had not validated any treatment protocols as yet and therefore could not recommend a particular protocol. The Foundation did, however, recognise that different treatment protocols may be required for acute and chronic disease:

Keen to see current best practise to be implemented immediately the KMF recognise that the Infectious Diseases Society of America (IDSA) present best practise treatment protocol for treatment of ACUTE forms of Lyme disease while International Lyme and Associated Diseases Society (ILADS) have developed best practise protocol for CHRONIC conditions. It is noted that the ILADS practice of long term antibiotic therapy is disputed by some and the two societies are split over TBDs treatment.³³

3.44 A submission from ACIIDS states that their views are closely aligned with those of ILADS and provided the committee with current treatment guidelines—the committee notes that these advocate cautious use of antibiotics where needed.³⁴

3.45 ACIIDS reports a considerable patient recovery rate, with peer review of this treatment conducted in Europe and the US:

In relation to the recovery rate of patients, of which the ACIIDS group of doctors have treated over 4,000, the general consensus is that 60-80% of

29 Dr Richard Horowitz, see *Submission 936*, p. 1.

30 ACIIDS, answer to question on notice, received 17 November 2016, p. 2.

31 Dr Gary Lum, Principal Medical Adviser, Office of Health Protection, Department of Health, *Committee Hansard*, 2 November 2016, p. 59.

32 ACIIDS, answers to questions on notice, received 17 November 2016, p. 3.

33 Karl McManus Foundation, answer to question on notice, received 18 November 2016, p. 3.

34 ACIIDS, *Submission 370, Attachment 24*. ILADS treatment guidelines can be found at <http://www.ilads.org/lyme/treatment-guideline.php> (accessed 23 November 2016).

our patients have considerable or complete recovery with appropriate treatment.³⁵

3.46 The committee asked the department about its consultations with ACIIDS. The department provided the following on its engagement with the organisation:

The department has met with medical practitioners who are treating patients. This has included meetings with members of the Australian Chronic Infectious and Inflammatory Diseases Society, separate meetings with Dr Richard Schloeffel and a treatment roundtable which brought together nine treating general practitioners along with other specialist medical practitioners to consider treatment options. Dr Lum has also attended a two-day meeting of the International Lyme and Associated Diseases Society.³⁶

3.47 The committee welcomes this engagement, and notes Dr Schloeffel's call for government support:

I am happy to have doctors sit in with me and I will teach them how to diagnose, treat and help these patients, but then someone else has to take them on. So we need funding for hospitals. We need an intellectual and a committed effort from the health departments, national and state, in our public system to help everybody who thinks they might have this illness...I do not think I am right or wrong; I am just seeing clinical evidence of a disease that needs to be managed...[I]t has got to come from the health minister, the Department of Health and the senior colleagues who direct policy and thought process, who have to say, 'Stop! We've got to stop. We've got to go over here. Maybe we got it wrong.' Admit you are wrong and come and talk to us. Actually make something happen. Support a pilot program with the Karl McManus Foundation. Let's look at 100 patients straight-up. Let's fund that. Let's do some proper medicine. Let's study that. Then we get 100 more. Then you will have 10,000 waiting in the queue. But they can be treated in all these peripheral hospitals, and doctors with interest and skill can start treating them. It is a process. I think that is the answer.³⁷

Committee view and conclusion

3.48 The committee concludes its inquiry without clarity on diagnosis or treatment of this illness. Given the magnitude of the dispute around tick-borne illness in Australia this is perhaps unsurprising.

3.49 What is clear, however, is that potentially infectious pathogens are being transmitted by Australian ticks, and treatment for the ensuing illnesses is currently suboptimal. The committee therefore returns to its starting premise: people are sick, and they must be helped. That people report avoiding engagement with medical staff at Australian hospitals for fear of being branded 'crazy' is concerning. That some

35 ACIIDS, answer to question on notice, received 17 November 2016, p. 1.

36 Department of Health, answer to question on notice, received 21 November 2016, p. 5.

37 Dr Richard Schloeffel, *Committee Hansard*, 2 November 2016, p. 51.

patients are contemplating suicide as a result, in part, of their distress at not receiving what they believe to be proper medical attention and care, is profoundly disquieting. The committee has no cause to doubt the veracity of these accounts.

3.50 Any suggestion that doctors should only treat patients if and when they have pinpointed the cause of illness is troubling—whilst not being comprised of medical professionals, the committee is persuaded that emerging diseases require safe and responsible treatment even when the science is in progress. Notwithstanding the absence of definitive answers on what the responsible pathogens are, it is the committee's view that medical authorities and doctors have a responsibility to address and treat illness. The patients are not responsible for the absence of vital research establishing which pathogens carried by which vectors are responsible for Lyme-like illness—this evidence is needed, and urgently, but so is treatment for patients who are unwell now.

3.51 The best possible treatment protocols need to be established as a matter of priority, and medical professionals educated on their use. The committee urges medical authorities to take advantage of the momentum created by this inquiry and consult extensively with researchers and clinicians focusing on tick-borne disease. With the right commitment from medical professionals and authorities, these treatment protocols will be refined and improved over time.

3.52 For this reason, the committee is recommending that treatment guidelines currently in use by doctors who claim significant recovery rates in their patients be assessed and a clinical trial conducted to determine their effectiveness. In parallel with scientific research into possible pathogens which is currently underway, this clinical trial of treatment protocols will serve to inform an evolving, evidence-based response to tick-borne disease. The committee urges medical authorities to act on this recommendation without delay and in consultation with relevant stakeholders including the Karl McManus Foundation and ACIIDS.

3.53 Patients cannot be asked to wait. The science will catch up, and it is critical that funding be made available for this to happen.

Recommendation 3

3.54 The committee recommends that government medical authorities, in consultation with stakeholders including the Australian Chronic Infectious and Inflammatory Diseases Society (ACIIDS) and the Karl McManus Foundation, establish a clinical trial of treatment guidelines developed by ACIIDS with the aim of determining a safe treatment protocol for patients with tick-borne illness.

Recommendation 4

3.55 The committee recommends that the Australian Government allocate funding for research into medically-appropriate treatment of tick-borne disease, and that medical authorities measure the value of treatment in terms of patient recovery and return to health. The best treatment options must then be developed into clinical treatment guidelines.

Recommendation 5

3.56 The committee recommends that the Australian Government Department of Health facilitate, as a matter of urgency, a summit to develop a cooperative framework which can accommodate patient and medical needs with the objective of establishing a multidisciplinary approach to addressing tick-borne illness across all jurisdictions.

Recommendation 6

3.57 The committee recommends that federal, state and territory health agencies, through the Council of Australian Governments Health Council, develop a consistent, national approach to addressing tick-borne illness.

Recommendation 7

3.58 The committee recommends that the Australian Government Department of Health urgently undertake an epidemiological assessment of the prevalence of suspected tick-borne illness in Australia, the process and findings of which are to be made publicly available.

Recommendation 8

3.59 The committee recommends that the Australian Government Department of Health establish the prevalence and geographical distribution of overseas-acquired Lyme disease in Australia.

Recommendation 9

3.60 The committee recommends that Australian medical authorities and practitioners addressing suspected tick-borne illness:

- consistently adopt a patient-centric approach that focusses on individual patient symptoms, rather than a disease label; and
- remove 'chronic Lyme disease', 'Lyme-like illness' and similar 'Lyme' phrases from diagnostic discussions.

Recommendation 10

3.61 The committee recommends that, to help the referral of patients for guided and comprehensive pathology testing, medical practitioners work with pathologists, especially microbiologists, immunologists, chemical pathologists and haematologists to optimise diagnostic testing for each patient.

Recommendation 11

3.62 The committee recommends that the Australian Government Department of Health work closely with the Australian Medical Association and Royal Australian College of General Practitioners to ensure that general practitioners have a better understanding of how to treat patients who present with complex symptoms.

Recommendation 12

3.63 The committee recommends that treatment guidelines developed by Australian medical authorities emphasise the importance of a multidisciplinary, case conference approach to patient care, involving consultation between general practitioners and specialists with expertise in neurology, psychiatry, rheumatology, immunology, infectious diseases and microbiology.

Senator Rachel Siewert

Chair