

Chapter 1

Patients first

People often say to me that I have coped with my situation with bravery and an astonishing amount of grace, but it is not really true. It is just that my fury has made me quiet.¹

1.1 The existence of tick—or other vector—borne, Lyme-like illness endemic to Australia is a controversial, polarising question. The committee considered evidence provided by many qualified professionals articulating considered, plausible, yet contradictory views. This evidence, presented over the course of two parts to this inquiry, mirrored the tangled public discourse which has been going around in circles for years: do pathogens responsible for Lyme disease exist in Australia, which pathology results are reliable, who do we believe?

1.2 The committee heard many moving personal accounts from patients over the course of this inquiry: eroding health, excruciating pain, complex manifestations, desperation, exasperation—in a few cases, even death. Ordinary, previously high-functioning members of the community rendered helpless and exhibiting symptoms many say are consistent with tick-borne illness. Years—sometimes decades—spent struggling just to get up and get on with life. It is undeniable that people are suffering.

1.3 Given that the committee accepts that the human toll is real, it is clearly necessary to go back to first principles—people are unwell, and they must be helped. It is therefore the committee's primary objective, in this, its final report on this inquiry, to put the patients first.

1.4 With this in mind, this report builds on the committee's interim report, tabled in May 2016, and seeks to define why there is so much confusion and disagreement. The committee hopes to establish how some progress can be made by cutting through the controversy and identifying areas of agreement. Put simply, why don't we know exactly what these patients have, and how do we help people suffering from an unrecognised, unidentified, but real illness?

1.5 These are the questions at the core of this inquiry.

Inquiry background

1.6 The inquiry into emerging evidence of a tick-borne disease was first referred to the committee on 12 November 2015, with a reporting date of 20 June 2016.²

1 Ms Fiona Caskie, *Committee Hansard*, Sydney, 2 November 2016, p. 32.

2 [*Journals of the Senate*](#), No. 126–12 November 2015, p. 3380.

- 1.7 The terms of reference for the inquiry were:
- a. the prevalence and geographic distribution of Lyme-like illness in Australia;
 - b. methods to reduce the stigma associated with Lyme-like illness for patients, doctors and researchers;
 - c. the process for diagnosis of patients with a Lyme-like illness, with a specific focus on the laboratory testing procedures and associated quality assurance processes, including recognition of accredited international laboratory testing;
 - d. evidence of investments in contemporary research into Australian pathogens specifically acquired through the bite of a tick and including other potential vectors;
 - e. potential investment into research to discover unique local causative agents causing a growing number of Australians debilitating illness;
 - f. the signs and symptoms Australians with Lyme-like illness are enduring, and the treatment they receive from medical professionals; and
 - g. any other related matters.³

1.8 Due to the federal election, however, the inquiry lapsed at the dissolution of the Senate on 9 May 2016, by which time the committee had held three hearings, in Perth, Brisbane and Canberra. Given the large volume of evidence received, the committee tabled a comprehensive interim report on 4 May 2016, just prior to the dissolution of the Senate.⁴

Interim report

1.9 The committee's interim report was a wide-ranging analysis of the evidence presented, and recognised that there is considerable debate in Australia and internationally about what constitutes Lyme disease and Lyme-like illness.

1.10 A large number of submissions were made by individuals detailing their personal experience, or that of others close to them. Many submissions were also received from doctors treating patients and researchers looking at tick-borne pathogens. The report detailed this experience, the trajectory of illness, access to medical treatment, and, in some cases, journey to recovery. For clarity, patients were divided into four clear groups:

- those who acquired and were diagnosed with classical Lyme disease in an endemic area overseas;
- those who acquired their illness overseas but weren't diagnosed;

3 *Journals of the Senate*, No. 126–12 November 2015, p. 3380.

4 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.

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- those who became ill following a tick or other insect bite in Australia; and
 - those who have experienced a long-term chronic illness in Australia and may or may not have been bitten by a tick or other insect.⁵

1.11 The committee noted the weight of evidence on the relationship between tick bites and people becoming ill.

1.12 The committee was concerned by reports of stigma attached to Lyme-like illness and the treatment of those patients potentially suffering the illness, and noted that more could be done to educate the public and medical professionals about the risk of tick bites and tick-borne illnesses in Australia, as well as classical Lyme disease acquired overseas.⁶

1.13 The committee also looked at diagnostic testing processes for Lyme disease and the recommended protocol for laboratory testing of patients with suspected Lyme disease. Testing, evidence suggested, was at the centre of the heated debate on whether or not Lyme disease itself can be contracted in Australia. Discordant laboratory results between accredited laboratories in Australia and non-accredited Australian and overseas laboratories, the committee concluded, were the cause of considerable confusion and frustration for patients.⁷

1.14 Although the committee's interim report was comprehensive and examined key evidence in detail, the committee identified a number of issues warranting further investigation.

1.15 Three recommendations were made:

Recommendation 1

4.52 The committee recommends that the Community Affairs References Committee continue its inquiry into this matter in the 45th Parliament.

Recommendation 2

4.56 The committee recommends that the Department of Health further develop education and awareness strategies for:

- the public about the prevention of tick bites and seeking medical attention; and

5 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, p. 19.

6 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, p. 31.

7 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, p. 58.

- the medical profession about how to diagnose and treat classical Lyme disease acquired overseas and known tick-borne illnesses acquired in Australia.

Recommendation 3

4.58 The committee recommends that the Chief Medical Officer continue to consult with the medical and patient communities through mechanisms such as the Clinical Advisory Committee on Lyme Disease, and for the Department of Health to continue to facilitate meetings with medical and patient representatives.⁸

Conduct of the inquiry

1.16 In light of the truncating effect the dissolution of Parliament had on the committee's inquiry, on 13 September 2016 the Senate agreed to re-adopt the inquiry with the same terms of reference and a reporting date of 30 November 2016.⁹

1.17 The committee did not call for further evidence upon re-adoption of this inquiry, having already received and considered over 1200 submissions prior to tabling its interim report. The committee did, however, hold an additional public hearing on 2 November 2016, in Sydney.

Structure of the report

1.18 This report is divided into three chapters:

- **Chapter 1** provides a background to the committee's inquiry and overview of evidence considered by the committee in its interim report.
- **Chapter 2** looks at diagnostic testing processes for Lyme disease, with the objective of establishing why these processes and test results are so controversial.
- **Chapter 3** examines treatment options available for patients suffering Lyme-like illness. The chapter examines the evidence around non-mainstream treatment, the position Australia's medical authorities take on such treatment, and how the existing impasse might be breached.

Acknowledgements

1.19 The committee thanks witnesses and submitters for their engagement with this inquiry, and recognises that a number of witnesses attended hearings at short notice on more than one occasion. The committee thanks them for their time, professionalism and evident commitment to acting in the best interests of the community.

8 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, p. ix.

9 See inquiry homepage, available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme_like_illness45 (accessed 14 November 2016).

1.20 The committee also extends particular gratitude and recognition to the individuals who came forward to relate their difficult personal experiences. The committee was deeply moved by these accounts, and by the patients' determination in having their voices heard and contributing in a positive way to the wider community's understanding of tick-borne disease.

