Report of the Health Committee

Petition of Belinda Hodson for the Thyroid Association of New Zealand: Help thyroid patients get treatment that works

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Contents

Dr Liz Craig
Chairperson

Petition of Belinda Hodson for the Thyroid Association of New Zealand

Recommendation

The Health Committee has considered the petition of Belinda Hodson for the Thyroid Association of New Zealand—Help thyroid patients get treatment that works—and recommends that the House take note of its report.

Request regarding treatment for thyroid patients

The petition was presented to the House on 13 March 2020. It requests:

> That the House of Representatives inquire into the diagnosis and treatment of patients with signs and symptoms of thyroid disease; that the inquiry consider increased access to the full range of thyroid blood tests, funding for treatments containing the active thyroid hormone T3, providing up to date education for all doctors and endocrinologists on thyroid diagnosis and treatment, and promoting positive open dialogue between doctors and patients; and note that 3,650 people signed an online petition in support of this.

The Health Committee of the 52nd Parliament began considering the petition. We resumed consideration in the 53rd Parliament.

Comments from the petitioner

Belinda Hodson, the lead petitioner, submitted oral and written evidence on this petition for the Thyroid Association of New Zealand. The association is a patient-to-patient support group which, among other things, provides support and information regarding the diagnosis and treatment of thyroid disease. It aims to raise awareness about thyroid disease, and advocates for better care for thyroid disease sufferers.

About thyroid disease

The thyroid is a butterfly shaped gland that sits in front of the windpipe, midway between the thyroid cartilage and the top of the sternum. The thyroid controls metabolism via two hormones—T4 (thyroxine) and T3 (triiodothyronine).

Thyroid disease is the general term for a medical condition where the thyroid does not make the right amount of those two hormones. Hyperthyroidism is when the thyroid makes too much of the thyroid hormones, and Hypothyroidism is when the thyroid makes too little of the thyroid hormones.

We were told that thyroid disease is more common than diabetes and heart disease, and that if left untreated it can influence the onset of other illnesses, such as cancer.

The petitioner wants better treatment for thyroid patients

The petitioner is concerned that thyroid patients are not receiving appropriate care through the current laboratory testing, treatment policies, and funding for medication for thyroid disease. Her submission included a range of evidence and testimonies that echoed her concerns, some of which are discussed further in our report.

We were told that clinicians do not take patients' symptoms seriously

In her written submission, the petitioner shared the testimonies of other thyroid disease patients who are unhappy with the treatment they receive. We were told that many patients feel unheard and mistreated by the medical professionals who are meant to help them. The petitioner said clinicians and endocrinologists can be dismissive of the symptoms their patients report. She said patients who report persistent symptoms can be blamed for their symptoms or told they must not have been taking their medication correctly.

The petitioner said the patient's voice is not at the centre of decision-making, and that it is treated as "subjective and unreliable". She said it is disappointing that people who are being advocates for their own health are having these degrading encounters with medical professionals.

The petitioner is concerned about the reliance on TSH test results

The petitioner shared that it took her 15 years and 8 endocrinologists and doctors before she found a doctor with the right skills and knowledge to help her. She said other doctors have told her that because her results for the thyroid-stimulating hormone (TSH) blood test sit in the normal range, the persistent symptoms she was experiencing must be "in her head".

The petitioner said this single blood test dominates the diagnosis and treatment of thyroid disease. She said patients experiencing persistent symptoms who return normal results are not supported to take other tests and get onto an effective treatment plan. Instead, she said, the patient's symptoms are dismissed because the results of this one test look normal.

The petitioner wants medications containing T3 to be funded

Levothyroxine is the standard medication used to treat thyroid disease, and is the only thyroid treatment funded by PHARMAC. The petitioner told us that levothyroxine does not work for all patients. When she used it, the petitioner told us, she suffered hair loss, debilitating fatigue, weight gain, brain fog, crippling pain, and many other symptoms. She said these symptoms stopped when she began taking medication containing T3, and she has been symptom-free for 13 years. The cost of this drug for the petitioner is $14,000 annually. We heard that an estimated 10,000 other thyroid patients only get symptom relief on medications containing the thyroid hormone T3.

The petitioner is concerned that alternative treatments, which many people find work better than levothyroxine, are not affordable. This means that those who cannot afford alternative treatments are having to live with severe symptoms. She said that those who can afford alternative treatments fear that they will not be able to continue taking them long term. She said patients fear having to fight against medical professionals who strongly prefer levothyroxine, and might want to take them off T3 medications.

The petitioner said that GPs are unable to give well-rounded advice and help when treating thyroid patients because they are not aware of the different options, or are not willing to trial them. She said many patients do not know that their care is being mismanaged because of this, so those patients accept their symptoms as the “new normal”.

The petitioner wants an inquiry so patients can share their stories

We asked the petitioner what outcome she wanted to see following her submission, and what could be done to improve the treatment of thyroid disease in New Zealand. The petitioner said that thyroid patients should be given an opportunity to tell their stories and be heard through an inquiry process, much like what happened for those who were suffering because of surgical mesh. The petitioner said there is a lack of patient input into the treatment guidelines and training material developed by endocrinologists. She believes an inquiry would provide an avenue for medical professionals to understand what patients are experiencing.

We asked why there is such a disconnect between the medical profession and the lived experience of patients. The petitioner said that a lot of science on thyroid physiology was not incorporated into the design of randomised control trials. She said people who do not benefit from levothyroxine have not been studied enough to develop guidance on what to do for those cases.

Comments from the Ministry of Health

The Ministry of Health told us that PHARMAC and district health boards are responsible for the funding and provision of health and disability services, including laboratory tests. The ministry itself does not provide clinical guidance or advice on the diagnosis and treatment of specific diseases. It said PHARMAC last examined the case for funding T3 in 2018, and decided against funding any thyroid treatments except T4 (Levothyroxine). PHARMAC has said it would be open to reviewing another application if “new evidence can be considered”.

We asked what consideration has been given to new evidence, and whether this will feed into new treatment guidelines. The ministry said there is evidence that some patients lack an enzyme to allow the breakdown of T4 into T3. However, we were told that GPs in New Zealand tend to focus on treatment options that are available and funded when treating a patient. The ministry suggested that the biggest factor in T3 not being discussed is that it is not funded, as opposed to a complete lack of understanding.

The ministry noted that the Health and Disability Commission states that health professionals have an obligation to raise any options the patient may wish to consider, including non-funded treatments. The ministry told us that it supports positive, open dialogue between doctors and their patients.

We were told that the Royal Australasian College of Physicians, through the endocrine section, would handle the guidelines for endocrinology practice. The ministry said it can play a role in stimulating an open discussion on these matters. It said that the Medical Council monitors and accredits New Zealand medical schools to ensure they provide high-standard training. We were told that when accreditation does occur there are opportunities for patient groups to feed into those processes. The ministry offered to discuss the advertisement of such opportunities with the Medical Council.

The ministry also suggested that the Thyroid Association could consult with the relevant professional colleges which provide training and professional development for medical professionals (for example, the Royal Australasian College of Physicians).

Our response to the petition

We acknowledge the courage of all the people who shared their story with us through this petition, and thank them for doing so. We also thank the petitioner and the Thyroid Association of New Zealand for their advocacy for patients affected by thyroid disease.

We encourage the Ministry of Health to facilitate discussions between the Thyroid Association of New Zealand and the Royal Australasian College of Physicians about the diagnosis and treatment of thyroid disease with a view to ensuring that:

- guidelines and position statements on thyroid function testing and the management of thyroid disease are kept up to date and aligned with international best practice
- the lived experience of those with thyroid disease is respected and taken into account in clinical decision-making processes
- ongoing professional development is available so that health practitioners are aware of the current best practice in this area.

Appendix

Committee procedure

The petition was referred to the Health Committee of the 52nd Parliament on 13 March 2020. The committee received a written submission from the petitioner.

On 26 November 2020, the petition was reinstated with the Health Committee of the 53rd Parliament. We met between 3 December 2020 and 25 August 2021 to consider it. We received written and oral evidence from the petitioner and the Ministry of Health.

Committee members

Dr Liz Craig (Chairperson)
Matt Doocey
Dr Elizabeth Kerekere
Dr Anae Neru Leavasa
Dr Tracey McLellan
Debbie Ngarewa-Packer
Sarah Pallett
Dr Gaurav Sharma
Penny Simmonds
Tangi Utikere
Brooke van Velden
Simon Watts

Evidence received

The documents we received as evidence in relation to this petition are available on the Parliament website, www.parliament.nz.