endometriosis
new zealand

2026

Election Manifesto

A plan for earlier diagnosis, improved treatment and better outcomes for New Zealanders with endometriosis

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Executive Summary

Endometriosis affects at least 120,000 New Zealanders. Yet for too many people, the path to diagnosis and care is too long, too difficult, and inequitable. Endometriosis is not a niche issue. It is a major health, education, workforce and productivity issue with significant consequences for individuals, whānau, communities and the wider economy.

New Zealanders living with endometriosis are still waiting close to 10 years, on average, for diagnosis. Māori and Pasifika can face even longer delays. Access to diagnosis, treatment and specialist care remains too dependent on where someone lives, what they can afford, and whether they are able to keep pushing through a fragmented system.

This manifesto sets out the proposed solutions and policy commitments Endometriosis New Zealand is asking political parties to adopt ahead of the 2026 General Election.

Priority Policy Actions

- **Develop, resource and implement a National Endometriosis Action Plan for New Zealand – Aotearoa needs a nationally-consistent government-backed framework to improve education and awareness, diagnosis, treatment, care and research.**
- **Adopt and implement the new RANZCOG Australian Living Evidence Guideline: Endometriosis – The current 2020 New Zealand guideline is outdated and no longer reflects international best practice. The newer RANZCOG guideline provides a stronger and more current framework for diagnosis and treatment.**

Supporting Policy Actions

- Ensure adenomyosis is addressed in any new clinical guideline for endometriosis and explicitly included in a National Endometriosis Action Plan.
- Continue improvements to Pharmac's funding model, including stronger patient input, greater transparency, and faster assessment of funding applications.

Endometriosis New Zealand

Endometriosis New Zealand is the country's national charity and advocacy organisation for endometriosis. It provides education, advocacy and support services across communities, schools and workplaces, and works with clinicians, researchers and government to improve the outcomes for those living with endometriosis. Endometriosis New Zealand is supported by a multidisciplinary Clinical Advisory Committee, helping ensure its recommendations are grounded in the most current evidence, research and clinical practice.

About Endometriosis in New Zealand

Endometriosis is a common yet frequently under-recognised whole-body, inflammatory condition where tissue similar to the lining of the uterus is found outside the uterus.

Symptoms can include severe pelvic and period pain, pain during and after sex, bladder and bowel symptoms, fatigue, heavy or abnormal bleeding, fertility issues, and significant impacts on mental wellbeing and everyday life.

Endometriosis is estimated to affect

at least 120,000

New Zealanders, or approximately 1 in 10 women, girls and those assigned female at birth.[1]

The Challenge

New Zealand's current approach to endometriosis remains fragmented, inconsistent and is failing many people with the condition. Despite recognition of the condition at a policy level (including in the Women's Health Strategy), the day-to-day reality for many patients has not materially improved, and New Zealand's delays to diagnosis remain among the longest reported in the world.[2]

Many New Zealanders face a difficult journey through primary care, poor access to specialists, inconsistent diagnosis, and insufficient access to publicly funded and affordable treatment options.

Delays to Diagnosis

People with endometriosis in Aotearoa face an average delay to diagnosis of almost 10 years. That means many are spending well over a decade navigating unmanaged pain, repeated appointments, misdiagnosis, disrupted education, missed work, financial pressure, and avoidable declines in quality of life. Māori (11.6 years) and Pasifika (12.4 years) face even longer average delays.[3]

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[1] Ellis, K. and Wood, R. (2024), A decade to wait: Update on the average delay to diagnosis for endometriosis in Aotearoa New Zealand. Aust N Z J Obstet Gynaecol, 64: 524-529. https://doi.org/10.1111/ajo.13836

[2] Ellis, Wood. (2024)

[3] Ellis K, Tewhaiti-Smith J, Munro D, Wood R. The Perspectives of Māori and Pasifika Mate Kirikōpū (Endometriosis) Patients in Aotearoa New Zealand. Societies. 2024; 14(4):46. https://doi.org/10.3390/soc14040046.

Access to Treatment

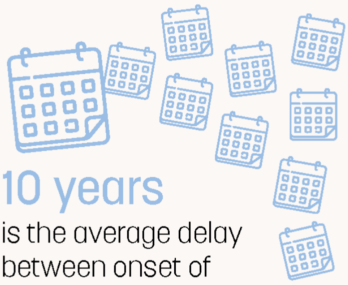
Access to treatment remains too dependent on geography and income. Long waits to see specialists, the lack of resources available in primary care to facilitate holistic, patient-centred care, and the absence of readily available non-surgical, non-hormonal management options all contribute to a system where care is inequitable. Those who can afford private care are frequently able to move faster through the system and get treated earlier than those who cannot. Around 66 percent of Māori and 60 percent of Pasifika respondents also reported that 'treatment was not readily available to them'.[4] Rural communities also face extra barriers because of distance, and uneven access to specialist services and imaging.

Personal and Economic Impact

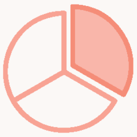
Endometriosis has substantial personal, social and economic consequences. Recent New Zealand-specific research points to a national economic burden in the billions of dollars annually, with a large proportion of that burden driven by lost productivity.[5] The impacts are seen not just in healthcare use, but in interrupted education, reduced work capacity, lower income, repeated out-of-pocket costs, strain on relationships, and diminished quality of life.

Endometriosis at a Glance

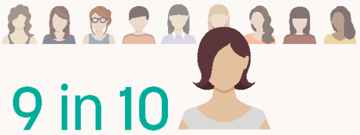
Affects at least 1 in 10
girls, women and those presumed female at birth



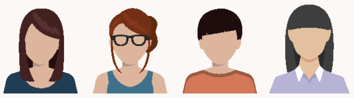
10 years
is the average delay between onset of
symptoms and diagnosis



One in three
of those with endometriosis experience
fertility problems

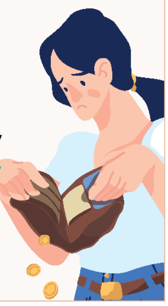


9 in 10
people with endometriosis have had their symptoms
dismissed or downplayed
by a medical professional



More than 1 in 4
have had to give up their studies because of their condition

More than 8 in 10
people with endometriosis say it has negatively impacted their financial wellbeing



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[4] Ellis et al. (2024).

[5] Tewhaiti-Smith, J., Gannott, M., Semprini, A., Bush, D., Anderson, A., Eathorne, A., Johnson, N., Girling, J. E., East, M., Marriott, J., Fisher, R., & Armour, M. (2025). The Cost of Endometriosis and Chronic Pelvic Pain Burden in New Zealand (Aotearoa): Results from a Nationwide Survey. Women, 5(4), 47. https://doi.org/10.3390/women5040047.

Priority Policy Actions

A National Endometriosis Action Plan for New Zealand

At present, there is no dedicated nationwide programme or investment specifically designed to address endometriosis in New Zealand. A National Endometriosis Action Plan would address that gap by providing a practical, national blueprint to reduce the human and economic cost of endometriosis through coordinated action in education and awareness, clinical management and care, research and data collection, and accountability back to government.

How a National Endometriosis Action Plan would help

DIAGNOSIS, TREATMENT AND CARE

- A national action plan would improve earlier recognition of endometriosis, creating more consistent treatment pathways, developing the workforce necessary to meet demand and supporting multidisciplinary care. This includes better triage, national treatment standards, integrated pain and fertility services, and improvements in training across gynaecology, pain management, primary healthcare and adolescent health services.

EDUCATION AND AWARENESS

- Improving public understanding of endometriosis and reducing stigma is critical to helping those with the condition lead full and productive lives. A national action plan would boost symptom recognition and support in schools, workplaces and communities, and strengthen education for GPs, nurses and frontline health professionals.

RESEARCH AND DATA COLLECTION

- More New Zealand-specific research into endometriosis, diagnosis and treatment challenges, and its impacts is needed. Better local evidence can help inform future policy and ensure services are more responsive to changing needs. Research into adenomyosis in New Zealand should also form part of this work. Currently, there is very little New Zealand-based research into adenomyosis.

ACCOUNTABILITY

- A national action plan should include clear leadership, measurable goals and regular public reporting so that progress can be assessed transparently. Cross-agency coordination, stakeholder involvement and staged implementation funding will all be important to ensure the plan delivers practical change.

The Australian Example

Australia provides a useful model of what a coordinated national action plan can look like. Since launching its National Action Plan for Endometriosis in July 2018, Australia has positioned itself as an international leader in endometriosis policy, moving beyond awareness-raising into funded, practical implementation across research, education, diagnosis and care.

The Australian Government has now committed around A$127 million across research, awareness and education, and clinical management and care. That investment has included A$37 million for 33 Endometriosis and Pelvic Pain Clinics, supporting multidisciplinary care and earlier pathways to diagnosis and treatment. The initial network of 22 clinics has already supported more than 10,000 women and girls and provided more than 28,000 services to those with endometriosis and persistent pelvic pain conditions.

Australia has also committed A$21.33 million for additional endometriosis research, plus A$5.1 million for the National Endometriosis Clinical and Scientific Trials Network; A$5.1 million for an Endometriosis Management Plan; A$2.0 million for awareness in priority populations; and A$1.9 million for the EndoZone digital platform to help people manage their endometriosis day-to-day.

It has also funded improved diagnostic support services, including A$25.5 million for a Medicare-funded MRI item related to severe endometriosis and infertility investigations.

What we are asking parties to commit to

- Develop a National Endometriosis Action Plan for New Zealand that includes input from people living with the condition, clinicians, researchers, and Māori and community health leaders.
- Include clear workstreams on improving education and awareness, clinical management and care, research and data, equity, and accountability
- Commit multi-year Budget funding for development and implementation of the National Endometriosis Action Plan.

The new RANZCOG Australian Living Evidence Guideline: Endometriosis

Endometriosis New Zealand is calling for government to urgently adopt and implement the RANZCOG Australian Living Evidence Guideline: Endometriosis as New Zealand's national clinical standard. The 2020 guideline currently in use in New Zealand is outdated and no longer reflects best practice.

The Living Evidence Guideline supports greater use of non-invasive imaging such as ultrasound andp elvic MRI as first-line investigation techniques, earlier use of hormonal treatment in parallel with diagnostic investigations, stronger multidisciplinary models of care, and clearer referral pathways. It provides a more modern framework for access, including better support for rural and remote communities. Importantly, it also includes recommendations for the assessment and management of adenomyosis.

The new guideline, which is already in use in Australia, can shorten the diagnosis journey, reduce reliance on diagnostic laparoscopy, improve access to treatment earlier, and support more equitable and less invasive care. For the guideline to be effective it is critical implementation is properly resourced, including workforce training and education, imaging capacity, primary care support, and application across the health sector.

What we are asking parties to commit to

- **Direct Te Whatu Ora – Health New Zealand to adopt the new RANZCOG Australian Living Evidence Guideline: Endometriosis as the national clinical standard for endometriosis care.**
- **Retire the outdated 2020 Ministry of Health guideline.**
- **Provide dedicated funding for implementation of the new guideline across primary care, specialist care, imaging resourcing and the health system generally.**

Supporting Policy Actions

Adenomyosis must be included

Adenomyosis is a common but underappreciated and under-recognised condition in which tissue similar to the lining of the uterus grows into the muscle wall of the uterus itself. By contrast, endometriosis occurs outside the uterus. The two conditions can be considered like siblings, not twins.

Symptoms of adenomyosis can include severe period pain, heavy or prolonged bleeding, pelvic pain, bloating and fatigue, and for some people those symptoms can be debilitating and have a major impact on quality of life.

Data from our endometriosis community indicates that one in three have also been diagnosed with adenomyosis.

Adenomyosis is often confused with endometriosis, and some people may have one condition on its own, while others may have both. That overlap, combined with the fact that the symptoms can resemble each other, is one reason adenomyosis has historically been overlooked or misdiagnosed.

Unlike New Zealand's current 2020 clinical guideline, the new RANZCOG Australian Living Evidence Guideline: Endometriosis includes clinical recommendations not only for endometriosis, but also for adenomyosis, and includes dedicated sections on the diagnosis of adenomyosis, hormonal treatment for adenomyosis, surgical management, hysterectomy considerations, pain management and non-surgical care.

Any National Endometriosis Action Plan should also explicitly include adenomyosis within its scope, particularly in relation to education and awareness, clinical care, and New Zealand-specific research.

What we are asking parties to commit to

- **Adoption of the new Living Evidence Guideline would improve recognition, diagnosis, treatment and long-term management of adenomyosis alongside endometriosis.**
- **Development, implementation and resourcing of a National Endometriosis Action Plan that includes adenomyosis within its scope, particularly in relation to education and awareness, clinical care, and New Zealand-specific research.**

Medicines access

Non-surgical medical therapies play an important role in the management of endometriosis. They can reduce pain, slow progression of disease activity, improve quality of life, and in some cases reduce the need for surgery or help people manage symptoms while waiting for specialist care.

Better symptom control through the use of hormonal and non-hormonal therapies can also reduce broader demand across the health system, decrease the number of hospital presentations and pressure on surgical services, lessen the financial and personal toll on patients and whānau, and the economic toll on New Zealand as a whole.

No single treatment works for everyone. Responses vary, side effects vary, and treatment needs to change depending on the individual, their symptoms and medical history. Access to a range of evidence-based hormonal and non-hormonal options is therefore important.

What we are asking parties to commit to

- **Continued improvements to Pharmac's funding model and access to medicines, including greater patient and consumer participation in assessment and decision-making processes, improved transparency around advice and funding decisions, and faster, more timely assessment of funding applications.**

Te Tiriti o Waitangi and Equity

The burden of endometriosis is not felt equally. While the average delay to diagnosis in New Zealand is close to 10 years, Māori face an average diagnostic delay of 11.6 years. Around 66 percent of Māori also reported that treatment was not readily available to them in comparison to 44 percent of a mixed cohort.[6] This points to persistent inequity in timely diagnosis and access to care for Māori.

Pasifika communities also face significant inequities. Pasifika experience an average diagnostic delay of 12.4 years, and around 60 percent of Pasifika respondents reported that treatment was not readily available to them, again significantly higher than the 44 percent reported by a mixed cohort.[7] This indicates a system in which access to diagnosis and treatment remains too uneven, and where Pasifika are also being disadvantaged.

Patients with endometriosis see an average of five GPs before diagnosis, which can deepen inequity for those facing cost, transport, workforce and access barriers.[8] Māori patients are more likely to report having their symptoms dismissed, particularly in primary care, while broader barriers including cultural stigma, systemic bias and healthcare distrust can further compound inequitable outcomes. Pasifika patients have also been shown to face long diagnostic delays and lower levels of knowledge at symptom onset, reinforcing the need for earlier recognition, stronger community awareness and more culturally responsive care.[9]

Endometriosis policy must address the issue of inequity, or it will fail many of the people most affected by current shortcomings in the system.

Implementation of new guidelines and any National Endometriosis Action Plan should:

- Give practical effect to Te Tiriti o Waitangi.
- Seek to improve access to diagnosis and treatment services for Māori.
- Seek to improve access to diagnosis and treatment services for Pasifika communities.
- Reduce postcode-based and income-based inequities in accessing diagnosis and treatment services.
- Improve access for rural and underserved communities, including through telehealth and better referral and imaging pathways.
- Ensure the needs of LGBTQIA+, disability, and ethnic and migrant communities are provided for in a National Endometriosis Action Plan.
- Include ongoing research aimed at measuring and promoting the reduction of inequity over time.

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[6] Ellis K, Wood R. (2025), 'I Wish I Fought for Myself More Instead of Just Letting Doctors Dismiss Me': A Combined Qualitative Analysis of Four Cohorts of Aotearoa New Zealand Endometriosis Patients. Aust N Z J Obstet Gynaecol. 2025;65:809-823. https://doi.org/10.1111/ajo.70038

[7] Ellis, K. and Wood, R. (2025).

[8] Tewhaiti-Smith, J., Semprini, A., Bush, D. et al. An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain. Sci Rep 12, 4425 (2022). https://doi.org/10.1038/s41598-022-08464-x

[9] Ellis et al. (2024).

Conclusion

Endometriosis in New Zealand is under-recognised, under-resourced and under-prioritised. The result is tens of thousands of New Zealanders living through years of avoidable pain and putting up with long delays to diagnosis, inconsistent care, inequitable access to treatment and major personal and financial impacts. These impacts are also having a broader effect on the country as a whole.

This election presents an opportunity for political parties to help change this course.

Endometriosis New Zealand is calling on parties to commit to:

- Development and funding of a National Endometriosis Action Plan.
- Adoption and implementation of the new RANZCOG Australian Living Evidence Guideline: Endometriosis.
- Ensuring adenomyosis is addressed in any new clinical guideline for endometriosis and explicitly included in a National Endometriosis Action Plan.
- Continued improvements to Pharmac's funding model, including stronger patient input, greater transparency, and faster assessment of funding applications.

For more than 120,000 New Zealanders these policy priorities would represent real change. They are practical steps toward earlier diagnosis, fairer access, better symptom management, and a health system that responds sooner, more consistently and more humanely for those living with endometriosis.

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