

## WHAT DOES ENDOMETRIOSIS NEW ZEALAND DO?

Endometriosis New Zealand is Aotearoa's national endometriosis organisation representing over 120,000 girls, women and those assigned female at birth that suffer with this condition.

We provide support, advocacy, research, information, education, and awareness on endometriosis. Our services educate and empower thousands of people living with the endometriosis.

Our purpose is to improve lives of those with endometriosis and we have been there for people living with endometriosis for over 30 years.



## Contact Us

We deeply understand the challenges you may be facing on your unique journey with endometriosis and we are committed to continuing to be the trusted source for information, education and support for those impacted by endometriosis in Aotearoa, New Zealand.

We are here for you, at any stage, at any time. Please do not hesitate to reach out, or ask a loved one to reach out on your behalf.

endometriosis  
new zealand

**Endometriosis  
New Zealand**

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Finding a way forward with  
*hope and strength.*

## WHAT IS ENDOMETRIOSIS?



### What

Endometriosis is a common, chronic inflammatory disease in which tissue similar to the lining of the uterus, is found in places outside of the uterus, most commonly in the pelvic region.

### Who

Endometriosis is generally considered to affect people in their reproductive years. For some, it can be as early as their first menstrual period, whereas, for others, it could begin to occur much later in life.

The disease affects an estimated 1 in 10 women, girls and those assigned female at birth, and approximately 120,000 people in Aotearoa, New Zealand.

### Why

We don't yet know the cause of endometriosis. Research shows that there is a strong genetic link, meaning it can run in families. Not everyone with symptoms may have been diagnosed.

## ENDOMETRIOSIS SYMPTOMS



**The severity and type of symptoms can differ for everyone; some people may not experience any pain or symptoms.**

**Symptoms associated with endometriosis include, but are not limited to**

- Painful periods (The most common symptom)
- Bowel problems
- Pain during or after sexual intercourse
- Abnormal menstrual bleeding
- Pain between periods e.g. with ovulation or intermittently throughout the month
- Fatigue, tiredness and low energy
- Bladder troubles like pain or frequent urination
- Pain in other places such as the lower back
- Premenstrual syndrome
- Migraine
- Irregular periods or heavy periods
- Difficulty getting pregnant

*Symptoms often have a significant impact on an individual's physical, mental and social wellbeing.*





WHAT DO I DO  
IF I THINK I MAY HAVE  
ENDOMETRIOSIS?

**Every person is different, and symptoms vary and are wide-ranging, which can make endometriosis difficult to recognise and diagnose.**

**We recommend speaking to your GP if anything in this pamphlet resonates with you.**

**Talk to your GP about your symptoms, discuss treatment options, and ask for a referral to a gynaecologist.**

**You can use these tools to assist you at your appointment:**

- Track your symptoms using our symptom tracker, an app, or a journal. Detail how your symptoms are affecting your quality of life, for example socially, physically, professionally, in relationships, and your mental well-being.
- Utilise The Raising Awareness Tool for Endometriosis (RATE). This tool is a quick-to-use electronic resource for health professionals and their patients to help identify and assess endometriosis - and endometriosis-associated symptoms - to reach a faster diagnosis and achieve more effective management of symptoms.

You can find the RATES tool here [www.ranzcog.edu.au/resources/raising-awareness-tool-for-endometriosis-rate](http://www.ranzcog.edu.au/resources/raising-awareness-tool-for-endometriosis-rate)



## Medical and Surgical Treatment

A doctor may suspect you have endometriosis based on your medical history and symptoms. They are likely to perform a physical examination and request investigations such as an ultrasound and blood tests. These tests usually do not diagnose endometriosis but can be useful in determining treatment options and/or next steps.

**There are three groups of treatments for period pain:**

1. Medical treatments (hormone medications and pain relief)
2. Surgical treatments (involving an operation)
3. Allied treatments (physiotherapy, psychology, alternate medicine, etc)

Usually a laparoscopy (keyhole surgery) is required to make a final diagnosis of endometriosis. You should discuss these options with your doctor and make sure that you understand how and why they might help you. You should feel comfortable to ask what the advantages and disadvantages are for the treatments you're offered and you may need different treatments at different times in your life. Sometimes it takes trialling a few things before finding the right combination for you.

## Self Management

Managing symptoms can be different for everyone and please know that there is no 'correct' or 'best' management. It is not limited to medical and surgical treatment, it's about working with your health professional and implementing self-management tools that work best for you.

We recommend exploring different lifestyle changes to help empower you to live well with endometriosis. You can adapt and prioritise your nutrition, sleep, exercise regime, mental health, and other areas of your life, to help symptom management.

Self-management tools and ideas can be found here:  
[www.nzendo.org.nz/managing-endo](http://www.nzendo.org.nz/managing-endo)



## HOW CAN WE HELP YOU?

We offer practical and emotional support to empower those who may be living with endometriosis and we have a variety of resources covering all aspects of endometriosis, that are accurate, comprehensive, and up-to-date.



**Website:** You can browse categories looking for information and contact us directly for more information. The website is a vital source of information for anyone struggling to navigate their endometriosis journey, or to help a loved one, colleague, educator, or anyone in need.

[www.nzendo.org.nz](http://www.nzendo.org.nz)

**Endo Help:** We offer free, private, 30-minute appointments to everyone across Aotearoa. Endo Help appointments are a safe environment for you to get information, advice and practical support about endometriosis from someone who is experienced, and well-informed in the understanding, and management of endometriosis and pelvic pain.

You can book an appointment via our website:  
[www.nzendo.org.nz/helping-you](http://www.nzendo.org.nz/helping-you)

**Social media:** We have both a Facebook and Instagram page that regularly posts information, self-management tools, and other endometriosis-related content.



[nzendo](https://www.facebook.com/nzendo)



[endometriosisnewzealand](https://www.instagram.com/endometriosisnewzealand)

**Online Support Group:** This group is a place to connect with others and an opportunity for people to share their personal experiences and feelings, and access reliable resources on endometriosis.

You can join the group here:  
[www.facebook.com/groups/endometriosisnz](https://www.facebook.com/groups/endometriosisnz)

**Membership:** Our membership group is a community of people with a connection or interest in endometriosis and everyone is welcome to join.

Members receive regular emails with the latest endometriosis research findings, news articles and other important, accurate, and up-to-date material.

You can become a member here:  
[www.nzendo.org.nz/join-us](http://www.nzendo.org.nz/join-us)

**Informative and educational events:** We host informative events that connect our endo community and discuss important endometriosis information. Events and seminars cover a variety of related topics including endo management, diet, relationships, advice and are held online and across the country.