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Endometriosis management in New Zealand – How can we do better?



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About the speaker



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This Goodfellow symposium 2022 webinar was presented online on Saturday 26 March 2022 by Dr Michael Wynn-Williams who discussed how the diagnosis and management of endometriosis are improving globally. These improvements are leading to a reduction in the long delays that are reported prior to the disease being diagnosed and managed. Dr Michael Wynn-Williams outlined how endometriosis is currently managed in New Zealand and discussed steps that can be taken to improve the management of this disease. The online session was moderated by Dr Vicki Mount from Mission Bay Doctors, Auckland. The webinar and this publication are supported by Allevia Hospitals.

What is endometriosis?

Endometriosis is a chronic inflammatory condition that is defined as the presence of endometrial-like tissue outside of the uterine cavity.¹⁻⁴ Symptoms of endometriosis may include pelvic pain, dysmenorrhoea, dyspareunia, and infertility.^{1,2} Some people with endometriosis may be asymptomatic.² Endometriosis impacts girls and women of reproductive age, individuals from the transgender community, and people who are nonbinary that may not identify as women.²

The latest Australian data indicate that 11.4% of women received a diagnosis of clinically confirmed or suspected endometriosis by age 44 years.⁵ There has been minimal New Zealand-based research regarding the prevalence of endometriosis within the various ethnic populations of Aotearoa.⁶

Pathophysiology

The pathophysiology of endometriosis is complex and is influenced by many factors.¹ Sampson's theory of retrograde menstruation has been a widely accepted theory. It is theorised that, in some people, the shed endometrium implants and grows within the peritoneal cavity.¹ However, this theory is becoming less popular, with other theories such as Müllerianosis becoming more widely accepted.⁷⁻⁹ According to this theory, defects in embryogenesis result in aberrant differentiation or migration of the Müllerian ducts causing spreading of cells or tracts of cells in the migratory pathway of foetal organogenesis.⁹ Other theories, such as those involving environmental factors, stem cells, genetic components, immunological factors, metaplasia, and neonatal uterine bleeding, have been proposed.¹⁰⁻¹³ It is thought that an interplay between all these different factors produces the different phenotypes in endometriosis.

There are different types of endometriosis, such as that involving the ovaries (endometrioma), superficial peritoneal endometriosis, or deep infiltrating endometriosis (DIE). Focal adenomyosis on the outer myometrium (FAOM) may be associated with deep infiltrating endometriosis, particularly in the bladder and/or the rectum, and is thought to arise from the uterus.^{14,15}

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Staging endometriosis

Several staging systems for endometriosis have been proposed. The American Fertility Society (AFS) (now the American Society for Reproductive Medicine [ASRM]) system involves stages 1-4.¹⁶ Stage 1 (minimal) involves superficial lesions, commonly on the pelvic walls or pouch of Douglas; Stage II (mild) involves superficial lesions, with some deep lesions (>5 mm infiltration below the peritoneal surface); Stage 3 (moderate) includes endometrioma, minor adhesions (often between the ovarian and uterine wall); and Stage 4 (severe) involves severe adhesions with bowel and bladder involvement and obliteration of the pouch of Douglas. The ASRM staging system is useful for staging minimal and mild disease, but as the disease progresses it becomes harder to describe the severity of the disease to a colleague or when a patient is being referred. Dr Wynn-Williams is encouraging his colleagues in New Zealand to use the new #Enzian staging system (Figure 1),¹⁷ which allows for the complete mapping of endometriosis, and includes an indication of the anatomical location (peritoneum, ovaries, and fallopian tubes), areas of deep disease, and the size of the lesion(s). The resultant formula that is produced results in a “really straightforward way of describing the disease”, Dr Wynn-Williams noted. The staging of the endometriosis can also be described on pre-operative advanced pelvic ultrasound or magnetic resonance imaging (MRI) using the same #ENZIAN system (Figure 1).¹⁷

Diagnostic delay

Globally, delays in the diagnosis of endometriosis of about 7-12 years have been reported,^{18, 19} with delays of 8.7 years reported in a recent EndoCost survey conducted in New Zealand (see below).⁶ Such delays may be due to patient-related factors, such as patients and their families considering painful periods to be normal. Delays may also be clinician-related, such as the clinician experiencing difficulty getting access to investigations such as transvaginal ultrasound or access to secondary care. Long diagnostic delays can impact the patient's health and wellbeing, social activities, mental and emotional health, work and finances, sexual relationships, and fertility.¹⁹⁻²¹

Diagnosis of endometriosis

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) have produced clinical practice guidelines that include a description of the signs and symptoms of endometriosis that may indicate a diagnosis. (Table 1).⁴

Table 1. Signs and symptoms of endometriosis (RANZCOG)⁴

Suspect endometriosis in people (including those aged 17 years and under) presenting with one or more of the following:

- persistent pelvic pain;
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life;
- deep pain during or after sexual intercourse;
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements;
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine;
- infertility in association with one or more of the above.

Management of endometriosis

In primary care, the management of endometriosis should be patient-centred, with the prioritisation of the symptoms that the patient wants to manage.²⁻⁴ For example, the patient may want to prioritise their symptoms of dysmenorrhoea, or pelvic pain. Patients may be concerned about creating a family or avoiding an unplanned pregnancy. Their endometriosis may be having significant effects on their work, education, or relationships. There is often a complex interplay between all of these factors.

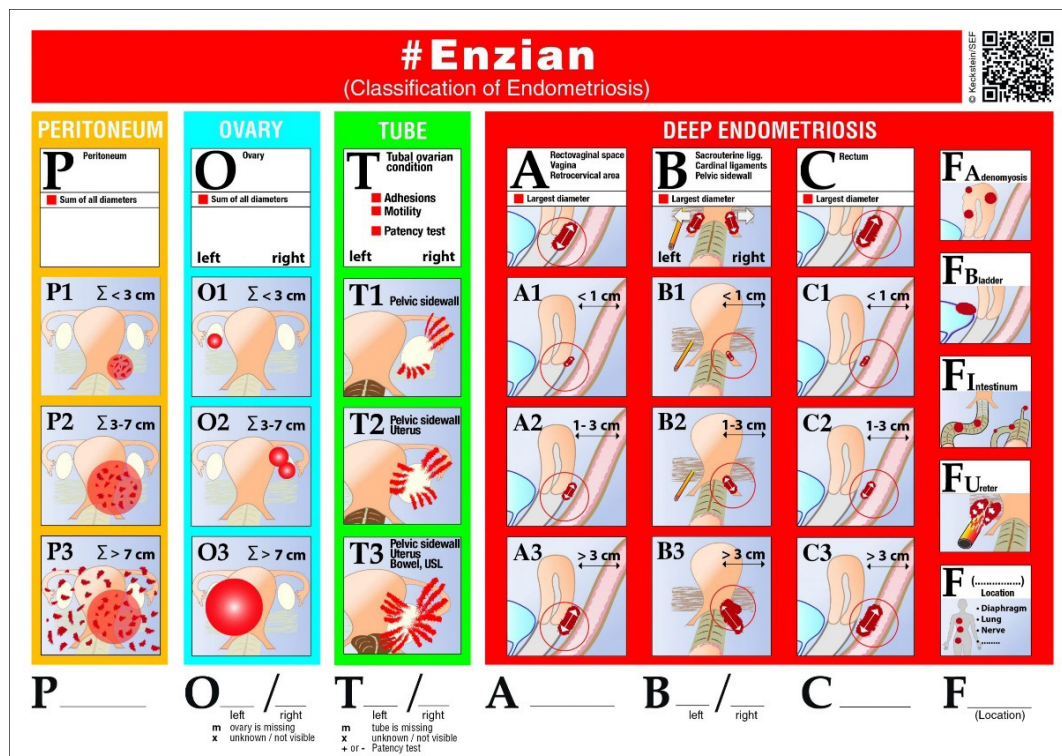


Figure 1. #Enzian classification system¹⁷

Keckstein J, et al. Acta Obstet Gynecol Scand. 2021;100(7):1165-75.



Medical therapy

Medical therapy should involve a stepwise strategy, starting with simple analgesia (e.g., paracetamol, non-steroidal anti-inflammatory drugs), with the avoidance of opioid derivatives.³ Other measures may include heat packs, stretches, exercise, avoiding constipation, or transcutaneous electrical nerve stimulation (TENS) machines. First-line hormonal medical therapy may involve the combined oral contraceptive pill or continuous oral progestins, levonorgestrel intrauterine delivery (IUD) systems, and other long-acting reversible contraception (LARCs) such as Depo-Provera or Jadelle, or a combination of these therapies. Higher doses of oral progestins, cyproterone acetate, and gonadotrophin-releasing hormone (GnRH) agonists are other options for medical therapy. The side effect profiles of these medications need to be balanced against their potential benefits.

Information and support for people with endometriosis

It is important to provide information to people with endometriosis. People with endometriosis may have complex needs and require long-term support.⁴ Clinicians should assess the individual information and support needs of people with suspected or confirmed endometriosis. They need to take into account factors such as the person's circumstances, co-existing conditions, their priorities, their desire for fertility, the constraints of daily living, work, and study, their cultural background, and their physical, psychosexual, and emotional needs.⁴

Referral of people with endometriosis to secondary care

New Zealand patients should be able to access secondary care when they have:⁴

- initial medical management, which is not effective, not tolerated, or contraindicated;
- pelvic signs of endometriosis on examination;
- severe, persistent, or recurrent symptoms of endometriosis;
- pelvic ultrasound or MRI imaging suggestive of a higher stage or infiltrating disease (e.g., endometrioma, adenomyosis, or disease invading other organs).

Patients with suspected or confirmed endometriosis should be referred to a gynaecologist. If they have suspected or confirmed deep endometriosis involving the bowel, bladder, or ureter, or disease outside of the pelvis (extra-pelvic endometriosis), they should be referred to a gynaecologist who specialises in endometriosis.⁴

Diagnostic tools for endometriosis

The diagnostic tools for endometriosis include the initial consultation, in which the patient's history is taken, the patient is examined, and biomarkers might be assessed.²² Imaging options include standard pelvic ultrasound, advanced pelvic ultrasound, and MRI. Laparoscopy with biopsy and surgical histology was, until just recently, widely considered the "Gold Standard" tool that enabled a diagnosis of endometriosis (Table 2).²²

Table 2. Diagnostic tools for endometriosis²²

Diagnostic modality	Strengths	Limitations
Clinical history	Non-invasive, feasible, low cost Symptomatology can predict disease location May facilitate therapeutic alliance May guide treatment choice, depending on complaints	Common symptoms of endometriosis have a wide differential diagnosis Symptoms are not predictive of disease extent
Physical examination	Accessible High specificity Opportunity to detect deep endometriosis by visualisation or palpation	Low sensitivity Outcomes are operator dependent Diagnostic accuracy varies by anatomic location of disease Examination may be considered invasive and painful by some
Biomarkers	Objective measure Biomarkers in combination may rule in endometriosis as a triage test (further research required)	Dependent on laboratory techniques and quality control protocols Some biomarkers vary with hormonal and menstrual fluctuations Some biomarkers are not specific to endometriosis Cannot discern DE, OE, SE
Ultrasound	High spec; high sensitivity for OE Overall high accuracy in detecting DE and POD obliteration Dynamic nature for organ mobility Allows anatomic mapping Offers opportunity to provide visual evidence to people High tolerability Cost-effective	Limited ability to detect SE The detection of DE requires highly trained sonographers/sonologists The outcome is operator dependent Examination may be considered invasive and painful Requires training to use successfully
MRI	Images obtained appear the same to all viewers Overall high accuracy in detecting DE and extra-pelvic endometriosis Allows anatomic mapping Offers an opportunity to provide visual evidence to people	Static assessment Limited ability to detect SE Variable imaging protocols reported in the literature Less accurate in defining bowel depth of invasion Training specifically in endometriosis diagnosis needed No consensus on how to describe findings High cost compared to ultrasound
Laparoscopy	Overall high accuracy, has been considered the gold standard Allows concomitant diagnosis and treatment Offers an opportunity to provide visual evidence to people Significant placebo effect	Invasive, people exposed to surgical risk Diagnostic accuracy is dependent on surgical experience Visual diagnosis challenged by heterogenous lesion appearance, inaccessible lesions
Histology	Ultimate confirmation of diagnosis Allows clinician to rule out other conditions Ability to diagnose without visual confirmation	Obtaining tissue for histology requires surgical excision Influenced by surgical environment and method of resection

DE = deep endometriosis; OE = ovarian endometriosis; POD = pouch of Douglas; SE = superficial endometriosis.

ESRHRE guideline

The European Society of Human Reproduction and Embryology Endometriosis (ESHRE) guideline was published in February 2022.³ This guideline no longer considers laparoscopy to be the "Gold Standard" by which endometriosis is diagnosed, and laparoscopy is now recommended only in patients with negative imaging results and/or where empirical treatment was unsuccessful or inappropriate.³ Instead imaging such as advanced pelvic ultrasound and pelvic MRI can be used. ESHRE also recommend that "Laparoscopy should only be used with those experienced in this technique where it is used to surgically remove or destroy endometriotic lesions or adhesions in previously diagnosed patients".^{3, 22}



Current New Zealand public endometriosis services

Dr Wynn-Williams conducted a survey, which was sent to the clinical directors of Obstetrics and Gynaecology departments at the end of 2020, with a 100% response rate. The survey found that 80% of the District Health Boards (DHBs) did not have a dedicated endometriosis clinic, and 35% of the DHBs refer their stage 4 endometriosis patients to out of district tertiary referral centres for surgery. Only 30% of the DHBs had multidisciplinary pelvic pain clinics. There were significant barriers to accessing care for Māori and Pacifica patients.

Dr Wynn-Williams also surveyed 21 "public" minimal access gynaecology surgeons (MIGS) from around New Zealand. A total of eight had completed the Australasian Gynaecological Endoscopy and Surgery (AGES) accredited training program (AATP) fellowship which produces highly trained advanced endometriosis surgeons. Within the New Zealand public system, most endometriosis surgeons and AGES AATP graduates are based within the North Island. There are two New Zealand AGES AATP training sites, one of which is led by Dr Wynn-Williams in the Auckland District Health Board and the other is in the Waikato District Health Board.

An Aotearoa/New Zealand EndoCost study

The recent EndoCost study used an online survey to explore the impact of chronic pelvic pain on various life domains for those aged over 18 years in New Zealand.⁶ There were 800 respondent (620 with self-reported endometriosis and 180 with chronic pain symptoms).⁶ Māori participants reached parity with the New Zealand Māori population.⁶ Irrespective of the final diagnosis, pain started prior to age 20 and negatively impacted multiple life domains including employment, education, and relationships.⁶ Mean diagnostic delay for those with endometriosis was 8.7 years.⁶ On average, five doctors were seen prior to a diagnosis.⁶

Improving services in New Zealand

Dr Wynn-Williams provided various suggestions for improving endometriosis services within New Zealand. These included:

- developing centralised endometriosis centres of expertise around New Zealand;
- improving access to multidisciplinary pelvic pain teams in all centres around New Zealand;
- co-ordinating endometriosis services within the greater Auckland region;
- developing a centralised endometriosis database to collect medical and surgical outcomes; and
- having an endometriosis clinician network, with annual updates and meetings to upskill and standardise treatment recommendations.

How can we do things better?

Developing a New Zealand Endometriosis Action Plan

As presented in the Australian action plan for endometriosis,²³ Dr Wynn-Williams outlined three areas of action, namely improving awareness and education; improving clinical management and care, and undertaking New Zealand-based research, taking into consideration the principles of the Treaty of Waitangi across all three areas (**Figure 2**). There is a desperate need for a New Zealand-based endometriosis action plan and medical practitioners from around the country need to lobby government for this to be developed.

Improvements in primary care

Within primary care, Dr Wynn-Williams noted that there is a need for consistent resources (see below), primary care guidelines, national referral pathways. There needs to be uniform funding across New Zealand for Mirena IUCD and LARCs. There needs to be consistent access across the country to advanced endometriosis imaging techniques and equitable patient access to secondary and tertiary care.

Improvements in secondary care

Within secondary care, Dr Wynn-Williams suggested that there is a need for well-trained laparoscopic surgeons around the country, who should be supported by tertiary units. Recent guidelines, such as the New Zealand Ministry of Health Endometriosis guidelines,² the RANZCOG guidelines,⁴ and ESHRE guidelines³, need to be adopted into practice. In addition, he noted that there is a need for expansion of advanced pelvic ultrasound services. It is the hope of Dr Wynn-Williams that around New Zealand there will be secondary care units that have endometriosis surgeons that can manage up to stage 3 disease, and up to stage 4 with accreditation. These units can be supported by endometriosis centres of expertise with regular multidisciplinary meetings. Complex patients would be referred to these tertiary centres, with support for travel and accommodation. It is also Dr Wynn-Williams hope that diagnostic laparoscopies will no longer be routinely conducted, leading to a reduction in the associated morbidity and mortality.

Improvements in tertiary care

Within tertiary centres, Dr Wynn-Williams suggested that four centres of endometriosis expertise and training can be developed around the country, with each centre serving a population of about a million persons. These centres would be led by an AGES AATP-trained MIGS, who would work with colorectal surgeons, urologists, endometriosis specialist nurses, a multidisciplinary pelvic pain service, and radiology with specialist expertise in gynaecological imaging of endometriosis (particularly advanced pelvic ultrasound and pelvic MRI). These tertiary centres would support smaller secondary centres, with regular multidisciplinary meeting to discuss and triage cases. The tertiary centres would provide ongoing educational support and surgical education to the clinicians in the secondary centres. Currently, the tertiary level clinicians at Waikato Hospital are providing an excellent example of how this system would work.

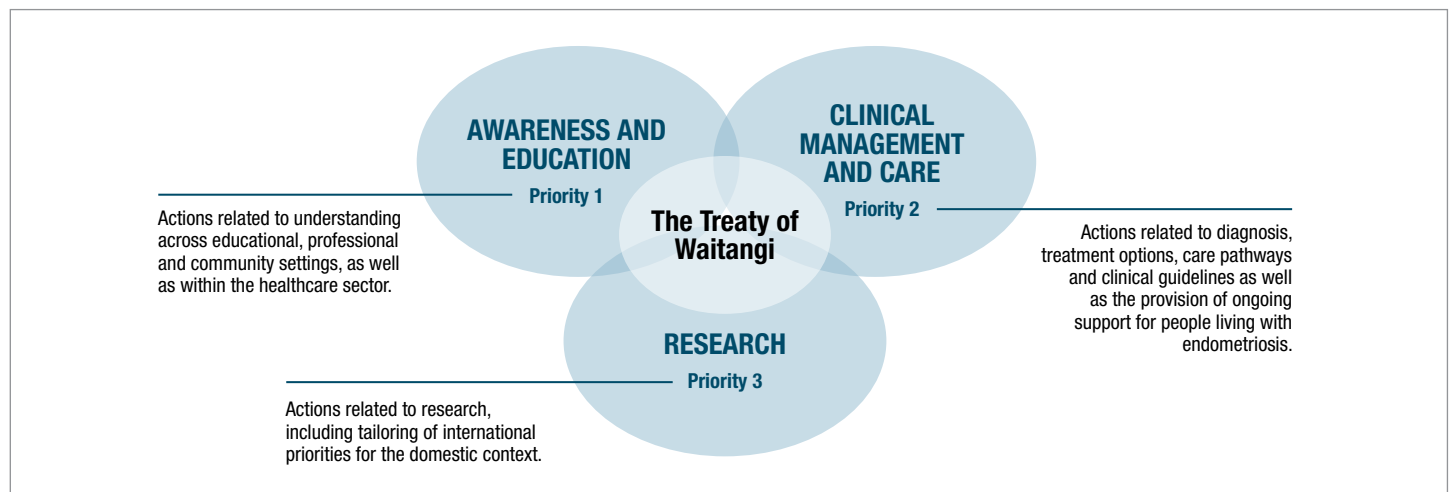


Figure 2. Suggested priorities for a National Action Plan for Endometriosis in New Zealand



Research

Dr Wynn-Williams suggested that research needs to focus on equity issues, particularly for Māori and Pacific Island patients, so that the barriers to access primary and secondary care can be removed. Research on the reasons for diagnostic delays, the personal cost, and economic burden of endometriosis should be conducted. Dr Wynn-Williams is currently investigating ways of integrating research in New Zealand with the NECST (National Endometriosis Clinical and Scientific Trials Network in Australia).²⁴ This initiative would require significant Government funding to get up and running.

The good news for endometriosis in New Zealand

In New Zealand, there is excellent primary care education such as that from the Goodfellow unit. The New Zealand Health reforms commence from July 2022, with a focus on equity and the postcode lottery that patients experience. The Ministry of Health have published a document on the diagnosis and management of endometriosis in New Zealand.² There are now 11 AGES AATP graduates, and AGES AATP training centres are present in Waikato and Auckland.

RESOURCE FOR PATIENTS

Books/booklets/leaflets

- [Endometriosis and pelvic pain \(2011\)](#). Dr Susan Evans with Deborah Bush²⁵
- [“Free” Introduction to pelvic pain \(2019\)](#). Dr Susan Evans²⁶
- [Information on endometriosis – patient leaflet \(2022\)](#). ESHRE²⁷

Websites

- [EndoActive Australia](#)
- [Pelvic Pain Foundation Australia](#)
- [Raising Awareness Tool for Endometriosis \(RATE\)](#)
- [Endometriosis New Zealand](#)
- [Endo Zone, Australia](#)

RESOURCES FOR CLINICIANS

Guidelines

- [Diagnosis and Management of Endometriosis in New Zealand \(2020\)](#). Ministry of Health²
- [Endometriosis - clinical practice guideline \(2021\)](#). RANZCOG⁴
- [Endometriosis - Guideline of the European Society of Human Reproduction and Embryology \(2022\)](#). ESHRA³

Websites

- [Endozone Clinicians, Australia](#)

Education

- [ACQUIRE \(2022\)– a RANZCOG endometriosis elearning module](#)

Podcast

- [What's new and important? \(2021\) Goodfellow unit](#)

CONCLUSION

In conclusion, Dr Wynn-Williams emphasised that the New Zealand Health System must improve the care and support provided for people with endometriosis. There must be a focus on equitable patient-centred care, with consistent support and funding in primary care, consistent referral pathways to secondary and tertiary care around New Zealand. The newly produced clinical guidelines from RANZCOG should be embraced. The use of radiological endometriosis imaging techniques, such as advanced pelvic ultrasound, and pelvic MRI should be made available to clinicians.

Ultimately, tertiary endometriosis referral centres of endometriosis expertise should be developed where patients can access care for advanced or complex disease. These centres would support regional areas with multidisciplinary meetings, advanced radiological imaging techniques, and supporting the development of clinicians' surgical skills. People across the country should have access to multidisciplinary pain clinics where they can receive care from gynaecologists, pain specialists, physiotherapists, and psychologists. In addition, quality New Zealand-based endometriosis research needs to be funded.

Dr Wynn-Williams strongly suggested that New Zealand, like Australia, needs a Government-funded Endometriosis Action Plan, that also adheres to the principles of Treaty of Waitangi. He encouraged clinicians in tertiary, secondary, and primary care to advocate for its development so that positive steps can be taken towards helping people with endometriosis from around New Zealand.

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