

1. Whakawhanaungatanga/About you

1.1. Mihimihi/Introduction To start off, would you please briefly introduce yourself (no names required) and tell us a wee bit about why you're interested in participating in this discussion forum.

1.2. Current Situation with Endometriosis (Single Choice Poll) Which of the following best describes where you currently are in your endometriosis journey?

Options:

Working diagnosis from my GP and/or OBGYN but not pursuing any particular treatment

Working diagnosis from my GP and/or OBGYN and pursuing non-surgical treatment (e.g. pain management or birth control)

Working diagnosis from my GP and/or OBGYN and waiting for surgery

Confirmed diagnosis and now post-surgery (or surgeries)

Other (Please Specify)

2. EXPERIENCE WITH ENDOMETRIOSIS

2.1. Onset Age At what age did you first notice endometriosis symptoms?

2.2. Symptoms (Multi Choice Poll) Which of the following symptoms have you experienced and believe are associated with your endometriosis?

Options

Chronic Pelvic Pain (for a period exceeding six months)

Period Pain (Dysmenorrhea)

Pain with Sex (Dyspareunia)

Pain with Urination (Dysuria)

Pain with Defecation (Dyschezia)

Ovarian Cysts

Mid-Cycle Pain

Mid-Cycle Bleeding (Metrorrhagia)

Diarrhea

Constipation

Infertility

Sub-Fertility

Pain with Ovulation

Fatigue

Nausea

Lower Back Pain

Other (Please specify if comfortable)

2.3. Level of Understanding (Single Choice Poll) What level of understanding did you have about endometriosis when you started experiencing symptoms?

Options

4 – I was very knowledgeable about endometriosis

- 3 – I was well informed about endometriosis
- 2 – I knew a bit about endometriosis
- 1 – I knew very little about endometriosis
- 0 – I had never heard of endometriosis

2.4. Effect of Understanding Do you believe the amount of knowledge you had when you first experienced symptoms, influenced your early experiences of endometriosis?

2.5. Endometriosis Information (Single Choice Poll) How did you FIRST hear about endometriosis?

Options

- My GP or OBGYN told me about it
- Education program at school
- From a family member/whanau
- From a friend
- From online research about my symptoms
- Flyer, advertisement, or public service announcement
- Other (Please Specify)

2.6. Early Resources What endometriosis resources did you find most helpful when you first started having symptoms? If you did not have adequate resources, what would have been helpful?

2.7. Support (Multi Choice Poll) When you first started having symptoms, which people did you turn to for support?

Options

- GP
- Specialist e.g. OBGYN
- Parents
- Siblings
- Partner
- Friends
- Other family members/whanau
- Teacher
- School Health Staff e.g. Nurse
- Workplace Health Staff e.g. Nurse
- Endometriosis Support Group
- Other (Please Specify)

2.8. Ongoing Support (Multi Choice Poll) Which people have provided your key ongoing support?

Options

- GP
- Specialist e.g. OBGYN
- Parents
- Siblings
- Partner

Friends
Other family members
Other (Please Specify)

2.9. Support Experience Please tell us about your experience seeking support.

In your response please cover:

- Anything that stopped you getting support
- Any particularly supportive members of your network
- Anything that helped you along the way
- Any issues you have faced

3. CULTURAL INFLUENCES

3.1. Reduced Difficulty Do you think any aspects of your cultural background have improved your experiences with obtaining a diagnosis of, and treatments for endometriosis?

3.2. Added Difficulty Do you think any aspects of your cultural background have made your experiences with obtaining a diagnosis of, and treatments for endometriosis more difficult?

3.3. Menstruation In your experience, is speaking about menstruation (periods) and menstrual-related health normal or encouraged amongst your family and friends?

3.4. IUCDs In your experience, are IUCDs (Intra-uterine contraceptive devices) considered an appropriate device to use amongst your family and friends? Is it appropriate to talk about them?

3.5. Hormonal Treatments In your experience, are hormonal treatments (including birth control pills, IUCDs, the Jadelle implant) considered an appropriate treatment to use amongst your family and friends? Is it appropriate to talk about them?

4. EXPERIENCE WITH DIAGNOSIS

4.1. Journey Story Please tell us your endometriosis diagnosis story, including whatever details you are comfortable with sharing.

In your own words, please share your experiences with:

- Developing symptoms
- Any misdiagnoses
- Getting a diagnosis and some of the challenges or support structures
- Time to diagnosis

4.2. Diagnostic Tools (Multi Choice Poll) Which of the following tools were used to inform your diagnosis? Choose all that you have had done to diagnose your endometriosis.

Options

Symptom history

Physical examination by a GP/OBGYN
Abdominal ultrasound
Transvaginal ultrasound
MRI
Laparoscopy
Specimen collection (e.g. blood test)
Other Diagnostic Test (Please Specify)

4.3. Diagnostic Tools Experience Please elaborate on each tool used to diagnose you that you have experienced. Please highlight anything that was particularly positive, or negative, about your experience.

4.4. Diagnosis Feelings (Multi Choice Poll) Which of the following best describes how you felt when you first received your endometriosis diagnosis?

Options

Upset
Overwhelmed
Relieved
Scared
Angry
Confused
Other (Please Specify)

4.5. Diagnosis Feelings In your own words, please elaborate how you felt when you received your diagnosis. Have your feelings changed or evolved over time?

4.6. Time to Diagnosis How long was it from when you first experienced endometriosis symptoms, to when you received your diagnosis? Were there any misdiagnoses along your journey?

4.7. Things to Change If there was one main thing you could change about your journey to your current diagnosis, what would it be?

4.8. Piece of Advice What advice would you give someone at the start of their endometriosis journey regarding diagnosis?

4.9. Surgery (Single Choice Poll) Have you had surgery to treat your endometriosis?

Options

Yes
No (Skip to Question 4.1)

4.10. Only for Surgery = Yes. Disease Stage (Multi Choice Poll) What stage was your endometriosis at the time of surgery?

Options

Stage I
Stage II
Stage III

Stage IV
I do not know

5. EXPERIENCE WITH TREATMENT

5.1. **Treatment Approach (Multi Choice Poll)** Which of the following treatment options have you experienced?

Options:

- Pain relief medication e.g. Ibuprofen or Panadol
- Neuropathic pain relief e.g. Amitriptyline, gabapentin, pregabalin
- Oral Contraceptive Pill with Estrogen and Progesterone e.g. Levlen, Brevinor, Yaz, Mercilon
- Progesterone Only Pill e.g. Cerazette, Primolut, Provera, Siterone, Noriday
- Intrauterine Contraceptive Device (IUCD) e.g. Mirena or Jaydess
- Pelvic Floor Physiotherapy
- Laparoscopic surgery
- Other surgical procedure
- Counselling
- Fertility Treatments
- Hysterectomy
- Hormone Replacement Therapy (HRT)
- Exercise
- Other (Please Specify)

5.2. **Effective Treatments (Multi Choice Poll and text response)** Which of the following treatment options have you both used AND found effective at treating your symptoms?

Options:

- Pain relief medication e.g. Ibuprofen or Panadol
- Neuropathic pain relief e.g. Amitriptyline
- Oral Contraceptive Pill with Estrogen and Progesterone e.g. Levlen
- Progesterone Only Pill e.g. Cerazette
- Intrauterine Device (IUD) e.g. Mirena or Jaydess
- Pelvic Floor Physiotherapy
- Laparoscopic surgery
- Other surgical procedure
- Counselling
- Fertility Treatments
- Hysterectomy
- Hormone Replacement Therapy (HRT)
- Exercise
- Other (Please Specify)

5.3. **Positive Experiences** Which endometriosis treatments have you had positive experiences with? Please explain.

- 5.4. Negative Experiences** Which treatments for endometriosis have you had negative experiences with? Please explain.
- 5.5. Advice** Based on your personal experiences with treatment, what treatments would you recommend someone at the start of their endometriosis journey discuss with their GP or OBGYN? Why?
- 5.6. Treatments** If you were to start your endometriosis journey again, please discuss:
- Which treatments would you like to start straight away?
 - Which treatment would you like to skip altogether?
- 5.7. Specialist Consults (Single Choice Poll)** Have you had specialist consults for your endometriosis?
- Options
- Yes
 - No
- 5.8. Non-Surgical Treatment (Single Choice Poll)** Have you had non-surgical treatments for endometriosis? e.g. progesterone-only pills, neuropathic pain relief, pelvic floor physiotherapy...
- Options
- Yes
 - No
- 5.9. Availability (Single Choice Poll)** Overall, do you agree treatment for endometriosis has been readily available to you?
- Options
- 5 – Strongly agree
 - 4 – Agree
 - 3 – Neutral
 - 2 – Disagree
 - 1 – Strongly Disagree
- 5.10. (Only for Specialist = Yes) Paying for Treatment (Multi Choice Poll)** How do you pay for your specialist consults?
- Options
- Privately
 - Publicly Funded
 - Medical Insurance
 - Other (Please Specify)
- 5.11. (Only for Non-Surgical = Yes) Paying for Treatment (Multi Choice Poll)** How do you pay for your non-surgical treatments?
- Options
- Privately
 - Publicly Funded
 - Medical Insurance

Other (Please Specify)

5.12. (Only for Surgery = Yes) Paying for Treatment (Multi Choice Poll) How did you pay for your surgical treatments?

Options

- Privately
- Publicly Funded
- Medical Insurance
- Paid for as part of a research study
- Other (Please Specify)

5.13. Cost Elaboration Please discuss how the costs of endometriosis treatments have influenced you.

- Has the cost of treatments been a barrier for you and impacted the treatment options you could access?
- Are the costs of treatments reasonable?
- Have you needed assistance (e.g. from family) to pay for treatments?

5.14. Elaborate Are there any other points you would like to raise about wait times, availability and costs of endometriosis treatment in New Zealand? If so, please elaborate.

6. FUTURE FOCUS

6.1. Changes (Ranking) Please rank the top THREE most important changes that you would like to see in New Zealand from the following. Then, please explain the reasoning behind your choice of the most important factor.

Options

- i. More social awareness about endometriosis
- ii. More research funding into endometriosis
- iii. More social/whānau acceptance of endometriosis
- iv. More education and readily available information about endometriosis
- v. More subsidised endometriosis care
- vi. More support groups for endometriosis

6.2. Changes for Patients What is the biggest change you would like to see regarding how endometriosis patients are viewed in New Zealand? This may be socially or medically. Why do you think this change should occur?

6.3. What Needs Research Focus (Single Choice Poll) For future research, which of the following two areas is more important to you?

Options:

- Improved Diagnosis of Endometriosis
- Improved Treatment of Endometriosis

- 6.4. **Ideas** Do you have any suggestions for how the diagnosis and treatment of endometriosis can be improved?
- 6.5. **Communication** How best can information about endometriosis be communicated back to your community?