ENDOMETRIOSIS

Strategies for pain management and infertility

education

THE SOCIETY OF
OBSTETRICIANS AND
GYNAECOLOGISTS
OF CANADA
What is endometriosis?

Endometriosis is the growth of tissue, similar to the kind that lines a woman’s uterus, elsewhere in her body. This misplaced tissue responds to the menstrual cycle in the same way that the tissue lining the uterus does: each month the tissue builds up, breaks down and sheds. Menstrual blood from the uterus flows out of the body through the vagina; however, the blood and tissue from endometriosis has no way of leaving the body. This results in inflammation and sometimes scarring (adhesions), both of which can cause the painful symptoms of endometriosis and may contribute to difficulty getting pregnant.

Endometriosis is a complex disease that can be challenging to diagnose and treat. Many symptoms — severe, painful menstrual cramps, painful intercourse, and gastrointestinal upsets such as diarrhea, constipation, and nausea — are similar to those for a wide variety of other conditions.

**FACT:**

*Endometriosis affects up to...*

1 in 10 women of reproductive age

5 in 10 women who are experiencing infertility*

5 in 10 women with chronic pelvic pain*

Heritability studies show that endometriosis is 3 to 10 times greater among first-degree relatives of women with the disease.

Women with abnormal reproductive tracts are at increased risk for endometriosis.

Having no previous pregnancies, sub-fertility and prolonged intervals since pregnancy are all associated with an increased risk of endometriosis.

*statistics based on women who undergo laparoscopic assessment of infertility and pelvic pain
What type of endometriosis patient are you?

The symptoms you experience will depend on where your endometrial growth is occurring and will be different for everyone.

- **Severe menstrual cramps**
  They are more severe than normal menstrual cramps and may begin earlier in the menstrual cycle and last longer.

- **Painful intercourse**
  Pain which is felt deep in the abdomen and/or pelvis during or following sex.

- **Painful urination or bowel movements**
  This may be experienced during menstruation or, in severe cases, pain may be felt even between periods.

- **Lower back or abdominal pain**

- **Chronic pelvic pain**
  Abdominal and pelvic pain that is not associated with menstrual cycles, but which occurs on a daily basis and which has lasted for six months or longer.

- **Other gastrointestinal upsets such as diarrhea, constipation and nausea**
  These symptoms are usually experienced during menstruation.

For some women, the pain associated with endometriosis can lead to fatigue, feelings of depression and isolation, problems with sex and relationships, and difficulty fulfilling work and social commitments.

**Diagnosis**

The first steps involve evaluating your pain and examining your abdominal area or performing a pelvic exam to locate where the pain comes from. You may also need an ultrasound to rule out other causes for your symptoms, and in some cases you may require a laparoscopy — but because this is a surgical procedure, it is only used when other diagnosis and treatment options are not effective.

**Endometriosis and infertility**

If you have endometriosis, it may be more difficult to become pregnant because scar tissue can block your Fallopian tubes, making it challenging for egg and sperm to meet. Endometriosis can also lead to an increased risk of ectopic pregnancy, when the fertilized egg implants and grows inside of the Fallopian tube.

The good news is that many women with endometriosis are able to conceive; however, for some it may take longer.

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**Are you...**

- An adolescent with chronic pelvic pain? [Go to page 3]
- An adult with no immediate plans for pregnancy? [Go to page 4]
- An adult with chronic pelvic pain and infertility? [Go to page 5]
- An adult with deeply infiltrating endometriosis? [Go to page 6]
- A perimenopausal woman with endometriosis? [Go to page 7]
Are you an adolescent with chronic pelvic pain?

- You are 18 years of age or younger
- You experience severe cramping several days per month
- The pain is primarily in your lower abdomen, though you may experience some aching elsewhere
- There may be nausea associated with your pain
- Occasionally, your symptoms may cause you to miss school or social events

Management of pain for adolescent patients with suspected endometriosis

Did you know?
The Endometriosis Association registry reports that 38 per cent of women with endometriosis had symptoms starting before the age of 15.

Counselling tips

- It may take a few months to experience results using combined hormonal contraceptives
- Consider NSAIDs for pain relief
- Combined hormonal contraceptives may provide pain relief but are not a cure
- You should remember to take your pills every day, on time
- You will likely need to return in about three months for a follow-up evaluation

Evaluation of your medical history and pain diary

This may help identify non-gynaecologic causes of pain

Examinations

- Abdominal exam
- Pelvic exam including bimanual exam and speculum exam

Diagnostic imaging

- Transabdominal ultrasound
- Transvaginal ultrasound

Examinations

- Abdominal exam
- Inspection of external genitalia and lower vagina
- Possibly a rectal exam and cotton-bud exam to evaluate vaginal length

Diagnostic imaging

- Transabdominal ultrasound

What if this doesn’t work?

Trial of cyclic combined hormonal contraceptives and NSAIDS

1st line medical therapy

Continuous or extended combined hormonal contraceptives or progestin-alone options (for a minimum trial of three months)

2nd line treatment options

- Laparoscopy for definitive diagnosis and conservative surgery, with post-surgical hormonal suppression (1st line medical therapy or GnRH agonist with add-back therapy)
- 2nd line medical therapy: GnRH agonist with add-back hormone therapy if age-appropriate** or LNG-IUS

Second line medical therapy

- GnRH agonist with add-back hormone therapy

Continue current 1st line medical therapy

- Are you less than 16 years old? No GnRH agonist
- Are you 16 to 18 years old? GnRH agonist with add-back therapy, if your endometriosis is surgically confirmed**
- Are you over 18 years old? Empiric GnRH agonist with add-back hormone therapy**

**A GnRH agonist with add-back therapy is not always appropriate for adolescents, because it may negatively affect bone mineral density. You may need to consider routine bone mineral density evaluation.
Management of pain for a woman with no immediate plans for pregnancy

**Are you a woman with no immediate plans for pregnancy?**
- You are not planning a pregnancy in the next three to four years
- You may eventually want to have your first (or another) child
- You may have experienced endometriosis before, but it has ‘come back’ or is getting worse
- You experience incapacitating lower pelvic pain
- You may have had severe dysmenorrhea since you started menstruating
- You may have been treated before with cyclic or continuous combined hormonal contraceptives and NSAIDs

**Clinical tips**
- Physical examination should include an assessment to determine the position, size and mobility of the uterus: a fixed, retroverted uterus may suggest severe adhesive disease
- Adnexal masses discovered on physical examination may suggest ovarian endometriomas
- Consider a retrovaginal exam to palpate the uterosacral ligaments and rectovaginal septum, which may reveal tender nodules suggestive of deeply infiltrating endometriosis
- Examination during menses may improve the chances of detecting deeply infiltrating nodules and the assessment of pain
- Ultrasonography allows detection of ovarian cysts and other pelvic disorders such as uterine fibroids

**What about diagnostic laparoscopy?**
*This is not required in all patients before treatment; although it is considered a minimally invasive procedure, it still carries the risks of surgery and is usually only considered if medical therapy has failed.*

**Evaluation of your medical history with physical and imaging exams**

Does a transvaginal ultrasound show an ovarian mass?

- **Yes**
  - Evaluate risk of malignancy
    - **Low risk**
      - Consider medical therapy or laparoscopy
    - **High risk**
      - Surgery (laparoscopy)

- **No**
  - 1st line medical therapy
    - Combined hormonal contraceptives (proceed to continuous if cyclic has failed)
    - Re-evaluate after three months
  - 2nd line medical therapy
    - GnRH agonist with add-back therapy
    - Progestin LNG-IUS
    - Progestins
    - Danzanol
  - Has the therapy been successful?
    - **Yes**
      - Continue medical therapy
    - **No**
      - Reconsider diagnosis
        - Additional testing and possibly non-gynaecologic referrals
  - Laparoscopy

Endometriosis: Strategies for Pain Management
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**Are you a woman with chronic pelvic pain and infertility?**

- You are experiencing severe pelvic pain and infertility
- Your pain may have begun or gotten worse after discontinuing combined hormonal contraceptives
- You have been attempting to conceive for 12 months or more
- You are otherwise healthy
- Your partner has no fertility issues which may account for the infertility

**Clinical tips**

- Several studies suggest that women with chronic or advanced endometriosis will benefit from long-term treatment with a GnRH agonist before an IVF cycle.
- Treatment of infertility caused by endometriosis consists of either surgical removal of endometriotic tissue with adhesiolysis in order to restore normal anatomy, or assisted reproductive technology.

**Laparoscopy is indicated when...**

- There is deep dyspareunia, severe dysmenorrhea, dyschezia, or chronic pelvic pain that is severe enough to cause distress
- When tender nodules are palpated in the uterosacral ligaments
- When there is a persistent adnexal mass

**Suspected endometriosis with infertility and pain**

Examination: infertility workup, with hysterosalpingogram and ruling out other causes of infertility (for example, male factor)

- Timely laparoscopy for diagnosis and treatment, with possible hysteroscopy
- Referral for assisted reproductive technologies (consider initiating GnRH with add-back therapy prior in order to improve IVF outcomes)
- Medical therapy
  - Progestins
  - GnRH agonist with add-back therapy
  - Progestin IUS
  - Danzanol

Check for tubal patency
Ablate or resect mild to moderate endometriosis
Be cognizant of ovarian reserve

There is an observed association between endometriosis and infertility, although a causal relationship has not been proven.
Are you a woman with deeply infiltrating endometriosis?

• You experience persistent, disabling and severe pelvic pain
• The pain is often in your lower back and abdomen
• You experience severe dyspareunia
• You do not wish to get pregnant immediately but may eventually wish to start a family

Management of pain for a woman with deeply infiltrating endometriosis

Are you experiencing deeply infiltrating endometriosis which has been non-responsive to 2nd line medical therapy?

Preoperative considerations:
Assessment of other organ structures, notably bowel and ureter

Special considerations:
• Surgery will often require a multidisciplinary approach, benefitting from the experience of several specialists
• Laparoscopy is the preferred surgical approach

Clinical tips

• When endometriosis is thought to have a deeply invasive component, ancillary tests such as colonoscopy, cystoscopy, rectal ultrasonography and MRI may be required.
• Deeply infiltrating endometriosis refers to lesions that penetrate 5 mm or more; they are often multifocal and deeper than is appreciated by visualization alone
• With ovarian endometriomas, it is important to consider your desire for fertility in order to determine the level of intervention required to preserve the ovaries and their function.

Surgical management of endometriosis is indicated for...

Patients with pelvic pain who...

• Do not respond to, decline or have contraindications for medical therapy
• Have an acute adnexal event
• Have severe invasive disease involving the bowel, bladder, ureters or pelvic nerves

Patients who have or are suspected to have an ovarian endometrioma where...

• The uncertainty of the diagnosis affects management
• There is infertility and associated factors (i.e. pain or a pelvic mass)

Conservative or definitive surgery?

• Conservative surgical management has the goal of restoring normal anatomy and relieving pain
• Definitive surgery involves bilateral oophorectomy to induce menopause and may include removal of the uterus and Fallopian tubes, and ideally excision of all visible endometriotic nodules and lesions
Management of pain for a perimenopausal woman

Are you a perimenopausal woman with endometriosis?
• You have reached perimenopause or menopause
• You have moderate cyclic pelvic pain
• You may have a history of endometriosis

Have you been diagnosed with endometriosis?

Indications for surgery:
Patients with pelvic pain not responding to medical therapy
Adnexal mass
Ovarian endometrioma
Other pathology (for example, fibroids)

Medical therapy:
1st line therapy: combined hormonal contraceptives, progestins
2nd line therapy: GnRH agonist, possibly with add-back therapy, progestin IUS, danazol

Re-evaluate after three months to determine if there’s been improvement

Yes
Continue until menopause

No
Surgery
Chronic pain management and multidisciplinary support
There are treatment options for endometriosis that can improve your quality of life: reducing your pain, shrinking or slowing the endometrial growth, preserving or restoring your fertility, and preventing or delaying recurrence of the disease.

**Lifestyle changes**
Changes to your exercise and relaxation routines, and maintaining a balanced diet to stay healthy, may help ease the symptoms of endometriosis.

**Pain management medication**
The therapies used to treat endometriosis may take at least one menstrual cycle to become effective, so you may need to use pain relief medication until the long-term treatment begins to work. Over-the-counter anti-inflammatory medication is often effective in treating the pain caused by endometriosis. These medications are inexpensive and non-addictive.

**Cyclic or continuous combined hormonal contraceptive therapy**
This therapy reduces the pain caused by endometriosis by suppressing menstruation and inhibiting the growth of endometriosis.

Taking combined hormonal contraception without the usual seven-day break each month will prevent you from menstruating, and may be a useful option for women who experience their worst endometriosis symptoms during their period.

**Progestin therapy**
This can be administered in a pill form or as an injection. Progestin therapy helps to lessen the effects of the estrogen that stimulates endometriotic growth in your body.

One drawback of injection-based progestin therapy is that there can be a delay between when therapy is stopped and when ovulation resumes. For this reason, this is not an effective option if you are planning to conceive in the near future.

**Suppression of ovarian function: a GnRH agonist and add-back therapy**
If combined hormonal contraceptives aren’t effective in treating your endometriosis, you may be prescribed a drug known as a GnRH agonist, which prevents your ovaries from functioning – the same process that happens during menopause. Because this type of medication can cause symptoms similar to menopause, “add-back therapy” will also be prescribed to add estrogen back into your body. This helps to prevent loss of bone mineral density and relieve the menopause-like symptoms, such as hot flashes.

**Intrauterine system (IUS)**
If combined hormonal contraception or progestin therapy isn’t effective in treating your symptoms, your health-care professional may recommend trying an intrauterine system (IUS). This is a common method of birth control, consisting of a T-shaped device which is inserted into your uterus and releases levonorgestrel, a type of progestin which counteracts the effects of estrogen in the same way that other progestin therapies do. The IUS can provide continuous therapy for five years or until it is removed by a health-care professional.

**Surgery**
If other treatments are not effective in managing your pain or improving your quality of life, laparoscopy can be performed to remove endometrial growths or legions and scarring. However, this doesn’t mean that the endometrial growth has stopped; endometrial growths return within five years in 20 to 40 per cent of women.

A hysterectomy (removal of the uterus) may be another option for some women; unfortunately, the pain may still return if the endometriosis has already spread to other organs. The only way to permanently stop endometriosis is to prevent ovarian function through the removal of ovaries (however, scar tissue may remain).

**Alternative therapies**
Some women find that alternative therapies, such as physiotherapy, massage and acupuncture, are effective ways of managing pain. There is no evidence from randomized control trials to support these treatments for endometriosis, but you shouldn’t necessarily rule them out if you think they are beneficial to your overall pain management and your quality of life.

**Did you know?**

Because endometriosis is a chronic, relapsing disorder, clinicians should develop a long-term plan of management with each patient that is dependent on her symptoms and goals for fertility and quality of life.
Other patient resources from the Society of Obstetricians and Gynaecologists of Canada

Public education website: endometriosisinfo.ca

Patient education brochure: Endometriosis, available at www.sogc.org


Clinical practice guideline: Endometriosis: Diagnosis and Treatment, available at www.sogc.org