PATIENT INFORMATION

Endometriosis

What is Endometriosis?

The endometrium (or uterine lining) grows each month to prepare for a pregnancy and sheds each month when pregnancy does not occur, this shedding is called menstruation, menses, or a period. Endometriosis is the name given to a condition where this endometrial tissue is found outside of the uterus and in other parts of the pelvis or body. Endometriosis can affect the ovaries, fallopian tubes, cervix, bladder, bowel, outer side of the uterus and peritoneum (the membrane lining the abdominal and pelvic cavities). Very occasionally it is found on more distant structures. Regardless of their location in the body these endometrium cells all respond to the monthly hormonal signals to grow ready for a pregnancy and to shed if one is not achieved. This shedding of endometriosis implants outside the uterus causes bleeding inside the pelvis which can result in a chronic, inflammatory reaction in the affected tissues potentially leading to scarring and adhesions that cause distortion of the pelvic organs as they join normally separate pelvic organs together as the body tries to heal itself.

What causes Endometriosis?

The cause of endometriosis is not well established but as we continue to learn about and treat endometriosis, it is generally believed that several factors contribute. These include a genetic pre-disposition, altered immunity, altered cell function, abnormal hormonal function, and abnormal movement of endometrial cells.

How prevalent is Endometriosis?

In Australia, at least 1 in 10 people with a uterus have endometriosis and are usually diagnosed between the ages of 25 to 35 years old. It can be difficult to diagnose, and diagnosis of endometriosis is often delayed, with an average of 7 years between the onset of symptoms and diagnosis. About a third of people diagnosed with endometriosis do not find out until they have trouble falling pregnant.

What are the common symptoms of Endometriosis?

There are a range of potential symptoms, and these can vary partly due to where the endometriosis implants are located in the pelvic cavity. The severity of symptoms is not always indicative of the size, grade, or number of endometriosis implants. The most common presenting symptom of endometriosis is pain with around 80% of those

Pink Palace
Level 1, 1 Collins Street
Melbourne
Victoria 3000

Emerald City
Level 2, 120 Jolimont Road
East Melbourne
Victoria 3002

Epworth Freemasons
Fertility and Gynae Surgery
166 Clarendon Street
East Melbourne 3002

Epworth Richmond
Fertility and Gynae Surgery
89 Bridge Road
Richmond 3121

Telephone 9132 9600
Facsimile 9132 9699
www.number1fertility.com
www.number1eggfreeze.com
www.drlynnburmeister.com.au

diagnosed with endometriosis effected but for some, infertility can be their main presenting issue instead of pain.

As endometriosis is directly affected by the menstrual cycle, it commonly causes cyclical pain that happens in conjunction with the symptoms of a period in the places the endometriosis implants have grown. Three out of four patients with endometriosis report pain is usually most pronounced during their period, but endometriosis can also cause pain during ovulation and sexual intercourse. Some people with endometriosis may not have any symptoms at all. Unfortunately, endometriosis is progressive, meaning it can become worse with time.

Common symptoms reported by sufferers of endometriosis include:

- Painful periods *(dysmenorrhea)*
- Pain during or around ovulation
- Pain during or after sex *(dyspareunia)*
- "Abnormal" bleeding including heavy bleeding with or without clots *(menorrhagia)*, irregular bleeding (with or without a regular cycle) and/or bleeding for longer than the normal 2-7 days
- Pain with bowel movements, diarrhoea, constipation and/or bleeding from the bowel
- Pain with urination, increased urinary frequency and/or bleeding from the bladder
- Pain in the pelvic area, lower back, or legs
- Nausea
- Fatigue
- Reduced fertility or delays in falling pregnant naturally *(subfertility)* or inability to fall pregnant naturally *(infertility)*

What are the effects of Endometriosis on fertility?
Endometriosis can make falling pregnant difficult and it is estimated that between 30-50% of those with endometriosis will struggle with subfertility or infertility. This is thought to be as a result of inflammation, scarring and adhesions which are known complications of endometriosis.

Inflammation, scarring and adhesions can affect the organs upon which the endometriosis implants have grown. On the ovaries, it can hinder and/or negatively impact the growth, development, release, and quality of an egg. On or in the fallopian tubes it can hinder the release and transportation of an egg or interfere with fertilisation by making it difficult for sperm to reach the egg. If the outer wall of the

uterus has been damaged or the pelvic anatomy has been distorted as a result of severe endometriosis it can also prevent the implantation of an embryo.

Some sufferers of endometriosis will not require any treatment with a fertility specialist and following surgical intervention by an experienced gynaecologist will be able to conceive naturally, although may continue to experience subfertility and delays in conception.

It is estimated that roughly a third of patients with endometriosis will require treatment with a Nº1 Fertility Specialist in order to conceive.

If a couple has been trying unsuccessfully to conceive for over a year (or for more than 6 months if over 35 years old) it is recommended that they speak to a Nº1 Fertility Specialist about their options.

What are the effects of Endometriosis on pregnancy?

It is not unusual to worry about how endometriosis will affect a pregnancy, developing baby and delivery. Most people with endometriosis will have a normal, uncomplicated pregnancy. Rarely, some will continue to experience pain throughout their pregnancy. Extra monitoring is not usually required but it is important to seek the advice of an obstetric care provider.

The symptoms of endometriosis may be reduced or absent for the duration of pregnancy as the hormonal communications that cause the growth and shedding of endometrial cells, are replaced with hormones communicating pregnancy. Symptoms may also be eased during breastfeeding if regular periods have not yet returned.

It is important to note that endometriosis is not cured by pregnancy and that symptoms of endometriosis may return as the menstrual cycle and periods return following delivery of a baby and/or the cessation of breastfeeding. It is possible for endometriosis symptoms to improve or resolve following pregnancy, but it is also possible for them to worsen.

How is Endometriosis diagnosed?

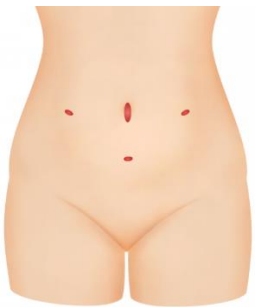
Pelvic ultrasound is the standard first line investigation for people with a uterus who are experiencing pelvic pain (and is also part of baseline examinations for infertility).

Ultrasound imaging may identify some features of endometriosis such as endometriomas (endometriosis related ovarian cysts), deep nodules in severe endometriosis or adhesions where tissue has stuck together. Ultrasound will not identify endometriosis in cases where these features are absent. As a result, a normal baseline pelvic ultrasound does not rule out endometriosis.

Magnetic resonance imaging (MRI) is also used for the assessment of endometriosis particularly in instances where severe endometriosis (deep invasive endometriosis) is suspected. It is particularly useful for surgical planning in complex cases. As with ultrasound examinations, MRI will not identify endometriosis in cases where severe features are absent and as such, a normal MRI does not rule out endometriosis.

Keyhole abdominal surgery (Laparoscopy) remains the recommended method for the diagnosis of endometriosis. (https://ranzcog.edu.au/womens-health/patient-information-resources/laparoscopy). While not always necessary, laparoscopy allows for both the visual diagnosis of the condition and collection of tissue biopsy for laboratory confirmation. If endometriosis is found during an investigative laparoscopy, usually it can be treated via excision of endometriosis deposits at the same time.

Laparoscopy is a procedure in which a surgical telescope and camera is passed through small “keyhole” incisions in the abdomen. These cuts are usually made at the umbilicus (belly button) with one or two others made on either side of the lower abdomen. These cuts are commonly 5mm in size though larger incisions are sometimes made. Carbon dioxide gas is used to gently inflate the abdomen to create space and allow your surgeon to see your pelvic organs on a screen and operate without damaging other structures. The surgeon can then assess and operate on the organs of the pelvis and abdomen. Instruments are passed through the incisions while operating and tissue can be removed this way.



Conventional Laparoscopy Incision Sites

How is Endometriosis treated?

There is no known cure for endometriosis, and it very rarely goes away without treatment. As such, the goal of treatment is to manage the symptoms of endometriosis, not cure it.

Endometriosis is commonly managed and treated with a multifaceted approach. Depending on severity the treating team can include a gynaecologist and fertility specialist, pain specialist, pelvic floor physiotherapist and dietician amongst others.

Medical management includes a combination of medication such as non-hormonal pain relief, and hormonal medications such as progestogens and laparoscopic surgery. Specific case management depends on the severity and location of endometriosis implants and each patient's clinical situation.

As endometriosis is directly affected by the menstrual cycle, most of the recommended hormonal medications that are ideal for treatment will often prevent pregnancy. Hormonal medications may slow endometrial tissue growth and prevent the development of new implants of endometrial cells, but they are not necessarily curative and instead aim to suppress the condition.

Surgical treatment of endometriosis is performed via operative laparoscopy, if the patient is not planning a pregnancy or not currently trying to conceive surgical treatment is often combined with hormonal suppression. At the time of laparoscopy, endometriosis deposits are either excised (cut out) or ablated (burned). Excisional surgery is preferred as it is more effective than ablation. Surgical treatment for pain can be effective at all levels of severity of endometriosis. Endometriosis often recurs and some patients may require multiple surgeries in their lifetime for relief of symptoms.

Operative laparoscopy for endometriosis has been shown to improve fertility in some but not all endometriosis cases:

- In patients with mild to moderate endometriosis there is evidence that operative laparoscopy improves the rates of ongoing pregnancy.
- In patients with endometriomas (endometriosis related ovarian cysts) there is limited evidence that shows removal of the cyst may improve rates of natural pregnancy. However, the risk of loss of healthy ovarian tissue at the time of surgery must also be considered before proceeding with treatment.

- In patients with severe endometriosis (deep invasive endometriosis) there is no strong evidence to suggest surgery is beneficial for fertility. Where fertility is the priority, your fertility specialist may advise you to consider undertaking assisted reproductive technologies such as IVF. This of course depends on individual circumstances.

<u>It is not possible to have a laparoscopy and/or endometriosis implant removal done at an egg collection; it must be a standalone procedure.</u>

As long as the ovaries produce the hormone oestrogen, it is possible for endometriosis implants to develop and grow and to experience symptoms. Following menopause, most former sufferers will report that their endometriosis symptoms have subsided as the decrease in oestrogen production impacts the growth and spreading of endometriosis implants. Rarely some sufferers might continue to experience symptoms even after menopause.

In some severe cases where patients have debilitating symptoms and no longer plan to carry a pregnancy more aggressive surgical treatments are considered. These include removal of the uterus *(hysterectomy)* and fallopian tubes *(salpingectomy)* and potentially the ovaries *(oophorectomy)*. This treatment is more invasive with increased surgical risk. It is not performed without careful consideration as it is possible to have ongoing endometriosis symptoms despite the surgery. There are also potential complications such as premature menopause which must be considered.

Management and treatment of endometriosis should be discussed with your Nº1 Fertility Specialist.

The information provided above is intended for educational purposes only and should not be used as a substitute or replacement for medical advice received from a medical professional. It is important to discuss your individual circumstances and situation with your treating doctor.