SURGERY AND HORMONAL MANAGEMENT FOR ENDOMETRIOSIS IN NZ INFORMATION GUIDE

insight ENDOMETRIOSIS

ABOUT INSIGHT ENDOMETRIOSIS

Insight Endometriosis is a community-based Charitable Trust working collaboratively to empower people with endometriosis (suspected or diagnosed). We are based in Hamilton but provide services throughout New Zealand, with a focus on:

- Improving access to quality evidence-based information.
- Connecting those affected by endometriosis to relevant support.
- Ensuring those affected by endometriosis are productive, feel valued in their workplaces, and nurtured to succeed in their places of study.
- Building a strong, connected community network amplifying the voices of those affected by endometriosis.
- Ensuring lived experiences of those affected by endometriosis informs policy development and health system change.
- Other relevant support and assistance.

ABOUT THIS INFORMATION GUIDE

This information guide is for those that suspect they have endometriosis, have a diagnosis of endometriosis, or have a whānau member, friend, or someone in your life that is experiencing endometriosis symptoms.

The purpose of this guide is to empower you with knowledge about managing endometriosis with surgery and ongoing hormonal therapies and/or using hormonal therapies on their own for management.

It is important to remember that each person's experience of endometriosis is different and this informative guide provides evidence-based information.

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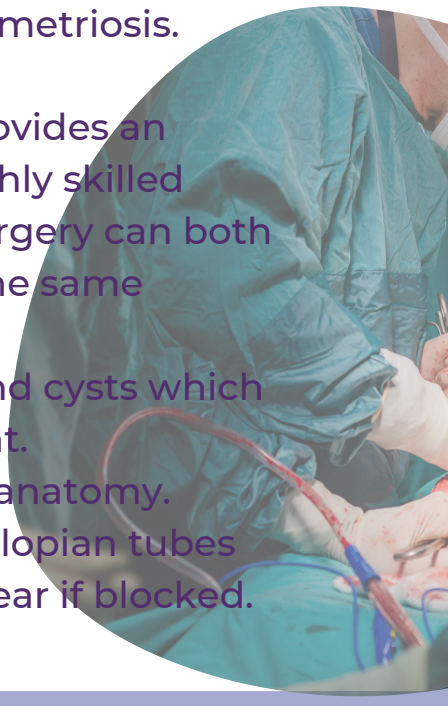
THE ROLE OF SURGERY

Without a definitive cure or even agreement as to the causes or nature of endometriosis, treatments aim to reduce or eliminate symptoms, and improve quality of life and fertility, if desired.

Studies have shown that following surgery, recurrence can be significantly reduced with long-term hormonal treatment, which may be a major consideration in the lifetime choice of therapies.

As well as reducing recurrence risk, treatment decisions depend on a range of factors:

- age
- symptoms
- clinical history
- the extent of the disease
- co-morbidities (other co-existing conditions)
- cultural considerations
- individual preference and priorities which may include pain/symptom management and/or fertility, this may change over the lifetime experience of endometriosis.



As well as a definitive diagnosis, surgery also provides an opportunity to treat in the same procedure. Highly skilled gynaecologists specialising in endometriosis surgery can both identify and remove (excise) endometriosis in the same surgical procedure, which aims to:

- Remove all endometriosis nodules, tissue, and cysts which will then be sent to pathology for assessment.
- Divide adhesions to free organs and restore anatomy.
- If fertility is of concern, the patency of the fallopian tubes can be checked with a dye test, aiming to clear if blocked.

SURGICAL METHODS

Excision surgery by laparoscopy is the gold standard of endometriosis treatment. The surgery is performed under general anesthetic by a gynaecologist with specialist surgical skills. Laparoscopy is the preferred surgical treatment because the smaller incisions lead to quicker healing and faster recovery time.

Sometimes a laparotomy may be necessary which involves a larger cut in the abdomen. Recovery times are much longer with a laparotomy than laparoscopy.

There are two methods for the removal of endometriosis during surgery - excision and ablation.

If your surgeon is not highly-skilled in excision techniques and is using ablation methods there is a risk that they don't know what endometriosis looks like. The surgeon may not recognise the many colours of endometriosis or be unable to recognise lesions formed underneath scar tissue. They continue to ablate what they see in a vicious cycle of leaving roots behind, letting scar tissue form, trapping endometriosis lesions, and the person's symptoms returning or worsening over time.

EXCISION SURGERY

Excision surgery involves cutting the disease out at the roots and also includes removing healthy tissue surrounding the lesions to ensure everything is removed. This surgery aims to preserve organs and fertility as well as restore anatomy. Excising endometriosis is the gold-standard treatment and is proven to remove disease, with a recurrence rate between 5-20% in a person's entire lifetime. For some people, even with excision surgery, there is recurrence at a higher rate and the disease can still progress.

ABLATION SURGERY

Ablation surgery involves burning the surface layer of the endometriosis off. Recurrence rates with ablation can be above 60% in a few months to years and if performed there can be no biopsy of tissue for diagnostic confirmation as the lesions are burnt away and not excised (cut out).

Ablation can aggravate active endometriosis lesions and with the roots left behind the lesions can continue to grow. Repeat surgeries are more than likely needed with a risk of the disease progressing and worsening over time. Scar tissue can also form on top of the roots left behind, trapping the endometriosis lesions.

QUESTIONS YOU MAY WANT TO ASK YOUR SURGEON BEFORE SURGERY:

- What is the goal of surgery?
- How likely is surgery to help with my pain? And fertility?
- What does endometriosis look like? What colours are you looking for?
- What is your experience with endometriosis surgery? What surgical method/s are you planning to use?
- What is your approach to endometrioma?
- What is your approach to deeply infiltrative endometriosis?
- What is your plan for adhesion prevention?
- If you find more than expected, what will you do?
- How long will the surgery take?
- What is the typical recovery time after surgery? When can I return to work? When can I have intercourse?
- What complications could arise?
- Under what circumstances would you consider a laparotomy or removal of organs?
- If I want to get pregnant, will this surgery improve my chances of getting pregnant?
- If I never want to become pregnant, would this affect my treatment plan?
- Will surgery permanently remove any endometriosis?
- What are the chances that my pain will return after surgery?
- Is hormone therapy (before or after surgery) part of the treatment plan? Why /why not?
- What are my pain management options while waiting for surgery?

LAPAROSCOPY

A laparoscopy (keyhole surgery) is an operation performed under general anesthetic by a highly-skilled gynaecologist who specialises in endometriosis. It may be day surgery or an overnight stay in the hospital, or sometimes longer depending on the extent of the surgery and recovery.

A laparoscope (fiber-optic tube) is inserted via a small cut (incision) in the belly button. Other instruments are inserted into the pelvic/abdominal area via small cuts.

The laparoscope is hooked up to a large screen to magnify the view of organs, endometriosis, and adhesions (scar tissue), as well as any cysts, polyps, and fibroids.

The surgeon will search for any signs of endometriosis deposits, lesions, and cysts as well as adhesions (scar tissue). These may be on the pelvic organs including the uterus (womb), ovaries, fallopian tubes, bowel, and the bladder - and surrounding areas including the peritoneum (membrane lining) and Pouch of Douglas (POD or cul-de-sac).

Less commonly endometriosis can be found in more distant locations including the liver, the diaphragm and thoracic (chest) cavity including the heart and lungs.

Endometriosis can be clear, pink, red, white, yellow, blue, brown and black. The darker colours often are often indicators of deeply invasive disease. You can have multiple colours and stages at the same time.

During surgery, tissue suspected to be endometriosis is excised (removed) and sent to a pathologist for histology (microscopic study) for a definitive endometriosis diagnosis.

HYSTERECTOMY

Hysterectomy refers to the removal of the uterus (womb) and is performed under general anaesthetic. It can often be completed vaginally using minimally-invasive surgical techniques.

It is important to have a gynaecologist who specialises in endometriosis for this surgery, so concurrent endometriosis can be removed in the same procedure.

OOPHERECTOMY

Oophorectomy is the removal of the ovaries; the removal of a single ovary is called a 'unilateral oophorectomy', while the removal of both ovaries is called 'bilateral oophorectomy' causing instant and irreversible menopause.

A hysterectomy is not a cure for endometriosis, however it may be suggested for adenomyosis, and is a cure for adenomyosis, if hormonal treatments have proven ineffective.

Due to considerable ongoing and long-term risks to health from cardiovascular and bone density issues, an oophorectomy would seldom be considered pre-menopause unless there is also a genetic risk of ovarian cancer. Those who have completed families and who have concerns about ovarian cancers may wish to discuss the option of removing fallopian tubes (salpingectomy) in conjunction with other surgeries.

Laparoscopic surgery is different for everyone, and your experience will be based on the extent of your surgery, length of stay, your surgeon, how you respond to pain and your expectations. Each person also heals differently - recovery can take from a few days to several weeks.

PREPARING FOR SURGERY

You may worry about the risks, anaesthesia, pain or what the surgeon may or may not find. If you're nervous it may help to think about what in particular you are troubled by then work towards minimising that concern. Many people have found that listening to relaxation recordings before and after surgery helps to mitigate general anxiety.

Bowel prep

If your surgeon requests a bowel-prep the evening before surgery, here are some additional tips:

- Start drinking more water and eat more fresh fruit and vegetables the week before.
- Consider having less solid food and more liquid-type foods and less fibre the closer you get to beginning your bowel prep.
- If the taste is unpalatable, focus on getting the bowel prep drink down as quickly as possible to limit how much you taste —try drinking through a straw, pinching your nose etc.
- Stay close to the bathroom - you will need unrestricted access to the toilet.
- Wet wipes can help to soothe a sore backside, particularly unscented wipes. A soothing lotion may also be helpful.

WHAT TO PACK FOR SURGERY

- [ ] Loose fitting pj's or nighty
- [ ] Bigger size underwear
- [ ] Socks or slippers
- [ ] Dressing gown
- [ ] Regular medications
- [ ] Toothbrush and toothpaste
- [ ] Deodrant
- [ ] Face wash
- [ ] Body wash
- [ ] Hair products - hair ties (no metal for surgery), hairbrush, dry shampoo
- [ ] Wipes
- [ ] Lip balm
- [ ] Throat lozenges
- [ ] Phone and charger (long cord)
- [ ] Headphones
- [ ] Ear plugs
- [ ] Eye mask
- [ ] Water bottle
- [ ] Snacks
- [ ] Entertainment - laptop, books, colouring

Some other useful items that others have packed, particularly for public hospitals:

- Menstruation pads - the hospital does provide pads but you may prefer using your own. You cannot use tampons or menstrual cups following surgery and your medical team may not want you to wear period underwear as they won't be able to gauge blood loss.
- Drink bottle.
- Snacks.
- Make up / baby wipes for cleaning face and hands.

FOLLOWING SURGERY

Length of stay

Ask your gynaecologist before your surgery about the anticipated length of stay so you and your family can be prepared.

Laparoscopy in the public hospital system may be done on an outpatient basis, but an overnight stay or longer may be required depending on the time of day you have your surgery and whether the surgery was complex or lengthy.

Post Op

- When you wake up from surgery you may have a sore throat from the breathing tube and you may feel cold as the anaesthetic wears off.
- You will have compression socks on to prevent blood clots forming in your legs.
- You will still have a catheter tube in, as well as a sanitary pad in between your legs for any bleeding.

Pain following surgery

If you have any pain when you come out of the anaesthesia, be sure to communicate with your medical team so this can be managed. You may also feel cold and have a sore throat from the breathing tube that is put in your throat during surgery.

You will likely feel some pain for a few days after your laparoscopy. The area around your scars may feel particularly sensitive. You may have pain in your shoulder(see below).

You are likely to be discharged with pain medication; follow the instructions and ensure you keep on top of your pain.

Shoulder pain
Shoulder pain is a common side effect of a laparoscopy. This is caused by the CO_2 gas used during surgery to expand your abdomen and lift it away from the internal organs, to prevent it becoming trapped against the diaphragm.

TIPS TO ALLEVIATE SHOULDER PAIN

- Walk around
- Take a warm shower
- Apply heat
- Take anti-inflammatories
- Rest in an upright position, using a pillow to help keep you propped up
- Drink peppermint tea or water
- Stay hydrated with water and fluids with electrolytes

Bowel Movements and Nausea
Nausea is often experienced and there are medications that can be taken to help with this. Talk with your doctor and anaesthesiologist beforehand about the methods they use to minimise nausea. Natural remedies such as ginger or peppermint tea may also help with nausea.

It is also common to experience a short-term change in your bowel habits after a laparoscopy. Constipation and bloating are the most common. Water, fibre-rich foods, and walking around may help. A stool softener or laxative may help if needed.

Bleeding
You may experience some light spotting or bleeding after the operation. Pads are recommended to monitor and gauge the amount of bleeding you are experiencing (menstrual cups and tampons should not be used).

The length of time you experience bleeding varies but can be up to eight weeks. If it is accompanied by an odour or smelly discharge and/or if you have an elevated temperature, or have any other concerns, contact the surgeon's office or you GP, or head to an after-hours clinic.

Incisions
Generally the small cuts on your abdomen will be closed with dissolvable stitches and protected by clear dressing after your operation. It's expected the stitches will dissolve within 14 days.

It's safe for the dressing and stiches to get wet, just gently pat dry after showering.

You may feel a 'pins and needles' sensation - over time the nerves causing this sensation should heal, and this should subside.

Contact your doctor if you have a knot, swelling or redness at your incision site/s.

RECOVERY AND RECUPERATION

Length of recovery

The time for recovery will depend on the complexity of your procedure including the length of time it took. You may be tired and groggy for 2-3 days following your laparoscopy. Expect your medical team to get you up and moving around as soon as you are able to. Make sure you continue to move around once you are discharged, as this will help with recovery, and reduce the risk of adhesions (scar tissue).

Returning to work will also depend on the type of job you have. If you have a job that requires sitting down for long periods of time or lifting heavy objects you may find you are not ready to return to your normal hours and tasks for several weeks (at least six for a hysterectomy).

Restrictions following surgery

You may not be able to drive following laparoscopy. Intercourse, tub bathing, douching and swimming will also be restricted for a time – discuss these with your health team before your discharge from hospital.

Mental wellbeing and post-op blues
Your attitude towards post-operative recovery is an important factor in both how your body heals and how you feel in yourself. Here are some tips:

- Recover at your own pace.
- Speak to someone about your feelings.
- Write down your emotions daily.
- At the end of every day, reflect on something you're proud of yourself for.
- Speak to your surgeon or medical team about any concerns.
- Set up a post-op care plan.
- Educate yourself on post-op treatment options.

Exercise
Increase your activity levels gradually and start with gentle exercise such as walking. Expect that around six weeks after your laparoscopy you should be able to start getting back into your normal exercise routine.

First menstruation
You may find that your first few periods are painful, longer, and/or heavier than usual. If you are concerned about the pain, or if your pain is severe, contact your doctor. If accompanied by an odour or smelly discharge and/or if you have an elevated temperature, or have any other concerns, contact the surgeon's office or you GP, or head to an after-hours clinic.

Follow-up appointment
A follow-up appointment with your gynaecologist will give you the opportunity to discuss an ongoing treatment and management plan, including the results of the histology.


RECOVER AT
your
OWN PACE

THE ROLE OF HORMONE THERAPIES

Some studies have shown that following surgery, endometriosis recurrence can be significantly reduced with a long-term hormonal treatment, which may be a major consideration in the lifetime choice of therapies.

Hormonal treatments can be used on their own, particularly if surgery currently isn't an option for you, if you are waiting for surgery, or have other conditions where stopping your menstrual periods altogether can help to manage your quality of life.

Hormonal treatments can also be used in combination with surgical treatment and/or analgesics, alongside nutritional and lifestyle changes such as exercise, sleep, and pain management, as well as complementary therapies.

Note that not all pain/symptoms are due to endometriosis. Adhesions may also be present and continue to cause symptoms, while chronic/persistent pain may respond to medications for neuralgia.

TYPES OF HORMONAL TREATMENTS

Endometriosis and adenomyosis respond to reproductive hormones. Hormone treatments aim to therapeutically change the cycle of these hormones to:

- control symptoms, especially pain
- improve quality of life
- significantly reduce risks of recurrence following excision surgery

Options are:

- Progestin-only contraceptives and medications that thin the endometrium are presumed to have a similar effect on endometriosis. They may also directly reduce inflammation.
- Combined Oral Contraceptives control ovulation which may be implicated in the development of endometrioma. Taken continuously (now the recommended method) they can also suppress periods.
- GnRH Analogues work by creating a temporary pseudo-menopausal state.

PROGESTIN OPTIONS

Progestin treatments can be delivered in pill form as well as long-term intra-uterine and implantable devices (see IUD and Jadelle below). These options can be combined if symptoms are not sufficiently controlled.

PROGESTIN-ONLY CONTRACEPTIVE PILL (POP / MINIPILL)

- Cerazette (which uses the progestin Desogestrel, and suppresses ovulation)
- Microlut (Levonorgestrel)
- Noriday (Norethisterone)

Minipills must be taken at about the same time each day. Generally they suppress periods (amenorrhoea) and will sometimes also suppress ovulation. While not fully funded, Cerazette is often recommended as it is known to suppress ovulation and is also less time-sensitive.

PROGESTIN MEDICATIONS (NOT CONTRACEPTIVES)

- Primolut (Norethisterone)
- Provera (Medroxyprogesterone acetate)
- Siterone (Cyproterone acetate)

These medications are more usually prescribed for other conditions such as abnormal menstrual bleeding, skin and hair conditions.

INTRAUTERINE DEVICES (IUD)

- Mirena
- Jaydess

Originally designed to treat heavy periods for women desiring contraception. Intrauterine Devices are small T-shaped frames made from a pliable plastic which are placed inside the uterus (womb). The devices contain the progestin Levonorgestrel which is slowly released over a period of time.

As a treatment for endometriosis, Mirena typically lasts for three years and the smaller Jaydess for two years (as a contraceptive Mirena for five years and Jaydess for three years).

IUDs are commonly fitted by Family Planning clinics, by some GP's, and may be placed during surgery.

Recent studies have shown that fertility quickly returns after removal.

IMPLANTABLE DEVICE (JADELLE)

Jadelle uses the same progestin as the IUD's (Levonorgestrel) and works similarly, but in the form of a pair of plastic rods inserted beneath the skin – generally on the inside of the upper arm. They have a similar lifetime to Mirena, but women over 60kg may find them less effective over time.

They are commonly fitted by Family Planning clinics, by some GP's and may be placed during surgery.

COMBINED ORAL CONTRACEPTIVES TAKEN CONTINUOUSLY

These work as a contraceptive by suppressing ovulation, and taken continuously (which is now the recommended regimen) also suppress periods. As well as considerably improving contraception efficacy, continuous usage also significantly reduces side effects such as headaches, bloating and mood swings.

It is also extremely important to remember that everyone's experience of side effects from hormonal treatments, and the length of time these last is different. Discuss the pros and cons with your doctor or pharmacist.

GNRH-AGONISTS

- Zoladex (Goserelin) – injectable implant
- Lucrin (Leuprorelin) – by injection

GnRH-agonists are synthetic versions of gonadotropin releasing hormone (GnRH), which have a role in controlling the menstrual cycle.

These medications are ‘anti-hormonal’, so when used continuously essentially create a temporary pseudo-menopausal state. They work by signalling the pituitary gland to stop producing luteinising hormone, which is responsible for stimulating the production of oestrogen from the ovaries.

An ‘add-back’ hormonal medication (HRT) may be recommended to reduce menopausal side effects and the risk of bone loss.

Generally, these therapies aren’t recommended for longer than 6 months and offer only a temporary symptom respite. They may be offered post-surgery, or for women who do not want surgery.

CHOOSING A HORMONAL TREATMENT

It's important to discuss the various treatments with your doctor to help choose options that best suit your needs. Treatments can come with side effects, and some of these can be lifelong and detrimental and you should be made aware of the side effects by your doctor.

There are advantages and disadvantages to all types of treatments, and it may take some time and trialling to find the right combination for you.

The best treatment combination for you may well change over your lifetime experience of endometriosis

Remember treatments are NOT a cure and do NOT remove, stop or slow the growth of endometriosis. Hormonal treatments suppress some symptoms and act like a bandaid.

Notes

REFERENCES

·Ministry of Health. 2020. Diagnosis and Management of Endometriosis in New Zealand https://www.health.govt.nz/publication/diagnosis-and-management-endometriosis-new-zealand

BPAC: NZ: Oral Contraceptives – Selecting a Pill: https://bpac.org.nz/2019/contraception/oral-contraceptives.aspx

Medsafe Jun 2016: Jadelle and the Impact of Weight: https://www.medsafe.govt.nz/profs/PUArticles/June2016/JadelleAndWeight.htm

DISCLAIMER

This Information Guide reflects current evidence-based research from New Zealand and worldwide at the time of writing. While we endeavour to update as new information becomes available, Insight Endometriosis cannot guarantee or assume legal responsibility for the currency, accuracy, and completeness of the information.

This Information Guide is for educational and support purposes only. It is not a substitute for professional medical or health advice.

A GP, gynaecologist, or specialist may provide new or different information that is more appropriate to an individual's needs and so Insight Endometriosis advises those seeking a diagnosis, medical advice or treatment to consult their doctor or an appropriate medical professional.

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Nothing contained in this guide is, or shall be relied on as, a promise or representation by Insight Endometriosis.

We encourage the distribution and photocopying of the information in this guide to support those affected by endometriosis; please acknowledge 'Insight Endometriosis - Surgery and Hormonal Management for Endometriosis in NZ Information Guide' as the source.

We support the Medical Council's statement that:
"... patients may need to be reminded that internet research cannot take the place of a face-to-face consultation."

INSIGHT ENDOMETRIOSIS INFORMATION GUIDES

Insight Endometriosis has the following information guides available on the website:

- Endometriosis Information Guide
- Adenomyosis Information Guide
- Diagnosing Endometriosis in NZ Information Guide
- Endometriosis Pain and Pain Management Information Guide
- Complementary Therapies and Lifestyle Changes for Endometriosis Information Guide
- Fertility and Endometriosis in NZ Information Guide
- Mental Well-Being and Self-Care with Endometriosis Information Guide
- Talking About Endometriosis with the People in Your Life Information Guide
- Self-Advocacy with Medical Professionals When You Have Endometriosis Information Guide
- Conditions Related to Endometriosis Information Guide
- Being a Teenager with Endometriosis Information Guide
- Supporting Students with Endometriosis Symptoms - A Guide for New Zealand Schools
- An Endometriosis Guide for Employers

NEED MORE INFORMATION OR SUPPORT?

Visit our website to:

- Book a free/koha-based appointment with our Educator, by zoom, phone, or at our Hamilton office
- Register for a "Let's Talk About....' session
- Join an Endo Meet-Up with other people with Endometriosis (suspected or diagnosed)

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