



# ADENOMYOSIS INFORMATION GUIDE



## 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

The purpose of this information guide is to empower you with knowledge about adenomyosis - whether you suspect you have adenomyosis, have a diagnosis of adenomyosis, or have a whānau member, friend, or someone in your life that is experiencing adenomyosis symptoms.

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



# CONTENTS

PAGE 1

WHAT IS ADENOMYOSIS

PAGE 2

WHO CAN HAVE ADENOMYOSIS

PAGE 3

SYMPTOMS OF ADENOMYOSIS

PAGE 4

IMPACTS OF ADENOMYOSIS

PAGE 5

DIAGNOSING ADENOMYOSIS

PAGES 6 - 9

HORMONAL TREATMENT FOR ADENOMYOSIS

PAGES 9 -11

PAIN MEDICATION FOR ADENOMYOSIS

PAGES 11 - 12

SELF-CARE STRATEGIES FOR ADENOMYOSIS

PAGES 13 - 14

PAIN MANAGEMENT TECHNIQUES FOR ADENOMYOSIS

PAGES 15 - 16

SURGICAL TREATMENT FOR ADENOMYOSIS

PAGE 16

PREPARING FOR SURGERY

PAGE 17

WHAT TO PACK FOR SURGERY

PAGES 18 - 21

FOLLOWING SURGERY



**PAGES 21 - 22**

**RECOVERY AND RECUPERATION**

**PAGE 23**

**ADENOMYOSIS SYMPTOMS CHECKLIST**

**PAGE 24**

**ADENOMYOSIS JIGSAW OF SYMPTOMS AND IMPACTS**

**PAGES 25 - 34**

**SYMPTOM, PAIN AND FOOD TRACKER**

**PAGES 35 - 36**

**NOTE PAGES**

**PAGE 37**

**REFERENCES**

**PAGE 38**

**DISCLAIMER**

**PAGE 39**

**AVAILABLE INFORMATION GUIDES**

## WHAT IS ADENOMYOSIS

Adenomyosis (pronounced ad-uh-no-my-o-sis) is a chronic and progressive condition where the lining of the uterus (the endometrium) grows into the uterine muscle (myometrium).

It is just as common as endometriosis, affecting 1 in 10 born with internal reproductive organs, although there is also little research so it could affect more people than realised.

Adenomyosis is often present alongside endometriosis, with overlapping symptoms. The distinguishing feature is the enlarged or 'bulky' uterus which may show on an ultrasound and/or MRI and often causes pelvic pressure or tenderness in the lower abdomen or pressure on the bladder alongside heavy periods - which are not usual symptoms of endometriosis.



## WHO CAN HAVE ADENOMYOSIS

People of all backgrounds and ages can have adenomyosis, including teenagers.

Some research regarding adenomyosis indicates that people that have given birth or have had uterine surgery such as a caesarean section or fibroid removal are more at risk of adenomyosis.

Some people are relatively unaffected by the condition, while a great many others suffer severe pain and distress from problems associated with adenomyosis. It tends to be a progressive condition - left untreated it tends to worsen over time with each period. Early diagnosis and treatment can alleviate symptoms and may preserve fertility.



## **SYMPTOMS OF ADENOMYOSIS**

The common symptoms of adenomyosis include:

- Pelvic pain and cramping
- Enlarged uterus, bloated abdomen and pelvic pressure
- Heavy or prolonged menstrual bleeding and anaemia
- Fertility problems
- Pain during and/or after intercourse
- Leg pain

Other symptoms include bleeding between periods, back and hip pain, fatigue and painful cervical smear tests.

Adenomyosis is often present alongside endometriosis, with overlapping symptoms. The distinguishing feature is the enlarged or 'bulky' uterus which may show on an ultrasound and/or MRI and often causes pelvic pressure or tenderness in the lower abdomen or pressure on the bladder alongside heavy periods - which are not usual symptoms of endometriosis.

You do not need to have all of these symptoms but the more you have, the higher the likelihood of adenomyosis. While pelvic pain and cramping (period pain) that stops you from doing things is the most common symptom, you may have other symptoms that seem vague and unconnected.



## What are the impacts of adenomyosis?

Some people are relatively unaffected by the condition, while a great many others suffer severe pain and distress from problems associated with adenomyosis. It tends to be a progressive condition; left untreated it tends to worsen over time.

Adenomyosis can have a significant impact on people's lives including on:



School



Study



Work



Relationships



Travel

## What should I do if I have symptoms of adenomyosis?

We have a range of tools that can help you determine what your symptoms are. These tools can help with the conversation with your GP or gynaecologist. You can find a checklist on page 23, visual jigsaws of symptoms and impacts on page 24, and symptoms and pain tracker on page 25.

We also have an Information Guide 'Self-Advocacy with Medical Professionals' that provides guidance on preparing for appointments with your GP or gynaecologist and how to advocate for yourself during and after appointments.





## DIAGNOSING ADENOMYOSIS

A definitive diagnosis of adenomyosis can only be made by removing the uterus (hysterectomy) for examination by a Pathologist. This may not be an option for those that wish to fall pregnant, and will also depend on a range of factors:

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

A hysterectomy is a significant surgery and not right for everyone.

It's also important to remember that a hysterectomy will only stop your adenomyosis symptoms and if you have endometriosis as well you may still experience endometriosis symptoms.

Adenomyosis can show on an ultrasound and/or MRI as an enlarged or 'bulky' uterus and may be suspected during a pelvic exam. A gynaecologist specialising in endometriosis excision surgery may be able to visualise adenomyosis during a laparoscopic surgery.

## HORMONAL TREATMENT OPTIONS FOR ADENOMYOSIS

Hormone treatments may control symptoms, such as heavy and prolonged bleeding. Options for hormonal treatments include:

- Progestin-only contraceptives and medications which thin the endometrium are presumed to have a similar effect as with 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 adenomyosis. Hormonal treatments suppress some symptoms and act like a bandaid.

## **PAIN MEDICATION, SELF-CARE STRATEGIES, AND PAIN MANAGEMENT TECHNIQUES FOR ADENOMYOSIS**

Pain is a symptom of adenomyosis and there are various pain relief and pain management options available. Pain medication does not prevent the growth of adenomyosis; however, the management of pain is an important part of managing the condition. It is important to understand how different medications work and should be taken, to improve their effectiveness.

The World Health Organisation recommends starting with simple analgesics for pain and if the pain is not controlled to add a NSAID and if the pain is still not controlled add the mildest possible opioid (Codeine is the most common opioid that is prescribed). It is important to add pain medications and not swap them and while the elimination of pain may not be possible, control of pain is generally attainable.



Our 'Endometriosis Pain and Pain Management Information Guide' provides more information on:

- what pain is
- the pain and recovery cycle
- how to describe your pain
- the spoon theory
- the different types of pain and ways to manage pain
- pacing for pain management

### **Chronic Pain**

For chronic pain (pain that lasts longer than 3 months and doesn't go away after an injury or illness), commonly pain relief medications are not effective and when used long-term can have more side effects.

The aim of pain relief medication is to reduce the impact pain has on your life rather than make the pain go away.

For some types of chronic pain, taking paracetamol at regular set times can be helpful.

NSAIDs treat inflammation and as this is not often the cause of chronic pain they may not help with chronic pain. They can be used for a short time though when you have a flare-up of symptoms.

Opioids don't work well to improve pain levels and are not recommended for chronic pain due to side effects and the risk of dependency and addiction if used long-term.

### **Neuropathic Pain**

For neuropathic pain (nerve pain that occurs when damage or changes to your nerves through disease or injury cause them to misfire and send pain signals to your brain) regular pain medication such as analgesics, NSAIDs, and opioids don't work.



Antidepressants, anti-epileptics, and anticonvulsants have all been found to be effective in relieving nerve pain.

Low doses of antidepressants can be effective with neuropathic pain. These medications can help stop pain messages from the central nervous system from reaching the brain and can also improve sleep and help with relaxation.

Anti-epileptics and anticonvulsants also treat nerve pain by blocking certain kinds of nerve activity by changing the way that nerves send messages to the brain.

### **SELF-CARE STRATEGIES**

If you are experiencing chronic or neuropathic pain here are some self-care strategies you can try:

- Identify your triggers to know what you can do to reduce your pain. Examples of triggers include alcohol, anxiety and stress, poor sleep, negative thinking, and overexertion.
- Pace yourself by avoiding doing too much in one go on good days, this can have a knock-on effect causing tiredness later on in the day or over the next few days.
- Change the way you think about pain, learn to respond to it with reassuring thoughts about it not causing you harm and positive thoughts about what you can do to manage the pain at that moment.
- Use distraction techniques by engaging in activities you enjoy to take your mind off the pain and help reduce stress, tension, and anxiety.

## Endo Fact

**PAIN THAT STOPS YOU FROM LIVING YOUR LIFE IS NOT NORMAL**

- Relaxation reduces muscle tension and helps your mind to unwind. Try listening to music, taking a bath, meditation or doing yoga.
- Walking, swimming and gentle stretching can help improve muscle strength and reduce pain and stiffness.
- Have a support network of whānau and friends to help you on bad pain days.

You can also try:

- Massage can ease tension in your muscles and distract you from your pain. Manipulation can help to increase your range of movement and reduce pain and mobilisation is a gentle movement where your joint is moved as much as possible within your existing range of motion.
- A TENS machine can reduce your pain by interfering with pain signals and blocking them from reaching your brain, or by stimulating production of your body's natural pain-relieving chemicals (called endorphins). It can also reduce the sensation of muscle tension and spasm.
- Cognitive behavioral therapy (CBT) is a type of counselling that focuses on teaching you techniques and skills to help you cope better with chronic pain.
- Acupuncture may help by stimulating your nerves to block pain signals and relax your muscles.
- A physiotherapist can design exercises that keep you active and build on what you can already do.



## **PAIN MANAGEMENT TECHNIQUES**

Pain management techniques are things that you can do yourself at home to help your pain. Pain management techniques that can help people with endometriosis include:

### **Heat**

Heat can help relax pelvic muscles and reduce cramping, it increases circulation, opens up blood vessels, heals damaged tissue, and affects pain receptors in the body. Moist heat can come in the form of warm baths, warm wet towels, wheat bags, or hot water bottles. Dry heat can come from electric heating pads or dry heating packs.

### **Transcutaneous Electrical Nerve Stimulator (TENS) machine**

TENS machines are small, unobtrusive machines with electrodes that attach to the skin and send electrical pulses into the body. The electrical pulses are thought to work by either blocking the pain messages as they travel through the nerves or by helping the body produce endorphins which are natural pain fighters.

### **Aromatherapy**

Some research indicates that aromatherapy can help relieve endometriosis symptoms. Individual oils and combinations that may be effective include:

- Clove, cinnamon, lavender, and rose
- Lavender
- Marjoram, sage, and lavender
- Clary sage, rose, and lavender

A person may apply essential oils to the chest, neck, or under the nose, to breathe in the vapors. Alternatively, a person could rub essential oils directly onto the lower belly.

People can also use drops of oil in a diffuser or pot of steaming water to help spread the aroma throughout the room.





### **Relaxation Techniques**

Stress can worsen pain sensations and practicing relaxation techniques can reduce stress levels. These include:

- Meditation
- Deep breathing
- Guided relaxations
- Visualisation
- Positive affirmations

### **Self-Hypnosis**

Self-hypnosis can help with pain, anxiety, helplessness and sleeplessness. Clinical hypnotherapists provide coaching in self-hypnosis techniques.

### **Distraction**

Keep busy doing things that are enjoyable such as reading, listening to music, dancing, exercising, gardening etc. Distraction can reduce pain by 30%.

## **SURGICAL TREATMENT FOR ADENOMYOSIS**

### **Endometrial Ablation**

Endometrial ablation removes or destroys (ablate) the endometrium and has been found to be effective in relieving symptoms in some patients where adenomyosis hasn't penetrated deeply into the muscle wall of the uterus (up to 2.5mm deep) and if there are no plans of pregnancy.

The aim of endometrial ablation is to reduce heavy menstrual bleeding to normal or below-normal levels.

### **Hysterectomy**

Hysterectomy may be considered if hormonal treatments have proven ineffective.

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.

While hysterectomy offers a cure for adenomyosis, it is important to have a gynaecologist who specialises in endometriosis for this surgery, so concurrent endometriosis can be removed in the same procedure. Note that hysterectomy in itself is not a cure for endometriosis.

### **Oophorectomy**

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.

**QUOTE /  
FACT BOX /  
CHART /  
STATS**

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.

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 from a hysterectomy can take 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

- |   |   |
|---|---|
| <input type="checkbox"/> Loose fitting pj's or nighty   | <input type="checkbox"/> Wipes                                    |
| <input type="checkbox"/> Bigger size underwear  | <input type="checkbox"/> Lip balm                                 |
| <input type="checkbox"/> Socks or slippers  | <input type="checkbox"/> Throat lozenges                          |
| <input type="checkbox"/> Dressing gown  | <input type="checkbox"/> Phone and charger (long cord)            |
| <input type="checkbox"/> Regular medications  | <input type="checkbox"/> Headphones                               |
| <input type="checkbox"/> Toothbrush and toothpaste  | <input type="checkbox"/> Ear plugs                                |
| <input type="checkbox"/> Deodrant   | <input type="checkbox"/> Eye mask                                 |
| <input type="checkbox"/> Face wash  | <input type="checkbox"/> Water bottle                             |
| <input type="checkbox"/> Body wash  | <input type="checkbox"/> Snacks                                   |
| <input type="checkbox"/> Hair products - hair ties (no metal for surgery), hairbrush, dry shampoo | <input type="checkbox"/> 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.

### **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 from 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 surgery. The area around your scars may feel particularly sensitive. You may have pain in your shoulder if your hysterectomy is performed laparoscopically (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 CO2 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 hysterectomy. 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 your 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 stitches 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 surgery. 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 at least six weeks.

### **Restrictions following surgery**

You should not drive for at least 24 hours after an anaesthetic. Some insurance companies will not allow you to drive for 4–6 weeks after an abdominal hysterectomy. Others may require your doctor to say you are okay to drive.

To drive safely you need to be able to sit in the car comfortably, make an emergency stop, wear your seatbelt and look over your shoulder to park. 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 hysterectomy you should be able to start getting back into your normal exercise routine.

## **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.



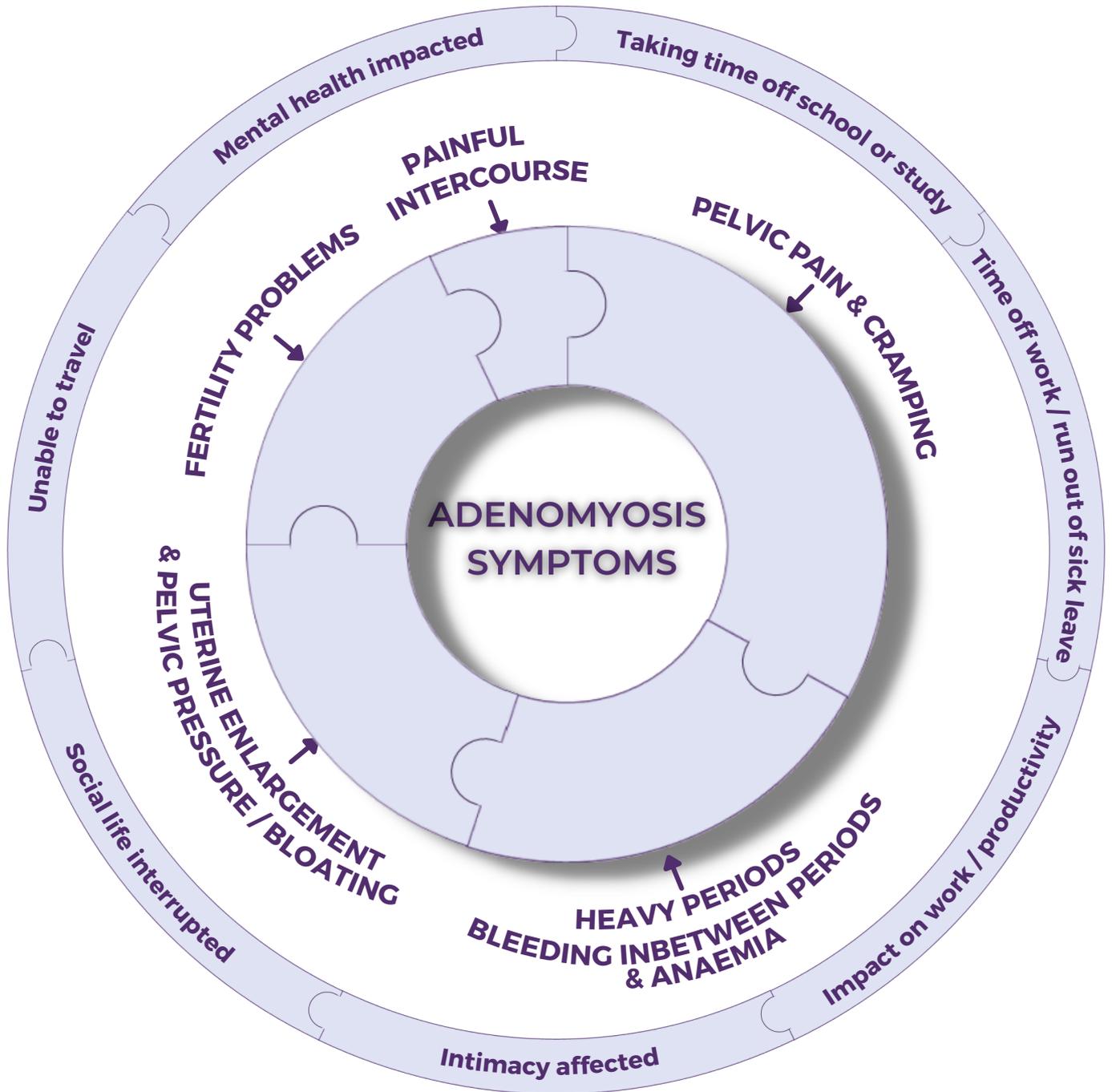
Use this checklist to help you decide if you need to seek medical advice:

- Do you experience a feeling of heaviness, enlarged or 'bulky' uterus?
- Do you experience cyclical pain in your pelvic region, lower back or legs?
- Do you feel pelvic pressure?
- Do you experience heavy bleeding?
- Do you take medication for pain at the time of your period?
- Do you need to take time off work or studies when you have your period?
- Do you need to rest when you have your period?
- Do you have pain during or after sex?
- Are you, or have you, had fertility problems?
- Do you experience abdominal bloating?
- Do you suffer from constant tiredness/fatigue?
- Do you find smear tests painful?
- Do you have endometriosis, or do you have a grandmother, mother, sister, or aunt who has had similar symptoms or been diagnosed with endometriosis?

If you answer 'yes' to a few of these symptoms you may have adenomyosis; the more you have, the higher the likelihood of adenomyosis. Take this checklist to your GP or gynaecologist to discuss your symptoms.



# ADENOMYOSIS JIGSAW OF SYMPTOMS AND IMPACTS



**ADENOMYOSIS HAS A COLLECTION OF SYMPTOMS AND WIDE IMPACTS. COLOUR IN THE SYMPTOMS YOU EXPERIENCE AND THE IMPACTS ON YOUR LIFE. THE MORE PIECES COLOURED IN THE MORE LIKELY YOU ARE TO HAVE ADENOMYOSIS.**

JIGSAW PIECE SIZING REPRESENTS THE MOST COMMON SYMPTOMS BASED ON RESEARCH

## HOW TO USE THESE TRACKERS

We have designed these trackers to help you to keep a record of your periods, ovulation, and symptoms related to endometriosis as well as track your well-being on a daily basis.

Tracking symptoms, pain, well-being, and what you eat can be a good way to communicate with health professionals what you are experiencing as well as uncover potential triggers that cause pain and other symptoms.

Please keep in mind that how you track your symptoms and pain needs to work for you, whether that's using these templates, making handwritten notes on a plain piece of paper, or using an app.

You can take these trackers to your next appointment with your GP or gynaecologist to help you explain your symptoms and pain.

### USING THE TRACKERS DIGITALLY

You can upload the PDF trackers in a note-taking app such as Goodnotes or Noteshef and use it on any table that has the ability to write or type on.

You can duplicate, move and delete pages.



## **MONTHLY SYMPTOM TRACKER**

Symptoms related to adenomyosis are on this tracker, the first section lists pain symptoms, and the second section other common symptoms. When tracking your pain, use Andrea Mankoski's pain scale (see page 28)

You might like to print out a few copies to fill out over 2-3 months, this will enable you to see if any of your symptoms are cyclical, which is often the case for those with endometriosis.

If you are using the trackers digitally, you can duplicate the page.

You don't need to start the tracker on the first day of the month, just start whenever you are ready.

## **DAILY PAIN AND WELL-BEING TRACKER**

### **Pain Tracker**

This tracker is beneficial to track in more detail the types of pain you experience and the impact the pain has on you on a daily basis. You can indicate where on your body you are experiencing pain and rate your pain, using Andrea Mankoski's pain scale.

You can also use this tracker to list the pain medications you take and the pain management techniques you try to relieve your pain.

### **Check-In and Mood Sections**

When using the 0-10 scale, 0 represents no tiredness / brain fog / discomfort / depression / PMS / anxiety and 10 represents the worst.

### **Meals Section**

If you suspect there are certain foods that trigger your symptoms you could use the meals section in the daily wellbeing tracker as a meal planner and the food and symptom tracker to record in more detail the symptoms you are experiencing after eating.



## **FOOD AND SYMPTOM TRACKER**

This tracker is ideal if you suspect that something you are eating is triggering your symptoms.

Make sure you write down the ingredients, as well as any medications or vitamins as these may contain ingredients that are triggering your symptoms. Remember to include additives such as food colourings and preservatives. Processed foods may have a lot of food colourings and preservatives and be hard work to record, but these may be the foods that are problematic for you.

Note the symptoms you experience and any other notes you would like to make.

It may take 4-6 weeks for a clear pattern to emerge.

### **NOTES SECTION**

Use the notes section to write down any other thoughts and feelings from the day and record details about your pain. You could do this morning, noon, and night or once at the end of each day. Include:

- What you were doing when your pain began.
- Your mood and how you were feeling when you experienced pain.
- Any other thoughts about your pain.



## ANDREA MANKOSKI'S PAIN SCALE

<b>0</b>	No medication needed	Pain free
<b>1</b>	No medication needed	Very minor annoyance Occasional minor twitches
<b>2</b>	No medication needed	Minor annoyance Occasional strong twitches
<b>3</b>	Mild painkillers effective	Annoying enough to be distracting
<b>4</b>	Mild painkillers relieve pain for 3-4 hours	Can be ignored if really involved in work Still distracting
<b>5</b>	Mild painkillers reduce pain for 3-4 hours	Cannot be ignored for more than 30 minutes
<b>6</b>	Stronger painkillers reduce pain for 3-4 hours	Cannot be ignored for any length of time Still able to work/study and participate in social activities
<b>8</b>	Stronger painkillers minimally effective	Physical activity severely limited Able to read and converse with effort Nausea and dizziness set in as pain factors
<b>7</b>	Stronger painkillers partially effective.	Difficult to concentrate Interferes with sleep Able to function with effort
<b>9</b>	Strong painkillers only partially effective	Unable to speak Crying or moaning uncontrollably Near delirium
<b>10</b>	Strongest painkillers only partially effective	Unconscious Pass out from pain



# MONTHLY SYMPTOM TRACKER



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Bleeding days																															
Ovulation days																															
<b>RATE YOUR LEVEL OF PAIN USING ANDREA MANKOSKI'S PAIN SCALE</b>																															
Pelvic pain																															
Cramping (period pains)																															
Leg pain																															
Back pain																															
Hip pain																															
Pain during sex																															
Pain after sex																															
<b>TICK THE DAYS YOU EXPERIENCE THE FOLLOWING SYMPTOMS</b>																															
Enlarged uterus																															
Bloated abdomen																															
Pelvic pressure																															
Heavy menstrual bleed																															
Prolonged menstrual bleed																															
Bleeding between periods																															
Constant tiredness/fatigue																															
Other symptoms																															
Medications taken and quantity																															



# DAILY PAIN MEDICATION TRACKER



M T W T F S S

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Pain medications																								
Pain management techniques																								

Pain Management Techniques can be:

- Heat (bath, wheat bag, hot water bottle)
- TENS Machine
- Aromatherapy
- Relaxation Techniques (meditation, deep breathing, guided relaxations, visualisation, positive affirmations)
- Self-hypnosis
- Distraction
- Acupuncture
- Physiotherapy
- Osteopathy
- Massage





# WEEKLY MEAL PLANNER

WEEK COMMENCING:



	BREAKFAST	LUNCH	DINNER	SNACKS
MON				
TUE				
WED				
THU				
FRI				
SAT				
SUN				



## FOOD AND SYMPTOM TRACKER



M T W T F S S

	TIME	FOOD & DRINK	MEDICINES & VITAMINS	SYMPTOMS	NOTES
<b>BREAKFAST</b>					
<b>SNACK</b>					
<b>LUNCH</b>					
<b>SNACK</b>					
<b>DINNER</b>					
<b>SNACK</b>					
<b>SAFE FOODS</b>					
<b>SUSPECT FOODS</b>					





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## 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>

[Center for Endometriosis Care](#)

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

## CONTACT US

Visit: [www.insightendometriosis.org.nz](http://www.insightendometriosis.org.nz)

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