



# CONDITIONS RELATED TO ENDOMETRIOSIS 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 endometriosis and related conditions - whether you suspect you have endometriosis, have a diagnosis of endometriosis, or have a whānau member, friend, or someone in your life that is experiencing endometriosis symptoms.

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



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## THE DIFFERENCE BETWEEN ENDOMETRIOSIS AND RELATED CONDITIONS

It is common for people with endometriosis to also have other conditions such as Adenomyosis, Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Fibroids, Fibromyalgia, CFS, and/or Polycystic Ovary Syndrome (PCOS).

Many of these conditions have symptoms that are similar to the symptoms of endometriosis and often people can be misdiagnosed, particularly with Irritable Bowel Syndrome.

The difference between endometriosis and related conditions is that symptoms of endometriosis are cyclical, and vary with the menstrual cycle, symptoms may be worse in the days before your period, during your period, or just after.

To help you determine whether your symptoms are endometriosis and/or another condition it can be extremely helpful to identify and track your symptoms. Figuring out what your symptoms are can be really helpful at GP or gynaecologist appointments and a symptom diary can reveal trends and the effectiveness of different strategies.

This information is valuable to you and your health professionals to develop the right management strategies for the right condition, and add to your feeling of control and your overall sense of well-being.

There are several apps available, or you can make notes on your phone or track things on paper. Insight Endometriosis has a PDF symptoms and pain tracker available on page 24 of this information guide.



## WHAT IS ADENOMYOSIS?

Adenomyosis (pronounced ad-uh-no-my-o-sis), occurs when the lining of the uterus (the endometrium) grows into the uterine muscle (myometrium). It is just as common as endometriosis, affecting 1 in 9 born with internal reproductive organs, although there is also little research so it may affect more people than realised.

## CAUSES OF ADENOMYOSIS

There are a number of theories:

- Invasive tissue growth: Direct invasion of the endometrial tissue cells, perhaps during a Caesarean section (C-Section).
- Developmental origins: From endometrial tissue displaced during the development of the foetus.
- Uterine inflammation related to childbirth: From inflammation of the uterine lining after childbirth
- Stem cell origins: A more recent theory proposing bone marrow stem cells invade the uterine muscle.



## 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.

## 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. 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 22, visual jigsaws of symptoms and impacts on pages 23, and symptoms and pain tracker on page 24.

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.

## **HOW IS ADENOMYOSIS DIAGNOSED?**

The only definitive way to diagnose adenomyosis is an examination and biopsy of the uterus AFTER hysterectomy, however, this is a significant surgery and not right for everyone 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
- individual preference and priorities which may include pain/symptom management and/or fertility, and which may change over the lifetime experience of adenomyosis.

Adenomyosis can be clinically diagnosed by:

- MRI: an enlarged or 'bulky' uterus can show on an MRI
- Laparoscopy: during a laparoscopy, an enlarged or 'bulky' uterus can be visualised. Adenomyosis in the uterus may also be seen
- Transvaginal ultrasound: an enlarged and tender uterus can be seen on transvaginal ultrasounds
- Pelvic exam: may also reveal an enlarged and tender uterus





## TREATING ADENOMYOSIS

Treatment options for adenomyosis include hormonal treatments, IUD's, GnRH Analogues, analgesics (pain medications) endometrial ablation, and hysterectomy.

Our Adenomyosis in NZ Information Guide can provide further information about all of the following treatment options.

### Hormonal Treatments

Hormone treatments may control symptoms, such as heavy and prolonged bleeding. 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 development of endometrioma. Taken continuously – now the recommended method – they can also suppress periods.
- GnRH Analogues work by creating a temporary pseudo-menopausal state.

### Pain Medication

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



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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 that while elimination of pain may not be possible, control of pain is generally attainable.

### **Surgical Treatment**

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 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.



## WHAT ARE FIBROIDS

Fibroids are non-cancerous growths, very common in child-bearing years (estimates 20-80%), which develop in the uterine muscle tissue, which can distort and enlarge the uterus.

There are often no symptoms, particularly for small fibroids, but they can cause painful or heavy periods, or put pressure on the bladder causing urinary frequency.

Being hormone-dependent, they may shrink in size at menopause.

## TYPES OF FIBROIDS

The location or type of fibroid determines typical symptoms:

- **Intramural fibroids:** grow within the muscular uterine wall. If large enough, they can distort the shape of the uterus and cause prolonged, heavy periods, as well as pain and pressure.
- **Submucosal fibroids:** bulge into the inner cavity of the uterus, and are more likely to cause prolonged, heavy menstrual bleeding and sometimes a problem for women attempting pregnancy.
- **Subserosal fibroids:** these project to the outside of the uterus, and can sometimes press on the bladder, causing urinary frequency or difficulty emptying the bladder. If they bulge from the back of the uterus, they may press on the rectum causing a pressure sensation, or on the spinal nerves, causing backache.
- **Cervical fibroids:** are located in the wall of the cervix (neck of the uterus).
- Rarely, fibroids are found in the ligaments supporting the uterus.

## CAUSES OF FIBROIDS

The current theory is uterine fibroids develop from a stem cell in the smooth muscular tissue of the uterus (myometrium). A single cell divides repeatedly, eventually creating a firm, rubbery mass



## **SYMPTOMS OF FIBROIDS**

- Heavy, prolonged or sometimes painful periods.
- Large fibroids can cause abdominal discomfort or pelvic pressure, which may feel like bloating, and urinary frequency or difficulty emptying the bladder.
- Pain during intercourse or lower back pain or leg aches.

## **DIAGNOSING FIBROIDS**

Fibroids may be found during a routine pelvic examination and can be confirmed by ultrasound.

## **TREATING FIBROIDS**

If symptoms are only mildly annoying, watchful waiting may be suggested as fibroids tend to shrink after menopause when levels of hormones drop.

Mild hormone therapies such as oral contraceptive and Mirena IUD can help with symptom control.

Myomectomy (surgical removal of fibroids) or other procedures may be suggested by a gynaecologist.

Iron supplements may help address anaemia.



## WHAT IS CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome (CFS) is a chronic condition characterised by ongoing exhaustion. It's also known as Myalgic Encephalopathy (ME), Tapanui or Yuppie Flu.

## WHAT CAUSES CFS?

The cause of CFS is not yet fully understood, but it is likely that several factors contribute to its development. There are changes in the immune system and body chemistry.

CFS is usually triggered by a viral infection, such as glandular fever or influenza, but any infection may be the trigger. It is likely that the potential for getting CFS is genetic and runs in families. Some people experience ongoing effects of COVID-19 infection, known as long COVID, which are very similar to the symptoms of chronic fatigue syndrome.

## SYMPTOMS OF CFS

- Extreme exhaustion lasting more than six months
- Cognitive and memory problems
- Insomnia and difficulty sleeping
- Muscle aches or weakness
- Pain or aches in joints or skin, without redness or swelling
- Sore throat
- Swollen glands
- Tender lymph nodes in neck or under arm
- Feeling dizzy or faint when sitting up or standing
- Post-exercise fatigue
- Headaches of a new type, pattern or strength



## HOW IS CFS DIAGNOSED?

CFS is diagnosed when symptoms match both of the following criteria:

- Severe chronic fatigue lasts 6 months or longer, other medical conditions are ruled out by clinical diagnosis, fatigue is not lifelong or the result of ongoing exertion, and is not relieved by rest
- Four or more of the other symptoms were not experienced before the fatigue started

Diagnosis may range from mild CFS to severe CFS.

## TREATMENT FOR CFS

CFS can be difficult to treat and the aim of a treatment plan is to relieve symptoms to improve the quality of life.

### Medication

Analgesics can help ease headaches as well as muscle and joint pain. Stronger painkillers can be prescribed, although they should be used on a short-term basis.

Medication may improve sleep quality and antidepressants can help if experiencing depression or anxiety as a result of living with CFS.

### Using the pacing technique

Pacing for CFS means breaking up your day into short periods of activity with rest in between. By prioritising important activities and dropping less important ones, energy may be found to fulfill activities that need to or want to be achieved.

### Stress and sleep management

Stress aggravates most symptoms. Relaxation methods and mindfulness can help- to reduce stress, tension, and anxiety by directing thoughts away from pain.



### **Nutritional changes**

Reducing processed foods, sugar and caffeine can help to maintain good nutrition.

### **Supplements**

If your diet lacks a good balance or if blood tests indicate deficiencies supplements may help.

### **Movement Therapies**

Yoga and Tai Chi can improve mobility and decrease muscle tightness.

### **Complementary Therapies**

Therapies such as acupuncture, massage, infra-red heat, hot packs and manipulation may help to ease muscle tension.

### **Cognitive Behavioural Therapy (CBT)**

CBT is a form of counselling that can help adjust to living with symptoms of Chronic Fatigue Syndrome.



## **FIBROMYALGIA**

Fibromyalgia (pronounced fye-bro-mye-al-ja) is a long-term condition in which people experience widespread chronic pain and tenderness in their body.

## **WHAT CAUSES FIBROMYALGIA**

The cause of Fibromyalgia is unknown however, emerging evidence suggests an association with abnormalities in both the central (brain and spinal cord) and peripheral (nerves) nervous systems. These abnormalities impair the nervous system's ability to inhibit pain messages.

## **SYMPTOMS OF FIBROMYALGIA**

- Widespread pain lasting more than 3 months, experienced on both sides of the body, both above and below the waist
- Pain in specific tender points
- Ongoing fatigue that does not get better with sleep or rest
- Cognitive and memory problems
- Trouble sleeping, sometimes associated with restless leg syndrome
- Morning stiffness
- Muscle fatigue, causing twitching or cramps
- Headaches
- Irritable Bowel Syndrome (IBS)
- Painful periods
- Numbness or tingling of hands or feet
- Temperature sensitivity such as 'feeling the cold'
- Sensitivity to loud noises or bright lights



## **HOW IS FIBROMYALGIA DIAGNOSED**

Fibromyalgia is diagnosed after all other possible causes have been disproven and pain is not a result of a recent injury but rather ongoing.

Part of the diagnostic journey is for pressure to be put on 18 tender points and if there is significant pain in eleven of these points then fibromyalgia is usually diagnosed.

## **TREATMENT FOR FIBROMYALGIA**

Fibromyalgia can be difficult to treat and the goal of treatment is to improve sleep and increase the ability to do things while also reducing pain as much as possible.

Medications are not very effective in treating pain due to Fibromyalgia. Pain medication such as paracetamol, anti-inflammatories, and opioids rarely give much relief from the pain.

### **Exercise**

Most people with fibromyalgia are likely to have pain when they first start exercising however, research has shown that the long-term effects of regular exercise includes a reduction in pain intensity and greater tolerance for daily activities. Exercise also leads to improved mood and better sleep. A physical therapist can help with a tailored exercise plan.

### **Movement Therapies**

Yoga and Tai Chi can improve mobility and decrease muscle tightness.

### **Complementary Therapies**

Therapies such as acupuncture, massage, infra-red heat, hot packs and manipulation may help to ease muscle tension.





### **Stress and sleep management**

Stress aggravates most symptoms. Relaxation methods and mindfulness can help- to reduce stress, tension, and anxiety by directing thoughts away from pain.

### **Nutritional changes**

Reducing processed foods, sugar and caffeine can help to maintain good nutrition.

### **Cognitive Behavioural Therapy (CBT)**

CBT is a form of counselling that can help adjust to living with symptoms of Fibromyalgia.

## **IRRITABLE BOWEL SYNDROME**

Irritable Bowel Syndrome (IBS) is a chronic condition that affects the large intestine.

IBS does not cause changes in bowel tissue and can often be controlled by managing diet, lifestyle, and stress which can all contribute to 'flares' of symptoms.

### **WHAT CAUSES IBS**

The exact cause of Irritable Bowel Syndrome (IBS) is unknown however there is emerging evidence that changes in your gut bacteria and inflammation of the immune system may play a role in its development.

Factors that may contribute to IBS include:

- a sensitive gut
- unusual digestion speed where the contents of the gut move unusually quickly or slowly
- an imbalance of 'good' and 'bad' bacteria in the gut
- a leaky gut when your gut may be slightly inflamed it may have small cracks or openings that allow partially digested food, toxins, and bugs to get through the gut barrier

- an infection that has triggered IBS

### **SYMPTOMS OF IBS**

The most common symptoms of IBS are abdominal pain or discomfort, as well as cramping and changes in bowel habits. Usually, the pain or discomfort will be associated with at least 2 of the below symptoms:

- feeling better after having a bowel movement
- bowel movements more or less often than usual
- having diarrhoea or constipation

Other symptoms of IBS include:

- feeling that a bowel movement is not completely finished
- mucus in the stool
- not being able to control your bladder
- not being able to control your bowel
- feeling bloated
- excess gas



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## DIAGNOSING IBS

IBS is usually diagnosed based on symptoms.

As symptoms of IBS are similar to more serious conditions, other tests may be necessary such as sigmoidoscopy, fecal testing, or a colonoscopy.

There is also a breath test to see if there are any intolerances to fructose or lactose. Breath testing can also determine if there is small bowel bacterial overgrowth.

## TREATMENT AND MANAGEMENT OF IBS

There is no cure for IBS but there are treatments that can make a difference.

### Following a low FODMAP diet

Research suggests that 3 in 4 people with IBS get symptom relief, usually within 1–4 weeks, from following a low-FODMAP diet, and that these positive effects can continue long-term. It's best if you can see a dietitian experienced in this diet to help support you make the changes needed.

## Reducing Stress

Researchers have found that reducing your stress can help to ease your symptoms.

## Increasing physical activity

Being more active can help reduce your IBS symptoms. This may be because it helps digested food move through your gut, reducing gas and bloating.

## Taking probiotics

Probiotics help to balance the 'good' and 'bad' bacteria in the gut.

## Taking medication

You can try laxatives for relief of constipation, anti-diarrheal medications to relieve chronic diarrhoea, anti-spasmodic medications to assist in relieving abdominal pain and cramps or antidepressant medication to help with the pain.

## Cognitive Behavioural Therapy (CBT)

Talking therapy such as CBT, has been found to be helpful in managing IBS symptoms because of the connection between the brain and the gut (the gut-brain axis).



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## **INTERSTITIAL CYSTITIS**

Interstitial Cystitis (pronounced IN-TUR-STISH-UL SIS-TIE-TIS) is a chronic condition characterised by bladder pressure, bladder pain, and sometimes pelvic pain from mild discomfort to severe.

### **CAUSES OF INTERSTITIAL CYSTITIS**

It's likely that many factors are at play causing Interstitial Cystitis, such as a defect in the epithelium (protective lining) of the bladder, allowing urine to irritate the bladder wall.

Other suggested factors that may contribute to interstitial cystitis include an autoimmune reaction, heredity, infection, or allergy.

### **SYMPTOMS OF INTERSTITIAL CYSTITIS**

Symptoms of Interstitial Cystitis include

- pain in the pelvis
- pain between the vagina and anus
- burning or stinging pain in the urethra
- chronic pelvic pain
- a persistent, urgent need to urinate
- frequent urination, often small amounts throughout the day and night
- pain or discomfort while the bladder fills followed by relief after urinating
- pain during intercourse

**ENDOMETRIOSIS ON  
THE BLADDER IS  
OFTEN MISDIAGNOSED  
AS INTERSTITIAL  
CYSTITIS**



## **DIAGNOSING INTERSTITIAL CYSTITIS**

There is no medical test to determine whether a person has interstitial cystitis.

To make a diagnosis of IC your doctor will need to understand your symptoms and medical history.

Other health issues will need to be ruled out and to do this you may have to have a pelvic exam, urine test, cystoscopy, biopsy, and/or urine cytology.

## **TREATMENT AND MANAGEMENT OF INTERSTITIAL CYSTITIS**

There is no simple treatment for interstitial cystitis, and each person responds differently.

You may need to try various treatments or combinations of treatments before you find an approach that relieves your symptoms including:

- Physical therapy to relieve pelvic pain associated with muscle tenderness, restrictive connective tissue, or muscle abnormalities in your pelvic floor.
- Medications such as NSAID's to relieve pain, tricyclic antidepressants to help relax the bladder and block pain, and antihistamines may reduce urinary urgency and frequency.
- Nerve stimulation may reduce urinary frequency, increase the blood flow to the bladder and strengthen the muscles that help control the bladder or trigger the release of substances that block pain.
- Bladder distention is the stretching of the bladder with water and some people notice a temporary improvement in symptoms after cystoscopy with bladder distention.
- Medications instilled into the bladder using a catheter.



## **POLYCYSTIC OVARY SYNDROME (PCOS)**

Polycystic Ovary Syndrome (PCOS) is a hormonal condition that affects, at least, 1 in 10 people assigned female at birth.

It is a hormonal condition characterised by high levels of testosterone and insulin, cysts in the ovaries, irregular or no periods.

### **CAUSES OF PCOS**

The cause of PCOS is unknown. The condition tends to run families and the main problem with PCOS is a hormonal imbalance with the ovaries making more testosterone than normal.

### **SYMPTOMS OF PCOS**

Symptoms of Polycystic Ovary Syndrome (PCOS) vary for each person but can include:

- irregular periods
- missed periods
- heavy periods
- ovarian cysts
- excess hair on the body or face
- severe acne
- male-pattern baldness
- weight gain or difficulties with weight maintenance
- fertility problems

### **DIAGNOSING PCOS**

To be diagnosed with PCOS, the Rotterdam Criteria is used and you must present with 2 of these 3 findings:

- Irregular periods, or no periods
- High levels of testosterone shown by blood tests or symptoms
- Polycystic ovaries visible on ultrasound





## **UNDERSTANDING OVARIAN CYSTS**

Ovarian cysts are a symptom of Polycystic Ovary Syndrome (PCOS) however you do not need to have polycystic ovaries to have PCOS and cysts can also be related to endometriosis.

The definition of a cyst is a fluid-filled sac and cysts can occur anywhere in the body. With PCOS, cysts develop due to eggs not being released from the ovaries. The follicles, where the egg is contained, keep growing and become a fluid-filled cyst. Over time multiple cysts can cover the ovary.

Ovarian cysts can sometimes be detected during a pelvic examination but normally an ultrasound is necessary to confirm the diagnosis.

Ovarian cysts do not always require treatment and often resolve on their own within 1-3 months. However, if a cyst is large, causing pain, or appears suspicious of cancer, treatment could involve surgery to remove the cyst or the entire ovary.



Most ovarian cysts are small and don't cause symptoms. Some people may not even know they have one until they have a pelvic exam or ultrasound. If there are symptoms they may include pressure, bloating, swelling, or pain in the lower abdomen on the side where the cyst is located.

If you know you have ovarian cysts or suspect you have and experience the below symptoms you should seek immediate medical attention:

- sudden, severe pelvic pain
- faintness, dizziness, or weakness
- pain with fever and vomiting

## **TREATMENT AND MANAGEMENT OF PCOS**

There is no cure for PCOS so treatment focuses on managing symptoms and this can look different for everyone and is based on the symptoms experienced.

Management of symptoms can include:

- regulating periods with hormonal birth control
- stabilising blood sugars through diet and/or medication
- surgical removal of cysts
- PCOS friendly movement
- excess hair treatment such as medication, electrolysis or laser therapy
- acne treatments which can include medication and topical agents



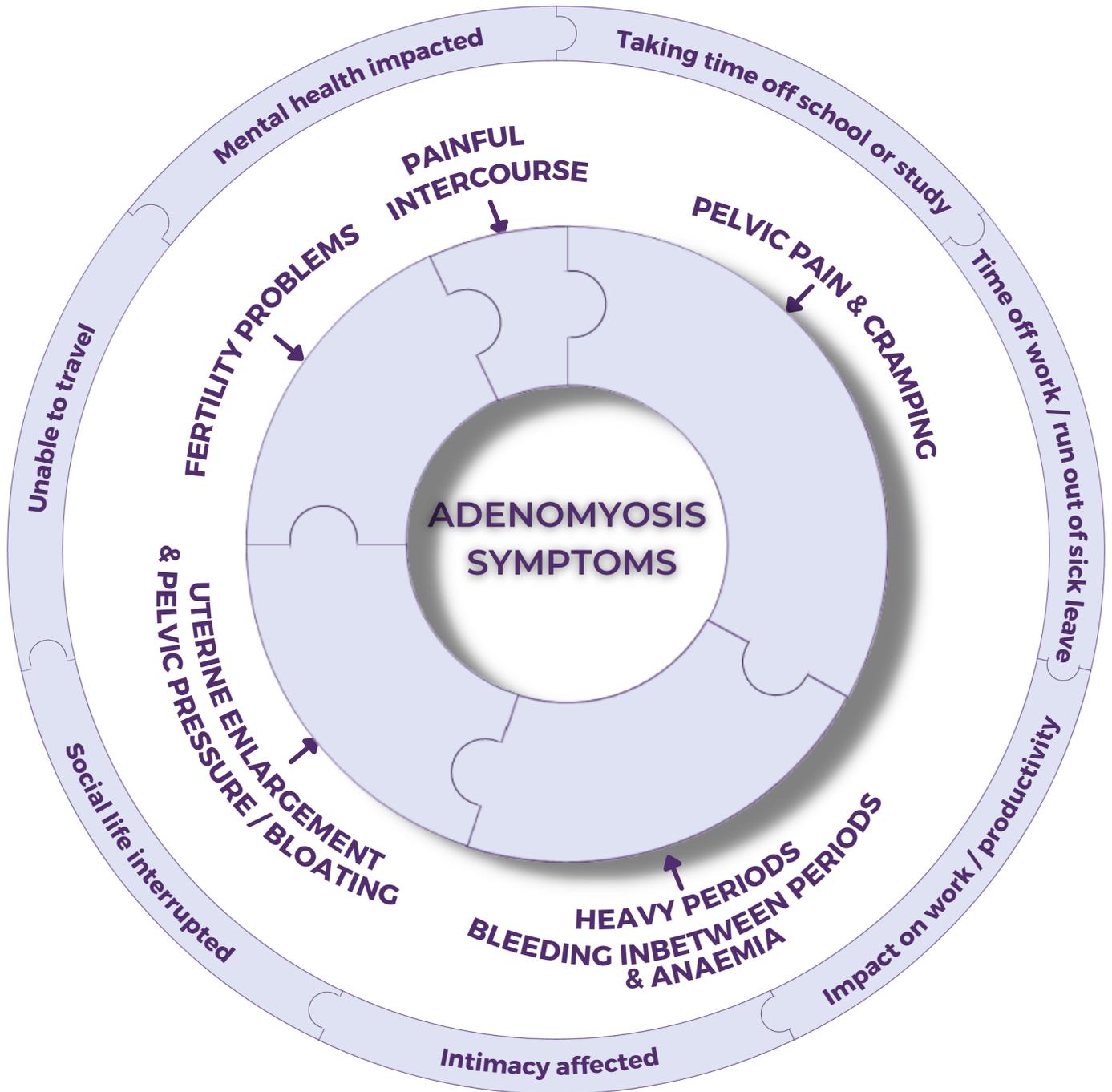
Use this checklist to help you decide if you need to seek medical advice:

- 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 endometriosis 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 27)

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

	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



# DAILY WELL-BEING TRACKER



M T W T F S S

## SLEEP

Sleep time 
 Wake time 
 Hours slept

## CHECK IN

**Tiredness**  0 1 2 3 4 5 6 7 8 9 10 **Notes**  
 \_\_\_\_\_  
 \_\_\_\_\_  
**Brain Fog**  0 1 2 3 4 5 6 7 8 9 10 \_\_\_\_\_  
 \_\_\_\_\_  
**Discomfort / pain levels**  0 1 2 3 4 5 6 7 8 9 10 \_\_\_\_\_  
 \_\_\_\_\_

## MOOD

**Low mood / depression**  0 1 2 3 4 5 6 7 8 9 10 **Notes**  
 \_\_\_\_\_  
 \_\_\_\_\_  
**PMS**  0 1 2 3 4 5 6 7 8 9 10 \_\_\_\_\_  
 \_\_\_\_\_  
**Anxiety**  0 1 2 3 4 5 6 7 8 9 10 \_\_\_\_\_  
 \_\_\_\_\_

## MEALS

**B**  
 \_\_\_\_\_  
**L**  
 \_\_\_\_\_  
**D**  
 \_\_\_\_\_  
**S**

## WATER



## NOTES

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# 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>					





Lined writing area for 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>

[Center for Endometriosis Care](#)

Health Navigator

<https://www.healthnavigator.org.nz/health-a-z/c/chronic-fatigue-syndrome/>

<https://www.healthnavigator.org.nz/health-a-z/f/fibromyalgia/>

<https://www.healthnavigator.org.nz/health-a-z/i/irritable-bowel-syndrome/>

<https://www.healthnavigator.org.nz/health-a-z/p/polycystic-ovary-syndrome/>

# 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 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
- 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
- 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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Call: 07 855 5123



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