



# SELF-ADVOCACY WITH MEDICAL PROFESSIONALS WHEN YOU HAVE ENDO 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 to advocate for yourself to receive the medical care and treatment that is right for you and your endometriosis - 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.



# CONTENTS

PAGE 1

WHAT IS SELF-ADVOCACY?

PAGE 1

WHY IS SELF-ADVOCACY IS IMPORTANT?

PAGES 1 - 2

HOW DO YOU SELF-ADVOCATE?

PAGE 3

ADVOCACY IN WRITING

PAGE 3

ADVOCACY ON THE PHONE

PAGES 4 - 5

ADVOCACY IN A FACE-TO-FACE MEETING

PAGE 5

UNSATISFIED WITH THE RESULT OF A CALL OR MEETING

PAGES 7 - 8

CODE OF RIGHTS

PAGES 8 - 10

INFORMED CONSENT

PAGE 10

PREPARING FOR A GP APPOINTMENT

PAGE 11

QUESTIONS YOU MAY WANT TO ASK YOUR GP

PAGE 12

DURING A GP APPOINTMENT



**PAGE 14**

**IF YOUR GP DOESN'T LISTEN**

**PAGE 14**

**AT THE END OF YOUR GP APPOINTMENT**

**PAGE 15**

**A GUIDE TO A GYNAECOLOGIST APPOINTMENT**

**PAGE 15**

**BEFORE YOUR GYNAECOLOGIST APPOINTMENT**

**PAGE 16**

**DURING YOUR GYNAECOLOGIST APPOINTMENT**

**PAGE 16**

**AT THE END OF YOUR GYNAECOLOGIST APPOINTMENT**

**PAGE 17**

**QUESTIONS TO ASK ABOUT SURGERY**

**PAGE 18**

**WHAT YOU CAN SAY TO A HEALTH PROFESSIONAL**

**PAGE 18**

**GETTING A SECOND OPINION**

**PAGE 19**

**SYMPTOMS CHECKLIST**

**PAGE 20**

**JIGSAW OF SYMPTOMS AND IMPACTS**

**PAGES 21 - 22**

**NOTE PAGES**

**PAGE 23**

**REFERENCES**

PAGE 24  
DISCLAIMER

PAGE 25  
AVAILABLE INFORMATION GUIDES

## WHAT IS SELF-ADVOCACY

Self-advocacy is the ability to speak up for yourself, about the things that are important to you. It's about being able to ask for what you need and want. Self-advocacy is making choices and decisions that affect your life and carrying out a plan to help you get there.

## WHY IS SELF-ADVOCACY IMPORTANT?

Self-advocacy allows you to achieve the things you want from life. Being a self-advocate means you will:

- improve your self-confidence and self esteem
- gain dignity and self-respect
- have the strength to guard against exploitation and abuse
- have power as an individual with rights.

Self-advocacy helps to empower you, to speak up for yourself and make decisions about your life. When you have good self-advocacy skills you can have more control and make the life decisions that are best for you. It can be fundamental to both asserting yourself and exploring yourself. This is important because it is directly linked to building confidence and self-esteem.

## HOW DO YOU SELF-ADVOCATE?

### 1. Believe in yourself

You are worth the effort it takes to advocate for yourself and protect your rights. You have the authority to be the expert on your life and nobody else knows how you feel or what you think.

### 2. Know your rights

Te Whatu Ora New Zealand or the Health and Disability Commissioner will have information on your rights.





You can find information on their websites but you may still have to make a few phone calls to get the exact information that suits your unique needs.

### **3. Decide what you want**

Think about what you want and need, and set yourself goals that will help you be clear to others about what it is that you want and need for yourself.

### **4. Get the facts**

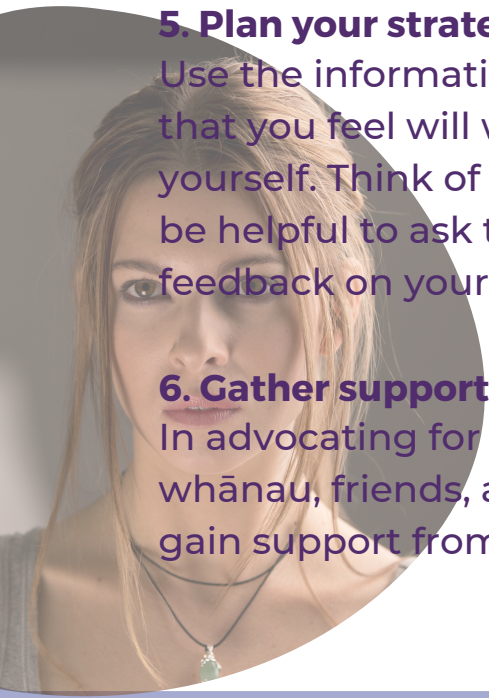
Quality information is important to your self-advocacy, so expect to spend time gathering information and facts, to ensure you are confident about what you are talking about or asking for. While the internet can be a useful source of information, make sure you are looking at reputable websites. You can also check with people who have expertise in what you are considering, ask others who have been in a similar situation to you, check references in the library, and contact reputable organisations for information and support.

### **5. Plan your strategy**

Use the information you have gathered and plan a strategy that you feel will work to get what you need and want for yourself. Think of several ways to address the problem. It may be helpful to ask those you trust for suggestions and for feedback on your ideas.

### **6. Gather support**

In advocating for yourself it is helpful to have support from whānau, friends, and others in a similar situation. You can also gain support from advocacy organisations.



## ADVOCACY IN WRITING

You can write to:

- ask for service
- request information
- present facts
- express your opinion.

**REMEMBER  
YOU ARE A  
Warrior**

Here some writing tips:

- Keep the message short and simple - under two pages if possible.
- It's fine to hand-write your message - just make sure it is readable.
- Be clear, specific, and to the point about what you want.
- Send copies of your letter to your advocacy agency, or others you want to inform. Put "cc" (copies circulated) at the bottom of the letter. Include a list of those to

whom you are sending copies.

- Keep a copy for your records.
- Be sure to follow up with a phone call or another letter.
- Create a file of your letters and responses in date order.

## ADVOCACY ON THE PHONE

Before you make your first call write down your problem or need, a short paragraph will help you organise your thoughts.

Gather background and personal information that you may need such as your:

- clinic number or national health number
- insurance details
- Community Services Card number

Try and find out the name of the person who can assist you. If you can't identify the person before making your call keep in mind you may need to call a few times to discover who can help or even which organisation can help. Keep trying until you find the right person, it is worth the effort.



## **Making your call**

Here are tips for advocacy on the phone:

- State your name, problem and what you need. Be brief with your initial comments. If the first person you talk to cannot help you, ask who can. Ask for the name and position of each person you talk to.
- Phone manners can make a difference. Express yourself clearly. Be brief. State your concern and how you want things changed.
- Assert yourself calmly. Stay cool. Speak out, but also remember to listen. Respect others' rights, but do not let them disrespect you.
- If necessary, ask when you can expect the person to call you back or when you can expect the situation to be resolved.
- If needed, make a follow-up call if you haven't heard back or the situation is not resolved as promised.
- Keep a list of the dates, times, names and positions of the people you spoke to and the result of each call. This information will be valuable if follow-up advocacy is needed.

## **ADVOCACY IN FACE-TO-FACE MEETINGS**

Advocating for yourself during face-to-face meetings can be daunting. Preparing for the appointment can help ease any anxieties; plan what you are going to say, then practice. Friends, tape recorders, or mirrors can help.

You may want to consider taking someone you trust to support your self-advocacy. Having a trusted person with you can provide support, help you stay focused, and can possibly assist you later if you have trouble remembering something that was said in the meeting.

Here are some tips for face-to-face meetings:

- Dress neatly and be on time.
- Look people in the eye and shake hands firmly when you greet them.



- Call the person by name.
- Use positive body language. How you say something often makes a greater impression than what you say.
- Speak loudly enough to be heard without shouting.
- State your message clearly and simply.
- Listen to what the other person is saying. If you do not understand, ask questions to clarify.
- Thank people for their time.
- Follow up.

## **IF YOU ARE UNSATISFIED WITH THE RESULT OF A CALL OR MEETING**

There may be times that you are not satisfied with the result of a phone call or meeting, here are some suggestions of things you can do next:

- Ask why the person cannot help you. Write down the answer.
- Ask for another person or agency that may be able to help you.
- If you have been treated unfairly, take action to defend your rights - address the issue directly with the person who has treated you unfairly.
- If necessary, talk to the person's immediate supervisor. Your complaint will seem more credible if you appeal one level at a time.
- Stay calm and respectful and focus on the problem.

Remember you have the authority to be the expert on your life. Nobody else knows how you feel or what you think; you need to tell people if you are not happy or you want something to change. If you are not happy with the way something is done then it is up to you to help change it.

# *Being a self advocate means you will*

**IMPROVE YOUR SELF-CONFIDENCE  
AND SELF-ESTEEM**

**GAIN DIGNITY AND SELF-RESPECT**

**HAVE THE STRENGTH TO GUARD AGAINST  
EXPLOITATION AND ABUSE**

**HAVE POWER AS AN INDIVIDUAL  
WITH RIGHTS**



## **CODE OF RIGHTS**

When you use a health or disability service in New Zealand, you have the protection of the Code of Health & Disability Services' Consumers' Rights and when communicating with health professionals, it can help to understand the Code of Rights as well as the guidance about informed consent from the Medical Council.

### **Right 1: The right to be treated with respect.**

This means that you have the right to be listened to, to be treated kindly by people, to have your beliefs and ideas respected, and to have your privacy respected.

### **Right 2: The right to freedom from discrimination, coercion, harassment, and exploitation.**

You have a right to be treated in the same way as other people. You should not be forced to do things you don't want to, and no one should abuse you or take financial, sexual or any other form of advantage of your situation.

### **Right 3: The right to dignity and independence.**

This means that you have a right to receive support in a manner that does not put you in awkward or embarrassing situations.

### **Right 4: The right to services of an appropriate standard.**

You have the right to receive support that is right for you;





to have services provided with care and skill; to have services provided according to applicable legal, professional, and ethical standards; and to have professionals working together to provide quality and consistent service.

**Right 5: The right to effective communication.**

This means you have the right to be told things in a way you understand, and the right to an environment that allows you to communicate openly and honestly.

**Right 6: The right to be fully informed.**

You have the right to have correct information about your condition, to be informed of available options, and to be told what is being done to you and why. This right mainly impacts the work of health practitioners when you need a medical check-up, treatment, or surgery.

**Right 7: The right to make an informed choice and give informed consent.**

This means you have a right to be consulted on every decision that affects you, and to be given explanations so you can make choices.

**Right 8: The right to support.**

You are allowed to have someone with you when you receive care and support.

**Right 9: Rights in respect of teaching or research.**

This means you have a right to be fully informed about the nature of others' involvement in the research, and to choose to refuse to be part of teaching or research.

**Right 10: The right to complain.**

You have a right to complain about the care and support you receive, a right to have your concerns and worries listened to, to know the complaints procedure, and to be told how and when your complaint will be dealt with. If you make a complaint, you still have the right to receive care and support that complies with the Code.



## INFORMED CONSENT

You have the right to 'informed consent' in choosing your care and must give permission. Under the Consumer Code, your health professional that is undertaking the treatment is responsible for ensuring they obtain your informed consent, and communicate and work with you to help you make the best decision for yourself.

Consent is an interactive process, not a one-off event. Obtaining consent is a process of shared decision-making where your health professional should be helping you to understand your medical condition and the options for treating (or not treating) your condition.

Consent is more than signing forms and completing paperwork. Your health professional should be taking the time to ask you questions so that they understand what matters to you, and what your concerns, wishes, goals, and values are.

Your health professional must give you the information you need to help you make a fully-informed decision by:

- Sharing information that is relevant to you, in a way you understand, and allows reasonable time for you to make your decision.
- Thinking about whether there is anything else they can do to make it easier for you to consider the different options and make a fully informed decision.
- Covering options available including those that they may not be able to provide themselves.
- Being open and honest and answering questions accurately.
- Including an explanation of your condition, the options available, and the results of tests and procedures.

Note that similar principles apply to you as the patient:

- You are the expert on your life, your concerns, wishes, goals, and values.

- You are a partner in shared decision-making so have an equal role in communication.
- Be open and honest and answer questions accurately.
- Take the time to ask relevant questions so you understand your condition, the options available, and the results of tests and treatments.

## **PREPARING FOR YOUR GP APPOINTMENT**

Most GP appointments are only 10-15 minutes long and if you feel you may need longer with your GP you can always ask to book a double appointment.

Think about what you want to gain from the appointment, such as:

- a treatment plan to try for the next month
- a change in treatment
- discuss new symptoms you are experiencing
- organise a referral to a gynaecologist, public outpatient clinic, pain clinic, or other specialists.

In preparation, write down all of your symptoms and questions, as well as the medications, supplements, and other treatments you are currently utilising.

You may want to use the checklist of symptoms on page 19 or the symptoms and impacts jigsaw at your appointment to initiate discussion and visually show what you are experiencing.

Consider taking a support person with you to appointments – they can help with your self-advocacy, ensure all your questions are answered and make notes. Make sure you share your questions and the outcomes you are looking for with your support person before the appointment – sometimes talking it over can really clarify what you want from the appointment.



## QUESTIONS YOU MAY WANT TO ASK YOUR GP

- What do you think is causing my symptoms?
- What treatment options are there?
- What do you recommend for me?
- How will these treatments help?
- How long do you think it will be before this treatment starts to make a difference?
- How long do you expect me to be on this treatment plan?
- What side effects can this treatment cause?
- What if the treatment is unsuccessful?
- Are there any lifestyle changes that might help?
- What do I do if my symptoms don't improve?
- What will happen if I do nothing?
- Will this affect my fertility? If so, how will we treat that?
- Could a previous surgery or another condition be causing my pain and period problems?
- What is the timeframe going forward for this treatment plan?
- When should I have a follow-up appointment?

## During the appointment

Take a notebook or use your phone to take notes during your appointment.

State the purpose of your visit clearly and concisely. For example “I am here today because I have been having pelvic pain for two weeks every month. I’ve taken paracetamol but that doesn’t help much. I wonder if my symptoms could be due to endometriosis and if a referral to a gynaecologist is warranted?”

It’s important not to minimise your symptoms or be vague about them. Also be clear about the impacts your symptoms are having on your lifestyle including work, study, social life, mental health and relationships.

There is no need to be embarrassed about your symptoms. Using straight-forward language that makes your symptoms clear to your doctor will be welcomed. For example the description of ‘sharp, twisting pain in my lower pelvis for five days each month’ is much clearer than ‘monthly cramps’. Specific descriptions will help you to obtain a correct diagnosis and help.

If you have been using our Endometriosis Symptom Tracker, take this along to discuss your symptoms and provide your GP with as much accurate information as possible to get to a diagnosis and treatment plan.

It is important to include every single symptom, even if they don’t initially seem related to endometriosis. Your GP needs to know about everything you are experiencing.

## QUESTIONS YOUR GP MAY ASK YOU

- What are your symptoms?
- When did they start?
- Do they happen or get worse at certain times?
- What makes them better or worse?
- Do any of your close female relatives suffer with period pain?
- When did you start menstruating?
- What is the date of your most recent period?
- How long do your periods last and what type of flow do you experience?
- What is your menstrual cycle (eg 25 – 30 days or irregular)?
- Do you bleed between periods or after sex?
- When was your last cervical smear test?
- What medications, birth control pills, or supplements do you take on a regular basis? Have these helped with symptoms? What side effects have you experienced from these?
- Any previous illnesses (including sexually transmitted diseases) or operations?
- Do you smoke and/or drink alcohol, and how much and often?

Your GP may suggest medicines and/or complementary therapies, as well as a referral to a gynaecologist for a more thorough assessment and further treatment. Treatments suggested should be tailored to your needs and be offered on an informed consent basis.

An ultrasound and other tests (e.g. blood tests, colonoscopy) may also be suggested, to rule out other potential causes of your symptoms.

If you are seeking a diagnosis of endometriosis, remember that a definitive diagnosis can only be made by surgical (laparoscopic) visualisation and biopsy of tissue suspected to be endometriosis. Under current NZ Guidelines, your GP would be expected to make a clinical (presumptive) diagnosis based on your symptoms, medical history and family history.

### **If your GP doesn't listen**

Symptoms of endometriosis are wide-ranging and may be similar to several other conditions, which can make it difficult for a GP to reach a clinical diagnosis. Endometriosis has been likened to a 'jigsaw' of symptoms which a GP should be prepared to explore and piece together with you.

If instead your GP has been dismissive or minimised your carefully-stated symptoms and concerns, you may want to consider seeking a second opinion with a different GP.

### **At the end of the appointment**

By the end of the appointment you should have a management and treatment plan that you feel comfortable with, and ideally referrals for other tests that are warranted, and to a gynaecologist if that is something you want.

Remember to also ask your GP when you should return for a follow-up appointment.

## **A GUIDE TO A GYNAECOLOGIST APPOINTMENT**

Going to a gynaecologist appointment can feel overwhelming, so being well-prepared and having a support person with you can relieve pressure and reduce any feelings of anxiety.

After an initial discussion of symptoms and their impact on your life, your gynaecologist may recommend laparoscopic (key-hole) surgery to definitively diagnose endometriosis as well as ongoing lifelong treatment options.

Below are some things to consider when preparing for your appointment and things to discuss at your appointment.

### **Before your gynaecologist appointment**

Write down all your symptoms and questions, as well as the medications and supplements you are currently taking.

You may want to ask your gynaecologist similar questions you asked your GP (see our GP Appointment Information Sheet) as well as:

- Will you want me to have an ultrasound or MRI scan? What are you looking for?
- Is a laparoscopy recommended? What will you look for and where?
- Do you think my fertility may be affected? What options should I consider?
- Are there waiting lists for scans, procedures and treatments and how do these work?
- How can I control my symptoms? What other treatments should I consider?



### **During the appointment**

It's important not to minimise your symptoms or be vague in any way. Don't say "It's probably nothing". You may not get the care you need and deserve if you under-report your pain and the impacts your symptoms are having on your lifestyle.

If your gynaecologist minimises your symptoms, tells you it's all in your head, to "just relax," or recommends pregnancy as a treatment, you may want to consider seeking an appointment with another gynaecologist who listens and understands.

Don't be embarrassed about your symptoms. Talk in straightforward language that makes your symptoms clear to your gynaecologist. Simply saying you have "cramps" usually doesn't raise a red flag in the doctor's mind. Telling the doctor you have sharp, knife-like pain in your lower pelvis for five days each month does.

By providing specific descriptions, you can play an important role in obtaining a correct diagnosis and treatment plan.

Taking a symptom tracker will help to discuss with your gynaecologist your symptoms and provide them with as much accurate information as possible to get to a diagnosis and manage your symptoms.

Your gynaecologist will have questions for you, which may be similar to what your GP asked.

### **At the end of the appointment**

You should be clear at the end of the appointment about the next steps that will now be taken to lead to a diagnosis such as blood tests, ultrasounds, MRI, colonoscopy, and/or laparoscopy, and what the expected timeframes are for these. Ask your gynaecologist if, and when you should expect to return for any follow-up appointments.



## IF SURGERY IS SUGGESTED YOU MAY WANT TO ASK THE FOLLOWING QUESTIONS:

- 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?



## WHAT YOU CAN SAY TO A HEALTH PROFESSIONAL

You live with your symptoms every day and you know your body better than anyone. Being able to say these things to your doctor can help you feel listened to and can help your doctor help you.

You can say:

- Can I get your opinion on something I read?
- Can you explain that more?
- I'm worried about these symptoms and I want to know for sure so I am requesting this test.
- If you haven't heard of this test/treatment, can you recommend a doctor who might have?
- What is the plan/timeframe going forward?
- Please print a copy of my test results.
- How will this medication help?
- I'm passionate about my health and I need a doctor that listens to me.

## SECOND OPINION

Remember if you don't feel listened to by any health professional you can get a second opinion and finding the right GP or gynaecologist is important for those with endometriosis.

You need to feel comfortable, and confident and leave appointments feeling certain and it may take a few appointments with a few different people before you find the right health professional for you.

It might be time to find a new doctor if they:

- don't show you compassion
- make you feel like your concerns aren't valid
- make you feel like your symptoms aren't real
- don't give you time to explain things
- don't take time to answer all of your questions
- don't explain all of your options to you
- don't explain potential side effects.

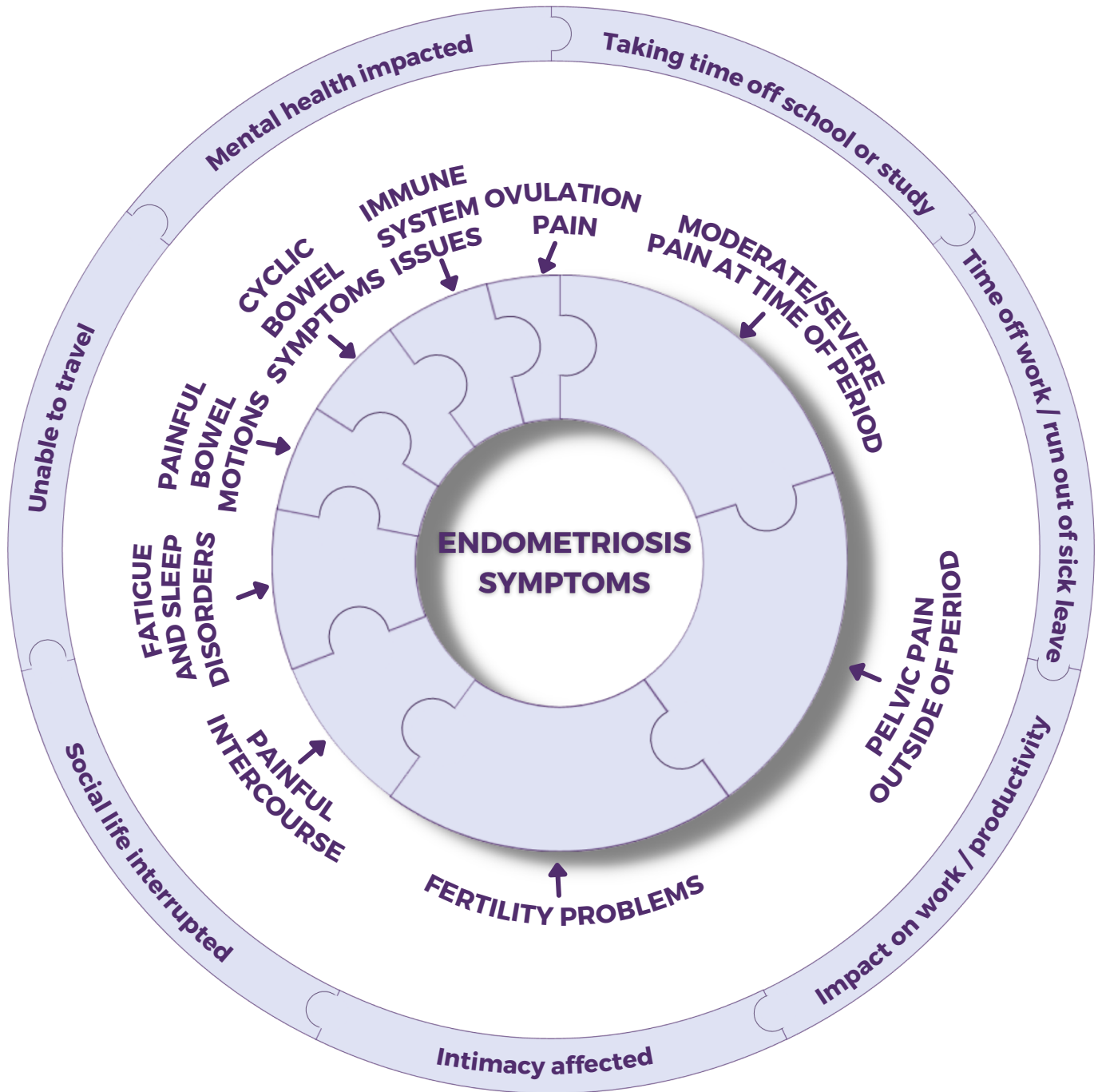
Use this checklist to help you decide if you need to seek medical advice:

- Do you take medication for pain at time of 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?
- Do you experience cyclical pain in your pelvic region, lower back or legs?
- Do you have pain midway through your cycle?
- Do you experience pain when you have a full bladder or when urinating?
- Are you, or have you, had fertility problems?
- Are your bowel motions painful, particularly around the time of your period?
- Do you experience cyclical abdominal bloating?
- Do you have diarrhoea or constipation related to your periods?
- Do you suffer from constant tiredness/fatigue?
- Do you experience cyclical depression, mood disturbances or PMS?
- Do you have premenstrual spotting?
- Do you experience heavy bleeding?
- Do you find smear tests painful?
- 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 endometriosis; the more you have, the higher the likelihood of endometriosis. Take this checklist to your GP or gynaecologist to discuss your symptoms.



# ENDOMETRIOSIS JIGSAW OF SYMPTOMS AND IMPACTS



**ENDOMETRIOSIS 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 ENDOMETRIOSIS.**

JIGSAW PIECE SIZING REPRESENTS THE MOST COMMON SYMPTOMS BASED ON RESEARCH





Lined writing area for notes.

## REFERENCES

Effective health behaviour change in long term conditions - A review of New Zealand and international evidence 2012

<https://www.health.govt.nz/system/files/documents/publications/effective-health-behaviour-change-long-term-conditions.pdf>

Code of Health and Disability Services Consumers' Rights

<https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

Active Listening

<https://www.verywellmind.com/what-is-active-listening-3024343>

<https://advocacy.org.nz/wp-content/uploads/2019/04/code-of-rights.pdf>

<https://www.mcnz.org.nz/assets/standards/79e1482703/Statement-on-informed-consent.pdf>

## 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.

Insight Endometriosis is not responsible for the content of other parties that reference or are referenced within this guide; such references should not be construed as endorsements. Any links to external websites are for your information only, and Insight Endometriosis cannot guarantee their accuracy.

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 - Self-Advocacy with Medical Professionals when you have 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

# 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
- 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)

Email: [info@insightendometriosis.org.nz](mailto:info@insightendometriosis.org.nz)

Call: 07 855 5123



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