

endometriosis
new zealand



**Managing your Emotional
and Psychological Wellbeing
with Endometriosis**

Welcome!

This resource is designed to help you better understand the relationship between endometriosis and your mental health and wellbeing.



Our goal is to help you understand some of the challenges you may be experiencing and offer practical tools and strategies to uplift your wellbeing. This guide aims to provide a pathway to further information and support that will empower you to take control of your condition.

Whether you have a confirmed diagnosis of endometriosis, are living with a working diagnosis/suspected endometriosis or are experiencing the symptoms common with this condition, this booklet is for you.

Please note, this resource focuses specifically on wellbeing.

For general information on endometriosis, and to explore our other resources we encourage you to go to our website, nzendo.org.nz.

Endometriosis and Mental Health

Endometriosis is not just a physical condition; it can significantly affect your emotional and psychological wellbeing. Living with a chronic condition like endometriosis can be overwhelming, and many people are facing challenges beyond the physical symptoms.

If you are struggling with these challenges, know that you're not alone. Understanding the link between your condition and your mental health is a huge step towards managing your wellbeing.

Endometriosis can touch every aspect of someone's life. This condition can impact the body, the mind, relationships, career, finances and important life plans such as travel or family life. As a result, it inevitably influences your view of yourself, your world and your future.

Experiencing endometriosis or symptoms of this condition can bring a range of stresses, often influenced by past experiences or in anticipation of future challenges. People may feel overwhelmed navigating any or multiple of the below:

- Feeling dismissed, particularly by medical professionals
- Feeling invalidated
- Lacking a clear diagnosis or reason for their symptoms
- Leaving a medical consultation without a clear management plan or treatment pathway
- Information overload or not knowing how to navigate misinformation versus reliable evidence-based information
- Experiences with lack of support or understanding of the condition
- Strained relationships or isolation
- Uncertainties or challenges with work, school or studies.
- Financial burdens
- Difficulty with intimacy
- Unpredictable symptoms and symptom management in general

These experiences are not uncommon and can leave someone feeling overwhelmed, frustrated and without a clear path forward.

PAIN AND THE BRAIN

You may have been told that you have 'central sensitisation' or that your pain experience is produced by central sensitisation. This is not a diagnosis but describes the process by which the brain becomes attuned to pain signals even when there is no actual organic pathology causing the pain.

It is now understood that pain involves neurological processes where the body sends pain signals to the brain and back again. Over time, these constant signals can cause the nervous system – particularly the spinal cord and brain – to become highly reactive.

This increased sensitivity is called 'central sensitisation', where nerve pathways that carry pain signals become overactive and more easily triggered. Pain signals are sent to areas in the brain responsible not only for sensation but also for emotion, which is why pain in endometriosis can impact on mood. It's almost as though the brain 'learns' to expect pain, which can make it harder to switch off these signals. In this sensitised state, the brain can amplify pain signals, making even small irritations feel intense.

When thinking about pain, it is firstly important to appreciate that pain is a warning signal. If we did not experience pain we would not be alive as we would remain in harmful situations unable to recognise risk. Pain is therefore essential to our survival.

When thinking about our pain experience we need to consider whether it is a danger or threat, or possibly just due to sensitisation. If we appraise the pain as not a threat to our survival, we can choose strategies which soothe or 'down regulate' the sensitised system. These strategies, which aim to unify the brain and body include breathing techniques, mindfulness practices, and many other options, even singing! We will explore some of these techniques further into this resource.

Managing Your Wellbeing

Living with Endometriosis

Managing your wellbeing with endometriosis can come with its challenges, however it is important to know that there are many evidence-based strategies available to support you. The following are just a few approaches that may help to improve your overall wellbeing or guide you through difficult times.

ACKNOWLEDGING YOUR EXPERIENCES

It is common for those navigating challenges with their endometriosis or its symptoms to be met with a range of complex emotions. You may have found yourself struggling with thoughts that do not reflect your true self or your situation and instead are a result of a difficult time or experience. It can help to actively challenge negative thoughts, as they arise, and consider reframing them in a way that more accurately represents your strength and resilience.



It's common to notice difficult or negative thoughts when navigating challenges with your endometriosis.

"People probably think negatively of me"

"I'm failing because I can't keep up with what I used to do."

"If I just pushed through it like everyone else, I'd be fine."

"I can't talk about this because it is too personal"

"I can't talk about my pain because no one will understand."

"I'm a burden to others because of my health."

"I'm not a good friend if I don't go to that event"

"My pain isn't real, it's all in my head"

"I have to figure this out by myself not rely on anyone else for help"

"If I rest or take time off, I'm being lazy."

"Everyone else is just stronger than me"

"I should hide my symptoms so I don't make anyone uncomfortable."



It can be helpful to try reframing negative thoughts in a way that responds with kindness and compassion and represents your strength.

"Prioritising my health does not make me a bad friend"

"Endometriosis does not define me"

"I am valuable to others, and needing support doesn't make me a burden."

"It's okay to ask for help and to seek support; I don't always have to manage alone."

"Taking care of myself helps me be a better friend in the long run."

"I am resilient, even when it feels difficult. Others' experiences don't diminish my own strength."

"I am worthy of kindness, patience, and understanding from myself and others."

"Everything at my own pace"

"My pain is real, and I deserve to be taken seriously."



BEING KIND TO YOURSELF

Self-compassion is about showing yourself the same kindness, understanding, and patience you would offer to a friend or loved one who might be facing similar challenges.

By practising self-compassion, you can approach difficult moments with greater empathy and resilience.

Here are some steps to help with managing feelings.

1. ACKNOWLEDGE FEELINGS:

It's okay to feel frustrated, disappointed, or overwhelmed by the impacts of endometriosis or its symptoms on your life. When feelings come up they deserve our attention. Be curious, recognise and validate these feelings without judgement. Instead of pushing yourself to "stay positive" or "just get through it", give yourself permission to feel. Remind yourself that you are not alone and struggling with difficult feelings doesn't make you any less strong.

2. RECOGNISE FEELINGS:

Take time to notice **what** you are feeling. Are you frustrated? sad? perhaps numb or confused? It can be common to feel drained and to suppress the stresses associated with this condition where emotional numbness can then evolve. Naming these emotions can help reduce their impact, recognising that they don't define you and instead, having a chronic health condition is taking a toll.

3. DIFFERENTIATE OR CONNECT

With endometriosis there can be a blurred line between physical symptoms and emotional stress. A low mood, for example, might be connected to fatigue, physical discomfort or could even be a side effect of a medication you are taking. By making these connections, you can better understand why you may be feeling a certain way and address both emotional and physical needs in a more productive manner.

4. FOCUS ON WHAT YOU CAN CONTROL

The unpredictable nature of endometriosis symptoms can sometimes lead to feelings of helplessness. It can help to shift your focus to areas where you feel you can make small, positive changes that work for you. It's important to have a plan of who you can ask for help when times are tough. Head to page 12 for practical support on creating a personalised action plan.

5. PRACTISE SELF-CARE

Prioritising your needs, especially during flare-ups or difficult times is so important. Find ways to comfort and care for yourself, whether that's by creating safe environments or engaging in activities that make you feel at ease. Self-care doesn't have to be elaborate and you don't have to be perfect at it for it to work - small, consistent acts can help ease emotional and physical strain.

6. ALLOW REST AND RECOVERY

Respect your body's need for rest. Rather than pushing through exhaustion or discomfort, give yourself permission to slow down and recuperate. Remind yourself that rest is not laziness or giving up, but sometimes a necessity in managing endometriosis symptoms.

FINDING COMMUNITY

Living with endometriosis can sometimes feel isolating, but remember, you're not alone. While each journey with this condition is unique, many people share similar experiences and understand the complexities of living with chronic illness on a deeply personal level. During tough times, it can help to remind yourself that there are others who can genuinely relate.

Connecting with others who have first-hand experience with endometriosis can offer validation, understanding, and a sense of solidarity. This might look different for everyone, whether it's simply following social media stories, engaging in an online peer support group, or attending community events and gatherings. Embrace these connections at your own pace and in a way that feels right for you. Just know that there are supportive communities out there.

Building these connections can help you to feel a sense of belonging. It may also help you to feel like you are positively contributing to someone else's journey by sharing your experiences.



[FACEBOOK.COM/GROUPS/ENDOMETRIOSISNZ](https://www.facebook.com/groups/endometriosisnz)

Consider who might be able to support you with these things?

Friends, family, peers, partners or significant others, healthcare professionals, colleagues, classmates, support group members, allied health professionals, community leaders or groups, online community members, religious leaders, caregivers, managers, educators and mentors.

CREATING A SUPPORT NETWORK

Building a reliable support network is important in effectively managing both the physical and emotional challenges that you might encounter, living with this condition. A strong support system can help you feel less isolated, ease the load, offer reassurance, understanding and comfort, while also being available for practical assistance when needed. You may find you prefer to manage your condition independently and that is completely okay, but it is important to remember that it is also okay to ask for help at any stage in your journey.

Consider what it is you might be seeking support with? Practical support? Emotional support? Support with information? Professional support? Community support?

Knowing your needs can help you understand who might be the right people to reach out to and better prepare you to connect with them.

I really need someone to come along with me to my appointments

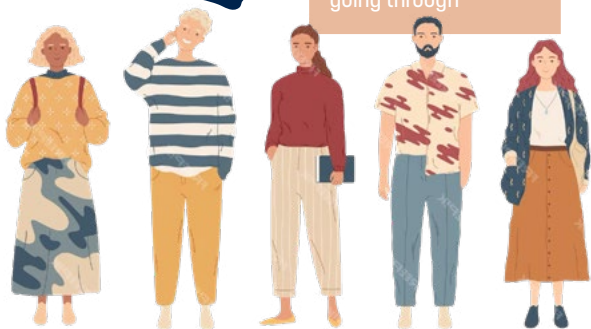
I could use some help around the house when I am in recovery

I want someone to talk to who will just listen

I need to better understand my condition with credible information

I'd like to meet with someone who can help me make a plan

I want to speak to someone who really understands what I am going through



MAKE A PLAN: FOR HOW TO INITIATE A CONVERSATION

Conversation starters for connecting with a potential support person:

"I wanted to share with you a bit about my experience with endometriosis and how it affects me and I wondered if you might have the capacity to listen _____"

"I am struggling with my endometriosis (or specific symptoms) and was hoping you might be able to support me _____"

"Thank you for being there for me, I really value your support and would appreciate it if you could _____"

"I am about to have an operation for my endometriosis which means I may need support with a few things. Could I please ask you to help me with _____"

Creating a support network is an ongoing process and can change as your needs change. You may find certain people are able to support you in certain situations while others are more frequently available or accessible. Creating a support network may feel daunting but communicating openly and being intentional about who you connect with, and for what, can make a significant difference. You deserve to feel seen and supported and there are people who are willing to help.

Remember that if someone is no longer supporting you in a positive way or negatively impacting your wellbeing, you do not have to continue to engage with them. Not everyone may respond in the way you hope and that can be understandably disappointing but there are compassionate and supportive people who are available to help.

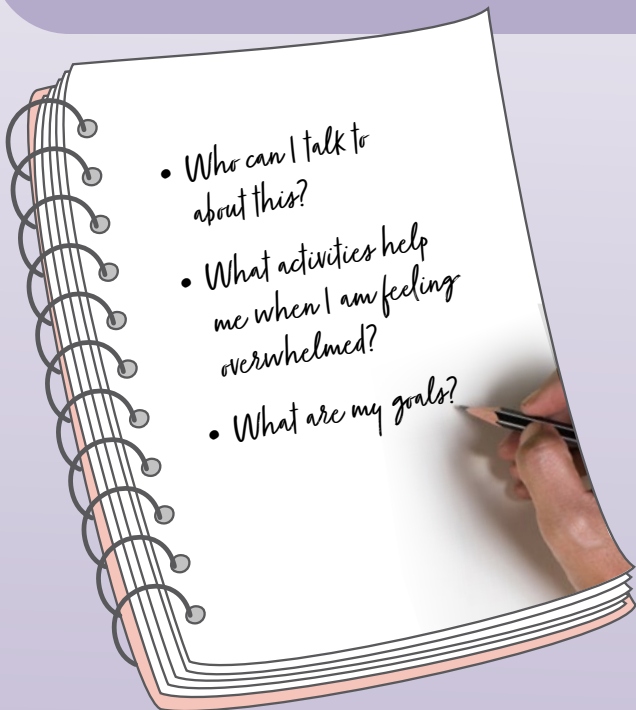
TAKING CONTROL

Creating a personalised action plan can help you feel more prepared and in control of your situation.

Use the following questions as a guide to setting up a plan that you might turn to during difficult moments.

A personalised plan can provide a sense of direction if things ever feel overwhelming or simply be a reminder of the positive steps you know that you can take to support your wellbeing.

Start with an empty space - it might be as simple as notes on your phone and begin to write down some of the things that you know or think might help during difficult moments. This is your plan so cater it to your experiences and your needs.



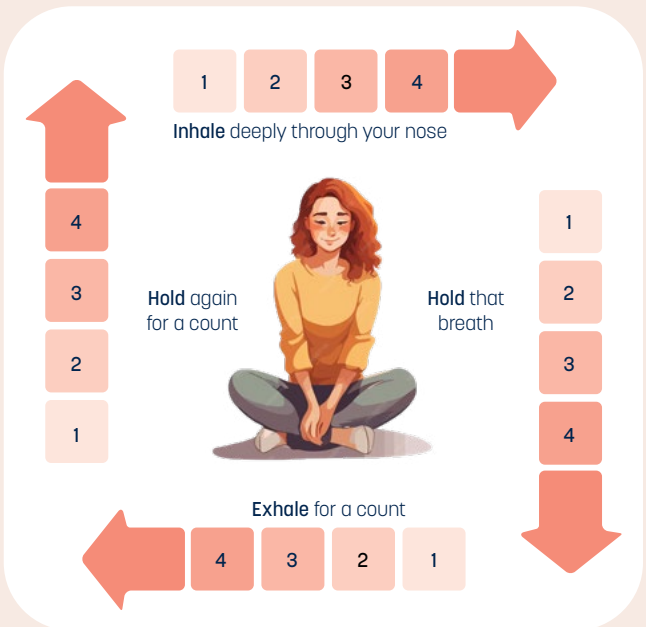
BEING MINDFUL

Mindfulness can be a helpful tool for managing endometriosis by calming the mind and the body. It can reduce stress and helps you feel more in touch with yourself and your needs. Implementing mindfulness into your management strategies can help you respond to challenges with greater awareness and compassion.

There are so many ways to incorporate mindful practices into your wellbeing toolkit and we wanted to share box breathing with you, it is a basic technique that can help to reduce stress.

TO TRY BOX BREATHING

1. Start in a comfortable position. If you like, close your eyes.
2. Take a few deep breaths
3. Inhale deeply through your nose for a count of 1,2,3,4.
4. Hold in that breath for a count of 1,2,3,4.
5. Exhale for a count of 1,2,3,4.
6. Hold again for a count of 1,2,3,4.
7. Repeat



Accessing Professional Support

Many find that seeking professional mental health support plays a key role in managing life with endometriosis. You may be referred to a psychologist, therapist, or counsellor by another medical professional at some point in your journey, but you do not have to wait for a referral to begin exploring these services on your own. Referrals may sometimes provide access to publicly funded options, but if you believe that professional support could help, you can take steps to seek this if or when you are ready.

WHY CAN PROFESSIONAL SUPPORT HELP?

Mental health professionals - particularly those who specialise in chronic illness and pain - can:

- Offer valuable management strategies for coping with the physical and emotional challenges of endometriosis.
- Provide a safe space to process your emotions, unpack your experiences, and address the psychological aspects of your condition.
- Help you gain a greater understanding of how endometriosis impacts your overall wellbeing.

WHAT ARE SOME EXAMPLES OF PROFESSIONAL SUPPORT?

Psychologists:

- Trained in mental health assessment and evidence-based therapies.
- Help individuals with endometriosis manage pain, emotional distress, and co-occurring conditions (e.g., anxiety or depression).
- Use interventions tailored to chronic physical health conditions.

Counsellors:

- Provide supportive, person-centred approaches.
- Create a safe space to explore the emotional impact of endometriosis and facilitate open self-expression.

Psychotherapists:

- Engage in deeper, often longer-term therapy.
- Address underlying emotional patterns, trauma, or psychosocial concerns.

THE ROLE OF A PSYCHOLOGIST IN ENDOMETRIOSIS MANAGEMENT

Some psychologists specialise in physical health conditions such as endometriosis, chronic pelvic pain, or other chronic pain disorders. This specialisation makes them a crucial part of a multidisciplinary approach to managing endometriosis.

A psychologist can help you:

- Understand how endometriosis affects you - acknowledging that everyone's experience is different.
- Identify personal goals and priorities - so you can focus on what matters most for your wellbeing.
- Feel empowered - by learning about your symptoms and the complex factors contributing to ongoing pain or discomfort.
- Develop strategies to lessen the impact of endometriosis on your life and emotional health.
- Benefit from collaborative care - ensuring coordinated communication among various healthcare providers.
- Connect to additional resources - directing you to other useful support, information, or services.



FINDING A MENTAL HEALTH PROFESSIONAL

If you're looking for a psychologist or another mental health professional, it can be helpful to ask for recommendations from your healthcare provider.

GPs are equipped to help you with pathways to specialist services, including conducting mental health screenings. Doing your own research can also be helpful in making informed decisions about your care.

Below are specific steps and resources to consider:

Visit Your GP

- Discuss your concerns and request a referral to a mental health professional specialising in chronic illness support.

Talk to Your Gynaecologist

- If you are under a specialist's care, they may be able to refer you to mental health professionals they work alongside.

Public Mental Health Services

- If you are accessing gynaecological care through the public health system, there may be a psychologist embedded in this service.
- Publicly funded options can sometimes be accessed via referral.

Search for Private Practitioners

- Use directories from professional organisations to find a suitable provider:
 - New Zealand Psychological Society
(Find a Psychologist)
 - NZ College of Clinical Psychologists
(Find a Clinical Psychologist)
 - New Zealand Association of Counsellors
 - Psychology Today New Zealand

Check Insurance Coverage

- If you have private health insurance, review your policy to see if psychological services are covered or partially reimbursed.

Contact Endometriosis New Zealand

- Join the online support group and become a member of the organisation to access information and education tailored for emotional and mental health support.

For Immediate Support

- Dial 1737 for free, 24/7 counselling if you need immediate help or someone to talk to.

You don't have to face this journey alone – there are compassionate and trained professionals ready to support you. If you are accessing professional support for the first time, it is completely normal to feel nervous or uncertain about the process, but know that seeking help is a positive step. You deserve a caring team on your side as you navigate these experiences.

PATHWAYS TO FURTHER SUPPORT

We understand that living with endometriosis can be challenging, and while this resource is not a substitute for professional support, we hope it offers comfort and insight as you navigate your experiences.

We also acknowledge that it may not address every aspect of your needs. To help you further, we have compiled a list of free external services that may be beneficial.

You can also find these resources on our website at

[HTTPS://NZENDO.ORG.NZ/USEFUL-LINKS/ :](https://nzendo.org.nz/useful-links/)




- NZPS Pain Resource
- Self-Compassion
- Just a Thought
- The Depression Website
- The Lowdown
- Tame the Beast
- Pelvic Pain Foundation of Australia
- Jean Hailes Pelvic Pain Resources
- Mental Health Foundation of New Zealand
- Anxiety New Zealand

We encourage you to explore these services for further information and support.

This resource was developed by Endometriosis New Zealand in consultation with the following members of our focus group:

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