



# MENTAL WELL-BEING AND SELF-CARE WITH 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 mental well-being and self-care when you have 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.





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## WHAT IS MENTAL WELL-BEING

Mental well-being is about feeling good, functioning well, and feeling connected.

For many of us, when we talk about mental health we're really talking about mental illness or mental distress. But, like physical health, mental health is something we all have, and we need to look after it. There is no health without mental health.

Good mental health boosts our physical health, creates resilience, and helps us to feel happy, confident, and secure.

The New Zealand Mental Health Foundation uses two key models of well-being to help individuals, whānau, communities, and society ensure that everyone can enjoy good mental well-being. One of these models is the 'Five Ways to Wellbeing'. Your well-being will be positively benefitted by building five actions into your day-to-day life.

## FIVE WAYS TO WELLBEING



INTRODUCE THESE FIVE SIMPLE STRATEGIES INTO YOUR LIFE AND YOU WILL FEEL THE BENEFITS.

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 Mental Health Foundation  
mauri tū, mauri ora  
OF NEW ZEALAND  
[www.mentalhealth.org.nz](http://www.mentalhealth.org.nz)

## THE LINK BETWEEN ENDOMETRIOSIS AND MOOD

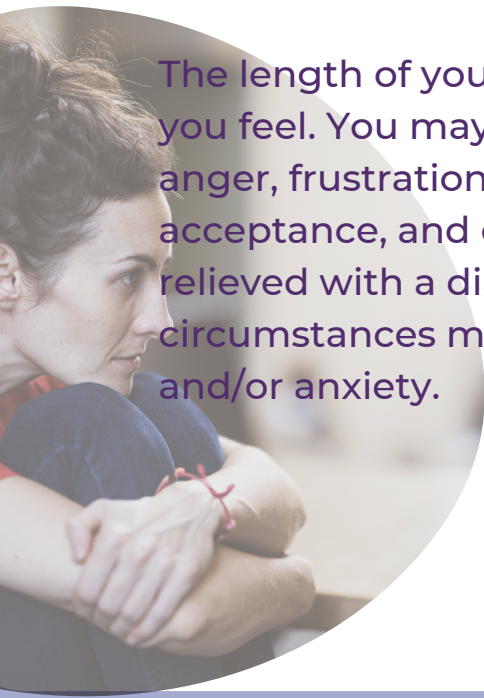
Living with endometriosis, its symptoms, and lifelong impacts can affect your mental well-being and emotional health. Alongside the diagnostic journey and getting to grips with lifelong impacts and treatments, often runs an emotional rollercoaster ranging from uncertainty through relief and depression, anxiety, loss, and grief.

Research has found that chronic pain can have significant impacts on quality of life, and the resulting impact on mood can also amplify pain, creating a 'pain cycle'.

There are a number of known links between endometriosis and mood:

- Living with chronic pain and its lifelong impacts.
- The long journey to diagnosis (typically 7-10 years).
- Stress and uncertainty, anger, irritability, frustration.
- Hormone fluctuations.
- Other symptoms such as fatigue.
- A lack of information.

The length of your diagnosis journey can contribute to how you feel. You may experience feelings of shock, disbelief, anger, frustration, sadness, numbness, fear, anxiety, acceptance, and determination. You may feel empowered and relieved with a diagnosis, but your experience and circumstances may also mean you experience depression and/or anxiety.





## COPING WITH UNCERTAINTY

Chronic illness is surrounded by uncertainty - will my symptoms flare today? What if I feel worse today than yesterday? Why isn't this treatment working? What treatment options do I have?

Uncertainty causes emotional distress, anxiety and depression and it can worsen perceptions of pain and stress. Here are some ways to cope with uncertainty that may have a positive impact on your mental wellbeing:

#1 Accept the uncertainty - resisting your current reality won't help you to recover, learn, grow, or feel better so instead practice acceptance. Acceptance allows you to see the reality of the situation in the present moment, it frees you up to move forward, rather than remaining paralyzed by uncertainty.

#2 Build your tolerance - you actually navigate uncertainty every day, like driving somewhere - will you get caught in traffic? Acknowledging these everyday uncertainties and focusing on the fact that you got through them and still went about your life can build your tolerance for more significant uncertainties.

#3 Practice mindfulness - mindfulness can reduce the suffering caused by uncertainty. When you start worrying about the uncertainties of your health, you can interrupt your thoughts with mindfulness practices and become grounded in the present moment and the certainties that do surround you.

HAVING A  
CHRONIC  
ILLNESS IS  
*hard*



#4 Follow a schedule - uncertainty causes stress and stress can cause changes to sleep and eating patterns. Try sticking to a schedule, including going to bed at the same time each day as this routine will give you a much-needed sense of structure and control when you otherwise lack it.

#5 Let go and focus on things you can control - if you find yourself unwilling to experience anxiety or intolerance to anxiety this may be leading to additional suffering as you are trying to fight uncertainty in ways that ultimately increase anxiety or create cultures of fear. Instead, step back, unplug from social media and news and focus on things you can control - like your work, family time, and daily routine.

## **CHRONIC PAIN AND LOOKING AFTER YOUR MENTAL WELL-BEING**

Living with chronic pain can affect your mood and in turn affect your perception of pain. It's often described as a cycle where your pain causes feelings of anxiety, low mood, fatigue, and sleeplessness, which can result in increased pain.

The increased pain then can cause a low mood, tiredness, and stress, so you can get caught in an endless cycle. But there are ways to break the cycle and reclaim your sense of well-being. You might find that some combination of the following tips can be helpful in managing your pain and reclaiming control over your life:

♥ Practice mindfulness - mindfulness reduces stress, tension, and anxiety. It can help you to avoid focusing too much on your pain as well as direct your thoughts in a way that is helpful for managing your pain.

♥ Follow an anti-inflammation diet - in some cases, chronic pain is linked to chronic inflammation and certain foods have been shown to increase or decrease inflammation.



♥ Improve your sleep - symptoms can make it difficult to sleep but that lack of sleep can worsen your pain the next day. Try following a consistent sleep schedule, don't take long naps during the day, and avoid stimulants such as coffee and bright screens before bedtime.

♥ Build and maintain social support - socialising calms your nervous system and decreases stress levels, it can also help alleviate feelings of depression and loneliness. As that emotional distress lessens, the severity of your pain may also decline.

♥ Join a support group - online or in-person support groups can help you to connect with others who are dealing with similar pain issues, and symptoms. These groups can provide social support and you might learn new coping strategies from other members.

♥ Try therapy - Cognitive Behavioural Therapy (CBT) can help you learn how to change negative thoughts and build coping skills to have more control over emotions, mood, and how you feel pain. There is also Acceptance and Commitment Therapy (ACT) which focuses on accepting yourself, being present, freeing yourself of negative thoughts, identifying what's meaningful to you, and using that to build a more satisfying life.

YOU ARE  
*Not*  
ALONE





## COMMON EMOTIONS WITH ENDOMETRIOSIS

There are some feelings that are a big part of having endometriosis and other chronic conditions. These feelings are ok to feel, they are normal to feel and you are not alone in feeling them.

It is common to feel:

- Frustration at your body, the limitations, the symptoms, and the changes your illness causes.
- Anger about living with a difficult condition, feeling resentful about it, and asking "why me?"
- Guilt for needing to rest, setting boundaries around health, or not being able to show up as often.
- Jealousy of non-chronically ill people and wishing you had their health and ability level.
- Fear of being out of control of your own health and how that might change in the future. Having anxiety about your symptoms each day.
- Loneliness, feeling distant, disconnected and withdrawn from others. Finding it hard to connect with people who understand so feeling rejected or isolated.
- Sadness about life with your condition and wishing things could be different.
- Lost, feeling like you aren't sure where your life is going or who you are because of a condition's impact on your life.



## GRIEF AND LOSS WHEN YOU HAVE A CHRONIC ILLNESS

The thoughts, feelings, and reactions we experience when faced with change and loss, are known as grief. Grieving is a very individual process.

For those with endometriosis and other chronic illnesses, changes in health and lifestyle can cause a feeling of grief and loss. The type of grief that comes with chronic illness is complex, and there is no 'right way' to grieve.

Chronic illness can impact a person's mobility as well as the ability to keep up usual everyday routines, to do familiar tasks, or be in usual roles. The ability to drive may be lost as well as opportunities to do things anticipated or planned such as study and travel. Your symptoms may impact your employment, income, and career plans, as well as your ability to socialise with friends and family and impact your relationships.

IT'S OK TO  
*grieve*  
THE LIFE  
YOU HAD

Grief and a sense of loss can start at diagnosis or earlier. With daily reminders and frustrations about what's been lost, or with new health issues arising or crises happening, you may feel you are in a continuous cycle of loss and grief.

## Signs of grief

Grief about health affects people in different ways, common feelings of loss include a person feeling that they have lost:

- their old self – how they used to be (identity)
- their sense of control over their body or mind
- independence
- confidence – in themselves, in the future
- self esteem
- privacy and dignity
- life as it was
- their sense of place in the world

Many factors will play a part including your personality, your life experiences, your ability to cope under stress, and also learned coping strategies.

## What can help?

Grief can affect us emotionally, physically, mentally, socially, and spiritually. Grief is a difficult thing to live with and live through and any kind of loss needs acknowledging and grieving for, whatever it is. Make time to grieve honestly for what has changed and been lost. It may help to think of grief as a process that helps to adjust gradually to what's happened.

Below are some tips to manage chronic illness grief:

- Allow yourself to feel and express your feelings; learn how to have those difficult conversations.
- Educate yourself as much as possible about your condition and take an active role in your treatment. This may help regain a sense of control and improve your self-esteem.
- Be realistic about what to expect from yourself.
- Let go of expectations, do what you need to do for yourself and understand that other people and society's definition of what's normal doesn't apply.
- Establish a good relationship with a supportive health care provider.





- Join a support group; talking to people that have similar experiences and feelings can help.
- Communicate with friends, family, and your partner.
- Learn to adapt, make substitutions and modifications so that you can still participate in life activities.
- Listen to your body, pamper, and nurture yourself through eating well, gentle exercise, and prioritising quality sleep and rest.
- Make peace with your chronic illness.
- Practice self-care and self-compassion (we have a fact sheet on this topic).

Sometimes grief can go unrecognised or unacknowledged by others, who don't realise the huge impact that a change in health can have. Talking assertively to those around you is important so they have a clear understanding of how your health is impacting you; this will enable them to have compassion for what you are experiencing and provide the support and practical help you need (see our 'Talking About Endometriosis with the People in Your Life Information Guide').



## ENDOMETRIOSIS AND COPING WITH FERTILITY PROBLEMS

Problems conceiving may involve a series of losses - loss of hopes and dreams, loss of control, loss of a positive self-image, loss of privacy, loss of feeling connected, belonging, and many more. These losses may be invisible to others. Those experiencing fertility problems may feel lonely and isolated from friends and family, and sometimes from their partner. Uncertain outcomes, and coping with fertility treatments can compound these issues.

Some social gatherings might be hard to cope with. While some conversations may be difficult or painful, with some preparation they may also be an opportunity to explain your situation to friends and seek support. Aim to be open and assertive rather than defensive. Remember that just because a question is asked does not mean you have to answer it.



Below are some coping strategies if you are experiencing infertility:

- Seek information from fertility specialists, counsellors or Fertility NZ and inform yourself about the options available to you.
- Join a local support group: sharing experiences can be helpful and help you to feel less isolated.
- Look after yourself: self-care can help minimise the negative impact that fertility problems can have on your mind, body and soul.
- Research shows that writing or drawing about painful experiences is therapeutic and can be a form of release during tense and stressful times.

### Seeking Help

Some people start to feel better in weeks or months, while for others it may take much longer. Whatever your grief experience is, it is important to be patient with yourself, take time to grieve, and seek help if you sense the need.

It's especially important that you talk to your doctor or a counsellor if you:

- feel disconnected
- are unable to perform your normal daily activities over an extended period
- feel life isn't worth living
- are having difficulty trusting others since your loss.







## DEPRESSION

If you've constantly been feeling down, feeling hopeless or have little interest or pleasure in doing things you used to do you could have depression. Other possible signs and symptoms of depression include:

- irritability or restlessness
- feeling tired all the time, or a general loss of energy
- feeling empty, lonely
- sleeping problems - too much, or too little
- losing or gaining weight
- feeling bad about yourself or things you have done
- problems with concentration
- reduced sex drive
- thinking about death a lot
- thoughts of harming yourself.

Some people with endometriosis get depression, this can be for many reasons including the diagnosis journey, changes to lifestyle, dealing with chronic pain and other symptoms, hormonal treatments which can affect mood and emotional wellbeing, unsuccessful treatments and recurrences that need ongoing treatments, dealing with fertility problems, the lack of support or understanding as well as the financial implications, such as treatment costs or taking time off of work for surgery or due to symptoms.

## ANXIETY

Feelings of anxiety with a chronic illness are very common and can be for many reasons such as:

- the diagnosis journey
- coming to terms with the diagnosis
- dealing with chronic pain and symptoms
- hormonal treatments
- unsuccessful treatments
- fertility problems
- lack of support or understanding
- financial problems such as treatment costs or taking time off work due to pain or surgery.

Feelings of anxiety are quite intense and can last for weeks, or months or can keep going up and down over many years. Anxiety negatively affects your thoughts, behaviours, and general health and can leave you feeling distressed and not enjoying life.

Some common anxiety symptoms include:

- hot and cold flushes
- shaking
- racing heart
- tight feeling in the chest or chest pains

- struggling to breathe
- snowballing worries that get bigger and bigger
- a racing mind full of thoughts
- a constant need to check things are right or clean
- persistent worrying ideas that seem 'silly or crazy'.

Anxiety can make you feel:

- like hiding away
- lightheaded and dizzy
- there are butterflies in your tummy
- unable to sleep
- that your heart beats faster
- easily irritated
- a loss of appetite
- easily fatigued.

If over the last two weeks, you've been constantly worried, afraid, or panicking about things that might happen or for no reason at all – you may be experiencing anxiety.

Reach out to someone in your life you can trust, or visit <https://mentalhealth.org.nz/help/lines> for organisations that can help.



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## **COPING WITH DEPRESSION AND ANXIETY**

Knowing when to ask for help is important. Even when it seems you can't control your feelings, you can control what you do about things. Just taking a small first step is enough to get you on the path to enjoying life again. It'll work so much better if you don't try to go it alone.



### **Start by talking to someone**

A good way to start dealing with what's going on is to share how you're feeling with someone you trust, or someone who understands what you are experiencing. This could be someone in your family, your partner, a friend or anyone in your community who you feel close to.

When you are dealing with stressful situations don't try to cope on your own, turn to family and friends to provide emotional support. They may also give you advice and share information, as well as provide practical support.

Endometriosis support groups can also give you the chance to talk to others who are experiencing the same ups and downs as you. Insight Endometriosis has endo meet-ups throughout New Zealand but if there isn't a group in your area, we do have online meet-ups. We can also recruit volunteers to facilitate a group in your area.

### **Things you can do yourself**

There are many self-help strategies that you can implement yourself to help cope with depression and anxiety. You are the expert in your own mental health and wellbeing. You can take charge of your recovery and do things that make you feel better, stronger and more in control.

When you have depression, it can be hard to find the energy or motivation to look after yourself.



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Start small and slowly build up to bigger things and try to notice what makes you feel better. Make a list of things that feel good and keep it on your phone, your diary or on the fridge. When you're struggling, check you list and pick one things you can do right now that might help.

Here are some things people with depression have found helpful:

- ♥ Simplify your routine - identify stressful activities and, where possible, reduce them. Create a regular routine for yourself.
- ♥ Look after your physical health - try to eat a balanced diet and get enough sleep. Get some exercise, even something as brief and gentle as a walk around the block or a few minutes of stretching.
- ♥ Spend time in nature - even just sitting in the sunshine listening to the birds singing for a few moments can be really helpful.
- ♥ Find entertainment and fun - Watch comedies or other gentle TV shows and movies. Have a playlist of music that you know helps. Make sure you regularly do things that you enjoy and that give your life meaning.
- ♥ Be kind to yourself - this could mean treating yourself to something small but special, like a cupcake or a new pen. It also means letting your feelings exist without judging them or trying to suppress them.
- ♥ Make small connections - if you don't feel like having a conversation, you can still reach out with something as simple as sending a gif, or asking your friends to spam you with pictures of cute animals.

### **People who can help you**

If it all seems overwhelming, don't forget you don't need to face these issues alone. If you need support, there are people trained to help with depression and anxiety, as well as those with lived experience who understand what you are going through. Reach out for help through a helpline or locate support through community organisations.



## SELF-CARE

Endometriosis changes your life and can impact you physically, your study or work, friendships, and relationships. Taking intentional steps to take care of your emotional, physical, and mental health can make life a little bit easier. Self-care is so important for everyone and it can look different for each person. There are six types of self-care - physical, emotional, spiritual, intellectual, social, and sensory.

♥ Physical self-care is about taking care of your body. It isn't about a vigorous exercise routine though, the key to physical self-care is it should be something you enjoy, and not feel like an obligation.

♥ Emotional self-care is about becoming more in tune with your emotions. It's about checking in with yourself, becoming more mindful of your triggers and thinking patterns, and finding ways to work through them, rather than bottling them up inside.

♥ Spiritual self-care doesn't always relate to religion, although it can be for some people. When you practice spiritual self-care, you are nourishing your soul, you are striving for inner peace, and you are seeking to find purpose and meaning in life.





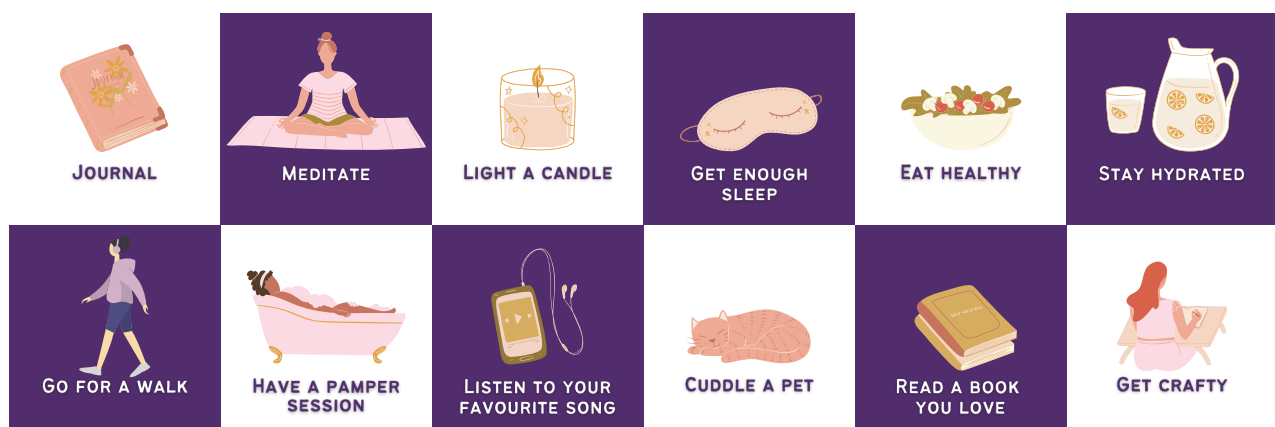
♥ Intellectual self-care includes doing something you enjoy that nourishes and challenges your mind. It expands your knowledge. Learning a new skill can be a type of self-care activity in this category.

♥ Social self-care may look different for introverts and extroverts - because our levels of comfort in social situations differ. But, the connection is important to loved ones, reconnecting with an old friend, striking up a conversation with someone at the coffee shop when you pick up your morning coffee.

♥ Sensory self-care helps you nourish your senses - sight, smell, touch, sound, which is an effective way of bringing your mind to the present moment and helping you lower your stress levels.

When feeling stressed or anxious you can try a self-soothing act, something simple that you can do to help calm your mind and body. Self-soothing acts help you to become more present and less lost in thought without shutting down your feelings or forcing a positive attitude. Think of self-soothing as a really good hug: it helps you to feel a bit more safe, present, and supported. Try positive self-talk, having a shower or bath, getting some sleep, listening to music, meditating, and hydrating as ways to self-soothe.

Here are some other ideas of things you could do that improve your health, reduce your stress, and bring you enjoyment:



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Handwriting practice area with 25 horizontal dotted lines on a white background.



## HELPLINES

1737, Need to talk? Free call or text 1737 to talk to a trained counsellor

Depression.org.nz 0800 111 757 or text 4202

Lifeline 0800 543 354

Mental Health Foundation 09 623 4812, to access its free resource and information service

Rural Support Trust 0800 787 254

Samaritans 0800 726 666

Suicide Crisis Helpline 0508 828 865 (0508 TAUTOKO)

Fertility NZ 0800 333 306

## REFERENCES

Anxiety and depression in patients with endometriosis: impact and management challenges:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5440042/>

Examining subjective well-being and health-related quality of life in women with endometriosis:

<https://pubmed.ncbi.nlm.nih.gov/29095116/>

Mental Health Foundation

[www.mentalhealth.org.nz](http://www.mentalhealth.org.nz)

Te Hiringa Hauora

[www.depression.org.nz](http://www.depression.org.nz)

Skylight

[www.skylight.org.nz](http://www.skylight.org.nz)

Grief Support Services

[www.griefsupport.org.nz](http://www.griefsupport.org.nz)

Fertility NZ

[www.fertilitynz.org.nz](http://www.fertilitynz.org.nz)



## 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 - Mental Well-Being and Self-Care with 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."



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# 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
- 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)

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

Call: 07 855 5123



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