



*Supporters guide to
managing endometriosis
in the workplace*

FOR EMPLOYERS, MANAGERS
AND COLLEAGUES

This resource aims to equip you with the tools to support an employee living with endometriosis or symptoms of this condition in the workplace.

Whether you are in the role of an employer, manager, or human resources staff member, responsible for the workplace well-being of an employee, potentially affected by endometriosis.



OR

If you are a colleague,
workmate or business partner
working alongside someone facing
this condition.

This guide aims to empower you to become a supporter. In this resource we work to help you understand this condition, the potential impact it can have on an employee and the ways in which you can help someone thrive in the workplace while they manage this condition.



Understanding Endometriosis

WHAT IS IT?

Endometriosis is a common, chronic inflammatory disease in which tissue similar to the lining of the uterus, is found in places outside of the uterus, most commonly in the pelvic region.

WHO MIGHT IT AFFECT?

Endometriosis is generally considered to affect people in their reproductive years. For some, it can be as early as their first menstrual period, whereas others may develop symptoms later in life. Endometriosis can impact individuals differently and the severity can vary widely. It affects a minimum 1 in 10 women, girls and those assigned female at birth.

WHAT ARE THE SYMPTOMS?

These are the symptoms most commonly associated with endometriosis. They include but are not exclusive to:

- Painful periods, urination, defecation and ovulation, back pain
- Bowel and bladder problems
- Abnormal menstrual bleeding, heavy periods, irregular periods
- Fatigue, tiredness, low energy, migraine
- Premenstrual syndrome
- Difficulty getting pregnant

FATIGUE WAS RANKED THE MOST CHALLENGING SYMPTOM TO MANAGE IN THE WORKPLACE IN OUR ENDOMETRIOSIS NEW ZEALAND COMMUNITY SURVEY.

SYMPTOMS VARY WIDELY AND WHAT ONE INDIVIDUAL WITH ENDOMETRIOSIS MIGHT EXPERIENCE, ANOTHER MAY NOT AND IT IS POSSIBLE FOR AN INDIVIDUAL TO HAVE THIS CONDITION AND EXPERIENCE NO SYMPTOMS AT ALL.

ENDOMETRIOSIS IS AN INVISIBLE CONDITION AND PEOPLE CAN BE REALLY GOOD AT MASKING THEIR STRUGGLES. THIS MEANS THAT WHILE SOMEONE WITH ENDOMETRIOSIS MAY NOT LOOK UNWELL TO YOU, IT IS IMPORTANT TO REMEMBER THEY MAY BE EXPERIENCING ANY OF THE ABOVE SYMPTOMS AT ANY GIVEN TIME.

HOW IS ENDOMETRIOSIS DIAGNOSED AND TREATED?

The precise cause of endometriosis is currently unknown and the available treatments do not always eliminate the condition or its symptoms and not everyone who experiences these symptoms may have received a diagnosis.

A medical professional will most often look at an individual's medical history, conduct a physical examination and request additional investigations such as blood tests and imaging (ultrasound/MRI) to consider endometriosis. A laparoscopy (keyhole surgery) is usually required to make a final diagnosis and treat the condition. This surgery can be life-changing for some. There is currently an 8.7 year delay to diagnose endometriosis in New Zealand, where people are living with this condition without a final diagnosis or official acknowledgement.

Everyone's experience with endometriosis is unique and it is important to acknowledge that there are many differences in people's experiences with symptoms, access to care and diagnosis. In the workplace, you may encounter employees with:

Diagnosed endometriosis: individuals who have undergone evaluation by a medical professional (laparoscopy), that confirms the presence of endometriosis and therefore have received a formal diagnosis of endometriosis.

Suspected endometriosis: individuals who are experiencing symptoms consistent with endometriosis and are therefore being considered for the condition. They may be undergoing review from medical professionals, including testing such as physical examinations, ultrasounds and blood tests, but a confirmed diagnosis has not yet been established. This also includes individuals who are waiting for a referral to a gynaecologist or on a waitlist for surgery.

Endometriosis symptoms: individuals who are experiencing symptoms consistent with endometriosis but have not yet taken the steps towards seeking medical support.

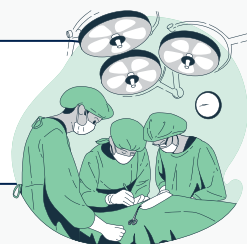
The management or treatment for endometriosis is also different for each individual and will depend on their specific situation.

Treatment options for endometriosis can include:



Medical treatments
(hormone medications
and pain relief)

Surgical treatments
(involving an operation)



Allied treatments
(physiotherapy, psychology,
alternate medicine etc)

IT IS IMPORTANT TO VALIDATE ALL EXPERIENCES AND THE FOLLOWING GUIDE WILL EQUIP YOU WITH THE TOOLS TO BE A SUPPORTER TO ANYONE WHO NEEDS IT, NO MATTER WHAT STAGE THEY ARE AT.

WHY IS ENDOMETRIOSIS A WORKPLACE ISSUE?

Within the workplace individuals may experience a number of challenges that can make it difficult to carry out everyday tasks and activities.

Some of the challenges people with endometriosis may face in the workplace include (but are not limited to):

- Symptom management
- Stigma or discrimination from employers, managers or colleagues
- Difficulty discussing their condition or relating to others
- Difficulty working within the restrictions of a role
- Being held back from career opportunities

"It can be difficult to communicate what I need, as flare ups can be unpredictable and random."

"It can be difficult to explain how endometriosis feels and the daily impacts it has"

"When I am having a bad day with pain, it makes it difficult to do my job right"

"I have to push through on days that I probably shouldn't"

"It has kept me in low paying entry level jobs... due to a lack of understanding and support"

"The owner had previous staff with endo, their cases were much less severe so I felt like I couldn't communicate how the disease affects me."

STATISTICS NEW ZEALAND SURVEY

92%

Respondents find it challenging to manage their endometriosis symptoms in the workplace

88%

Respondents have had to take sick leave to manage their condition

66%

Respondents disclosed that workplace stress negatively impacts their endometriosis symptoms

48%

Respondents have had to take unpaid leave

Endometriosis and the workplace, NICM Health Research Institute study (Armour et al. 2022)

65%

Respondents had taken unpaid leave to manage the condition

1 IN 3

Respondents missed out on a promotion as a consequence of the condition

1 IN 6

Respondents lost their job from managing their condition



The experience of someone in the workplace living with endometriosis symptoms, can be significantly improved by those around them and the environment they are working in. It is very possible to succeed as an employee with endometriosis and you can be a part of that success.

"Having support from my boss has made a world of difference"

"Knowing that my health and wellbeing is a priority for my company relieves me of the stress I hold in knowing my condition could impact me again in the future, meaning right now I can just live well and do my best work"

"Flexible working arrangements and being able to work from home has had a positive impact on my ability to manage endometriosis in the workplace"

"My workplace being compassionate and open to considerations has made me feel safe to voice my needs"

"The open-mindedness and support of colleagues and management has really helped"



HOW DO YOU SUPPORT SOMEONE WITH ENDOMETRIOSIS IN THE WORKPLACE?

While endometriosis can bring about challenges for an individual, supporting them doesn't need to be challenging. There are a few key things you can do to positively impact their experience.

1. Empathy and understanding



Educate yourself:

Recognise the importance of learning about endometriosis and utilise available resources to gain knowledge and insight into the condition. You've taken the first step by picking up this resource and you can head to nzendo.org.nz for more information, additional resources or to contact us.

Acknowledge the condition:

Validate individual experiences with endometriosis. If you are in the position where you have direct experience with endometriosis in your own life, this can be great opportunity to show empathy through shared experiences. However, it is important to remember that endometriosis symptoms do not always present in the same ways and what you have experienced or seen may not be the same as what they are experiencing.

2. Establish their needs



Build trust:

Emphasise the importance of trust in a relationship before you jump into active conversations. Connection can go a long way in helping someone manage their endometriosis. Be reliable, consistent, show empathy, avoid gossip and follow through on commitments to the person.

Respect privacy and boundaries:

It is important to note that there are individuals who live with endometriosis and do not want or need support with their condition. This may be clear in how they choose to share their condition or what they are willing to discuss. Ensure you communicate that you are willing to listen but never force a conversation or the sharing of specific details that haven't been offered.

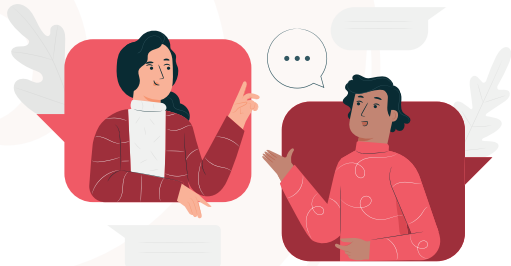
Remember this is a personal health condition and it is important an individual is consenting to the discussion and what they share remains confidential unless otherwise arranged.

Make it a joint effort:

Collaborate with individuals to find solutions that address their specific needs and encourage teamwork to manage the challenges related to their condition.

Keep an open mind:

Embrace an open and positive attitude towards finding a solution that will be of benefit to both the individual and the organisation.



Encourage transparent communication:

Create opportunities for open dialogue such as 1-1 meetings, informal catch-ups and regular check-ins.

Create safe spaces:

Create an environment where they may feel comfortable to discuss their needs. If a meeting is established, avoid involving others without permission and find comfortable private spaces to conduct these in.

Reduce stigma:

Foster an open and understanding work culture by breaking down stereotypes and calling out bad behaviour or misconduct.

People with endometriosis often worry about how they are being perceived by others, for example whether staff who work flexibly or take leave are seen as unreliable or untrustworthy. If flexible working arrangements or leave have been offered to a staff member ensure you get permission from the individual about what you share and how these arrangements are communicated to others in the workplace.



Raise Awareness:

Raising awareness of endometriosis is a great way to help an entire workplace understand the condition a little better. People don't always have awareness of the health conditions that others around them may face but educating them on people's lived experience can lead to a shift in perspective. This can help people learn how to support someone with endometriosis, but it can also help create a culture where people may feel more comfortable talking openly about their condition.

Reach out to Endometriosis New Zealand for more information or support in doing this.

Leadership modelling:

If your workplace has systems in place to support someone to manage their endometriosis, we encourage you to model the use of these systems so that an employee sees this and feels comfortable to access this arrangement for themselves. For example, if your workplace has the ability to work from home, ensure that as a person in a leadership position you also work from home where possible to help them know it is okay.



What are some practical opportunities to support the management of endometriosis in the workplace?

1. OFFERING FLEXIBLE WORK ARRANGEMENTS

This could include a change in shift patterns, shorter hours, flexible hours, job sharing, an agreed period of paid or unpaid leave, or the ability to work from home.

Flexible work arrangements can greatly benefit employees with endometriosis by providing them with the flexibility needed to manage their symptoms effectively. This approach allows individuals to tailor their work schedule to their health needs, accommodating variations in pain levels and energy levels. This flexibility can contribute to improved overall well-being and job satisfaction, as they can better balance their health needs with work responsibilities.

Working from home allows an employee managing endometriosis to:

- maximise comfort while working with access to a personal bathroom, comfortable clothing, heat tools, pain relief and a personalised work set up or seat.
- minimise the physical effort or discomfort required of getting to and from work.
- eliminate commuting time which could be used for more rest, gentle exercise, catching up on work or whatever is needed for that day.

IF YOU SEE YOUR COLLEAGUE REQUIRING FLEXIBLE WORKING ARRANGEMENTS THAT YOU DO NOT REQUIRE, BE RESPECTFUL

2. ALLOWING REASONABLE JOB MODIFICATIONS

This may be a slight change in role responsibilities which could include reducing the pace of work, systems for managing workloads, modifying workstations and modifying work uniforms or dress requirements.

Similarly to flexible working arrangements, job modifications can result in increased productivity and job performance, as well as a decrease in the likelihood of triggering symptoms. They offer a targeted and personalised approach to reasonable accommodations in the management of endometriosis in the workplace.

3. PROVIDING ACCESS TO SUPPORT SERVICES

This may include directing employees to organisations who are able to provide support for managing endometriosis and the impacts of its symptoms. It may also include access to health professionals who may be able to provide additional support.

If your workplace is able to provide services such as an employee assistance programme or medical health insurance, these can be of great help in the overall management of their condition and wellbeing.

Endometriosis New Zealand has a free appointment-based help service, Endo Help, available to all who need it. Individuals can visit our website at nzendo.org.nz to book a time with one of our team. We aim to provide valuable guidance and support and a kind and understanding ear to listen.

[NZENDO.ORG.NZ/HELPING-YOU](https://nzendo.org.nz/helping-you)

4. CONSIDER IMPLEMENTING HELPFUL WORKPLACE POLICIES AND PROCEDURES

Policies and procedures that specifically address chronic conditions like endometriosis can establish a clear pathway towards effectively managing health-related challenges through creating a supportive framework within the workplace. Endometriosis New Zealand has an endometriosis workplace policy template free on our website to guide you on developing and implementing an effective policy within your organisation.

It is important that all staff are aware of any workplace policy and how it might apply to them to ensure they understand how to access this if required.

[NZENDO.ORG.NZ/RESOURCES](https://nzendo.org.nz/resources)



5. PROVIDE ADDITIONAL LEAVE

Your workplace may already have or be willing to allow additional leave allocations such as menstrual leave, sick leave in advance, special leave, leave for surgery or unpaid leave.

Additional leave allocations can provide employees with the necessary time to manage their endometriosis-related challenges without the fear of negative repercussions. This benefit recognises the unique needs of individuals dealing with chronic conditions and supports their ability to prioritise health without compromising their job or financial security.

6. ACCESS TO FACILITIES AND AMENITIES TO MANAGE ENDOMETRIOSIS

Facilities beneficial for endometriosis include:

- Private toilets rather than stalls and access to showers. A quiet or private breakout space. Kitchens that take into account diet considerations.

Amenities beneficial for endometriosis include:

- Hygiene products, period products, heat packs.

7. INTERNAL PEER SUPPORT GROUP

A workplace with a number of employees with suspected or diagnosed endometriosis presents an opportunity to set up an internal peer support group to meet and connect individuals who may have shared experiences. We have a guide to setting up an endometriosis peer support group on our website available at:

nzendo.org.nz/resources

ENDOMETRIOSIS SURGERY



Your employee or colleague may require surgery for the diagnosis or treatment of endometriosis in the future and will require time away from work to recover.

You can learn more on endometriosis surgery on our website but we have some Frequently Asked Questions below:

WHO MIGHT HAVE ENDOMETRIOSIS SURGERY?

Endometriosis laparoscopy can be used in both the diagnosis and treatment of endometriosis. A medical professional may refer a patient for surgery if they suspect endometriosis or if they require further treatment (multiple surgeries). The decision to have this surgery is down to the individual and likely made in consultation with both the medical professional and those close to them.

SOME INDIVIDUALS CAN EXPERIENCE LONG WAIT TIMES AND/OR CANCELLED OR POSTPONED SURGERIES, WHICH CAN BE UNDERSTANDABLY DISAPPOINTING. IN THE PUBLIC HEALTHCARE SYSTEM, INDIVIDUALS MAY SPEND YEARS ON THE WAITLIST FOR SURGERY AND SPOTS MAY BECOME AVAILABLE AT SHORT NOTICE. UNFORTUNATELY THIS IS THE REALITY FOR A LOT OF PEOPLE AND IT IS IMPORTANT TO BE AS SUPPORTIVE AS POSSIBLE SHOULD YOUR EMPLOYEE BE BOOKED IN FOR SURGERY.

WHAT IS THE RECOVERY LIKE?

Majority of patients will need time away from work to recover from this surgery. The length of time differs depending on what happened during the surgery, the support they have available during recovery and what duties they will be returning to in their personal and/or work life.

WHAT IS THE RETURN TO WORK LIKE?

As the recovery differs for everyone, the time required away from work does too. This is where flexibility and modifications may be of value. For example a phased return to work programme or the ability to work from home during this time. It is important to promote an open dialogue and offer kindness and patience to ensure they can return to full health and back to a thriving employee.

WHERE DO ENDOMETRIOSIS NEW ZEALAND COME IN?

Endometriosis New Zealand is Aotearoa's national endometriosis organisation representing more than 120,000 girls, women and those assigned female at birth that live with endometriosis.

We provide practical and emotional support services, advocacy, education, and awareness on endometriosis to all, no matter where they are on their journey with endometriosis.

How Endometriosis New Zealand can support you in the workplace




Workplace Services

- **Resources:** There are further resources available to support individuals through different stages of their journey, as well as resources for your employer or manager on creating an endometriosis friendly workplace nzenzo.org.nz/resources
- **EndoTalk Workplace Presentation:** If your workplace would be interested in a workplace presentation from us on understanding endometriosis, its impact and managing the condition in the workplace - contact us today to register your interest: info@nzenzo.org.nz
- **Support Services:** We offer a free 30-minute appointment service with our Endometriosis New Zealand coordinator. Here you will speak to someone who will listen, understand and guide you, with a strong understanding of the condition and lived experience.

We also have a 0800 phoneline for a more on-demand service: nzenzo.org.nz/helping-you



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