

endometriosis
new zealand



*Managing your
endometriosis in the
workplace*

A GUIDE FOR EMPLOYEES

Welcome to our comprehensive guide to managing your endometriosis in the workplace. 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.

We understand that this condition can be challenging to manage, particularly in a workplace setting so we are committed to providing you with effective strategies to navigate this. Refer to this guide whenever you need it, taking on board what is relevant for you and your specific journey with endometriosis. Everyone's situation is unique but we hope to equip you with the tools to manage your condition, engage in comfortable conversations, connect with your colleagues and work to create spaces tailored to your needs.

This resource has been developed by Endometriosis New Zealand (ENZ), with support from a team of experts in the field of endometriosis and changemakers in New Zealand workplaces. Our ENZ community have generously shared their insights and practical advice which has been weaved throughout this resource.



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
- Bowel problems
- Pain during or after sexual intercourse
- Abnormal menstrual bleeding
- Pain between periods (e.g. with ovulation or intermittently throughout the month)
- Fatigue, tiredness and low energy
- Bladder troubles like pain or frequent urination
- Pain in other places such as the lower back
- Premenstrual syndrome
- Migraine
- Irregular periods or heavy periods
- Difficulty getting pregnant.

Know that the severity and type of symptoms can differ for everyone, some people may not experience any symptoms and some may struggle with one symptom more than others. Your environment may make some symptoms more challenging to manage than others. Our ENZ community ranked fatigue as the top most challenging symptom to manage at work.



Managing your Endometriosis

When managing your endometriosis symptoms, it is important to look at a holistic, multi-disciplinary approach that incorporates medical, surgical, and self-care strategies. We encourage you to work with your healthcare professionals to develop a tailored treatment or management plan that is based on you and your needs. This will likely include collaboration with a range of healthcare professionals to ensure a well-rounded approach. This is because endometriosis doesn't just impact people physically, you also need to consider your mental, emotional and spiritual needs.

There's no one size fits all approach to managing your endometriosis but there are amazing people who want to help! You can access information and



detailed resources on managing your endometriosis including self-help tips and advice on our website at nzendo.org.nz.

Endometriosis can be challenging

If it has been tough, you are not alone!

The journey isn't always easy, but with the right care and support you can thrive in the workplace environment while living with endometriosis or the symptoms of this condition.

Our resource aims to equip you with the strategies to navigate challenges that may arise and find a way forward. Our goal as an organisation is to help you flourish in all aspects of your life including your professional life. The following sections are designed to help you do just that!

MANAGING YOUR ENDOMETRIOSIS IN THE WORKPLACE



Sharing your experience with endometriosis

Unless your condition affects your ability to do your job safely, you do not need to discuss your condition with your employer. However, open communication with the people around you can play a positive role in managing your condition. Below are some considerations for discussing your situation with management and/or your colleagues.

Should I tell my employer or manager that I have endometriosis?

ASK YOURSELF:

"Are my symptoms affecting my ability to complete tasks or activities in this job? Or is workplace stress having an impact on your symptoms?"

If your condition affects your ability to perform your job comfortably, sharing may be beneficial. This can help your employer/manager understand any work-related limitations you may have and how best to set you up for success. If you feel your role is negatively impacting your symptoms, we would encourage you to discuss this with your manager too. If you consider your condition could impact the performance of your role in a safe way, you should tell your employer so that measures can be implemented to support a safe and healthy workplace for all.



If yes then when is the right time?

A) DURING THE RECRUITMENT PROCESS FOR A POSITION.

Consider whether sharing about your condition would provide you with a better chance of progressing as a candidate, allowing any necessary changes to the recruitment or interview process. This upfront communication can pave the way for an honest and supportive working relationship.

During a recruitment process, an employer may ask you to tell them if you have any medical condition that may impact your ability to do the role. You must answer this question honestly. Employers are not allowed to ask you wide-open questions like, 'Do you have any medical conditions of any kind?' Any questions employers ask you must be linked to your ability to perform the role.

B) IF YOU ARE GOING TO REQUIRE SURGERY TO DIAGNOSE OR TREAT ENDOMETRIOSIS

This may be a suitable opportunity to disclose your condition as you will likely require time off for your surgery. Your specialist, surgeon or relevant medical professional will be able to provide you with a medical certificate which can serve as documentation for your leave, as well as a way to begin this conversation.

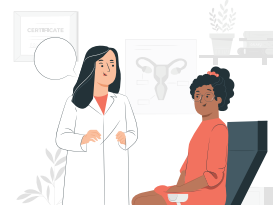


Understanding surgery for endometriosis and what you are going to be having is important in empowering yourself to manage this conversation. We have a section on this on page 15.

C) IF YOU ARE NOTICING YOUR CONDITION IS IMPACTING YOUR WORK PERFORMANCE OR YOU ARE RECEIVING FEEDBACK RELATED TO ACTIONS INFLUENCED BY YOUR CONDITION

Ask yourself if you could achieve more within your role with better support and reasonable accommodations could be of benefit to you and your condition. Your employer can only suggest these changes if they are aware of your needs, so this might be a good time to discuss how to improve your work situation.

Ultimately the decision to disclose your endometriosis journey is yours to make (as long as it is not impacting your ability to do your job safely). You may determine that your symptoms are being effectively managed and you do not feel that sharing would help you and that is okay. We also understand that past experiences may influence your decision and that it may take time to build trust with a new employer, so ensure you are patient and kind to yourself and take it step by step.



If you have chosen not to disclose but...

your symptoms are worsening to the point where your condition creates a safety risk for yourself or others around you then you are required to inform your employer of your condition. If you need to take sick leave to manage your symptoms, you do not need to give your employer the reason for the sick leave. However, if you are absent from work due to sickness for 3 or more days in a row, your employer may require you to provide a medical certificate (an employer can also require a medical certificate if you are absent for less than 3 days but it would be at the employer's cost).



Keep checking in with yourself, and if anything changes, you can revisit this decision in the future, considering your evolving needs and circumstances.

Who should I speak to?

Choosing the right person to disclose your situation is important as it may require a level of trust and safety in the relationship for you to feel comfortable sharing your personal experience.

BELOW ARE SOME OF THE OPTIONS YOU MAY HAVE AVAILABLE TO YOU:

IMMEDIATE MANAGER OR SUPERVISOR:

Your immediate manager or supervisor is a valuable first option to consider as they are the most likely to be informed on your role and responsibilities, making it easier to navigate the next steps best suited to you.

OTHER LEVELS OF MANAGEMENT:

In some cases, it might be appropriate to discuss your condition with higher levels of management, especially if your immediate manager isn't responsive or understanding. These managers can provide guidance on your relationship with that manager moving forward or help to put things in place to address your needs more effectively.

HUMAN RESOURCES, PEOPLE AND CULTURE OR HEALTH AND SAFETY TEAM MEMBER:

HR professionals are skilled in handling confidential matters, providing guidance, and ensuring compliance with company policies and legal regulations. People and Culture teams can offer assistance with interpersonal matters and help create a more inclusive work environment. Health and Safety team members can be involved when health-related concerns arise, ensuring your well-being at the workplace.

COLLEAGUES:

While colleagues may not have the same level of authority as managers or HR professionals, they can still be supportive and empathetic. Sharing your experiences with co-workers can create a network of understanding and emotional support which may be most beneficial to you. They can also help you navigate day-to-day challenges and foster a more inclusive work culture by being allies in your experience.

If you do not feel comfortable speaking to someone inside of the company, you may be able to arrange a conversation with an external employee service to assist you.

This might include:

- Union representative
- Employee Assistance Program
- Employment consultant
- Community Law



Some individuals may find it difficult to discuss their personal health experiences or symptoms with a person of another gender to themselves. If there is nobody internally available to you who you feel comfortable speaking to then this is a good consideration for approaching an external service.

Determine who you would like to speak to, based on your immediate needs and who is most likely to be of assistance. When engaging with someone, you may determine that it is no longer serving you to continue discussing your condition with this person particularly if they are unkind or unable to engage in the conversation appropriately. We hope this is not the case but your safety and comfort is of utmost importance so always know that you are empowered to end the conversation if this is the case.

It is important to remember employees and employers have a duty to be active and communicative with each other. This means employees should continue to remain in contact and provide information to their employer while on sick leave and raise any employment concerns early.

Not everyone may respond in the way you hope and that can be understandably disappointing but there are compassionate and supportive people who understand what you are going through and are available to speak to you. Endometriosis New Zealand has appointment-based help service Endo Help, visit our website at nzendo.org.nz to book a time.

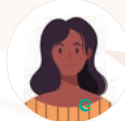


HAVING COMFORTABLE CONVERSATIONS

How do I talk to my employer about endometriosis?

1. DEVELOP A PLAN

Before you speak to your employer, create a plan for the conversation. Think about what you want to say, what accommodations you may need, and any potential solutions that may help to minimise the impact of your condition on your work. Examples of accommodations or adjustments are included on page 13.



You may determine that the most comfortable approach for you to address this is through email, where you are able to take your time to articulate everything.

2. PRACTISE WITH SOMEONE YOU TRUST

Before speaking to your employer, you may like to rehearse your conversation to yourself or with a trusted friend, family member, or colleague. They can provide feedback and help you refine your message. Practising with someone you trust can boost your confidence and ensure you communicate your needs effectively.



If you are not communicating in person, you may like to run your email draft by a trusted person for feedback.

3. BOOK A TIME AND PLACE

Schedule the conversation with your manager. You may choose to add this to an agenda of another 1-1 meeting or book a separate time. Choose a place that allows for a private and focussed discussion.



When planning for your meeting you may like to consider bringing a support person along with you. This could be a supportive colleague, a friend or family member or one of the external service representatives discussed earlier.



CONVERSATION STARTERS THAT YOU MAY LIKE TO USE WHEN FIRST ENGAGING WITH SOMEONE

I live with endometriosis, which can impact me in the following ways _____

I am exploring the possibility with a medical professional that I might have endometriosis, and my symptoms can affect me in the following ways _____

I experience _____ which can affect me in the following ways _____

I live with _____ and I manage this by _____

I live with _____, do you know much about this condition or its symptoms?
a) I would be happy to share...
b) I would be happy to direct you...

I would be happy to direct you to some resources on endometriosis.

I experience _____ and I am committed to self-management and having a positive contribution to our team/the company's goals. These are the things that could help me to do my best work...

I manage endometriosis and would like to talk to you about some ways you may be able to support me to improve and perform my job at a high level.

CUT ME OUT



OPPORTUNITIES IN THE WORKPLACE TO SUPPORT THE MANAGEMENT OF ENDOMETRIOSIS

TIPS AND THINGS TO KEEP IN MIND DURING THE CONVERSATION

1. Respond openly and honestly to questions they may ask, but only share what you feel comfortable with (unless you are concerned about your ability to perform your role safely, then you should tell your employer).
2. Remember that you have no obligation to share detailed, personal information. Focus on your symptoms or concerns that directly affect your role.
3. Assist them to understand endometriosis and utilise resources to become better informed.
4. Discuss the potential impacts on your workplace performance and the key challenges you face in that particular environment.
5. Be prepared to explore potential solutions that you are willing to consider if your performance is temporarily or permanently affected by endometriosis.
6. It is helpful to document conversations and requests in writing to ensure both of you have a record of discussions and agreements. This can be as simple as a follow up email after the meeting.

QUESTIONS DURING RECRUITMENT THAT EMPLOYERS ARE LEGALLY NOT ALLOWED TO ASK:

- How many sick days did you take last year?
- Have you ever had to leave a role for health reasons?
- Have you ever been hospitalised? If so for what condition?
- Have you ever been treated by a psychologist or psychiatrist, and for what condition?
- Are you taking any prescribed drugs?
- Are you pregnant or planning on starting a family?



When engaging in these conversations, you may also encounter shared experiences that can help you connect with someone who understands aspects of what you are going through. It is important to know that everyone has a unique experience with endometriosis and their journey may not always be the same.

1. 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.

2. JOB MODIFICATIONS

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

3. SUPPORT SERVICES

This may include signposting to organisations to provide support for managing endometriosis and the impacts of your condition/symptoms. It may also include access to alternative health professionals who may be able to provide additional support.

4. POLICIES AND PROCEDURES

Your workplace may already have or be willing to implement policies that support chronic conditions like endometriosis.

5. ADDITIONAL LEAVE

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

6. FACILITIES AND AMENITIES TO MANAGE ENDOMETRIOSIS

Facilities and amenities beneficial for endometriosis include: private toilets rather than stalls and access to showers. A quiet or private breakout space. A kitchen that takes into account diet considerations. Hygiene products, period products and heat packs.

7. INTERNAL PEER SUPPORT GROUP

Where there is a workplace with a number of employees with endometriosis – suspected or diagnosed, there is 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

HELPING THEM HELP YOU

When establishing a work environment or accommodations that are responsive to your needs, it is important for this to be a collaborative effort, involving both you and the person you are working on this plan with.

Open and effective communication, along with a mutual understanding of your requirements, are essential components that enable your employer to proactively make adjustments to support you.

You may also wish to share our employer pamphlet which is a guide to supporting employees with endometriosis. They can access this here: nzenzo.org.nz/resources



ENDOMETRIOSIS SURGERY AND RETURNING TO WORK POST-SURGERY:

If you may require surgery for the diagnosis or treatment of endometriosis in the future you will require time away from work to recover. Understanding what to expect and how to prepare for your surgery is important in empowering yourself to manage this process. Endometriosis New Zealand has a resource on “Preparing for your Endometriosis Laparoscopy”, available at nzenzo.org.nz/resources

OPPORTUNITIES TO RAISE AWARENESS ABOUT ENDOMETRIOSIS IN YOUR WORKPLACE:

Raising awareness on 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 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.

ENDOMETRIOSIS NEW ZEALAND IS HERE:

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 you through different stages of your 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 Endometriosis New Zealand on understanding endometriosis, its impact and managing the condition in the workplace - contact us today to register your interest: info@nzenzo.org.nz



Endometriosis New Zealand

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