

Endo



Breaking the *stigma*
in the workplace

This guidebook is strictly a guide and not a legal or medical document. This guidebook is developed as a project through Griffith University and is a resource to inform employers of Endometriosis with a very top level approach. References for this sourced information can be found on page 24.

If you require immediate or emergency help please call 000 or contact the one of the listed professionals on page 18.

Disclaimer



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What is Endo?

“Endometriosis is disease where the tissue similar to the tissue of the uterus grows outside the womb”

– Endometrosis Australia



Endometriosis also known as ‘Endo’ is a disease that causes severe inflammation and scarring that as the tissue grows out the uterus.

This disease impacts more than 190 million women and girls in the world.

It is important to note there is no current cure for Endo and the cause for it is still unknown. It is a disease that flares up particularly during the menstrual cycle for a female and makes every day tasks very difficult to achieve. Achieving a diagnosis for some women can takes years, sometimes up to 10 years.

Many women that suffer with Endo report that their quality of life is diminished. This therefore impacts work and social participation which are key activities that most are involved in.

It is a common misconception that Endometriosis is merely severe period pain that women with a low pain tolerance cannot handle; however, this is inaccurate. Some women are “lucky enough” to not suffer immense side effects and can go most their life without any knowledge of their condition.

Why does Endometriosis recognition matter?

Recognising Endometriosis is crucial because it affects a significant portion of the population, with many Australian’s knowing at least one person who suffers from the disease in their lifetime. Much like mental health issues, Endometriosis can be very isolating, which leads to further frustration, misunderstanding and impacts on both work and social life. Increasing awareness and understanding particularly in the workplace is extremely important. Without recognition and understanding, an employee may feel unsupported which may lead to lack of motivation, decrease in productivity and overall wellbeing.

By fostering a healthy workplace and approaching a discussion from a place of care and knowledge will build trust with your employee. Appropriate actions put in place will further benefit the relationship of trust your employee has with you but ultimately overall contribute to better outcomes managing the disease.

Recognising Endometriosis is essential to creating supportive environments that improve the quality of life, productivity and wellbeing of those affected by this often misunderstood disease.

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This disease always comes with a *stigma* and you are often not believed because others can't see it.

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- Annoymous





Signs & symptoms

Extreme cramping:

Women diagnosed with Endo often experience extreme menstrual cramps that are significantly worse than a typical period cramp or pain. This can extend from the lower back, lower abdomen or even travel down the spine and legs of the person.

Chronic pelvic pain:

Consistent and long standing pelvic pain, often correlated with menstruation can be a clear symptom of Endo. This can impact an employee's work performance, attention span and overall wellbeing.

Infertility:

As Endo tends to invade the reproductive organs first, there can be a build up of scar tissue and further surgery scars and adhesions. All of these actions can have a large impact on a woman's fertility which further leads to impacts on one's mental health, hope and motivation if they choose they would like children.

Noticable Fatigue:

Many women experience feeling tired or exhausted as a result of Endometriosis as it's both a physical and mentally draining disease. Chronic pain and inflammation can also lead to fatigue.

Frequent sick days or absences:

Increased time off can be a result of pain particularly during woman's menstrual period. Further reasons for time off can be for medical appointments or treatments.

Changes in behaviour/ depression/anxiety:

The consistent chronic pain and severe side effects of having Endo can result in an individual spiralling into a state of anxiety and depression. The unpredictable nature of the disease may lead to feelings such as frustration, helplessness or isolation. In other cases, a woman experiencing these feelings/effects may not have a diagnosis yet as they are awaiting surgery or further specialist direction which can in-turn exacerbate feelings of frustration, disappointment, and the feeling of being unsupported. Changes in behaviour, like increased irritability or intolerance to unusual situations, may indicate that a person is in pain or discomfort.

Endometriosis's impact extends far beyond physical pain, affecting every aspect of a person's life.



Steps to support your employees

Supporting your employees that may present with Endometriosis is key to creating an inclusive and compassionate workplace.

As the condition is already very isolating, providing a safe and inclusive environment can make a huge impact on your employee and their wellbeing.



Starting a open conversation:

Endometriosis can be a debilitating and uncomfortable disease to talk about. If an employee approaches you to discuss their condition it is important to have an open and caring approach and let them be in control of the conversation.

It's important to note, it is not your role to diagnosis, analyse or judge an employees condition. Your support should come from a place of care and understanding of how you can help make their work environment comfortable and accessible.

Providing a support and flexible environment for employees:

Ensuring an employee experiencing immense pain during a work day requires an important level of empathic support from team leaders and colleagues. If possible you may consider providing a flexible working environment such as working from home, full-time or part-time to help the employee navigate this difficult time particularly when their condition flares up.

Further recommendations include; 20 minute rest breaks, healthcare benefits and mental health support such as counselling and meditation.

Medical certificates and recognition:

As Endometriosis is a long-term condition, you may consider requesting an overarching medical certificate as

recognition of their diagnosis and therefore does not require frequent and ongoing requests for certificates. Support plans with their GP or specialist may also be a good way of providing support to continue the employees place within your organisation.

Work/desk equipment

Providing an employee with an ergonomic chair can help provide comfort during a work day for an employee suffering from Endometriosis. Additional recommendations such as; adjustable desks, stand up desks, a quiet environment to take breaks, heating pads if requested and foot rests under the desk can help to make the person feel more comfortable and ease the discomfort throughout a normal work day.

Reviewing workload

Where applicable, accessing the current workload of your employee maybe an option to show support and provide flexibility for their wellbeing. Making arrangements to reduce stress, accommodate any health-related challenges they maybe experiencing.

By taking these steps or providing your employee options once they have approached you will help make the workplace more inclusive and supportive to further help break the stigma attached to Endometriosis.

Words to support an open conversation

01

Understanding

"I understand that Endometriosis can be challenging, and I want you to know we're here to accommodate your needs."

"We encourage you to communicate openly about what support you need your health and wellbeing are priority. You've got this!"

02

Encouragement

"Please know that taking time for your health is not something you need to feel concerned about. We're here to ensure you have the flexibility you need."

03

Reassurance

04

Validation

"We acknowledge that living with Endometriosis can impact your workday, and we take that seriously. Please let us know if there's anything we can do to help ease your discomfort."

"If you need adjustments to your schedule or workspace, we're happy to support you in finding a solution that works."

05

Support

06

Acknowledgement

"We appreciate your contributions, and we recognise the additional challenges you're managing. Your efforts are noticed and valued."



**1 in 7 women
in Australia live
with Endo**

(Endometriosis Australia, 2023)

Helpline Contacts

Endometriosis can be a very isolating disease. When having a conversation with an employee suffering from Endometriosis it's important to offer support not only internally within your level of management but externally. Listed are important contacts for professionals that can provide support for those that are in need.

In an emergency please call 000.

Fight ENDO Foundation

Call: +61 03 9772 4441

Email: contact@endofoundationaus.org

Emergency contact

Call: 000

Quendo- 24/7 support line

Call: 1800 275 73636

Your local GP

**1 in 6 women
lose their job due
to managing Endo**

(Armour et al., 2021)



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I thought about taking time off from work, but I couldn't bring myself to do it because this disease and women's pain is often overlooked and dismissed in our society. I wasn't going to risk my job. I took time off for surgery and that was very helpful along with some medication.

- Anonymous

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Work Health and Safety (WHS) laws require you to take reasonable steps to ensure a safe work environment and protect the health and safety of all employees, including those with existing injuries or illnesses.

More information can be found on [‘How to manage work health and safety risks’ Code of Practice Document](#)

Discriminating against an employee or harassing an employee based on their health condition or disability is illegal under the employment law. Discrimination includes failure to make reasonable adjustments to an employee's conditions so they can maintain their job adequately. The goal is to ensure and support an employee so that they can effectively do their job without being disadvantaged due to their condition unless it is outside your control i.e. their condition escalates to the point they are medically unfit to work but this would need to be advised by a medical practitioner.

For more information refer to the [Australian Human Rights Commission](#) or the [Fair Work Ombudsman \(FWO\)](#).



***Legal
information***

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