

Supporting workers with endometriosis in the workplace

This information sheet has been prepared as part of the 2018 *National Action Plan on Endometriosis*. It is aimed primarily at employers to increase awareness of the prevalence and impact this chronic disease has on workers and its potential impact on workplace safety.

Informing yourself about endometriosis can lead to better workplace outcomes. You will be prepared to support workers affected by endometriosis if you have a good understanding of the disease and the reasonable steps that you can take to help workers manage their symptoms. Women, girls and other individuals¹ with endometriosis say that having the disease recognised and acknowledged by people around them, such as their managers, can positively influence their experience.²

What is it?

Endometriosis is a chronic disease where cells similar to those that line the uterus (the endometrium) are found in other parts of the body. There is no known cure for endometriosis and the cause is unknown. Once diagnosed, many people will have endometriosis effectively managed. You can read more about it on the endometriosis page at the [Jean Hailes website](#).

How common is it?

It is estimated that endometriosis affects 1 in 10 women, girls and other individuals of reproductive age, with the average diagnosis taking between seven to twelve years.

It is reported to cost more than \$7.7 billion in healthcare, absenteeism and lost social and economic participation.³

What are the signs and symptoms?

They vary. Some people have many symptoms, whereas others have none. Common symptoms include:

- Pain – this is one of the biggest symptoms and can occur at any time not just during a menstrual cycle. It may be felt in the stomach, back, and pelvis.
- Bladder and bowel problems. For example pain, constipation or diarrhoea, a need to urinate more frequently and bloating.
- Nausea, lethargy and fatigue.
- Heavy and painful menstrual bleeding.

¹ Endometriosis can affect all women and girls, transgender, non-binary, and gender-diverse people assigned female at birth, regardless of age, background or lifestyle, from pre-pubescence to beyond menopause (*National Action Plan for Endometriosis*, p 1).

² <https://theconversation.com/women-with-endometriosis-need-support-not-judgement-37340>.

³ National Action Plan for Endometriosis, page 2.

Managing and treating endometriosis

Managing the pain may involve medication such as anti-inflammatory drugs and pain medication.

Treatment options include:

- Hormone therapy such as the contraceptive pill or progestins.
- Surgery to diagnose and remove patches of endometriosis, cysts, nodules, endometriomas and adhesions, to repair any damage caused and improve fertility.
- In extremely serious cases (including chronic pelvic pain), surgery to remove the uterus, ovaries, tubes and any areas of endometriosis present in the bladder or bowel.

Information for employers

Work Health and Safety (WHS) laws require you do what is reasonably practicable to provide a safe working environment and to ensure the health and safety of workers whilst at work, including workers with existing injuries or illness. More information on managing WHS risks can be found in the model Code of Practice, [How to manage WHS risks](#).

A selection of patient experiences for sufferers of endometriosis have been published in the National Action Plan and highlight that people suffering from endometriosis experience a range of challenges both in the workplace and in their personal lives.⁴

Endometriosis may at times contribute to increased stress levels in some workers when managing uncomfortable and painful symptoms. The Guide: [Work-related psychological health and safety](#) describes a systematic approach to managing work-related psychological health and safety, including preventing harm by eliminating or minimising risks, intervening early and supporting recovery.

People respond in different ways to their disease. These individual differences may affect a workers' capacity to perform work safely, potentially creating risks to their health and safety, and the health and safety of others. For example, there may be an increased risk of serious accidents due to reduced attention levels and fatigue, particularly in organisations where working with heavy machinery or manual handling is required.

Not all workers suffering from endometriosis will require increased time off, but by talking to your workers and asking how they are coping, you can assess if they need additional support so they can do their work safely. This could include adequate access to toilets and rest facilities.

Severe endometriosis can also amount to a physical disability. Discriminating against or harassing a person in their employment because of a disability is against the law. Discrimination includes failing to make [reasonable adjustments](#) so a worker can do their job effectively. You also must not take adverse action against a worker or prospective worker because of their disability (such as for accessing sick leave). For more information about legislative protections for workers, please contact the [Fair Work Ombudsman \(FWO\)](#) or the [Australian Human Rights Commission](#).

Simple steps you can take to support your workers⁵

1. **Build a supportive workplace culture** – Train managers to be supportive and react appropriately to concerns raised by workers. A worker experiencing endometriosis may not want to disclose their disease. However, a supportive environment may encourage workers to share their health issues more confidently and enable managers to find ways of supporting them to stay engaged, productive and comfortable at work.

⁴ National Action Plan for Endometriosis, page 4

⁵ Intended as a guide only.

2. **Start a conversation** – While not all workers will want to discuss private health issues, people may be more open to participate in a conversation when it is conducted in a supportive manner. When discussing issues of a sensitive nature with a worker, be mindful not to ask for more information than necessary. It is not your role to assess whether a worker has a chronic disease such as endometriosis. Any questions should be about helping workers perform their job without risk to their health and safety. The FWO has detailed [advice](#) for having difficult conversations with workers.

Workers' privacy should be protected. There are privacy laws that protect personal information (including health information) from misuse, interference and unauthorised access, modification or disclosure.⁶ You cannot share, store or restrict a worker's access to personal information (including health information) held by you without their consent, except in limited circumstances.⁷

3. **Medical certificates** – In many cases, the symptoms of endometriosis will be ongoing. When a worker is suffering from a chronic disease such as endometriosis they may require varying periods of leave from work. You may consider allowing workers an overarching medical certificate recognising their condition from their treating doctor. It may also be useful to consider putting in place a support plan with the assistance of their treating doctor so both you and the worker will be able to manage their symptoms at work.
4. **Flexible work arrangements** – A worker with endometriosis may be managing significant pain on a regular basis and/or undergoing treatment where they are required to attend multiple medical appointments for a period of time. You may wish to discuss formal or informal flexible working arrangements with the worker to support them during these periods. This could include a change in shift patterns or start and finish times, shorter hours, graduated return to work, an agreed period of paid or unpaid time off, or working from home.
5. **Job modifications** – You may wish to discuss job modifications to support a worker with endometriosis such as changing responsibilities, reducing the pace of work, managing workloads or modifying workstations. While not all proposed accommodations will work for your business (for example working from home as a retail worker), you should take the time to consider options that may work for you and the worker.⁸
6. **Policies and procedures** – Developing, implementing and promoting policies and procedures in relation to chronic diseases such as endometriosis, can assist in raising awareness and understanding of the disease. To be effective, these policies and procedures should be:
 - developed in consultation with employees and health and safety representatives
 - available and communicated to all workers
 - included in induction programs
 - discussed at team meetings, and
 - reviewed regularly.

Information for workers

Under WHS laws you have a duty to take reasonable care of your health and safety and not adversely affect others' health and safety. You should consider whether your symptoms, or the medications you are using to treat the symptoms, are affecting your ability to work safely or could impact on the safety of other, for example, whether:

⁶ Commonwealth, state and territory privacy laws may apply. The Office of the Australian Information Commissioner can provide information on Commonwealth privacy laws and referral to state and territory privacy regulators (<https://www.oaic.gov.au/privacy-law/other-privacy-jurisdictions>).

⁷ There are some exemptions in relation to records held for an employee where it is directly related to their employment. For further information related to how the Commonwealth privacy law deals with employee records, see <https://www.oaic.gov.au/individuals/faqs-for-individuals/workplace/>

⁸ Any job modifications or new work arrangements must be permitted under the relevant industrial instruments and any laws that apply..

- your pain or other symptom is causing you to become distracted or distressed
- your pain is stopping you from performing your work in a safe way, or
- your fatigue is affecting you in a way that could be harmful to others or yourself.

You know best how to manage your endometriosis at work but if possible, discuss ideas about managing your symptoms with your employer.

If you do talk to your employer:

- your privacy must be protected. There are privacy laws that protect personal information from misuse, interference, loss and unauthorised access, modification or disclosure.⁹ Your employer is not allowed to disclose, record or store your personal information without your consent, except in limited circumstances permitted by an Australian law.¹⁰
- you have the right to be free from discrimination or harassment at work.

The FWO provides free information about your workplace rights and responsibilities, including the right to request flexible working arrangements and the right to take personal leave. This includes what evidence your employer may request relating to your disease. You can contact the FWO on 13 13 94 or at www.fairwork.gov.au.

The Australian Human Rights Commission's National Information Service can provide information and referrals if you feel you have been discriminated against or harassed at work. You can contact the National Information Service on 1300 656 419 or at www.humanrights.gov.au.

You can contact your WHS regulator if you want to raise a concern about a WHS issue. Contact details for your regulator can be found on the [Safe Work Australia website](#).



¹⁰ There are some exemptions in relation to records held by an employer where it is directly related to your employment. For further information on how the Commonwealth privacy law deals with employee records see <https://www.oaic.gov.au/individuals/faqs-for-individuals/workplace/>