Introduction

Creating an open culture in the workplace where everyone feels able to talk openly about health issues, such as endometriosis, can help employees thrive at work. Here, we suggest some tips and advice to effectively support all members of your team.
What is endometriosis?

In endometriosis, cells like those that line the womb – endometrial tissue – appear in other parts of the body. This tissue thickens, breaks down and bleeds during a menstrual cycle. Although the body gets rid of this broken down tissue and blood, it happens very slowly. While the tissue is there, it causes scarring, irritation and as a result, pain.

- Endometriosis usually affects the pelvis, and can lead to fertility problems.
- About 1 in every 10 people assigned female at birth and of child-bearing age has endometriosis.
- Endometriosis usually eases after the menopause but not always.
- There isn’t a cure for endometriosis but there are treatments that can help with the symptoms.

Symptoms and treatments

One of the most common symptoms of endometriosis is pain in the pelvis, which is usually worse just before, and during a period. The pain can get worse over time and painkillers, such as ibuprofen, don’t always help. Endometriosis can cause other symptoms too, such as:

- extreme tiredness (fatigue)
- heavy periods
- painful sex

Endometriosis can be difficult to diagnose because the symptoms may vary and other health conditions can cause similar symptoms, such as fibroids, pelvic inflammatory disease or Coeliac disease. This can delay diagnosis and getting the treatment that’s needed.

On average it takes around 8 years from symptoms starting to getting a diagnosis for endometriosis in the UK.

Endometriosis in the UK: time for change. Endometriosis APPG Report 2020
How endometriosis affects mental health

Endometriosis can have a big impact on a person’s quality of life and normal day-to-day activities.\textsuperscript{6} It can affect everything from relationships and fitness, to work productivity and mental health.\textsuperscript{6}

The pain from endometriosis can lead to depression or anxiety, particularly if it’s long-term.\textsuperscript{11} The stress from a likely delayed diagnosis, and possible concerns about fertility, can also be challenging to live with.\textsuperscript{11, 14}

95% of people with endometriosis say it impacts their wellbeing negatively or very negatively.

Endometriosis in the UK: time for change. Endometriosis APPG Report 2020\textsuperscript{15}
Endometriosis in the workplace

Endometriosis affects people during their most active working years. And this can be a significant proportion of a workforce, since 1 in every 10 people assigned female at birth and of child-bearing age has endometriosis.

The pain caused by endometriosis can happen often, be severe and long-lasting. This, combined with severe tiredness, can have an effect on productivity at work. This can lead to more days off work sick. In fact, a report by the All Party Parliamentary Group on endometriosis found that endometriosis costs the UK economy £8.2 billion a year in loss of work and healthcare. Better support in the workplace could make a big difference to an employers’ own productivity and profitability.

Endometriosis and the law

Various employment rights may be important for employees with endometriosis. For example, The Equality Act 2010 contains the law on discrimination and requires employers to make reasonable adjustments for workers who have a disability. Disability is defined as a physical or mental impairment that has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities. So if endometriosis prevents a person from carrying out their day-to-day tasks, they may be entitled to the protection of the Equality Act.
Support for endometriosis

Endometriosis is a long-term condition that’s often difficult to manage. It’s important to support employees with endometriosis and allow for the impact that it can have on work. 16, 17

- There should be active engagement and support from the top to help employees with endometriosis. Senior leadership may need to consider HR policies, for example, and ensure managers have the information and guidance to support someone with endometriosis.

- Where possible, offer to reallocate daily tasks when someone is struggling with fatigue, or adapt deadlines.

- Support flexible working options (if appropriate for the work environment) and offer time off work when needed. This may be for tests or treatment, or if pain or fatigue are severe that day/week.

- Offer emotional support at work.

Conversations about endometriosis

It can be daunting for an employee to share a health problem, or to ask for help at work. They might be worried about the outcome of the conversation and what it means for their career.15

Being open and approachable will help people feel more comfortable to speak up about their condition and any support they might need.

40% of employees with endometriosis worry about losing their job.

27% say they’ve missed out on promotion because of their endometriosis.

Endometriosis in the UK: time for change. Endometriosis APPG Report 202015
As a manager, there may be times you need to ask for more information to make workplace adjustments. Try to make sure your conversations remain professional and respectful. You can do this in a few ways.

- Ask if they would like somebody to be in the room when they speak to you, such as another colleague.
- Ask if they have any solutions or ideas about how they could be better supported.
- Focus your conversation on how you can make things better, instead of being negative.
- Reassure them that these conversations will be kept confidential unless they want some or all of the information to be shared.

Creating a health-friendly workplace culture

Employees can’t perform well at work if they’re struggling with their health. That’s not good for them or their employers. It’s vital that both managers and staff feel comfortable talking about health issues, such as endometriosis, and the impact it may have on their work. Without open communication, it can lead to valued employees finding alternative, and more supportive, places to work.15

A good way to support those affected with endometriosis is to create a respectful and inclusive workplace culture. A supportive culture is key.

You might be worried about making mistakes or upsetting people if you get something wrong. This may happen, even if you do your best to avoid it. And if it does, it’s important to apologise, and you can learn from any feedback you receive.
Find out more

Vital support services, reliable information and a community for those affected by endometriosis.
www.endometriosis-uk.org

Sources

1. Diversity and inclusion at work. Chartered Institute of Personnel and Development.
   www.cipd.co.uk/knowledge/fundamentals/relations/diversity/diversity-inclusion-report, accessed published June 2018

2. Diversity and inclusion at work. Chartered Institute of Personnel and Development.
   www.cipd.co.uk/knowledge/fundamentals/relations/diversity/diversity-inclusion-report, accessed published June 2018

3. The last workplace taboo: Women's experiences of endometriosis, adenomyosis and polycystic ovary syndrome. Politicshome.

   www.cks.nice.org.uk/topics/endometriosis/, accessed Last revised in February 2020

5. Endometriosis patient information leaflet. Royal College of Obstetricians and Gynaecologists.

   www.bestpractice.bmj.com/patient-leaflets/en-gb/html/1591421782649/Endometriosis%3A%20what%20is%20it%3F, accessed Last published: 10 October 2022

   www.cks.nice.org.uk/topics/endometriosis/background-information/complications-prognosis/, accessed Last revised in February 2020

   https://bestpractice.bmj.com/topics/en-gb/355, accessed Last reviewed: 29 October 2022

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