March is Endometriosis Awareness Month

Here’s what you need to know about an often painful condition that affects more than 700,000 women in Australia.

Endometriosis is a chronic condition that affects at least one in nine women of reproductive age in Australia. However, that figure could be even higher because ‘endo’, as it’s commonly known, is difficult to diagnose; on average it takes 7-12 years for a woman to be given a diagnosis.

Endometriosis can affect women and girls, transgender, non-binary and gender-diverse people assigned female at birth, regardless of age, background or lifestyle.

It cannot be cured, but endo can be treated.

How does endometriosis happen and what causes it?

The condition occurs when cells similar to those found in the lining of the uterus grow in other parts of the pelvis, such as the bladder, bowel or ovaries. The symptoms can include uncomfortable sex (dyspareunia), pelvic pain and particularly heavy periods (dysmenorrhoea).

The cause of endometriosis is not known, but there are a number of factors associated with it. Women who have a close relative with the condition, for example, are up to 10 times more likely to get endometriosis. It is also commonly found in twins, especially identical twins.

Other factors that play a role in developing endometriosis include:

- having a first pregnancy at an older age
- heavy periods and periods lasting longer than five days
- the first period occurring before the age of 11
- low body weight
- alcohol use.

How is it diagnosed?

Some women only learn they have endometriosis when they struggle to become pregnant, or it is discovered during a procedure for some other medical issue.

A lot of women have no symptoms at all, though pain in the lead-up to a period occurs in most women. Many women think painful periods are normal, but it is not OK or normal to have severe period pain – one that does not respond to over-the-counter pain medication.
The symptoms of endometriosis can be different for each woman and they can change over time. At present there is no effective screening test for endometriosis and the only means of diagnosis is a laparoscopy – a minor procedure done under anaesthetic.

How is it treated?

There are a number of treatment options available to women diagnosed with endometriosis. The combined oral contraceptive can be prescribed to control hormones. Jean Hailes gynaecologist Dr Janine Manwaring, who has a special interest in endometriosis, says hormonal suppression can make a difference in treating these women.

In addition to the oral contraceptive pill, a woman might also be treated with progestins – synthetic versions of the female hormone progesterone – which can be given as tablets, an implant, an injection or an intrauterine device.

“But a woman’s needs may change over time,” says Dr Manwaring. “The pain can be managed, but further down the track, you may be dealing with fertility issues.”

When to see your doctor

If your pain is so severe that you are missing school, work, or other activities, you need to get help. Your GP can refer you to a specialist gynaecologist.

Having a baby

While most women with endometriosis will become pregnant without any medical assistance, about a third of those with the condition will struggle with fertility. There are, however, treatments available. Keyhole surgery can improve fertility by removing endometrial patches and adhesions by either cutting them out (excision), or destroying them with the use of electrical energy.

IVF (in vitro fertilisation) can also be considered for women with more severe endometriosis, or for those who are still having trouble getting pregnant after keyhole surgery.

What you can do

A healthy lifestyle can help. If you can, try to fit in 20-30 minutes of physical exercise on most days. A good night’s sleep can boost your immune function. Limit caffeine and alcohol and try to avoid heavy meals at night.
To manage the stress associated with endometriosis, consider some gentle yoga techniques or practise mindfulness therapy. If you are struggling emotionally, you might want to talk to a counsellor or a psychologist.

**Smart technology support**

There are a couple of helpful apps that are now available for women to help track and manage their endometriosis.

*The QENDO app,* developed by the Brisbane-based organisation of the same name that provides support and education around endometriosis, allows women to record their personal experiences so they have their data on hand if and when they need to enter the health system.

Available free in Australia and New Zealand, it enables women to track their pain, their bleeding, symptoms, exercise, and food intake.

*The Raising Awareness Tool for Endometriosis (RATE)* has been developed by a team of experts working with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) to support a faster diagnosis and achieve more effective management of symptoms.

The app allows users to complete a questionnaire and to provide answers which can then be used during discussions between them and their healthcare providers.

**Where to go for more information**

For more information on endometriosis, go to: [https://www.jeanhailes.org.au/health-a-z/endometriosis](https://www.jeanhailes.org.au/health-a-z/endometriosis)

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