

# How you can support women diagnosed with endometriosis

Endometriosis affects one in 10 women of reproductive age, with an estimated 176 million women worldwide having the condition. So, chances are you know someone with this condition – a partner, sister, daughter or friend. If someone you care for has been diagnosed with 'endo', as it's often called, it may well have taken a long time; the average time of diagnosis from the first onset of symptoms is seven to 10 years. This is because symptoms can vary between women and can change over time.

This common delay in diagnosis can in itself take a toll on a woman, who may have endured years of having her symptoms repeatedly dismissed as 'normal', or as simply something to be tolerated.

When a loved one has endometriosis, their journey will, in many ways, also become yours. This fact sheet is designed to help both of you navigate it.

## What is endometriosis?

Endometriosis is a progressive, chronic condition in which cells similar to those in the lining of the uterus – called the endometrium – grow in other parts of the body, usually in the pelvic region.

These cells respond to a woman's menstrual cycle in the same way as endometrial cells – by bleeding. However, with the blood having no way to escape, this is when often painful symptoms can arise.

While some women suffer no symptoms at all, many women endure pain so severe that they are forced to miss work, study and social events.

## What are the signs and symptoms?

The symptoms vary from woman to woman. Some have many symptoms and severe pain occurs, while others have no symptoms.

**Pain** is one of the biggest symptoms, experienced by three out of four women.

- Where – in the tummy, back and pelvis.
- When – immediately before and during a menstrual period, during ovulation, during or after sex, with a bowel movement and passing wind or urine.

**Heavy bleeding** can occur with or without clots. Bleeding may be irregular, continue for a long time or there may be spotting before a menstrual period.

**Bladder and bowel problems** may occur, eg, constipation or diarrhoea, feeling the need to urinate more frequently at different times in the menstrual period, and bloating.

**Reduced fertility** and trouble getting pregnant affects about 30% of women with endometriosis. However, it's important to know that most women with endo will become pregnant without any medical assistance such as IVF.

## Treatment

Endometriosis cannot be cured, but there are various ways to manage it, such as:

- pain relief medication
- hormonal therapy, such as the Pill, an implant or an IUD to reduce symptoms
- surgery, such as laparoscopy to remove patches of endometriosis and other related growths or, rarely, hysterectomy (removal of the uterus) if the case is severe and hasn't responded to other treatment or surgery.

## What can I do?

### Learn about 'endo'

As endometriosis is not a 'visible' illness, it can be hard for some people to understand the physical and mental pain it can cause. So, one of the best things you can do is to learn about endo, to better understand what the woman you care about is dealing with, and help you explain it to others. We've also listed further resources for you at the end of this sheet.

### Support

Your love and support is very important. Supporting a woman with endometriosis can take many forms, both physical and emotional, but can include the following:

- Physical support
  - offer heat packs, or even just to hold her, if she is in pain
  - give her the time to rest and relax, if her symptoms are draining and/or painful
  - help with day-to-day activities, such as chores and shopping
  - join her in healthy lifestyle choices – a healthy diet, regular physical activity and solid sleep habits. These can all help improve her overall wellbeing, which can help her to better cope with symptoms and reduce the risk of her becoming depressed or anxious due to the impact of endo on her quality of life.
- Emotional support
  - it is normal for a person to feel anger, disbelief, shock, sadness, or maybe even relief when they are diagnosed with endometriosis. They are also at greater risk of depression or anxiety. If your loved one is struggling emotionally, encourage her to seek a doctor's referral for professional help from a pain clinic, psychologist or counsellor

- accompany her to medical appointments
- advocate for her. As a woman with endometriosis may not appear unwell, she may struggle to get the support and understanding she needs
- let her know you're there if she wants to talk; that you're there to listen, not judge
- support her in pursuing everyday activities and interests. While it's important to be there for her in managing her symptoms, it's just as important to ensure 'endo' does not become seen – by herself or others – as what defines her as a person. Endometriosis is part of her life, but not her life.

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

To learn other women's stories of endometriosis, visit [jeanhailes.org.au/endowise](http://jeanhailes.org.au/endowise)

Endometriosis Australia  
[endometriosisaustralia.org](http://endometriosisaustralia.org)

For more tips on supporting a loved one with endometriosis, visit [www.jh.today/endo\\_org](http://www.jh.today/endo_org)

Better Health Channel  
[www.jh.today/BHCendo](http://www.jh.today/BHCendo)

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This fact sheet is designed to be informative and educational. It is not intended to provide specific medical advice or replace advice from your medical practitioner.

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Jean Hailes for Women's Health takes a broad and inclusive approach to the topic of women's health. This fact sheet generally uses the terms 'women and girls'. These terms are intended to include women with diverse sexualities, intersex women, and women with a transgender experience.

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