

ENDOMETRIOSIS^{UK}

HOW TO SUPPORT SOMEONE WITH ENDOMETRIOSIS

www.endometriosis-uk.org



WHAT IS ENDOMETRIOSIS?

Endometriosis occurs when cells similar to the ones in the lining of the womb are found elsewhere in the body. These cells can grow and change in response to hormones in the menstrual cycle. This can cause inflammation, pain and scar tissue.

COMMON SYMPTOMS INCLUDE:

- Pelvic pain
- Painful periods that interfere with everyday life
- Heavy menstrual bleeding
- Pain during or after sex
- Painful bowel movements or when having a poo
- Pain when urinating or peeing
- Difficulty getting pregnant – up to 70% of those with endometriosis will be able to get pregnant naturally
- Fatigue, with one or more of the above symptoms

HOW DOES IT AFFECT THOSE WHO HAVE ENDOMETRIOSIS?

Endometriosis can interfere with work, school, and personal relationships. A good support network can make a real difference to people who are living with the condition.

Whether you're a partner, sibling, parent, friend or colleague, it may sometimes feel hard to know how to help but there's plenty you can do.



WHAT DO I NEED TO KNOW?

Educate yourself

Find out more about endometriosis so that you don't have to ask your loved one too many questions. It also means that you'll be more able to spot the signs and symptoms, know the side-effects of treatments, what helps and what makes symptoms worse. Importantly, it can help you know when to call for medical help if it's needed.

It's a good idea to have their **GP or clinic phone numbers** on your phone.

Get to know their menstrual cycle

The experience of endometriosis can vary across the month, so if you're aware of where a person is in their cycle, this can help you to understand what they need and how they might be feeling.

Know that sex can be painful

If you're the partner of someone with endometriosis it's important to know how the condition can affect someone's sex life. Painful sex is a common symptom of endometriosis so sex may have to be avoided sometimes. There are other ways to be intimate, such as kissing, cuddling and touch. Talking about sex is very important so that it doesn't build into a big issue.

Endometriosis can affect fertility

Endometriosis does not always mean infertility. Up to 70% of those with endometriosis will be able to get pregnant naturally. However, fertility concerns can still be distressing, regardless of whether your loved one wants children.

Listen with empathy and avoid making assumptions. They may not want children, may be unsure or not ready, or may be experiencing difficulties getting pregnant. Understanding endometriosis and fertility can help you offer informed support so they don't have to face uncertainty alone.

Be aware of worries that surround endometriosis

Managing their condition at work or school and finding it difficult to socialise and carry out usual activities are common for those with endometriosis. These can be overwhelming and are as much a part of the condition as the physical symptoms. Listening can help, so letting them talk about how they feel and empathising without offering solutions can make a real difference.

Be aware that those with endometriosis may isolate themselves

If they don't feel like going out or explaining how they're feeling, it can start to feel easier to stay in and not communicate with anyone. Self-silencing is also common. They may be putting on a brave face and not revealing their suffering because they don't want to be perceived as ill or negative. Check in with your loved one. They may not want to speak but a supportive message or check in can make them feel less alone.

You don't always have to know what to say

Listening with empathy can go a long way. Many of us want to find solutions or make practical suggestions but we don't always have the right words. It's better to take the lead from your loved one and let them tell you what they need or just talk about how they're feeling. Just being there is often enough and allowing silence is OK.

**"LISTENING WITH
EMPATHY CAN GO
A LONG WAY"**

WHAT CAN I DO TO HELP?

Listen carefully

Tell them what you understand from what they have told you about their experience of endometriosis. Ask if it's correct and if there's anything else they'd like you to know.

Be patient

Your loved one may not be able to attend events, stay up late or do chores and activities that they usually do. They may find this hard enough, so being flexible and understanding can relieve the stress they feel around it. It's also important to know that endometriosis can be very unpredictable, so what they could do yesterday, they might not be able to do today.

Be present at appointments

If your loved one would want you there and it's possible for you to attend, your support during appointments can be helpful. You can listen and take notes if a lot of information is given. This can help to recap the information afterwards. You can also advocate for them if a healthcare practitioner says something that upsets them or comes across as insensitive.



Give them space if they need it

Endometriosis can be a very difficult condition to manage both physically and emotionally, and sometimes your loved one may need time to just be alone to recharge or to simply sleep. Don't take this personally or it can become a burden to them. This may especially be the case when they've just had appointments and received bad news. It can take time to process and accept.

Help in practical ways

Make hot water bottles, run baths, change beds or put blankets on the sofa. Make sure there are enough painkillers and period products in the house, collect medication from the pharmacy, make food for them, offer lifts to work or school. Your loved one may feel deeply fatigued and in pain and taking on simple tasks like these can really make a difference. It's generally better to just do the things you think will help, rather than relying on them to ask.

"IT'S GENERALLY BETTER TO DO THE THINGS YOU THINK WILL HELP, RATHER THAN RELYING ON THEM TO ASK."



WHAT SHOULD I AVOID?

Try not to suggest things that might make you feel better, such as going for a walk or a swim. Everyone's experience of endometriosis is unique to them and things that may help you might not be possible for them or could even make them feel worse.

Avoid phrases such as 'I know how you feel' or 'it's just a bad period'. Each person's experience of endometriosis is unique and it's impossible to know how they feel.

YOU MAY NEED SUPPORT TOO!

It can be very hard watching someone you care about experiencing pain and not be able to do anything about it. You may sometimes feel pushed away for many reasons. Your loved one may feel like a burden to you, may not want to upset you, or they may think you won't understand. Understanding where these behaviours are coming from can help you manage your own feelings around them.

Endometriosis UK has produced a webinar, Supporting Someone with Endometriosis. It features one of our volunteers sharing their experiences of being supported while living with endometriosis. It also features specialist nurses sharing practical support methods and psychological support tips for those supporting others.

endometriosis-uk.org/webinar/supporting-someone-endometriosis

There are also detailed resources on the website on topics such as sex and relationships, treatments and pain relief.



 Visit www.endometriosis-uk.org

FURTHER SUPPORT

NURSE-LED SUPPORT LINE:

Our experienced nurse support team is ready to provide expert information and guidance on endometriosis.

Book a call: endometriosis-uk.org/nurse-support
or email: nurses@endometriosis-uk.org

VOLUNTEER PEER SUPPORT SERVICE

Our peer support service is operated by trained volunteers who have a personal experience of endometriosis.

Find out more about our support services:

endometriosis-uk.org/talk-someone