

# Speaking up when you think you may have endometriosis



This fact sheet is for people who think they may have endometriosis. It helps you speak up during appointments, explain your symptoms clearly, and ask for the care you need – even if tests are normal or your symptoms have been dismissed in the past.

Speaking up for yourself can help you get the care and support you need. Taking an active role can make a difference to your health and care.



## Preparing for appointments

### Before your appointment

- Learn more about endometriosis from reliable information sources – see Where to get help and information at the end of this fact sheet.
- Understanding the basics will help you ask questions and make informed choices.
- Keep track of your symptoms with an app such as [CHARLI](#) or a symptom diary.
- Write down your symptoms – when they happen, how they feel, how they affect school, work or your social life, and what helps.
- Make a list of questions so you remember what you want to ask.
- Bring a parent, friend, partner or chosen family member for support. They can take notes and join the discussion.
- Bring any test results or scans you've had.

### During your appointment

- Give examples of how pain and other symptoms affect your daily life, not just where the pain is. For example: 'My pain makes it hard to work/study/do things at home.'
- If relevant, share your pronouns and words you prefer for your body.
- Ask your doctor to explain things clearly and write them down.
- If you don't understand something, you could say: 'Can you explain that in another way?'
- If you feel rushed or like you're not being heard, you could say: 'I'd like to finish explaining this before we move on.'
- Before you leave, ask what will happen next – tests, treatment or follow up.

### After your appointment

- Read through your notes and check what you need to do next.
- Make a follow-up appointment if needed.
- Get a second opinion if you feel your concerns weren't heard or your condition isn't improving.

## Talking with your doctors

### Start the conversation clearly

Use the word 'endometriosis' to help focus the discussion and show you're informed:

- 'Could my symptoms be related to endometriosis? What tests can help us find out?'
- 'I've heard a pelvic ultrasound is often used to look for endometriosis. How reliable is it at diagnosis?'

### Describe how symptoms affect your life

Doctors need to know the impact, not just the symptoms. Use short, specific statements such as:

- 'My pain stops me from sitting through class.'
- 'I miss school/work at least twice a month because of pain.'
- 'I've stopped exercising because of pain.'
- 'I can't sleep well when I'm in pain.'

### Use 'I' statements

These help you express your needs respectfully and clearly:

- 'I feel worried that my pain isn't improving.'
- 'I'd like to understand all my options before deciding.'
- 'I'd like to know which tests we can start now and what they can and can't show?'

### Be specific about the need for expertise

'I've read that severe pain that stops you from doing daily activities is not normal. Can I have a referral to a gynaecologist who has experience with endometriosis?'

## Ask about pain relief

Make it clear you want pain management while you wait for test results or a referral:

- 'I understand you see a lot of patients with pain, but my symptoms are affecting my daily life. Can we talk about what might be causing them?'
- 'While we wait for test results or a referral, can we make a plan for managing the pain?'

## If you feel your concerns aren't being heard

It can be hard to speak up, but you can say:

- 'I am worried I may have endometriosis. I've read diagnosis can take a long time. I want to avoid delays.'
- 'If you feel this is not endometriosis, can you explain what else could be causing my symptoms?'

### When speaking up is not easy

You may find it hard to speak up about your symptoms or needs for many reasons, such as language or cultural differences or past experiences with healthcare.

#### You could:

- bring a support person, such as a parent, friend, partner or chosen family member if you don't feel comfortable speaking up alone
- write down what you want to say and give it to your doctor
- practise what you want to say before the appointment.

## Caring for yourself while advocating

Speaking up can be empowering, but it can feel exhausting.

Rest when you need to, set boundaries with people who dismiss your experience. Talk to a counsellor, psychologist or peer support group.



## Getting the right care

- Keep copies of paperwork, including referrals, test results and treatment plans.
- Get a second opinion if you feel like you're not being heard or your condition isn't improving.
- You have the right to safe, respectful and informed care.
- Your care should be based on current evidence and tailored to your situation.

## Advocating at school, work and in your community

### At school or university

Ask for adjustments such as flexible attendance, extra time for assignments or rest breaks.

### At work

- Talk to your manager or human resources (HR) about adjustments such as flexible hours, work-from-home options or access to a quiet space.
- You only need to share information with people you trust and feel comfortable telling.
- Tell your HR or wellbeing manager about the EndoThrive workplace program. Work Safe also has a factsheet for supporting employees with endometriosis.

### With family and friends

- Telling others about your experience can help them understand what you're going through. You may be surprised how many others have similar stories or symptoms.
- Talking openly can reduce stigma about endometriosis and help you feel less alone.