

GP Appointment Toolkit: Suspected Endometriosis

This toolkit is designed to help you prepare for a GP appointment about symptoms that could be related to endometriosis. Endometriosis is often misunderstood or misdiagnosed, and this document aims to give you the tools and confidence to ask the right questions and advocate for yourself. Where relevant, references to the NICE NG73 guideline on the diagnosis and management of endometriosis (updated November 2024) are included.

Informed Questions to Ask Your GP (with Context and NICE Guideline References)

- Could my symptoms be consistent with endometriosis, and if so, what steps can we take to investigate that possibility?

→ Use the word 'endometriosis' explicitly to focus the conversation and signal that you're informed.

NICE Guideline Reference: NICE NG73 (1.3.1): Suspect endometriosis in people presenting with chronic pelvic pain, dysmenorrhoea affecting daily life, deep dyspareunia, cyclical bowel or urinary symptoms, or infertility.

- I experience pelvic pain that interferes with my daily activities. Given that endometriosis pain is often under-recognised, how seriously will this be investigated?

→ This emphasises the functional impact of pain and challenges dismissal.

NICE Guideline Reference: NICE NG73 (Context): Delays in diagnosis of 4–10 years are common and often due to symptoms being dismissed as 'normal period pain'.

- Can we discuss a referral to a gynaecologist with experience in diagnosing and managing endometriosis, especially deep infiltrating or non-ovarian types?

→ Be specific about the need for expertise.

NICE Guideline Reference: NICE NG73 (1.5.6): Refer to a specialist endometriosis centre for suspected or confirmed endometrioma, deep endometriosis, or disease outside the pelvic cavity.

- What investigations can we start now — such as a pelvic ultrasound — and are there limitations in what this can detect when it comes to endometriosis?

→ Ultrasounds can miss superficial or bowel-related endometriosis.

NICE Guideline Reference: NICE NG73 (1.5.4): Do not exclude endometriosis if the abdominal or pelvic examination and ultrasound scan are normal — referral may still be needed.

- Do you know that period pain that is severe, disabling, or not controlled by regular painkillers is not considered 'normal' by gynaecological standards?

→ Helps reframe outdated assumptions.

NICE Guideline Reference: NICE NG73 (1.3.1): Period-related pain that affects quality of life should trigger suspicion of endometriosis.

- Can we discuss pain management options now while we wait for further investigation, including hormonal and non-hormonal treatments?

→ Pain relief should not be delayed while awaiting referral or diagnosis.

NICE Guideline Reference: NICE NG73 (1.4.1–1.4.6): Begin pharmacological treatment (e.g., NSAIDs or hormonal therapy) alongside investigation and referral.

- Would you be open to recording a detailed symptom history, including bowel, bladder, sexual, and ovulation-related pain, to support diagnosis or referral?

→ Endometriosis symptoms are often multi-system. A comprehensive symptom record supports better care.

NICE Guideline Reference: NICE NG73 (1.3.3): Keeping a symptom diary can aid diagnosis and guide care decisions.

- Are you aware that it takes an average of 8 years & 10 months to diagnose endometriosis, partly due to under-recognition of symptoms? I'd like to avoid that delay.

→ Politely informs the GP of diagnostic delays and asserts your wish to avoid this.

NICE Guideline Reference: NICE NG73 (Context): Diagnostic delay remains a serious problem leading to worse health outcomes.

- Can we document in my records today that I am experiencing suspected endometriosis symptoms and that I have requested investigation or referral?

→ Creates a record of your concerns in case you need to follow up or seek a second opinion.

NICE Guideline Reference: NICE NG73 (1.5.5): If symptoms persist or affect daily life, referral to a gynaecology service is advised even with normal scans.

- If you feel this isn't endometriosis, can you explain clearly what else might be causing these symptoms, and how we can test or rule those out?

→ Encourages a thorough differential diagnosis and avoids vague dismissal.

NICE Guideline Reference: NICE NG73 supports full clinical assessment and alternative explanations if endometriosis is excluded.

Optional Notes to Share with Your GP

- I'm aware that some people with endometriosis do not have visible findings on ultrasound or even in blood tests. A normal scan does not mean there is no disease.

NICE supports this: Laparoscopy can be considered **even if ultrasound or MRI is normal**, especially in the presence of symptoms ([NG73, 1.5.11]).

- Pain that disrupts my work, relationships, or ability to function should not be minimised, even if it is cyclical.
- I'd like my pain and symptoms to be believed and investigated with the seriousness they deserve.

Tips for Delivering These Questions Effectively

- **Bring a written list.** It signals preparation and seriousness.
- **Use 'I' statements** (e.g., "I'm concerned", "I'd like to understand") to stay collaborative.
- **Keep emotion in check** where possible, but **don't minimise your distress.**
- **Bring a symptom diary or pain tracker** to back up your report.
- **Consider bringing someone with you** as support and a second witness.

