

## Assessment and management of endometriosis in young people in primary care

Endometriosis is a chronic inflammatory condition resulting from the presence of endometrial tissue, glands, and stroma in extra-uterine sites. It is a common condition affecting approximately 1% to 5% of women, although this is a likely underestimation, with symptoms often beginning in teenage years.<sup>1</sup> The 2022 European Society of Human Reproduction and Embryology (ESHRE) Guideline for the first time has new recommendations for the diagnosis and management of endometriosis in adolescents (<20 years).<sup>2</sup> This clinical practice article provides an update on best practice for the assessment and management of likely endometriosis in young people up to 25 years.

### PATIENT EXPERIENCES

Endometriosis impacts on all areas of a young person's life: education or work life, social life, and relationships.<sup>3</sup> Young women have experienced substantial disruption to careers and education from symptoms of severe pain, tiredness, and side effects of analgesia such as nausea. Pain has been described as 'crippling' and 'horrific' with duration of pain important.<sup>3</sup> Young women have described GPs normalising endometriosis-related pain and be reluctant to refer to a specialist.<sup>3</sup> Patients have described preferring surgical treatments over pharmacological treatments because there were perceived to be fewer side effects and enhanced symptom relief.<sup>3</sup>

### ASSESSMENT

For young people, the consideration of endometriosis as a diagnosis may be overlooked for painful periods, for example, resulting in a protracted patient journey (upto 12 years from onset to diagnosis), affecting quality of life, and possible future fertility. Risk factors for endometriosis specific to young people include family history, early menarche, and a short menstrual cycle. Endometriosis should be considered in young women presenting with one or more

of: chronic cyclical or acyclical pelvic pain with nausea; dysmenorrhea (affecting activities of daily living); deep dyspareunia; cyclical gastrointestinal symptoms (dyschezia); cyclical urinary symptoms (dysuria or haematuria), or infertility with any of the preceding conditions.<sup>4</sup> Fatigue is also commonly described in endometriosis. Endometriosis should also be considered in young women presenting with cyclical absenteeism from school and use of oral contraceptives for dysmenorrhea.

Ultrasound (if appropriate, a transvaginal ultrasound can diagnose ovarian endometriosis) and magnetic resonance imaging (MRI) can be used to diagnose endometriosis, but negative findings do not exclude endometriosis.<sup>2</sup> To rule out other conditions in primary care, the practitioner should undertake an abdominal and pelvic examination (where appropriate and with consent of the young person) to exclude masses. On examination, elicited pain, vaginal nodules, and adnexal masses can support suspicion of endometriosis.<sup>5</sup> Appropriate differentiating investigations include a mid-stream urine, faecal calprotectin, vaginal swabs, blood tests, and ultrasound to exclude urinary tract infections, fibroids/myomas, pelvic inflammatory disease, irritable bowel, and inflammatory bowel disease. Endometriosis can be misdiagnosed as irritable bowel syndrome.<sup>5</sup> The CA-125 blood test is not recommended for suspecting endometriosis.<sup>2</sup>

In young women with suspected endometriosis, where other potential diagnoses are excluded and medical treatment is not successful, practitioners should refer them to an age-appropriate gynaecology service for consideration of diagnostic laparoscopy, ideally in a specialist endometriosis centre, or to a gynaecologist with a specialist interest.

### TREATMENT

In young people with dysmenorrhea and/or endometriosis-associated pain,

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### Box 1. Key actions

- To suspect endometriosis in a young person after exclusion of other appropriate aetiologies. Endometriosis can occur in young people: make use of advice and guidance/referral to gynaecology for prompt person-centred care.
- Ensure to respond compassionately to young people with concerns about endometriosis, validate pain, and recognise that symptoms can be cyclical or persistent. Consider offering aids such as a symptom tracker.
- Treat the young person and not the disease: check expectations on functioning in education or work, relationships, timing, and preparation for starting a family. Use digital communication systems to share patient information from recognised sources such as Endometriosis.org.
- Prescribers should have a 'can do' attitude in initiating hormonal therapies with patient advice and support. These treatments can improve symptoms and allow the young person to function at work and in education.
- Ensure that people with confirmed diagnosed endometriosis have clear explanations of the condition and access to specialists for long-term symptom control and discussions around conception, assisted reproductive technology, and the potential risk of obstetric complications.
- Encourage young people to use patient-initiated follow-up (PIFU) for accessing gynaecological services during exacerbations. Primary care can offer initial clinical assessment and examination to support the PIFU discussion by responding to specific queries from gynaecology specialists.

hormonal contraceptives (combined oral contraceptive pill) or progesterone (for example, levonorgestrel-intrauterine system) is recommended as first line. Non-steroidal anti-inflammatory medications are suggested for pain at age-appropriate doses where hormone therapy is not suitable. Where endometriosis is confirmed and initial hormonal therapy unsuccessful, specialist gynaecology services can consider offering young people gonadotropin-releasing hormone (GnRH) agonists for up to 1 year after a full discussion of benefits and risks.

Where medical treatment has not helped, surgical removal of endometriosis lesions by an experienced surgeon to manage symptoms is suggested; however, postoperative hormone treatment may well be needed to prevent symptom recurrence.<sup>2</sup> Non-pharmacological interventions such as pelvic physiotherapy and talking therapies may help to reduce the impact of symptoms, although the evidence is weak.<sup>4</sup>

An outline of key actions for practitioners suspecting endometriosis in a young person in primary care is shown in Box 1.

### CONCLUSION

Clinically, endometriosis is an enigmatic condition with sequelae that range from minor discomfort to a frozen pelvis and lifelong pain. Updated National Institute for Health and Care Excellence guidance is expected in December 2023 and will be welcomed to provide clearer direction as more is being understood about this condition. Primary care-initiated hormonal contraception can be beneficial for young people with suspected endometriosis as it downregulates endometrial activity and

may ameliorate pain. However, this should not prevent a referral for confirmation.

It is important that families are involved where consent is gained. A holistic approach is imperative in guiding and supporting the individual and family in the assessment and treatment of possible endometriosis.

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### Competing interests

Liz Hare and Faraz Mughal are members of the RCGP Adolescent Health Group. Liz Hare is a digital GP and works voluntarily for the National Confidential Enquiry into Patient Outcome and Death as a Case Reviewer on the Endometriosis and Transition project. Liz Hare works voluntarily for the UK Dermatology Clinical Trials Network.

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