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NICE
guideline

Endometriosis: diagnosis and management

NICE guideline
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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS172.

Overview

This guideline covers diagnosing and managing endometriosis, including where fertility is a priority. It aims to raise awareness of endometriosis symptoms, and to provide clear advice on referral, diagnosis and the range of treatments available.

Who is it for?

- Healthcare professionals
- Commissioners and providers
- Women and people with suspected or confirmed endometriosis, their families and carers

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Using inclusive language in healthcare is important for safety, and to promote equity, respect and effective communication with everyone. This guideline does not use inclusive language in whole or in part because:

- the evidence has not been reviewed, and it is not certain from expert opinion which groups the advice covers, or
- the evidence has been reviewed, but the information available for some groups was too limited to make specific recommendations, or
- only a very limited number of recommendations have been updated in direct response to new evidence or to reflect a change in practice.

Healthcare professionals should use their clinical judgement when implementing recommendations, taking into account the individual's circumstances, needs and preferences, and ensuring all people are treated with dignity and respect throughout their care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Organisation of care

1.1.1 Set up a managed clinical network for women with suspected or confirmed endometriosis, consisting of community services (including GPs, practice nurses, school nurses and sexual health services), gynaecology services (see the recommendation on gynaecology services) and specialist endometriosis services (see the recommendation on specialist endometriosis services [endometriosis centres]). **[2017]**

1.1.2 Community, gynaecology and specialist endometriosis services (endometriosis centres) should:

- provide coordinated care for women with suspected or confirmed endometriosis
- have processes in place for prompt diagnosis and treatment of endometriosis, because delays can affect quality of life and result in disease progression. **[2017]**

Gynaecology services for women with suspected or confirmed endometriosis

1.1.3 Gynaecology services for women with suspected or confirmed endometriosis should have access to:

- a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery
- a gynaecology specialist nurse with expertise in endometriosis
- a multidisciplinary pain management service
- a healthcare professional with an interest in gynaecological imaging
- fertility services. **[2017]**

Specialist endometriosis services (endometriosis centres)

1.1.4 Specialist endometriosis services (endometriosis centres) should have access to:

- gynaecologists with expertise in diagnosing and managing endometriosis, including advanced laparoscopic surgical skills
- a colorectal surgeon with an interest in endometriosis

- a urologist with an interest in endometriosis
- an endometriosis specialist nurse
- a multidisciplinary pain management service with expertise in pelvic pain
- a healthcare professional with specialist expertise in gynaecological imaging of endometriosis
- advanced diagnostic facilities (for example, radiology and histopathology)
- fertility services. **[2017]**

1.2 Endometriosis information and support

1.2.1 Be aware that endometriosis can be a long-term condition, and can have a significant physical, sexual, psychological and social impact. Women may have complex needs and require long-term support. **[2017]**

1.2.2 Assess the individual information and support needs of women with suspected or confirmed endometriosis, taking into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs. **[2017]**

1.2.3 Provide information and support for women or people with suspected or confirmed endometriosis, which should include:

- what endometriosis is
- endometriosis symptoms and signs
- how endometriosis is diagnosed and the pathway of care, including referral criteria
- treatment and management options
- local support groups, online forums and national charities, and how to access them.

Ensure that information is provided and updated throughout the woman or person's care journey, and that it is appropriate for the stage they are at in their care. **[2017, amended 2024]**

1.2.4 If women agree, involve their partner (and/or other family members or people important to them) and include them in discussions. For more guidance on providing information to people and involving family members and carers, see the NICE guideline on patient experience in adult NHS services. **[2017]**

1.3 Endometriosis symptoms and signs

1.3.1 Suspect endometriosis in women (including young women aged 17 and under) presenting with 1 or more of the following symptoms or signs:

- chronic pelvic pain
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- deep pain during or after sexual intercourse
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- infertility in association with 1 or more of the above. **[2017]**

1.3.2 Ask if any first-degree relatives have a history of endometriosis, as this increases the likelihood of endometriosis. **[2024]**

1.3.3 Inform women with suspected or confirmed endometriosis that keeping a pain and symptom diary can aid discussions. **[2017]**

1.3.4 Take into account that every person's experience of pain is unique to them and may be expressed in different ways, both verbally and non-verbally. In particular, this may vary because of:

- their cultural background and beliefs
- their socioeconomic status
- any neurodiverse conditions they may have. **[2024]**

1.3.5 Offer an abdominal and pelvic (internal vaginal) examination to women and people with suspected endometriosis to identify abdominal masses and pelvic signs, such as reduced organ mobility and enlargement, tender nodularity in the posterior vaginal fornix, and visible vaginal endometriotic lesions. **[2017, amended 2024]**

1.3.6 Offer an abdominal examination to exclude abdominal masses if a pelvic (internal vaginal) examination is declined, or not suitable for the person. **[2017, amended 2024]**

For a short explanation of why the committee made the new and updated 2024 recommendations and how they might affect practice, see the rationale and impact section on endometriosis signs and symptoms.

Full details of the evidence and the committee's discussion are in evidence review B: diagnosing endometriosis.

1.4 Initial pharmacological treatment for women and people with suspected or confirmed endometriosis

Analgesics

1.4.1 For women with endometriosis-related pain, discuss the benefits and risks of analgesics, taking into account any comorbidities and the woman's preferences. **[2017]**

1.4.2 Consider a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination for first-line management of endometriosis-related pain. **[2017]**

1.4.3 If a trial of paracetamol or an NSAID (alone or in combination) does not provide adequate pain relief, consider other forms of pain management and referral for further assessment. **[2017]**

Neuromodulators and neuropathic pain treatments

1.4.4 For recommendations on using neuromodulators to treat neuropathic pain, see the NICE guideline on neuropathic pain in adults. **[2017]**

Hormonal treatments

1.4.5 Explain to women with suspected or confirmed endometriosis that hormonal treatment for endometriosis can reduce pain and has no permanent negative effect on subsequent fertility. **[2017]**

1.4.6 Offer hormonal treatment (for example, the combined oral contraceptive pill or a progestogen) to women with suspected, confirmed or recurrent endometriosis. **[2017]**

In September 2017, this was off-label use for some combined oral contraceptive pills or progestogens. See NICE's information on prescribing medicines.

1.5 Diagnosis and referral for women or people with suspected or confirmed endometriosis

1.5.1 Carry out additional investigations such as ultrasound and referral (if necessary, see recommendations 1.5.5 to 1.5.7) in parallel with each other, and in conjunction with initial pharmacological treatment. **[2024]**

Ultrasound

1.5.2 Offer a transvaginal ultrasound scan to all women or people with suspected endometriosis, even if pelvic or abdominal examination is normal, to:

- identify ovarian endometriomas and deep endometriosis, including that involving the bowel, bladder or ureter
- identify or rule out other pathology which may be causing symptoms
- guide management options and enable referral to an appropriate service, depending on the ultrasound findings. See recommendations 1.5.5 to 1.5.7.

  This ultrasound scan should be organised by the person's general practice. **[2024]**

1.5.3 If a transvaginal ultrasound scan is declined or not suitable for the person, consider a transabdominal ultrasound scan of the pelvis. **[2017, amended 2024]**

1.5.4 Do not exclude the possibility of endometriosis if the abdominal or pelvic examination and ultrasound scan are normal, and recognise that referral may still be necessary even with a normal scan. **[2017, amended 2024]**

1.5.5 Refer women or people with symptoms of, or confirmed, endometriosis to a gynaecology service (see the recommendation on gynaecology services) for further investigation and management if:

- initial treatment is not effective, is not tolerated or is contraindicated, **or**
- they have symptoms of endometriosis which have a detrimental impact on activities of daily living, **or**
- they have persistent or recurrent symptoms of endometriosis, **or**
- they have pelvic signs of endometriosis, but deep endometriosis is not suspected. **[2017, amended 2024]**

1.5.6 Refer women or people to a specialist endometriosis service (see the recommendation on specialist endometriosis services [endometriosis centre]) if they have suspected or confirmed:

- endometrioma, **or**
- deep endometriosis, including that involving the bowel, bladder or ureter, or
- endometriosis outside the pelvic cavity. **[2017, amended 2024]**

1.5.7 Refer young women or people (aged 17 and under) with suspected or confirmed endometriosis to a paediatric and adolescent gynaecology service or specialist endometriosis service (endometriosis centre) for further investigation and management. **[2017, amended 2024]**

Serum CA125

1.5.8 Do not use serum CA125 to diagnose endometriosis. **[2017]**

MRI

1.5.9 Consider specialist transvaginal ultrasound scan or pelvic MRI scan to diagnose deep endometriosis and assess its extent. **[2017, amended 2024]**

1.5.10 Ensure that specialist transvaginal ultrasound scans and pelvic MRI scans are planned and interpreted by a healthcare professional with specialist expertise in gynaecological imaging. **[2017, amended 2024]**

Diagnostic laparoscopy

Also refer to the section on surgical management and the section on management if fertility is a priority.

1.5.11 Consider laparoscopy to diagnose endometriosis in women or people with suspected endometriosis, even if the ultrasound scan or MRI scan was normal. **[2017, amended 2024]**

1.5.12 For women or people with suspected deep endometriosis consider a specialist pelvic ultrasound scan or MRI scan before an operative laparoscopy. **[2017, amended 2024]**

1.5.13 During a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis and record the findings (including normal and abnormal areas and intra-operative imaging). **[2017, amended 2024]**

1.5.14 During a diagnostic laparoscopy, consider taking a biopsy of suspected endometriosis:

- to confirm the diagnosis of endometriosis (be aware that a negative histological result does not exclude endometriosis)
- to exclude malignancy if an endometrioma is treated but not excised. **[2017]**

1.5.15 If a systematic laparoscopy with recorded findings of normal and abnormal areas and intra-operative imaging is performed and is normal, explain to the woman or person that it is unlikely that they have endometriosis, and offer alternative management of their symptoms. **[2017, amended 2024]**

For a short explanation of why the committee made the new and updated 2024 recommendations and how they might affect practice, see the rationale and impact section on diagnosis of endometriosis.

Full details of the evidence and the committee's discussion are in evidence review B: diagnosing endometriosis.

1.6 Staging systems

1.6.1 Offer endometriosis treatment according to the woman's symptoms, preferences and priorities, rather than the stage of the endometriosis. **[2017]**

1.6.2 When endometriosis is diagnosed, the gynaecologist should document a detailed description of the appearance and site of endometriosis. **[2017]**

1.7 Monitoring for women with confirmed endometriosis

1.7.1 Consider outpatient follow-up (with or without examination and pelvic imaging) for women with confirmed endometriosis, particularly women who choose not to have surgery, if they have:

- deep endometriosis involving the bowel, bladder or ureter **or**
- 1 or more endometrioma that is larger than 3 cm. **[2017]**

1.8 Non-pharmacological management

1.8.1 Advise women that the available evidence does not support the use of traditional Chinese medicine or other Chinese herbal medicines or supplements for treating endometriosis. **[2017]**

1.9 Surgical management

1.9.1 Ask women with suspected or confirmed endometriosis about their symptoms, preferences and priorities with respect to pain and fertility, to guide surgical decision-making. **[2017]**

1.9.2 Discuss surgical management options with women with suspected or confirmed endometriosis. Discussions may include:

- what a laparoscopy involves
- that laparoscopy may include surgical treatment (with prior patient consent)
- how laparoscopic surgery could affect endometriosis symptoms
- the possible benefits and risks of laparoscopic surgery
- the possible need for further surgery (for example, for recurrent endometriosis or if complications arise)

- the possible need for further planned surgery for deep endometriosis involving the bowel, bladder or ureter. **[2017]**

1.9.3 Perform surgery for endometriosis laparoscopically, unless there are contraindications. Record the results with intra-operative imaging. **[2017, amended 2024]**

1.9.4 During a laparoscopy to diagnose endometriosis, consider laparoscopic treatment of the following, if present:

- peritoneal endometriosis not involving the bowel, bladder or ureter
- uncomplicated ovarian endometriomas. **[2017]**

1.9.5 As an adjunct to surgery for deep endometriosis involving the bowel, bladder or ureter, consider 3 months of gonadotrophin-releasing hormone agonists before surgery. **[2017]**

In September 2017, this was off-label use for some gonadotrophin-releasing hormone agonists. See NICE's information on prescribing medicines.

1.9.6 Consider excision rather than ablation to treat endometriomas, taking into account the woman's desire for fertility and her ovarian reserve. Also see the section on ovarian reserve testing in the NICE guideline on fertility problems. **[2017]**

Combination treatments

1.9.7 After laparoscopic excision or ablation of endometriosis, consider hormonal treatment (with, for example, the combined oral contraceptive pill), to prolong the benefits of surgery and manage symptoms. **[2017]**

In September 2017, this was off-label use for some hormonal treatments (including some combined oral contraceptive pills). See NICE's information on prescribing medicines.

Hysterectomy in combination with surgical management

1.9.8 If hysterectomy is indicated (for example, if the woman has adenomyosis or heavy menstrual bleeding that has not responded to other treatments), excise all visible endometriotic lesions at the time of the hysterectomy. **[2017]**

1.9.9 Perform hysterectomy (with or without oophorectomy) laparoscopically when combined with surgical treatment of endometriosis, unless there are contraindications. **[2017]**

1.9.10 For women thinking about having a hysterectomy, discuss:

- what a hysterectomy involves and when it may be needed
- the possible benefits and risks of hysterectomy
- the possible benefits and risks of having oophorectomy at the same time
- how a hysterectomy (with or without oophorectomy) could affect endometriosis symptoms
- that hysterectomy should be combined with excision of all visible endometriotic lesions
- endometriosis recurrence and the possible need for further surgery
- the possible benefits and risks of hormone replacement therapy after hysterectomy with oophorectomy (also see the NICE guideline on menopause).**[2017]**

1.10 Management if fertility is a priority

The recommendations in this section should be interpreted within the context of NICE's guideline on fertility problems. The management of endometriosis-related subfertility should have multidisciplinary team involvement with input from a fertility specialist and access to fertility services. Depending on the severity of the endometriosis this may be in a secondary care gynaecology service or a tertiary care specialist endometriosis service.

This should include the recommended diagnostic fertility tests or preoperative tests, as well as other recommended fertility treatments such as assisted reproduction that are included in the NICE guideline on fertility problems.

1.10.1 Offer excision or ablation of endometriosis plus adhesiolysis for endometriosis not involving the bowel, bladder or ureter, because this improves the chance of spontaneous pregnancy. **[2017]**

1.10.2 Offer laparoscopic ovarian cystectomy with excision of the cyst wall, or laparoscopic drainage and ablation, to women or people with endometriomas, because this improves the chance of spontaneous pregnancy. Take into account:

- the possible impact on ovarian reserve
- that ablation and drainage may preserve ovarian reserve more than cystectomy (also see the section on ovarian reserve testing in the NICE guideline on fertility problems). **[2017, amended 2024]**

1.10.3 Discuss the benefits and risks of laparoscopic surgery as a treatment option with women or people who have deep endometriosis (including endometriosis that involves the bowel, bladder or ureter) and who are trying to conceive so they can make an informed decision on its use. Topics to discuss may include:

- the possible impact of deep endometriosis on pregnancy outcomes
- whether laparoscopic surgery may alter the chance of future pregnancy
- the possible impact on fertility if complications arise
- alternatives to surgery
- other fertility factors. **[2017, amended 2024]**

1.10.4 Do not offer hormonal treatment alone or in combination with surgery to women or people with endometriosis who are trying to conceive, because it does not improve spontaneous pregnancy rates. **[2017, amended 2024]**

For a short explanation of why the committee made the updated 2024 recommendations and how they might affect practice, see the rationale and impact section on treatment of endometriosis when fertility is a priority.

Full details of the evidence and the committee's discussion are in evidence review A: treatment of endometriosis when fertility is a priority.

Terms used in this guideline

Chronic pelvic pain

Defined as pelvic pain lasting for 6 months or longer.

Paediatric and adolescent gynaecology service

Paediatric and adolescent gynaecology services are hospital-based, multidisciplinary specialist services for girls and young women (usually aged under 18).

Ovarian cystectomy

Ovarian cystectomy is a surgical excision of an ovarian endometriotic cyst. An ovarian endometrioma is a cystic mass arising from ectopic endometrial tissue within the ovary.

Managed clinical networks

Linked groups of healthcare professionals from primary, secondary and tertiary care providing a coordinated patient pathway. Responsibility for setting up these networks will depend on existing service provision and location.

Recommendations for research

The guideline committee has made the following recommendations for research.

1 Pain management programmes

Are pain management programmes a clinically and cost-effective intervention for women with endometriosis?

Why this is important

Pain is one of the most debilitating symptoms of endometriosis. Endometriosis-related pain can be acute or chronic, and can adversely affect the woman's quality of life, ability to work, and can affect partners and their families.

Pain management programmes have been found to be effective in managing chronic pelvic pain, and can improve quality of life. However, it is unclear how much of this small evidence base can be generalised to women with endometriosis for which evidence is lacking. Furthermore, pain management programmes have not been compared with other treatments available for endometriosis. Pain management programmes promote self-management and are often provided in the community.

If found to be effective for endometriosis, pain management programmes would provide an additional or alternative treatment option for women experiencing endometriosis-related pain. Groups of particular interest are women for whom hormonal and surgical options have been exhausted, women who would prefer an alternative to a pharmacological or surgical approach, and women who may be prioritising trying to conceive.

2 Laparoscopic treatment of peritoneal endometriosis (excision or ablation)

Is laparoscopic treatment (excision or ablation) of peritoneal disease in isolation effective for managing endometriosis-related pain?

Why this is important

Isolated peritoneal endometriosis can be an incidental finding in women who may or may not experience pain or other symptoms.

Research is needed to determine whether laparoscopic treatment of isolated peritoneal endometriosis in women with endometriosis-related pain results in a clinical and cost-effective improvement in symptoms.

The current literature does not provide a clear answer because the stage of endometriosis is often not sufficiently clearly defined in research studies, and the treatment modalities used are multiple and varied. The resultant amalgamation of various stages of endometriosis and variable treatment modalities leads to loss of certainty of outcome in this specific group of women.

Establishing whether treating isolated peritoneal endometriosis is cost effective is important, because this forms a large part of the workload in general gynaecology, and uses considerable resources.

3 Lifestyle interventions (diet and exercise)

Are specialist lifestyle interventions (diet and exercise) effective, compared with no specialist lifestyle interventions, for women with endometriosis?

Why this is important

Endometriosis is a long-term condition that can cause acute and chronic pain, and fatigue. It has a significant and sometimes severe impact on the woman's quality of life and activities of daily living, including relationships and sexuality, ability to work, fertility, fitness and mental health.

Supporting self-management is critical to improving quality of life for women living with endometriosis. In order to successfully self-manage the condition, women need evidence-based, easily accessible information about the condition and ways of managing it that support surgical and medical treatment. However, no high-quality research was identified on the effectiveness of lifestyle interventions such as diet or exercise and other non-medical treatments in reducing pain, fatigue and other symptoms.

Studies should aim to provide evidence-based options to support self-management of endometriosis. This would improve the quality of life of women with endometriosis, enabling them to manage pain and fatigue, and reducing the negative impact on their career, relationships, sex lives, fertility, and physical and emotional wellbeing.

4 Information and support

What information and support interventions are effective to help women with endometriosis deal with their symptoms and improve their quality of lives?

Why this is important

This guideline has identified that women with endometriosis and their partners feel that information and support is not always provided in the way that best meet their needs. However, the direct effectiveness of different types or formats of information and support interventions on measurable outcomes such as health-related quality of life and level of function (for example, activities of daily living) have not been tested. Good practice in this area in non-specialist and specialist settings can improve satisfaction with the care provided. It may also improve quality of life and positively affect relationships between healthcare professionals and the woman with endometriosis, as well as the woman's personal family relationships.

5 Hormonal treatments for people with endometriosis where fertility is a priority

What is the effect of different doses and durations of hormonal treatments given either before, after, or both before and after surgery on fertility outcomes in people with endometriosis where fertility is a priority?

For a short explanation of why the committee made the recommendation for research, see the rationale section on treatment of endometriosis when fertility is a priority.

Full details of the evidence and the committee's discussion are in evidence review A: treatment of endometriosis when fertility is a priority.

Rationale and impact

This section briefly explains why the committee made the recommendations and how they might affect practice. They link to details of the evidence and a full description of the committee's discussion.

Endometriosis signs and symptoms

Recommendations 1.3.2 and 1.3.4 to 1.3.6

Why the committee made the recommendations

Based on their knowledge and experience the committee agreed that a family history of endometriosis should be taken into account when assessing a person with signs or symptoms suggesting endometriosis, as there was an increased likelihood of endometriosis if there was a positive history in a first-degree relative.

Based on stakeholder feedback and information in the 2018 All Party Parliamentary Report on endometriosis that many ethnic minority groups do not feel believed when reporting their symptoms, and based on the committee's knowledge and expertise, a recommendation was added to highlight the need take diversity into account when assessing pain symptoms.

How the recommendations might affect practice

Knowling that there is a family history of endometriosis may increase the suspicion of endometriosis, which may lead to investigations such as ultrasound being used sooner, and consequently an earlier diagnosis.

Increased awareness of the need to take diversity issues into account when assessing pain symptoms will help minority groups feel that their pain symptoms are believed.

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Diagnosis of endometriosis

Recommendations 1.5.1 to 1.5.13 and 1.5.15

Why the committee made the recommendations

Based on the committee's knowledge and experience, an additional recommendation has been added to clarify that initial pharmacological treatment, a non-specialist ultrasound and referral do not need to happen sequentially and can happen in parallel so that the overall pathway of care is more timely.

Ultrasound

There was evidence that transvaginal ultrasound was, in the majority of studies, moderately to highly sensitive at detecting deep endometriosis, particularly when involving the ovaries. However, the committee were aware that these data were when the ultrasound was carried out by a specialist operator, and that ultrasounds carried out in a non-specialist setting may not achieve this degree of sensitivity. The committee also agreed, however, that non-specialist ultrasound was still a useful tool that would help identify deep endometriosis or endometrioma or other pathology. They therefore recommended that all women or people with suspected endometriosis should have an ultrasound examination as this will allow identification of ovarian endometriomas or deep endometriosis, may identify other pathology which could be leading to the symptoms (such as fibroids or malignancy), and will help determine the need for a referral and the most appropriate referral option. The committee agreed that an ultrasound should be offered to all women or people presenting with symptoms suggesting endometriosis as part of the standard diagnostic work-up, as failure to diagnose endometriosis was a common problem.

The recommendation on alternatives to transvaginal ultrasound has been amended to clarify that the reasons for not carrying out a transvaginal ultrasound may be because the woman or person with suspected endometriosis does not wish to have this internal scan, or if there are other reasons which mean it is not suitable for the person. This clarifies that it is not just the healthcare professional who makes a decision on the use of a transvaginal ultrasound.

Based on the committee's knowledge and experience, the recommendation on referral to a gynaecology service after ultrasound has been updated to 'refer' instead of 'consider referring' as in the previous version of this guideline, as the committee agreed that there was no other option but to refer people who met the listed criteria for referral so that they can receive appropriate further investigations and treatment. People would still have the option to decline the referral. In addition, the criteria for referral to a specialist endometriosis service were amended to include the presence of an endometrioma and the location of deep endometriosis has been clarified. Endometriomas are often associated with deep endometriosis or severe endometriosis, and management, particularly if fertility is a priority, can be complicated so specialist services are most appropriate for this. The recommendation on referral of young women or people has similarly also been updated.

Serum CA125

There was some new evidence for the sensitivity and specificity of CA125 to diagnose endometriosis, but the committee agreed that this was insufficient to change the existing recommendation which advised that it was not a suitable tool to diagnose endometriosis.

MRI

There was evidence from the majority of studies that MRI was moderately to highly sensitive at detecting deep endometriosis. The evidence for the use of transvaginal ultrasound for the diagnosis of deep endometriosis involving a number of locations (vaginal, rectosigmoid, rectovaginal, uterosacral ligaments, pouch of Douglas, bowel, bladder and ureters) showed that, in the majority of studies, it was moderately sensitive, although the committee agreed this may depend on operator experience, and that sensitivity would be optimal with more experienced operators who would be likely to be carrying out ultrasounds in gynaecology or specialist endometriosis services. Based on this, the committee agreed that suspected deep endometriosis could be diagnosed and assessed by specialist ultrasound or MRI, and the choice of imaging technique should be a clinical decision based on available resources.

The committee agreed, based on their knowledge and experience, that both specialist ultrasound and MRI scans should be both planned and interpreted by someone with expertise in gynaecological imaging to maximise diagnostic accuracy.

Diagnostic laparoscopy

The committee agreed that laparoscopy (which had been considered the gold standard diagnostic technique in the evidence review) could be used as an option for women or people with symptoms of endometriosis even if ultrasound or MRI results were normal. The committee noted, based on their knowledge and experience, there was a need to ensure the imaging results were recorded when carrying out a diagnostic laparoscopy.

The committee noted that even a normal laparoscopy could not rule out endometriosis fully, as there was a possibility of microscopic endometriosis causing the symptoms. The committee therefore updated the existing recommendation and clarified that management of symptoms was the aim of treatment.

How the recommendations might affect practice

Ultrasound

Early investigation using ultrasound reflects what is now current best practice but it is possible there will be some increase in the use of early transvaginal ultrasound. An early ultrasound scan may replace the need for a transvaginal ultrasound scan after referral to gynaecology services for some women or people (particularly those who are referred and then seen without undue delay), and so is unlikely to greatly increase the total number of transvaginal ultrasounds for diagnosis of endometriosis. This change is therefore not expected to lead to a large increase in resource use in terms of the number of ultrasound scans, but there will be a need for additional training of sonographers to increase their competency to detect features associated with endometriosis.

The change to referring all women and people with symptoms of, or confirmed endometriosis who meet the specified criteria, compared to considering referral in the previous version of this guideline may lead to more people being referred, but this will improve the diagnosis and management of endometriosis, and is likely to lead to earlier diagnosis and treatment and less damage to organs and structures from the disease, and therefore reduce subsequent treatment costs.

MRI

The use of specialist ultrasound as an alternative to MRI to diagnose deep endometriosis may lead to cost-savings in the NHS, as MRI is more expensive than ultrasound. The specialist planning and interpretation of scans may increase the number of people whose endometriosis is successfully identified.

Serum CA125 and diagnostic laparascopy

These recommendations reinforce current practice.

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Management of endometriosis when fertility is a priority

Recommendations 1.10.2 to 1.10.4

Why the committee made the recommendations

There was no evidence of an important difference in the pregnancy rate between laparoscopic cystectomy and laparoscopic ablation and drainage of ovarian endometriomas larger than 3 cm, but drainage and ablation may lead to increased ovarian reserve (measured in terms of anti-Mullerian hormone levels, ovarian volume and antral follicle count) compared to laparoscopic cystectomy, so ablation and drainage has been included as an option if ovarian reserve is a priority.

Based on the committee's knowledge and experience and stakeholder feedback, the definition of deep endometriosis has been clarified to state that it includes endometriosis involving the bowel, bladder or ureter but is not limited to these sites, so that people are not excluded from treatment inappropriately. The need to discuss that deep endometriosis can impact on pregnancy outcomes has been added to the topics to discuss to provide a broader consideration of the benefits and risks of surgery.

There was some limited evidence of increased rates of clinical pregnancy and live birth with combinations of hormonal treatments with laparoscopic surgery compared to surgery alone, but the evidence was mixed, with other evidence showing no difference. As there was mixed evidence, the committee made a recommendation for research on hormonal treatments. The committee clarified that this recommendation applied to hormonal treatment alone or in combination with surgery.

How the recommendations might affect practice

The inclusion of ablation and drainage as a treatment option is not expected to have a resource impact as the cost of the 2 treatment options (cystectomy and ablation/drainage) are similar. This change will allow the option of a treatment which may have less of an impact on ovarian reserve.

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Context

Endometriosis is one of the most common gynaecological diseases needing treatment. It is defined as the growth of endometrial-like tissue (the womb lining) outside the uterus (womb). Endometriosis is mainly a disease of the reproductive years and, although its exact cause is unknown, it is hormone mediated and is associated with menstruation.

Endometriosis is typically associated with symptoms such as pelvic pain, painful periods and subfertility. Endometriosis is also associated with a lower quality of life. Women with endometriosis report pain, which can be frequent, chronic and/or severe, as well as tiredness, more sick days, and a significant physical, sexual, psychological and social impact. Endometriosis is an important cause of subfertility and this can also have a significant effect on quality of life.

Women may also have endometriosis without symptoms, so it is difficult to know how common the disease is in the population. It is also unclear whether endometriosis is always progressive or can remain stable or improve with time.

Delayed diagnosis is a significant problem for women with endometriosis. Patient self-help groups emphasise that healthcare professionals often do not recognise the importance of symptoms or consider endometriosis as a possibility. In addition, women can delay seeking help because of a perception that pelvic pain is normal. Delays of 4 to 10 years can occur between first reporting symptoms and confirming the diagnosis. Many women report that the delay in diagnosis leads to increased personal suffering, prolonged ill health and a disease state that is more difficult to treat.

Diagnosis can only be made definitively by laparoscopic visualisation of the pelvis, but other, less invasive methods may be useful in assisting diagnosis, including ultrasound. Management options for endometriosis include pharmacological, non-pharmacological and surgical treatments. Endometriosis is an oestrogen-dependent condition. Most drug treatments for endometriosis work by suppressing ovarian function, and are contraceptive. Surgical treatment aims to remove or destroy endometriotic lesions. The choice of treatment depends on the woman's preferences and priorities in terms of pain management and/or fertility.

Endometriosis can be a chronic condition affecting women throughout their reproductive lives (and sometimes beyond). Women's priorities and preferences may change over time, and management strategies should change to reflect this.

Women with endometriosis typically present to community services (including GPs, practice nurses, school nurses and sexual health services) with pain, and may then be referred to gynaecology services for diagnosis and management. Some women may present to fertility services. Complex surgical treatment is carried out in specialist endometriosis services (endometriosis centres), which incorporate a multidisciplinary team.

This guideline makes recommendations for the diagnosis and management of endometriosis in community services, gynaecology services and specialist endometriosis services (endometriosis centres).

The guideline also covers the care of women with confirmed or suspected endometriosis, including recurrent endometriosis. It includes women who do not have symptoms but have endometriosis discovered incidentally. Special consideration was given to young women (aged 17 and under). The guideline does not cover the investigation of fertility problems related to endometriosis, care of women with endometriosis occurring outside the pelvis, nor postmenopausal women.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic pages on gynaecological conditions and fertility.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews and full guideline. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see resources to help you put guidance into practice.

Update information

November 2024: We have reviewed the evidence for, and updated and made new recommendations on, diagnosis of endometriosis. As part of this update some recommendations on signs and symptoms were also amended. These new and updated recommendations are marked **[2017, amended 2024]** or **[2024]**. Additionally, the diagnosis and referral section has been reviewed and reordered to better reflect current clinical practice and the care pathway. Unless otherwise indicated no changes have been made to recommendations that have been reordered.

We have also made an editorial update to a recommendation on information and support to clarify what information should be provided and when. This recommendation is marked **[2017, amended 2024]**.

April 2024: We have reviewed the evidence and updated some recommendations, and made a recommendation for research, on treatment of endometriosis when fertility is a priority. These recommendations are marked **[2017, amended 2024]**. We have also amended the heading 'Surgical management when fertility is a priority' to 'Management if fertility is a priority' to recognise that this section also covers non-surgical options.

Minor changes since publication

December 2021: We amended the recommendations on referral to clarify that women with endometriosis outside the pelvic cavity should be referred to a specialist endometriosis centre. For more information, see the surveillance report.

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