Endometriosis: diagnosis and management

NICE guideline: short version

Draft for consultation, February 2017

This guideline covers the diagnosis and management of endometriosis. It aims to raise awareness of the symptoms of endometriosis, and to provide clear advice on what action to take when women with signs and symptoms first present in healthcare settings. It also provides advice on the range of treatments available.

Who is it for?

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

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the guideline committee's discussions and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.

Contents

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your 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 non-specialist services, gynaecology services (see recommendation 1.1.3) and specialist endometriosis services (endometriosis centres; see recommendation 1.1.4).

1.1.2 Non-specialist, 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.

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 nurse with an interest in endometriosis
- a multidisciplinary pain management service

- a healthcare professional with an interest in gynaecological imaging
- fertility services.

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 experience in pelvic pain
- a healthcare professional with specialist expertise in gynaecological imaging of endometriosis
- advanced diagnostic facilities (for example, radiology and histopathology)
- fertility services.

1.2 Endometriosis information and support

1.2.1 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, and physical and emotional issues.

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

- what endometriosis is
- endometriosis symptoms and signs (see recommendation 1.3.1)
- how it is diagnosed
- treatment options
- potential long-term effects
- local support groups, online forums and national charities, and how to access them.

1.2.3 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.

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 associated with 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.

1.3.2 Inform women with suspected or confirmed endometriosis that keeping a pain and symptom diary can aid discussions.

1.3.3 Offer an abdominal and pelvic examination to women 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.

1.3.4 If a pelvic examination is not appropriate (for example, in women who have never had sexual intercourse), offer an abdominal examination to exclude abdominal masses.

1.4 Referral and monitoring

Referral

1.4.1 Consider referring women to a gynaecology service (see recommendation 1.1.3) for an ultrasound or gynaecology opinion if they have:

- severe, persistent or recurrent symptoms of endometriosis **or**
- pelvic signs of endometriosis.

1.4.2 Refer women to a specialist endometriosis service (endometriosis centre; see recommendation 1.1.4) if they have suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.

1.4.3 Consider referring young women (aged 17 and under) with suspected or confirmed endometriosis to a paediatric and adolescent gynaecology service, gynaecology service (see recommendation 1.1.3) or specialist endometriosis service (endometriosis centre; see recommendation 1.1.4), depending on local service provision.

Monitoring

1.4.4 Consider outpatient follow-up (with or without examination and pelvic imaging) for women with 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.

1.4.5 Explain to women that endometriosis is associated with a small increased risk of ovarian cancer.

1.4.6 Do not offer surveillance for gynaecological cancers to women with endometriosis. For guidance on the recognition and referral of suspected gynaecological cancers, see the NICE guideline on suspected cancer.

1.5 Diagnosing endometriosis

Ultrasound

1.5.1 Consider transvaginal ultrasound:

- to investigate suspected endometriosis even if the pelvic and/or abdominal examination was normal (also see recommendations 1.3.3 and 1.3.4)
- to identify endometriomas and deep endometriosis involving the bowel, bladder or ureter.

1.5.2 If a transvaginal scan is not appropriate (for example, in women who have never had sexual intercourse), consider a transabdominal ultrasound scan of the pelvis.

1.5.3 Do not exclude the possibility of endometriosis if the ultrasound is normal. If clinical suspicion remains or symptoms persist, consider referral for further assessment and investigation.

Serum CA125

1.5.4 If a coincidentally reported serum CA125 level is available, be aware that:

- a raised serum CA125 (that is, 35 IU/ml or more) may be consistent with having endometriosis
- endometriosis may be present despite a normal serum CA125 (less than 35 IU/ml).

1.5.5 Do not use serum CA125 to diagnose endometriosis.

MRI

1.5.6 Do not use pelvic MRI as the primary investigation to diagnose endometriosis in women with symptoms suggestive of endometriosis.

1.5.7 Consider pelvic MRI to assess the extent of deep endometriosis involving the bowel, bladder or ureter.

1.5.8 Ensure that MRI scans are interpreted by a healthcare professional with specialist expertise in gynaecological imaging.

Diagnostic laparoscopy

Also refer to section 1.9 on surgical management and section 1.10 on surgical management if fertility is a priority.

1.5.9 Consider laparoscopy to diagnose endometriosis in women with suspected endometriosis, even if the ultrasound was normal.

1.5.10 For women with suspected deep endometriosis involving the bowel, bladder or ureter, consider a pelvic ultrasound or MRI before an operative laparoscopy.

1.5.11 During a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery should perform a systematic inspection of the pelvis.

1.5.12 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.

1.5.13 If a full, systematic laparoscopy is performed and is normal, explain to the woman that she does not have endometriosis, and offer alternative management.

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.

1.6.2 When endometriosis is diagnosed, the gynaecologist should document a detailed description of the appearance and site of endometriosis (for example, ovarian [endometriomas], superficial or deep endometriosis, bowel, bladder or ureter involvement, and presence of adhesions).

1.7 Pharmacological pain management

Also refer to section 1.8 on non-pharmacological management, section 1.9 on surgical management, and section 1.10 on surgical management if fertility is a priority.

Analgesics

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

1.7.2 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.

1.7.3 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.

Neuromodulators and neuropathic pain treatments

1.7.4 For recommendations on treating pain with neuromodulators, see the NICE guideline on neuropathic pain.

1.7.5 Do not use local anaesthetic injected through the cervix and fallopian tubes to manage endometriosis-related pain.

Hormonal treatments

1.7.6 Explain to women with suspected or confirmed endometriosis that hormonal treatment for endometriosis can reduce pain and has no negative effect on subsequent fertility.

1.7.7 Offer hormonal treatment (for example, the oral contraceptive pill or long-acting reversible contraception) to women with suspected, confirmed or recurrent endometriosis.

1.7.8 If initial hormonal treatment for endometriosis is not effective, not tolerated or is contraindicated, refer the woman to gynaecology services (see

recommendation 1.1.3), specialist endometriosis services (endometriosis centres, see recommendation 1.1.4) or paediatric and adolescent gynaecology services for investigation and treatment

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.

1.9 Surgical management

1.9.1 Ask women about their symptoms, preferences and priorities with respect to pain and fertility, to guide surgical decision-making.

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, risks and complications 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.

1.9.3 Perform surgery laparoscopically unless there are contraindications.

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.

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.

Ablation compared with excision

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

Combination treatments

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

Hysterectomy

1.9.8 Combine hysterectomy with excision of all visible endometriosis.

1.9.9 Perform hysterectomy laparoscopically unless there are contraindications.

1.9.10 For women thinking about having a hysterectomy, discuss the possibility of having oophorectomy at the same time. Discussions should include:

- what a hysterectomy involves and when it may be needed
- how hysterectomy with and without oophorectomy could affect the woman's endometriosis symptoms
- the risks and benefits
- recurrence and the possible need for further surgery
- hormone replacement therapy (also see the NICE guideline on menopause).

1.10 Surgical 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. 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.

1.10.2 Offer laparoscopic ovarian cystectomy with excision of the cyst wall to women with endometriomas, because this improves the chance of spontaneous pregnancy and reduces recurrence. Take into account the woman's ovarian reserve. (Also see ovarian reserve testing in the NICE guideline on fertility problems.)

1.10.3 Consider laparoscopic surgery for women with deep endometriosis involving the bowel, bladder or ureter and who are trying to conceive (working in conjunction with a fertility specialist), because it may improve the chance of spontaneous pregnancy.

1.10.4 Do not offer postoperative hormonal treatment to women with endometriosis who are trying to conceive, because it does not improve spontaneous pregnancy rates.

Terms used in this guideline

Chronic pelvic pain

Defined as pelvic pain lasting for 6 months or longer.

Non-specialist services

Non-specialist services include: GPs, sexual health services, practice nurses and school nurses.

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.

Putting this guideline into practice

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

[Optional paragraph if issues raised] Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- [add any issues specific to guideline here]
- [Use 'Bullet left 1 last' style for the final item in this list.]

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

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 associated with menstruation. Delaying childbearing, either by choice or because of subfertility, may be a risk factor for endometriosis.

Endometriosis is typically associated with symptoms such as pelvic pain, painful periods and subfertility. Endometriosis is also associated with lower quality of life, and women with endometriosis report frequent pain, tiredness, more sick days and feeling depressed. 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 these symptoms, so it is difficult to know how common the disease is in the population. It is also unclear whether the disease 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. 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 is mainly by laparoscopic visualisation of the pelvis, but other, less invasive methods may be used, 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 deposits of endometrial tissue. The choice of treatment depends on the woman's preferences and priorities in terms of pain management and/or fertility.

Endometriosis is a chronic condition affecting women throughout their reproductive lives. Women's priorities and preferences may change over time and management strategies should change to reflect this.

This guideline makes recommendations for the diagnosis and management of endometriosis in non-specialist settings, gynaecology services (see recommendation 1.1.3) and specialist endometriosis services (endometriosis centres; see recommendation 1.1.4). Women with endometriosis typically present to non-specialist 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.

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 care of women with endometriosis occurring outside the pelvis, nor postmenopausal women.

More information

[The following sentence is for post-consultation versions only – editor to update hyperlink with guideline number]You can also see this guideline in the NICE pathway on [pathway title]. [Note: this should link to the specific topic pathway, not to the overarching one.]

To find out what NICE has said on topics related to this guideline, see our web page on [developer to add and link topic page title or titles; editors can advise if needed].

[The following sentence is for post-consultation versions only – editor to update hyperlink with guideline number]See also the guideline committee's discussion and the evidence reviews (in the full guideline), and information about how the guideline was developed, including details of the committee.

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 increase 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 do not experience any pain. This raises the possibility that isolated peritoneal endometriosis may not actually be the cause of pain.

Research is needed to determine whether laparoscopic treatment of isolated peritoneal endometriosis in women with endometriosis-related pain results in a 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 various. 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.

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