

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 \[endometriosis centres\]](#)).

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.

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.

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.

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.
- 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.
- 1.2.3 Provide information and support for women with suspected or confirmed endometriosis, which should include:
- what endometriosis is
 - endometriosis symptoms and signs
 - how endometriosis is diagnosed
 - treatment options

- local support groups, online forums and national charities, and how to access them.

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](#).

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.
- 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, offer an abdominal examination to

exclude abdominal masses.

1.4 Referral for women with suspected or confirmed endometriosis

- 1.4.1 Consider referring women to a gynaecology service (see the [recommendation on gynaecology services](#)) for an ultrasound or gynaecology opinion if:
- they have severe, persistent or recurrent symptoms of endometriosis
 - they have pelvic signs of endometriosis **or**
 - initial management is not effective, not tolerated or is contraindicated.
- 1.4.2 Refer women to a specialist endometriosis service (see the [recommendation on specialist endometriosis services \[endometriosis centre\]](#)) if they have suspected or confirmed:
- deep endometriosis involving the bowel, bladder or ureter, or
 - endometriosis outside the pelvic cavity.
- 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 or specialist endometriosis service (endometriosis centre), depending on local service provision.

1.5 Diagnosing endometriosis

- 1.5.1 Do not exclude the possibility of endometriosis if the abdominal or pelvic examination, ultrasound or MRI are normal. If clinical suspicion remains or symptoms persist, consider referral for further assessment and investigation.

Ultrasound

1.5.2 Consider transvaginal ultrasound:

- to investigate suspected endometriosis even if the pelvic and/or abdominal examination is normal
- to identify endometriomas and deep endometriosis involving the bowel, bladder or ureter.

1.5.3 If a transvaginal scan is not appropriate, consider a transabdominal ultrasound scan of the pelvis.

Serum CA125

1.5.4 Do not use serum CA125 to diagnose endometriosis.

1.5.5 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).

MRI

1.5.6 Do not use pelvic MRI as the primary investigation to diagnose endometriosis in women with symptoms or signs 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 pelvic MRI scans are interpreted by a healthcare professional with specialist expertise in gynaecological imaging.