MANAGEMENT OF ENDOMETRIOSIS - FULL CLINICAL GUIDELINE

Reference No. UHDB/Gynae/12:20/E4

Contents

1. Introduction

Endometriosis is a very common gynaecological condition affecting up to 10% of women of reproductive age. It is characterised by the presence of endometrial-like tissue outside the uterine cavity, which induces a chronic inflammatory reaction. It is frequently associated with severe and debilitating chronic pelvic pain. In some patients, pain is severe enough to ruin and disrupt their lives on all levels. On a social level, it can damage family life and threaten marital relationship. On a professional level, it could lead to poor work performance, high absenteeism and could seriously hamper a women's career progress. On the academic level, it could seriously impact on performance at school/university.

Endometriosis develops in four different pathological entities including:

- ovarian cysts (endometriomas),
- superficial peritoneal lesions,
- deep infiltrating endometriosis (DIE) and
- uterine endometriosis (adenomyosis).

DIE is by far the most complex form of the disease, which is usually associated with the severest symptoms. The disease usually infiltrates deeply into surrounding tissues including the pelvic side wall, the uterosacral ligaments, the anterior rectal wall, the posterior vaginal wall and recto-vaginal septum. Bowel involvement occurs in about 7%-19%. As far as treatment is concerned, DIE is challenging and should be referred to an endometriosis centre with a dedicated multi-disciplinary team including a nurse specialist, a colorectal surgeon and an urologist in addition to a Gynaecologist with expertise in management of endometriosis.

Clinical presentation

Endometriosis is a disease of women of reproductive age, which commonly presents between 25 and 29 years, although it can present in early adolescents and has been reported in postmenopausal women. It is asymptomatic in about one fifth of patients.

Main presenting symptoms include:

- dysmenorrhoea,
- non-cyclical pelvic pain and or dyspareunia (deep pain during sexual intercourse)
- Dyschezia (painful bowel movements) and
- haematochezia (blood in stools) due to bowel involvement and
- Dysuria and haematuria due to bladder involvement.

- Infertility in association with 1 or more of the above

Rarely, dysmenorrhoea may be associated with symptoms due to extra pelvic endometriosis:

- sciatica,
- groin pain,
- haemoptysis and chest pain.
- Other rare associations include bleeding, swelling and/or pain at uncommon sites affected by endometriosis such as the umbilicus, abdominal wall, or perineum.

Over 50% of women with dysmenorrhoea and chronic pelvic pain are found to have endometriosis at laparoscopy. Generally, the severity of the pain varies significantly between patients and does not correlate with the severity of the disease. Whilst patients with minimal or mild but active disease could have significant pain, patients with severe endometriosis could be completely pain-free. On the other hand, in women with deep rectovaginal or uterosacral endometriosis, the depth of infiltration of endometriosis is positively correlated with the pelvic pain and dysmenorrhoea. Midline disease is generally more painful than lateral disease.

Diagnosis

Diagnosis of endometriosis is essentially based on the pattern of pain in addition to other associated symptoms as described above.

- Offer an **abdominal examination** to exclude abdominal masses.
- **Pelvic examination and imaging may aid the diagnosis, but negative findings do not exclude endometriosis.**
- **Bimanual examination** could detect deep infiltrating disease and large ovarian cysts. , reduced organ mobility and enlargement, tender nodularity in the posterior vaginal fornix, and visible vaginal endometriotic lesions
- **Ultrasound scan** is useful in diagnosing endometriomas and deep endometriosis involving the bowel, bladder or ureter.
- If a transvaginal scan is not appropriate, consider a transabdominal ultrasound scan of the pelvis.
- **Magnetic resonance *is only required*** to identify DIE and bowel involvement. In women with severe endometriosis, renal tract imaging is essential to exclude hydro-ureter and hydronephrosis caused by peri-ureteric DIE. *Symptoms that warrant MRI*:
    - Cyclical Rectal symptoms: Dyschezia & rectal bleeding
    - Suspected nodular disease on pelvic examination
    - Fixed pelvis on examination
    - Previously diagnosed complex endometriosis

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

Further investigations for other organ involvement may be required e,g, colonoscopy, cystoscopy, etc.

The gold standard for the diagnosis is laparoscopic examination of the pelvis. It is recommended the laparoscopy should be undertaken by a Gynaecologist with advanced laparoscopic surgical skills to apply that a see-and -treat policy when endometriosis is found. Histological diagnosis of biopsies of endometriotic deposits is not necessary for the diagnosis but is considered good practice.

Management strategies

Three main management options are available for endometriosis including

- analgesics,
- hormonal treatment, and
- surgery (conservative or radical).

The choice of treatment must be tailored to everyone's circumstances depending on four main factors including:

(1) pattern & severity of symptoms,
(2) pattern and extent of endometriosis,
(3) patient's special circumstances (e.g. fertility wishes, surgical fitness, etc) and
(4) patient's wishes.

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.
Do not use serum CA125 to diagnose endometriosis. - 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).

Although effective in controlling the disease and relieving its associated pain, hormonal treatment usually produces a short-term effect, which usually wears off after discontinuation of treatment. Furthermore, medical treatment does not help infertility patients and most of the drugs have a contraceptive effect. Moreover, deep infiltrating endometriosis and endometriomas may not respond to hormonal therapy. Another disadvantage of medical treatment is the significant side effects associated with most of the drugs used in endometriosis, which limit their use. Hormonal therapy is therefore mainly used for short- or medium-term alleviation of pain. On the other hand, surgery offers a more definitive treatment, which can achieve a long-term control of painful symptoms and may improve fertility.

Analgesia:
For women with endometriosis-related pain, discuss the benefits and risks of analgesics, considering any comorbidities, allergies and the woman's preferences.
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.
- If a trial of paracetamol or an NSAID (alone or in combination) does not provide adequate pain relief, consider other forms of pain management, egs
- Oromorph
- Codeine
- Amyptriptaline
- Baclofen
- If further support is required, then referral to pain team is warranted for further assessment.

Hormonal therapy

Patients suspected on clinical grounds to have endometriosis could be initially offered empirical medical management including simple analgesia and/or hormonal therapy such as

- combined oral contraceptive pills or
- progestogen only pill.
- Depo injection
- Implant
- MIRENA
- Norethisterone tablets
- GnRHa inj (with add back therapy)

If medical treatment fails, laparoscopy could be offered, which in addition to confirming the diagnosis, allows the surgical elimination of mild and moderate endometriotic lesions. It also allows an accurate diagnosis and staging of severe endometriosis, which will help in planning further surgical procedures. Imaging is required prior to this.
During a laparoscopy**, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.**
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.
Perform surgery for endometriosis laparoscopically unless there are contraindications.
Consider excision 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. AMH levels should be checked in young women undergoing excision of endometriomas.

After laparoscopic excision of endometriosis, consider hormonal treatment (with, for example, the combined oral contraceptive pill, POP, MIRENA, etc), to prolong the benefits of surgery manage symptoms and delay recurrence of disease.

Patients resistant to the above treatments or those diagnosed or suspected to have complex endometriosis with DIE should be referred to the Endometriosis centre.

Endometriosis information and support
It is important to realise that endometriosis can be a long-term debilitating condition with significant physical, sexual, psychological and social impact. Women may have complex needs and require long-term support. Every individual patient's needs should be assess considering their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs.

All patients should be provided with information on all aspects of endometriosis and access to support e.g. endometriosis PIL, endometriosis UK website link, CNS contact details.

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

2. Purpose and outcomes

The purpose of this document is to provide a practical and informative guideline to the clinical management of women with endometriosis based on recognised national (BSGE, NICE & RCOG) and international guidelines (ESHRE). It is designed to assist gynaecologists in establishing an early diagnosis, planning the management of less severe endometriosis and identifying complex cases that require referral to the endometriosis centre. It also provides a clear pathway from primary care through to the Endometriosis Centre.

3. Abbreviations / Definitions Used

CPP	-	Chronic pelvic pain: defined as pelvic pain lasting for six months or longer with a significant negative impact on the quality of life.
DIE	-	Deep infiltrating endometriosis: nodular disease, infiltrative disease, diffuse superficial disease or endometriosis over the ureters or rectum.
Endometrioma	-	an ovarian endometrioma is a cystic mass arising from ectopic endometrial tissue within the ovary.
Endometriosis	-	it is defined as the growth of endometrial-like tissue outside the uterus.

4. Key Responsibilities and Duties

Clinical Director of Gynaecology
- Ensure all clinical staff are aware of the guidelines.
- Ensure that patients are managed by medical staff in accordance with the guidelines.

Lead of endometriosis centre
- Ensure that these guidelines are updated regularly as per trust policy and in events of new national guidance.

- The lead clinician will ensure that patients are managed by medical and nursing staff in accordance with these guidelines.
- Will be responsible for monitoring referrals and allocating in line with referral criteria to the nurse led clinic.
- ensure efficient, effective service provision.

Medical staff
All medical staff are responsible for ensuring management of patients with endometriosis in accordance to the guideline

Nursing staff
All nursing staff involved in providing direct patient care for patients with endometriosis are responsible for ensuring the care is in line with these guidelines.

5. Process for Assessment and Management of Endometriosis

Initial assessment in gynaecology clinic:
- Pattern of pelvic pain suggestive of endometriosis:
  - Dysmenorrhoea: starts few days premenstrually the worsens during menses & settles down towards the end
  - Deep dyspareunia
  - Noncyclical pain, usually worsens around the time of ovulation
- Severity of pain:
  - VAS: Pain score
  - Effect on daily activities & quality-of-life
- Cyclical period related Non-gynecological symptoms:
  - Cyclical Dyschezia, bleeding per-rectum period-related or cyclical.
  - Cyclical dysuria, haematuria, painful micturition

Imaging:
- USS for all
- 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.
- If a transvaginal scan is not appropriate, consider a transabdominal ultrasound scan of the pelvis.
- MRI only for women with any of the following:
  - Cyclical Rectal symptoms: Dyschezia & rectal bleeding
  - Suspected nodular disease on pelvic examination.
  - Fixed pelvis on examination
  - Previously diagnosed complex endometriosis
  - Ensure that pelvic MRI scans are interpreted by a healthcare professional with specialist expertise in gynaecological imaging.

Treatment pathway (see figure 1)
Following the initial assessment:
- Treatment is initiated in general gynae clinic if:
  - No DIE or complex diseases suspected clinically or on imaging
  - No previous diagnosis of severe endometriosis
  - No previous surgery for endometriosis
  - 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.

- **Refer to Endometriosis centre if:**
  - DIE is suspected clinically, on imaging.
  - Previous diagnosis of Complex endometriosis

- Evidence of bladder, bowel or ureteric involvement
- Previous surgery for endometriosis
- Recurrent or persistent symptoms after initial treatment

- Refer to pain clinic if
  - Laparoscopy is negative. If a full, systematic laparoscopy is performed and is normal, explain to the woman that she does not have endometriosis, and offer alternative management.
  - Two or more treatments in a specialised endometriosis centre
  - Patient does not respond to hormonal therapy
  - Patient declines or not suitable for surgery

Support and information
Assess the individual information and support needs of every patient with suspected or confirmed endometriosis, taking into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, Cultural background, physical, psychosexual and emotional issues.

Information should cover definition, symptoms, diagnosis, management options, possible long-term effect, reproductive consequences, local and national support groups and forums.

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.

Further assessment by endometriosis centre
- Further assessment with input from Urologist and Colorectal surgeons:
  - Urinary tract imaging
  - MRI
  - Colonoscopy
  - Cystoscopy
- Nurse specialist to support and get QoL
- Discuss Medical, surgical & pain management
- If surgery is considered:
  - Discuss at MDT
  - Plan surgery, joint if necessary
- Counsel patient re extent of surgery, possibility of stoma

- **Management in general gynaecology clinic**
  - **Medical management:**
    - COC, POP, NET
    - GnRHa
  - **Counselling for surgery:**
    - Discuss surgical options and what it involves
    - Explain the See and treat policy
    - the possible benefits, risks and complications of laparoscopic surgery
    - Chances of pain improvement after surgery, which is not guaranteed
    - the possible need for further planned surgery for DIE or complex disease
    - Possible recurrence of disease after surgery
  - **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.
    - 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).

- 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.

- **Outcome of Laparoscopy:**
  - If negative: refer to pain clinic
  - If mild – moderate endo: treat [ablation, excision, cystectomy]
  - If severe: refer to endometriosis centre

- **Surgery for DIE and complex endometriosis by endometriosis centre:**

  - Offer 3-months GnRH treatment before surgery.
  - Aim for laparoscopic surgery for all
  - Aim for complete excision of DIE after careful discussion with women concerning risk and implications
  - After laparoscopic excision of endometriosis, consider hormonal treatment (e.g. COC), to reduce or delay recurrence.
  - If hysterectomy is performed,
    - Ensure complete excision of all endometriosis.
    - Consider BSO
    - Discuss HRT: Women with endometriosis should ALWAYS be given combined HRT to prevent recurrence of endometriosis if BSO has been undertaken. This as per the BMS and ESHRE guidance
    - 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).

<u>Surgical endometriosis if fertility is a priority</u>

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.

Offer excision of endometriosis plus adhesiolysis for endometriosis not involving the bowel, bladder or ureter, because this improves the chance of spontaneous pregnancy.

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.). AMH level testing is recommended in excision of endometriomas in women of reproductive age groups

Discuss the benefits and risks of laparoscopic surgery as a treatment option for women who have deep endometriosis involving the bowel, bladder or ureter and who are trying to conceive (working with a fertility specialist). Topics to discuss may include:

- whether laparoscopic surgery may alter the chance of future pregnancy
- the possible impact on ovarian reserve (also see ovarian reserve testing in the NICE guideline on fertility problems)
- the possible impact on fertility if complications arise
- alternatives to surgery
- other fertility factors.

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

Endometriosis management pathway

GP

When to suspect endometriosis?

- Severe chronic pelvic pain
- > 6 months - Affecting QOL
- Not responding to pain killers

What to do?

- **Arrange a pelvic scan**
- **Refer to Gynae clinic**

General Gynae clinic

Initial assessment:

- History, Examination,
- USS (if not already done)
- ***No MRI*** except if DIE is suspected

Refer to endometriosis centre if:

- DIE suspected clinically or on imaging
- Previous diagnosis of Complex endometriosis
- Evidence of bladder, bowel, or ureteric involvement
- Previous surgery for endometriosis
- Recurrent or persistent symptoms after initial treatment

Initiate management in general gynae if:

- No DIE clinically, on imaging
- No previous diagnosis of severe endo
- No previous surgery for endometriosis

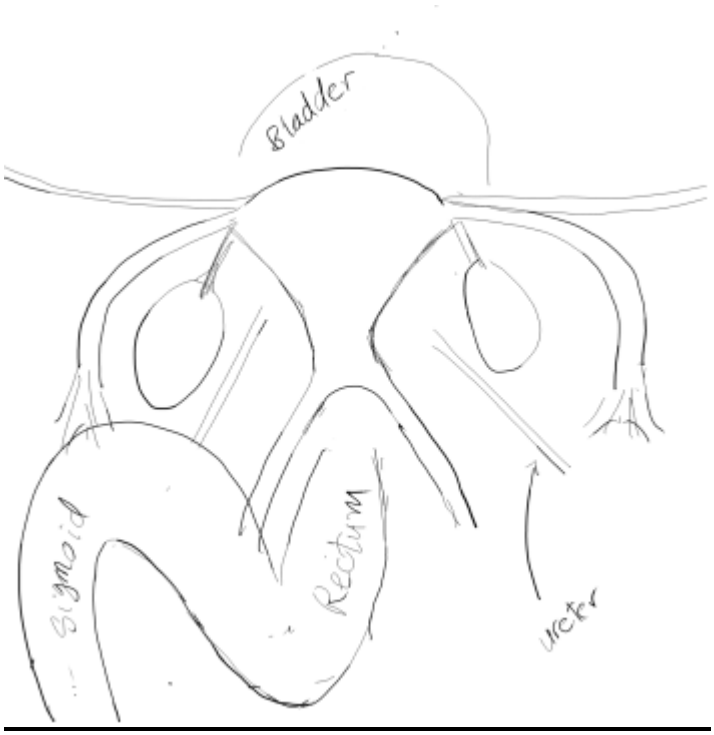
Specialist endometriosis Management:

- Further assessment e.g.
  - Urinary tract imaging
  - MRI
  - Colonoscopy
  - Cystoscopy
- Nurse specialist to support and get QoL
- Discuss Medical, surgical & pain management
- If surgery is considered:
  - Discuss at MDT
  - Plan surgery, joint if necessary
  - Counsel patient re extent of surgery, possibility of stoma

General gynaecology treatment options:

- Medical management:
  - COC, POP, NET
  - GnRHa
- Laparoscopy / EUA
  1. ***If negative***: consider empirical hormonal treatment or referring to pain clinic
  2. ***If mild – moderate*** not close to ureter, bladder, or bowel: treat [ablation, excision, cystectomy].
  3. ***If mild - moderate*** but close to ureter, bladder, or bowel: refer to Endometriosis Centre
  4. ***If severe*** with extensive adhesions, DIE, palpable nodule, or involvement of ureter, bowel, or bladder: refer to endometriosis centre

Diagram that can be used by surgeons as part of their operative notes where they can draw the endometriotic lesions



6. Monitoring Compliance and Effectiveness

Compliance audit cross site within a year of implementation of this guideline

7. References

NICE guideline NG73. Endometriosis: diagnosis and management. September 2017

Documentation Control

Reference Number: UHDB/Gynae/12:20/E4	**Version: 1**		**Status: Final**	
Version Amendment	**Version**	**Date**	**Author**	**Reason**
	1	June 2020	Mr S Amer – Consultant Gynaecologist	New
	2	December 2023	Miss S Bazmi - Consultant Gynaecologist	3 year review. Updated to ensure NICE compliance.
Intended Recipients: All staff within the Gynaecology Service				
Training and Dissemination: Cascaded electronically through senior sisters/midwives/doctors via NHS.net; Published on Intranet;				
To be read in conjunction with:				
Consultation with:	Gynaecologists			
Business Unit sign off:	21/12/2023: Gynaecology Guidelines Group:– Miss B. Purwar 21/12/2023: Gynaecology Development & Governance Committee: – Mr V. Asher			
Divisional sign off:	21/12/2023 - G Hatton			
Implementation date:	28 /12/2023			
Review Date:	December 2026			
Key Contact:	Joanna Harrison-Engwell			