

Management of Endometriosis - Full Clinical Guideline

Reference No. UHDB/Gynae/11:20/E4

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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. 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.

CPP caused by endometriosis can be associated with other symptoms due to involvement of other organs such as Dyschezia and hematochezia due to bowel involvement and Dysurea and

haematuria due to bladder involvement. Rarely, dysmenorrhoea may be associated with symptoms due to extrapelvic endometriosis such as 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.

Diagnosis

Diagnosis of endometriosis is essentially based on the pattern of pain in addition to other associated symptoms as described above. 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. Ultrasound scan is useful in diagnosing endometriomas. Magnetic resonance ***is only required in severe cases*** 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. 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 intermediate 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 patient's wishes.

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.

The principals of hormonal therapy are based on inducing pseudo-pregnancy (e.g. by progestogen-containing medications) or pseudo-menopause by gonadotrophin releasing hormone agonists (GnRHa).

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. 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.

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 assessed 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.

All patients should be provided with information on all aspects of endometriosis and access to support

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
 - 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

- 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

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
- 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
 - 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, and physical and emotional issues.

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

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 or ablation 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

Endometriosis management pathway

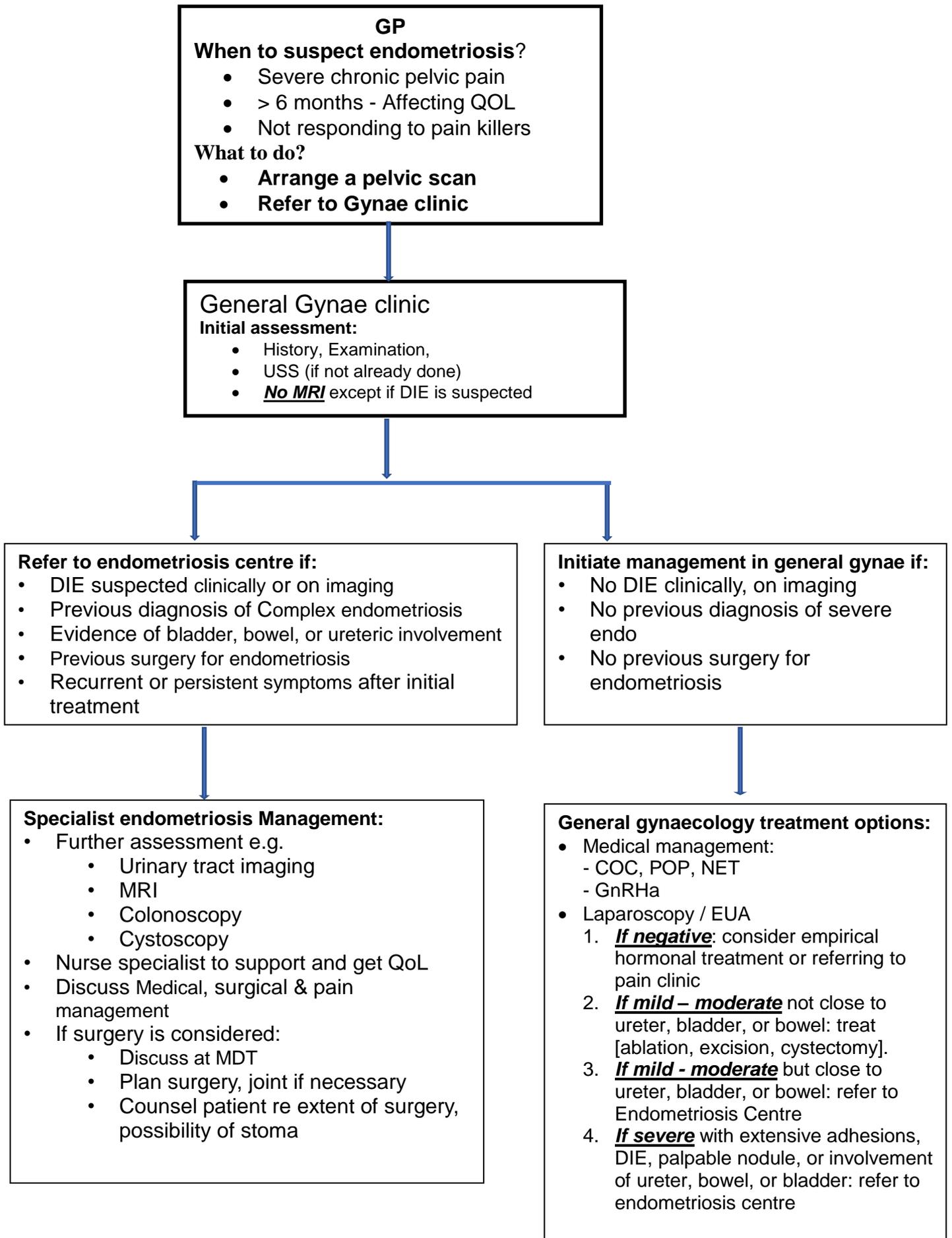
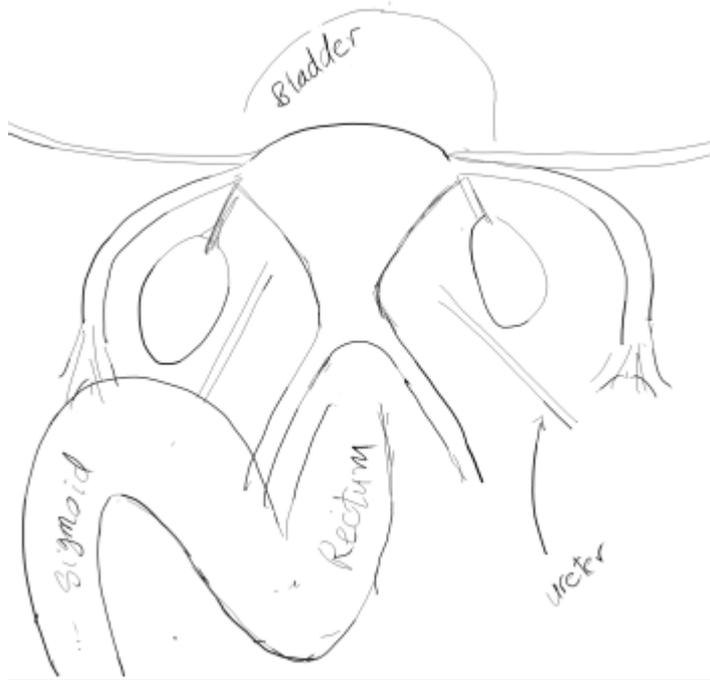


Diagram that can be used by surgeons as part of their operative notes where they can draw the endometriotic lesions



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

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