Centre for Sustainable Delivery

NHS SCOTLAND

Modernising Patient Pathways Programme:

Endometriosis

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Background

The endometriosis pathway for Scotland has been adapted from NICE guidance. It provides a streamlined integrated primary, secondary and tertiary care pathway aimed at holistic approach and timely care for those with endometriosis and endometriosis like symptoms.

Pathway recommendations

Integrated Primary to Secondary Care Pathway for Women with Suspected, Confirmed or Recurrent Endometriosis

(from NICE Guideline 73 and adapted for NHS Scotland)

PRIMARY CARE

First Presentation

Suspect endometriosis (including in young women aged 16 and under) with 1 or more symptoms of:

- 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.

Assess women's individual information and support needs

Take 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.

Initial Assessment

Initial Assessment and Investigations

- discuss keeping a pain and symptom diary
- offer abdominal and pelvic examination to identify abdominal masses and pelvic signs
- **consider transvaginal** or **transabdominal ultrasound scan** to investigate pain even if examination is normal
- **do not use Pelvic MRI** or **CA-125** to diagnose endometriosis
- **do not exclude** the possibility of endometriosis if the **abdominal** and/or **pelvic examinations** or **ultrasound** are **normal**
- consider STI screening for women under 25 or those who have any risk factors
- discuss the diagnosis of suspected endometriosis and provide information about endometriosis, symptoms, diagnosis, management and long term impact including fertility - Endometriosis patient information leaflet
- Consider management of chronic pain including pharmaceutical and non-pharmaceutical strategies – SIGN 136

Be aware that endometriosis can be a long-term condition that can have a significant physical, sexual, psychological and social impact.

Women may have complex needs and may require long-term support.

Initial Management

Offer **initial management** with:

- paracetamol or non-steroidal anti-inflammatory drug (NSAID) for the management of pain in combination with;
- Hormonal contraception (combined hormonal contraception such as; combined pill, patch or ring, LNG-IUS, progestogen only pill, DMPA injection) for 6 months.
- refer to SIGN 136 Management of Chronic Pain for treatment of neuropathic pain.

If **fertility is a priority**, the management of endometriosis-related subfertility should have multidisciplinary team involvement with input from a fertility specialist. This should include recommended diagnostic fertility tests or preoperative tests and others recommended fertility treatments such as assisted reproduction.

Consider referral to a **gynaecology** if;

- a trial of pain management in combination with hormonal treatment does not provide adequate pain relief **AND / OR**
- initial hormonal treatment for endometriosis is not effective, not tolerated, is contraindicated or symptoms recur following surgical treatment of endometriosis.

Referral

Consider referral to a **gynaecology service**:

- for severe, persistent or recurrent symptoms of endometriosis
- for pelvic signs of endometriosis, **or**
- if initial management is not effective, not tolerated or is contraindicated.

Refer women to a **specialist endometriosis service** (endometriosis centre) if they have **surgically confirmed** deep endometriosis involving the bowel, bladder and/or ureter.

Consider referring young women (aged under 16) to a **paediatric and adolescent gynaecology service**, or **paediatric service** depending on local service provision.

Investigation and Management of Endometriosis in Secondary Care

Undertake **pelvic ultrasound scan (transvaginal preferred)** if not already carried out in Primary Care.

Consider MRI scan;
- if evidence of deep endometriosis on examination.
- if ultrasound scan shows large endometrioma or features of hydronephrosis.

Investigations

Consider laparoscopy to diagnose endometriosis, even if ultrasound or MRI was normal.
Discuss surgical management options with women with suspected/confirmed endometriosis:
- what laparoscopy involves, and that it 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, including the possible need for further planned surgery for deep endometriosis involving the bowel, bladder and ureter

During diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis and treat as appropriate.

If a **full systematic laparoscopy** is performed and is normal, explain to the woman that she does not have endometriosis and **offer alternative management and / or referral** for her symptoms.

Discuss alternative medical treatment for suspected or recurrent endometriosis, including treatment such as GnRHa for patients not suitable for or not wishing a laparoscopy.

If pain persists despite surgical and hormonal treatment of endometriosis, consider input from specialist pain services.

Management

If planning a pregnancy in next 12 months

Do not offer hormonal treatment to women with endometriosis who want to conceive.

Offer excision or **ablation plus adhesiolysis** to women with endometriosis.

Offer laparoscopic ovarian cystectomy to women with endometriomas.

For women with deep endometriosis involving the bowel, bladder and/or ureter **discuss** the **benefits and risks** of **laparoscopic surgery and refer to Tertiary Centre if expertise not available locally**. This may include:
- effect on the chance of future pregnancy
- the possible impact on ovarian reserve
- the effect of complications on fertility
- alternatives to surgery
- other fertility factors.

If fertility is not currently a priority

During diagnostic laparoscopy consider laparoscopic treatment of (if present):
- peritoneal endometriosis not involving the bowel, bladder or ureter
- uncomplicated ovarian endometriomas.

Consider excision rather than ablation to treat **endometriomas**.

Prior to excision of deep endometriosis involving the bowel, bladder or ureter, consider:
- pelvic MRI before operative laparoscopy
- 3 month course of GnRHa before surgery.

Consider hormonal treatment after laparoscopic excision or ablation to reduce the risk of reoccurrence

If hysterectomy is indicated;
- excise all visible endometriotic lesions at the time of hysterectomy
- discuss with the woman what a hysterectomy is, its risks & benefits, related treatments and likely outcome.
- Discuss conservation versus removal of ovaries.

SECONDARY CARE

Referral criteria to tertiary endometriosis centres for surgical management of endometriosis
- Complex or deep endometriosis involving bowel, bladder, ureters (confirmed at laparoscopy) in those wishing surgical treatment
- Extrapelvic endometriosis (such as but not limited to diaphragmatic or thoracic endometriosis) confirmed at laparoscopy or imaging (MRI/CT)
- BMI less than 35

Some of the centres may provide additional services e.g. integrated pain management, joint endometriosis fertility services etc.

For any complex endometriosis cases that do not meet the above criteria, please discuss with your regional centre on an individual case basis.

TERTIARY

References and further resources

[Endometriosis; diagnosis and management, NICE guideline (NG73) Published 06 September 2017]

[NHS Inform - Endometriosis]

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