Reference Number: **Version Number: 2**	**Date of Next Review: September 2024** **Previous Trust/LHB Reference Number:**

Title: Diagnosis and Management of Endometriosis

Introduction and Aim

This guideline indicates the pathway for patients with suspected or known endometriosis towards effective diagnosis; medical and surgical management. UHW provides care at second and tertiary service level. Appropriate tools and surgical techniques are discussed to enable optimal assessment; diagnosis and management to enable positive patient experience and effective service delivery.

Objectives

- to ensure women presenting to C&V UHB with endometriosis have access to standardised care for the diagnosis and treatment of endometriosis.
- to ensure clinicians investigate and treat endometriosis according to evidence-based practice
- provide coordinated care to ensure clinicians treat and refer appropriately according to severity of disease
- to provide appropriate management for tertiary referrals to BSGE accredited endometriosis service

Scope

This policy applies to all healthcare professionals in all locations including those with honorary contracts

Equality Health Impact Assessment	*An Equality Health Impact Assessment (EHIA) has not been completed.*
Documents to read alongside this Procedure	*Endometriosis NICE guidelines 2017* https://www.nice.org.uk/guidance/NG73 *Endometriosis Task and Finish Group 2018* https://gov.wales/sites/default/files/publications/2019-03/...
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Summary of reviews/amendments			
Version Number	**Date of Review Approved**	**Date Published**	**Summary of Amendments**

Overview

What is Endometriosis?

Endometriosis is a common chronic condition prevalent in 10% of women of reproductive age, although it can affect women post menopause. It is a condition where the cells in the lining of the uterus is implanted in other areas of the body, most commonly the ovaries and pelvic areas. Each cycle the cells react the same as cells in the endometrium and react and bleed in a similar pattern. It can lead to problems with chronic pain, sub-fertility and affect other systemic organs in the body, e.g. urinary, gastro-intestinal system and thoracic.

Often misdiagnosed, this can lead to a delay in diagnosis affecting the patient, their family and wider society. Symptoms can commence from onset of periods. Endometriosis cost the UK economy £8.2 billion a year in cost of treatment, loss of work and healthcare costs and can impact on access to education and quality of life. It is essential girls and women are treated appropriately and in a timely fashion when they present to our unit to minimise the effect on the patient, their families and the wider community.

Cardiff and Vale UHB is a BSGE tertiary endometriosis centre receiving complex referral from across South Wales. The centre collects data on complex cases of rectovaginal endometriosis cases operated in the unit contributing to the BSGE national database allowing the unit to gain accreditation and benchmark the progress with other units in the UK.

There is a dedicated MDT with input from specialist gynaecologist, colorectal, urological surgeons, radiologist, endometriosis clinical nurse specialist, physiotherapist and dietician with an interest in endometriosis as well as established links with fertility services. There is access to pain specialist with expertise in chronic pelvic pain. The centre also provides training of endometriosis specialist within the RCOG Advanced Laparoscopic Surgery of Benign Disease ATSM.

Signs and Symptoms:

Women should have a thorough history and examination prior to appropriate investigation to ensure prompt diagnosis and treatment.

Common signs and symptoms include:
Dysmenorrhoea
Menorrhagia
Cyclical and or Non-Cyclical pelvic pain
Dyspareunia
Dysuria
Dyschezia
Fatigue
Back pain

These can present in a variety of ways and vary in presentation.

Investigations:

Ultrasound (preferably TVUS. TAUS if not appropriate e.g. not sexually active or patient declines)

- Assess for pelvic masses

- Ovarian Pathology – see C&V guideline on Ovarian Cyst guidelines. Relation of ovaries to uterus
- Uterus (adenomyosis, fibroids), mention if anteverted / retroverted
- Pouch of Douglas-? fluid ?free ?sliding sign
- A normal pelvic ultrasound does not exclude endometriosis
- Other findings associated with endometriosis include fixed retroverted uterus, endometriomas, kissing ovaries or loss of sliding sign or ovaries close to uterus.

CT/MRI – not used to diagnose endometriosis. MRI can be useful to help surgical planning in suspected cases of deep infiltrating endometriosis.

Rectal Endoscopic Ultrasound Scan (REUS) – pre-operative tool in detection of rectal involvement in rectovaginal endometriosis.

- Women should have proven rectovaginal endometriosis, suspected involvement of rectum/rectosigmoid junction or full thickness retro-vaginal endometriosis nodule into the vagina.
- REUS is performed by specially trained consultant radiologist.
- Request form to be filled by Endometriosis team
- If REUS shows rectal muscularis involvement this will need a joint procedure with a colorectal surgeon.

Ca-125 should not be used to diagnose Endometriosis

- Ca-125 can be raised in cases of endometriomas and deep infiltrating endometriosis

Diagnostic Laparoscopy – This is the gold standard in diagnosis of endometriosis. A gynaecologist should perform a systematic inspection of the abdomen & pelvis. When endometriosis is diagnosed, the gynaecologist should document a detailed description of the appearance and site of endometriosis. (NICE guideline 2017).

Every gynaecologist performing the diagnostic laparoscopy needs clear photographic evidence of all areas checked during the procedure. Any evidence of disease should be described as superficial or deep with documentation of features such as adhesions, endometriomas, involvement of bladder, bowel or ureters. As a minimum, the procedure should have information regarding the following sites:

- Abdomen: both left and right hemi-diaphragms; anterior liver surface; both anterior abdominal walls and note if the bowel is adherent or the appendix affected.
- Pelvis: utero-vesical fold; broad ligaments including round ligaments; whole surface of ovaries; ovarian fossae; both pelvic side walls; utero-

sacral ligaments; para-rectal spaces; pouch of Douglas (with use of rectal probe to ensure complete analysis of POD); anterior rectum.

- If views are not obtained along with photographic evidence, then this is deemed inadequate laparoscopy and any referral to the endometriosis centre will not be accepted.
- If views are not obtained along with photographic evidence, then this is deemed inadequate laparoscopy and any referral to the endometriosis centre will not be accepted.
- Age of initial normal diagnostic laparoscopy should be noted as may require repeat investigation.

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

If endometriosis is seen at laparoscopy, excision of disease should be undertaken by a gynaecologist with the skills and training to do so. Severe cases of endometriosis should be referred to the Endometriosis team for outpatient review prior to counselling and listing for a further 2nd stage procedure. Second stage surgery for tertiary level endometriosis should be performed by a gynaecologist with advanced laparoscopic skills and accreditation.

Operative scheduling of laparoscopy should be timed accordingly (BSGE/RCOG Framework Document).

Management

It should be emphasised not all women need a laparoscopy to diagnose endometriosis and quite often analgesia and hormonal management is sufficient to treat and control symptoms. If symptoms improve with hormonal contraception it is deemed acceptable to have a working diagnosis of endometriosis without the need of a laparoscopy (NICE guidelines Endometriosis). Management should take into account the individual's circumstances, symptoms, priorities, desire for fertility, cultural and emotional needs.

Discuss keeping a pain / symptom diary to assess impact of treatment initiated.

Analgesia

- Paracetamol +/- Codeine Phosphate
- Non-Steroidals – consider a short trial e.g 3 months
    - Ibuprofen
    - Mefanamic Acid

- Naproxen

Encourage the use of a transcutaneous electrical nerve stimulation (TENS) machine.

Consider the use of neuromodulating medication for neuropathic pain (unlicensed use). See NICE guidelines on Neuropathic pain in adults CG173

Hormonal Management:

Hormonal therapies should be trialled for 3 (COCP) or 6 (POP/Mirena/Jaydess) months. Individualised patient risk factors should be considered prior to prescribing the progestogen-only pill (POP) or continuous combined oral contraceptive pill (COCP)

- If starting POP, use Desogestrel 75mg as first line – inhibit ovulation in 97% of cycles. The dose can be doubled once daily if initial dose not effective or erratic bleeding.
- COCP – tricycling COCP initially. Alternatively the COCP can also be used continuously without break.
- Consider levonorgestrel-releasing IUS (does not suppress ovulation in all women) as long-term medical management.
- Other long-acting reversible contraceptives (LARCs) can be considered, including Depo-Provera/ Dianette/Implanon can be used with caution due to erratic bleeding which may exacerbate pain.

GnRH analogues with addback HRT

- Prostap 3.75mg s/c every 4 weeks and Tibolone 2.5mg od as addback HRT. Tibolone is commonly used as it regulates oestrogenic activity in a tissue selective manner in brain, vagina and bone, but not in endometrium
- Licenced use of Prostap is 6 months for endometriosis. Longer use than 6 months of Prostap has to be used in conjunction with addback HRT.
- If no symptom control by 3 months, consider stopping and using alternative treatment or another cause of pain
- Patients on Prostap can be seen in Nurse led Prostap clinic.
- Patients on long-term use of Prostap should have a DEXA scan every 2 years to check for osteopenia/osteoporosis.

Some of this treatment is off-label but been endorsed by NICE and local gynaecologists.

If not responding to maximal medical treatment after 6 months:

- consideration of surgical management.

Surgical Management:

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

Discuss surgical management options with women with suspected or confirmed endometriosis. Discussions may include:

- what a laparoscopy involves
- that laparoscopy may include surgical treatment e.g excision of endometriosis (with prior patient consent)
- how laparoscopic surgery could affect endometriosis symptoms
- the 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 infiltrating endometriosis (DIE) involving the bowel, appendix, bladder, ureter and diaphragm.

All patients should be given an information leaflet when a surgical procedure is booked.

During a diagnostic laparoscopy to diagnose endometriosis, consider laparoscopic treatment of the following, if present:

- peritoneal endometriosis not involving the bowel, bladder or ureter
- uncomplicated ovarian endometriomas which may be drained or excised.

After laparoscopic excision of endometriosis, consider hormonal treatment to prolong the benefits of surgery and manage symptoms.

If hysterectomy is indicated (for example, if the woman has adenomyosis or heavy menstrual bleeding that has not responded to other treatments), excise all visible endometriotic lesions at the time of the hysterectomy.

If performing a hysterectomy it should be via a laparoscopic approach when combined with surgical treatment of endometriosis, unless there are complications.

For women considering 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).

Surgical management if fertility is a priority

Endometriosis often affects approximately 25% of fertility patients and patients are referred for surgery to excise endometriosis to aid fertility. The management of endometriosis-related subfertility should have multidisciplinary team involvement with input from Wales Fertility Institute.

If pain is not an issue offer excision of endometriosis plus adhesiolysis for endometriosis not involving the bowel, bladder or ureter, because this improves the chance of spontaneous pregnancy along with 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.

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. 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 unless it is being used to control symptoms.

Patients undergoing rectovaginal excision of endometriosis with involvement of the pararectal space should fill in the BSGE Pelvic Pain questionnaire sheet prior to surgery with the corresponding surgical form filled by endometriosis team for the BSGE database collection. Questionnaires can be obtained from the Endometriosis team.

Specialist Endometriosis Clinic:

Patients with complex endometriosis should be seen in the specialist endometriosis clinic.

Clinic consist of Consultant Gynaecologists with specialist interest in endometriosis and Endometriosis Nurse Specialist with longer appointment times to address complex needs and requirements.

Endometriosis specialist clinics are held every Monday morning once weekly.

Endometriosis MDT occurs weekly at 1pm after the Endometriosis clinic. If patients are referred for MDT, please ensure Endometriosis MDT criteria is met prior to MDT request or referral will be rejected.

Referral Criteria Tertiary Endometriosis Clinic:
Deep Endometriosis Involving bladder, bowel or ureter.
Endometriosis involving diaphragm.
Referrals should be accompanied by clear laparoscopic images identifying areas of deep endometriosis or diaphragm.

There is a self-referral/GP/Consultant endometriosis and pelvic pain nurse led clinic. This is currently available to all current patients including tertiary referrals and residents of Cardiff and Vale University Health Board. Due to lack of funding all enquiries from other areas are declined if this criteria does not apply.

Referral to Chronic Pain Clinic can be made from the Endometriosis clinic if other options have been attempted.

The role of the Endometriosis Specialist Nurse includes:

Manage and develop Nurse led self-referral clinic for management of endometriosis and pelvic pain. Develop on-line email help line to support women

Manage and develop preoperative consent clinic for advanced laparoscopic procedures.

Participate in the weekly endometriosis clinic and MDT.

Assess develop and implement acute and chronic management plans and arrange follow up care where necessary.

Provide extended roles such as nurse sonographer; surgical assistant and non-medical prescriber.

To provide post-operative support by explaining findings and organising further management and appointments

As an autonomous nurse practitioner manage complex clinical situations provide guidance, supervision and training to peers and junior members of staff.

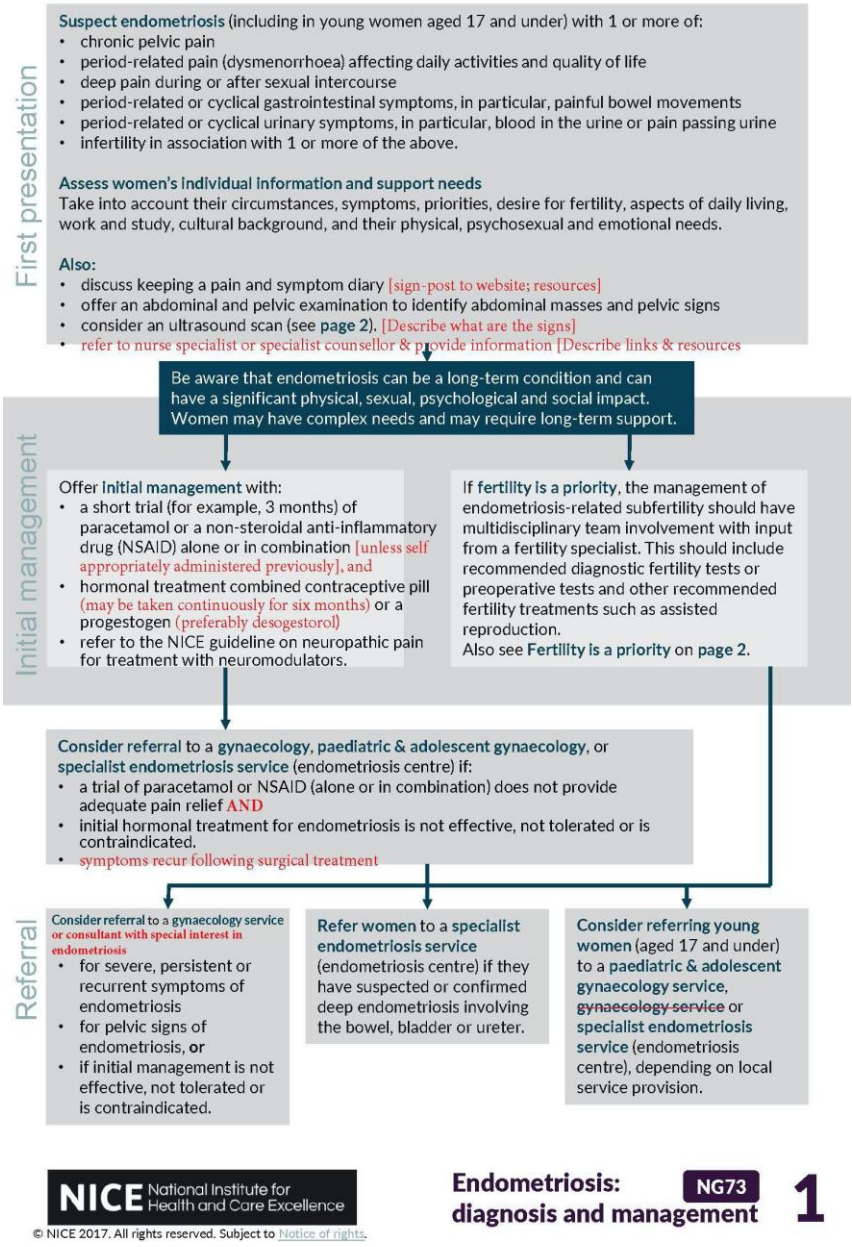
Provide support to monitor, assess and review unscheduled admissions with symptom exacerbation and to prevent readmission.

Develop relationships with local and national support groups and education programmes to promote knowledge, awareness and understanding.

To ensure with support of MDT that clinical procedures and protocols are in place which ensure the safety of women and staff and meet local and national guidelines.

Participate/ lead on clinical audit and database.

If there are any questions relating to the management of patients with endometriosis, please approach a member of the team for further guidance.


First presentation
Suspect endometriosis (including in young women aged 17 and under) with 1 or more 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.
Also:
discuss keeping a pain and symptom diary [sign-post to website; resources]
offer an abdominal and pelvic examination to identify abdominal masses and pelvic signs
consider an ultrasound scan (see page 2). [Describe what are the signs]
refer to nurse specialist or specialist counsellor & provide information [Describe links & resources
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 may require long-term support.
Initial management
Offer initial management with:
a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination [unless self appropriately administered previously], and
hormonal treatment combined contraceptive pill (may be taken continuously for six months) or a progestogen (preferably desogestorol)
refer to the NICE guideline on neuropathic pain for treatment with neuromodulators.
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 other recommended fertility treatments such as assisted reproduction.
Also see Fertility is a priority on page 2.
Consider referral to a gynaecology, paediatric & adolescent gynaecology, or specialist endometriosis service (endometriosis centre) if:
a trial of paracetamol or NSAID (alone or in combination) does not provide adequate pain relief AND
initial hormonal treatment for endometriosis is not effective, not tolerated or is contraindicated.
symptoms recur following surgical treatment
Referral
Consider referral to a gynaecology service or consultant with special interest in endometriosis
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 suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.
Consider referring young women (aged 17 and under) to a paediatric & adolescent gynaecology service, ~~gynaecology service~~ or specialist endometriosis service (endometriosis centre), depending on local service provision.
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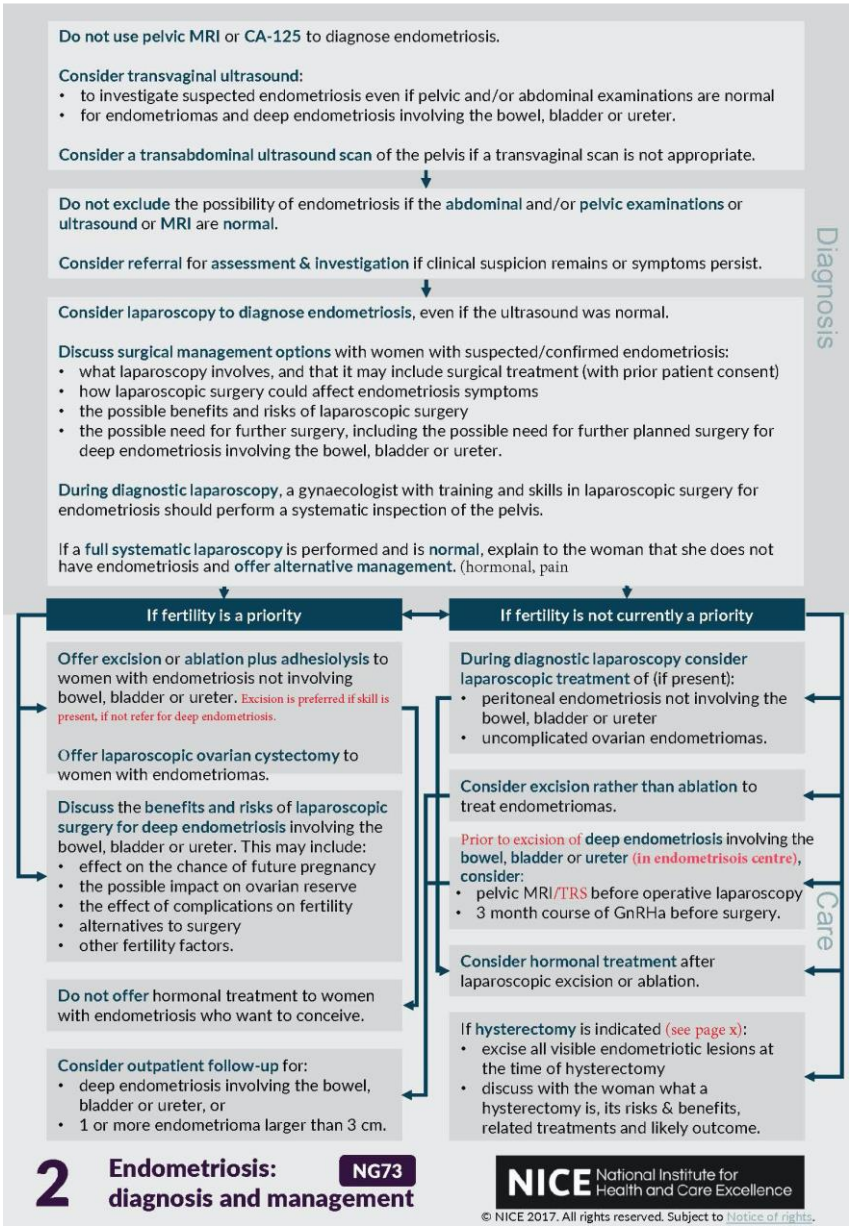
Do not use pelvic MRI or CA-125 to diagnose endometriosis.
Consider transvaginal ultrasound:
• to investigate suspected endometriosis even if pelvic and/or abdominal examinations are normal
• for endometriomas and deep endometriosis involving the bowel, bladder or ureter.
Consider a transabdominal ultrasound scan of the pelvis if a transvaginal scan is not appropriate.
Do not exclude the possibility of endometriosis if the abdominal and/or pelvic examinations or ultrasound or MRI are normal.
Consider referral for assessment & investigation if clinical suspicion remains or symptoms persist.
Consider laparoscopy to diagnose endometriosis, even if the ultrasound 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 or ureter.
During diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.
If a full systematic laparoscopy is performed and is normal, explain to the woman that she does not have endometriosis and offer alternative management. (hormonal, pain
Diagnosis
If fertility is a priority
If fertility is not currently a priority
Offer excision or ablation plus adhesiolysis to women with endometriosis not involving bowel, bladder or ureter. Excision is preferred if skill is present, if not refer for deep endometriosis.
Offer laparoscopic ovarian cystectomy to women with endometriomas.
Discuss the benefits and risks of laparoscopic surgery for deep endometriosis involving the bowel, bladder or ureter. 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.
Do not offer hormonal treatment to women with endometriosis who want to conceive.
Consider outpatient follow-up for:
• deep endometriosis involving the bowel, bladder or ureter, or
• 1 or more endometrioma larger than 3 cm.
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 (in endometrisois centre), consider:
• pelvic MRI/TRS before operative laparoscopy
• 3 month course of GnRHa before surgery.
Consider hormonal treatment after laparoscopic excision or ablation.
If hysterectomy is indicated (see page x):
• 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.
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