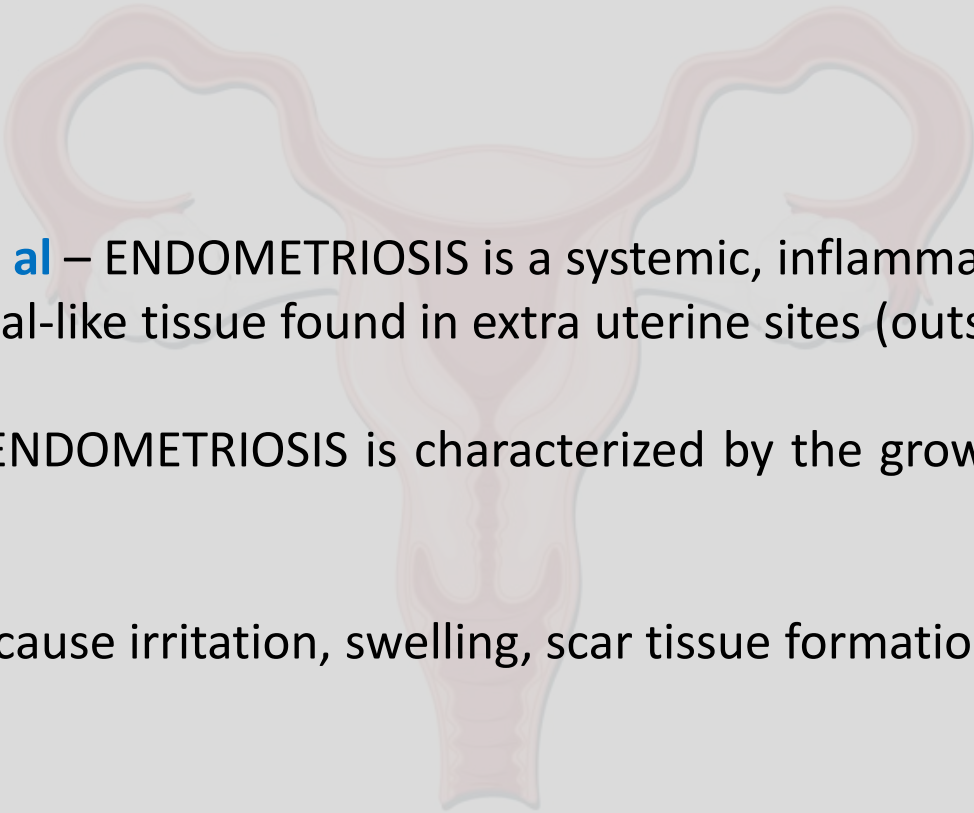


ENDOMETRIOSIS / ADENOMYOSIS TOOL KIT

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ENDOMETRIOSIS DEFINITION

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- **According to Kennedy S et al** – ENDOMETRIOSIS is a systemic, inflammatory disease characterized by the presence of endometrial-like tissue found in extra uterine sites (outside of the uterus)
 - **According to NICE CKS** – ENDOMETRIOSIS is characterized by the growth of endometrial-like tissue outside of the uterus
 - Endometriosis lesions can cause irritation, swelling, scar tissue formation (adhesion) and pain

SYMPTOMS

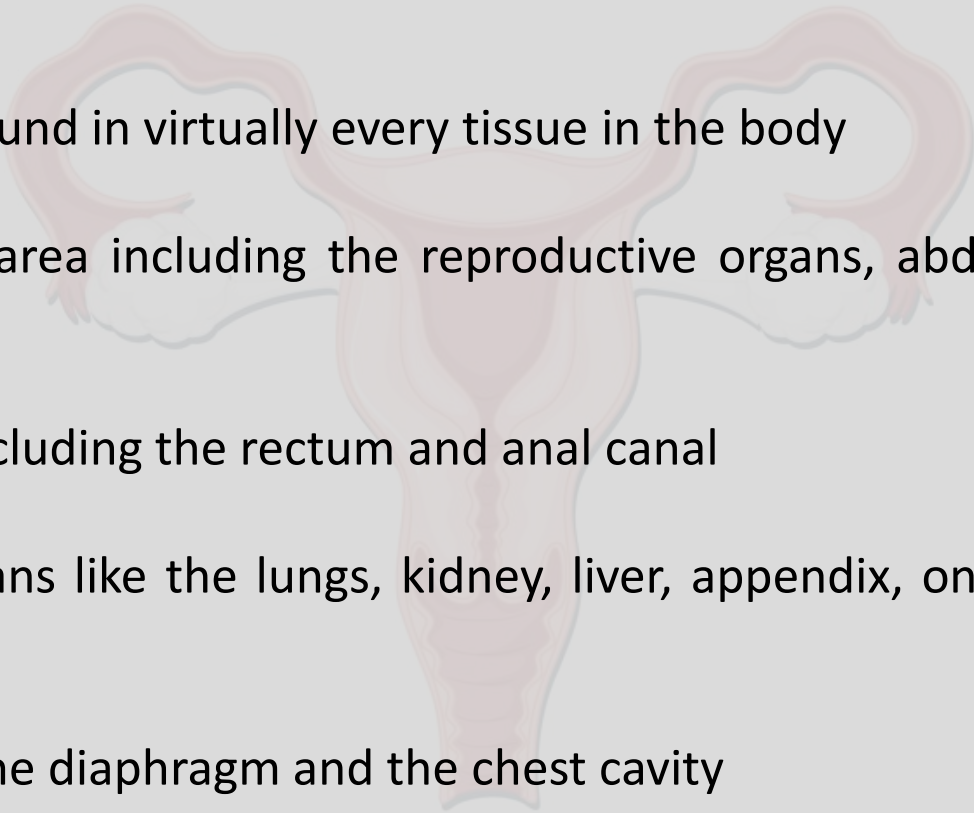
Symptoms vary depending where they are found

Common ones include:

- 1) Pelvic pain, period pain, heavy periods, pain during intercourse
- 2) Painful bowel movements and pain passing urine
- 3) Change in bowel habits, Nausea and Vomiting
- 4) Low back pain, infertility
- 5) Brain fog and fatigue
- 6) Chest pain, shortness of breathe and difficulty breathing if present in the chest cavity
- 7) General feeling of unwellness



SITES OF ENDOMETRIOSIS

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- 1) Endometriosis has been found in virtually every tissue in the body
 - 2) Common sites are Pelvic area including the reproductive organs, abdominal wall, fallopian tubes, ovaries, bladder etc.
 - 3) Also found in the bowel including the rectum and anal canal
 - 4) They can be found in organs like the lungs, kidney, liver, appendix, on the nerves and the brain to name a few
 - 5) It has also been found in the diaphragm and the chest cavity

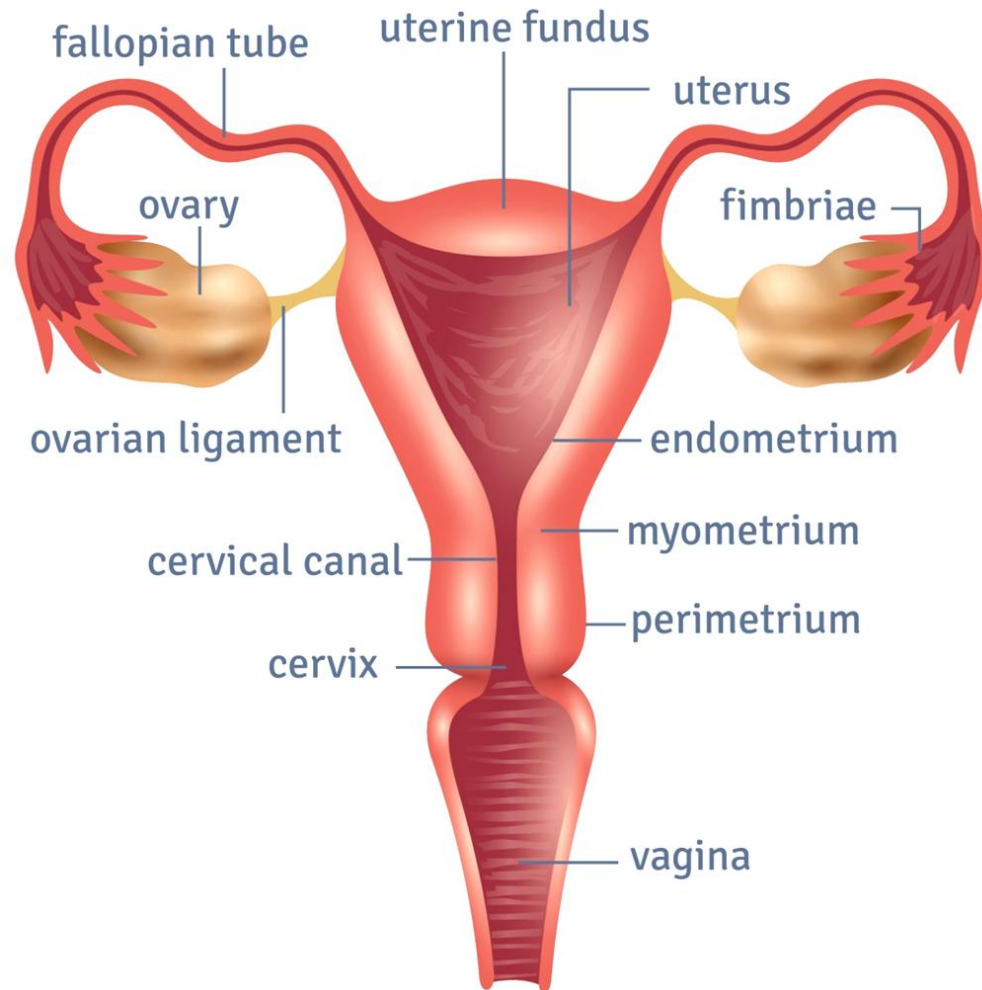
EPIDEMIOLOGY / STATISTICS

- 1) 1 in 10 have Endometriosis but could be more(over 200million women globally)
- 2) The average time before diagnosis is 7.5 years
- 3) 3 out 4 women experience misdiagnosis
- 4) According to this article on National Library of Medicine – PubMed Central, About 25 to 50% of infertile women have endometriosis, and 30 to 50% of women with endometriosis are infertile
- 5) Endometriosis has been found on every organ in the body and has also been found in the fetus
- 6) Up to 5% of women with Endometriosis are post menopausal
- 7) The prevalence of Endometriosis in women with Adenomyosis was 80.6% and the prevalence of Adenomyosis in women with Endometriosis was 91.1%
- 8) Endometriosis costs the UK economy about £8.2 billion in treatment, loss of work and healthcare. In the US, it is estimated at about \$70 billion annually
- 9) It is the second most common gynecological condition globally (after fibroids)
- 10) It is linked with higher rates of autoimmune diseases and endocrine disorders, chronic fatigue and irritable bowel disease.
- 11) According to NHS.UK, There is no cure and it can be difficult to treat

WHAT IS A NORMAL PERIOD

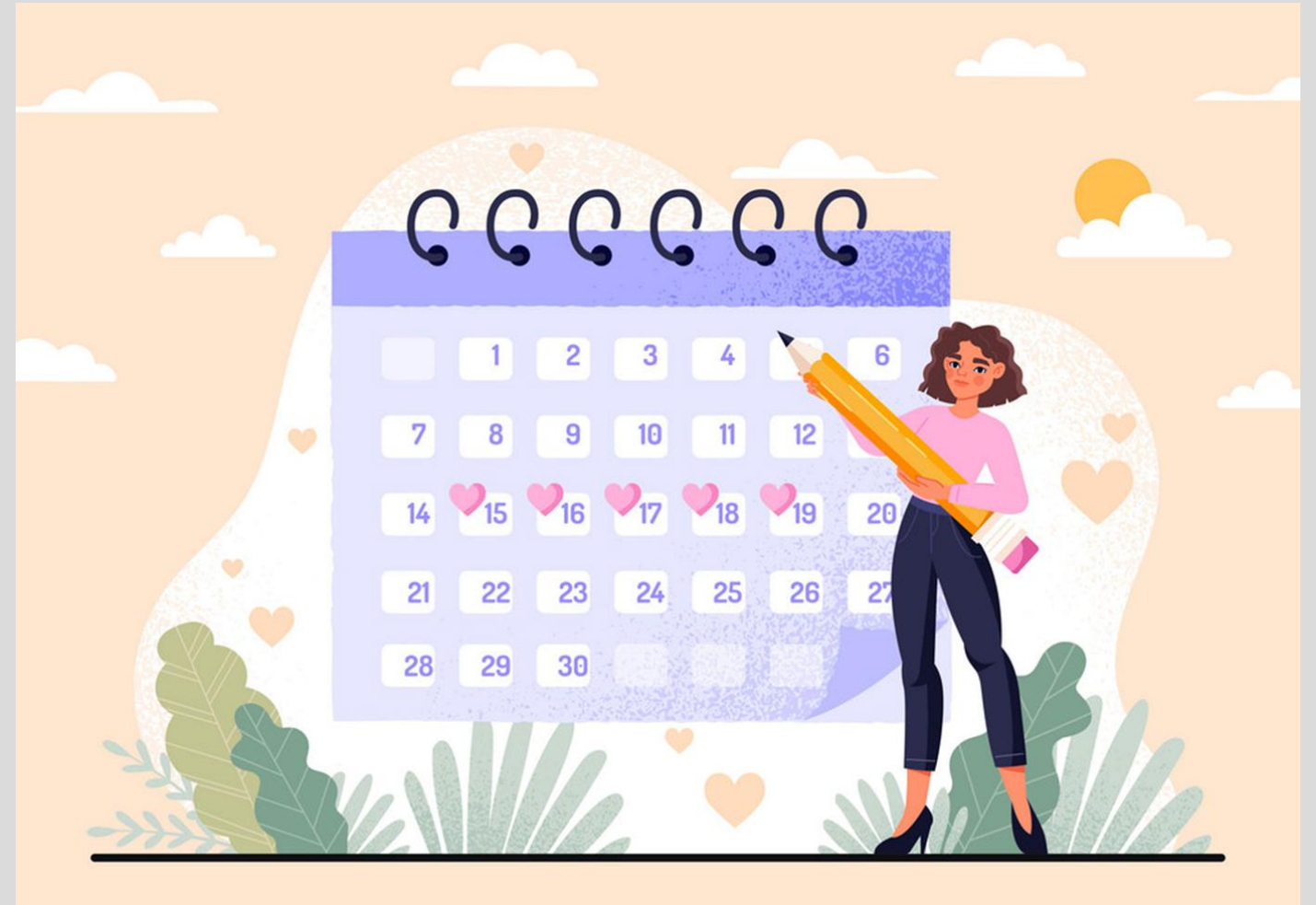
- 1) During a female's reproductive years, she experiences a monthly flow of blood known as the menstrual period
- 2) The Length and quantity of flow of a normal period varies from one female to another
- 3) A Normal period occurs every 21 to 35 days. It Lasts from 2 to 7 days and can be light or moderate flow (averaging no more than 1 soaked pad/tampon every 3 hours)
- 4) **However, it is not normal when your period related symptoms can not be managed with over the counter medications, or when they significantly affect your daily activities**
- 5) Chronic Pelvic Pain which flares up during the menstrual cycle with or without heavy menstrual bleeding could be an early presentation of endometriosis
- 6) In other words, Pelvic pain in women should not be normalized. **Period symptoms can cause discomfort but should not be distressing**

FEMALE REPRODUCTIVE SYSTEM



KEEPING A DIARY

- Keeping a diary is an important tool to monitor, track and understand your menstrual cycle
- It also forms the basis of evidence with dates for your doctor's appointment



KEEPING A PERIOD DIARY

- Tracking your menstrual cycle is a good way to determine what is 'Normal' for you
- It can also give your healthcare provider a more complete understanding of your symptoms, presentation and its impact on your daily activities

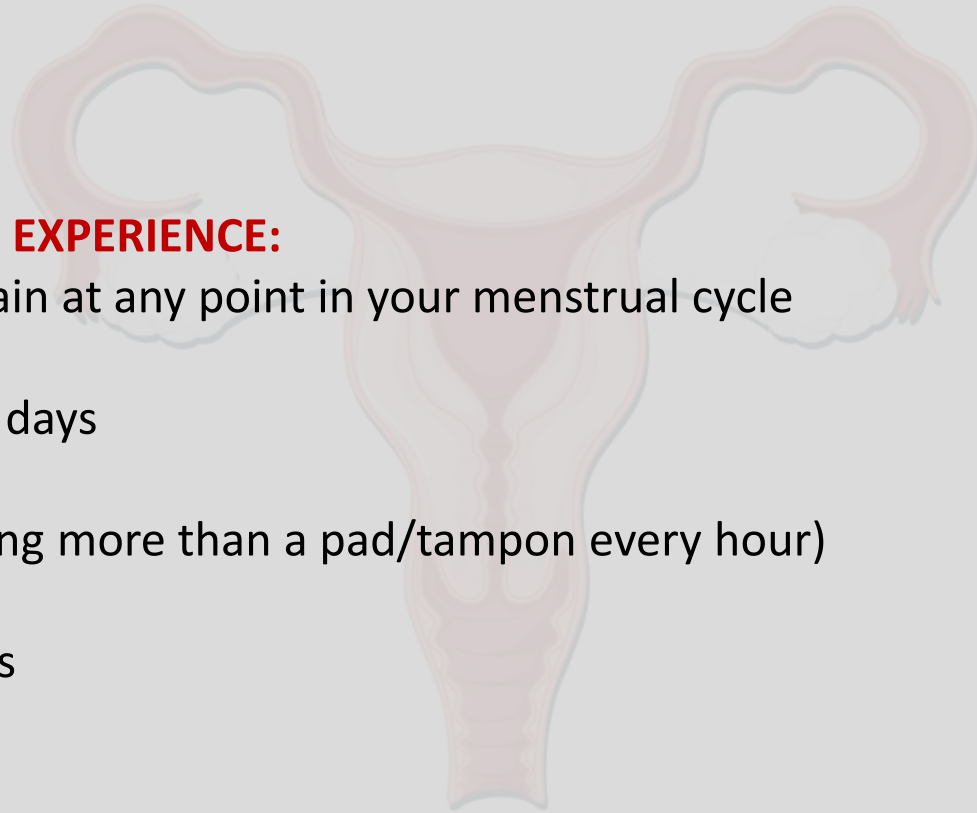
WHAT SHOULD BE IN YOUR DIARY:

- 1) Period start and end dates
- 2) **Menstrual flow** – quantity of flow and how many pads or tampons used per day. ◦ Pelvic Pain/cramps, before, during and immediately after your cycle; and its influence on your day to day activities
- 3) Other symptoms such as constipation, lower back pain, nausea and vomiting, diarrhea, any pain with urination or opening your bowels
- 4) Anything out of the ordinary, e.g. abnormal bleeding, late or missed periods, mood changes, sleep problems, etcetera

KEEPING A PERIOD DIARY (cont...)

CONSULT YOUR DOCTOR IF YOU EXPERIENCE:

- 1) Abnormal or high level of pain at any point in your menstrual cycle
- 2) Period lasting longer than 7 days
- 3) Heavy Bleeding/clotting(using more than a pad/tampon every hour)
- 4) Bleeding in between periods



PREPARING FOR YOUR DOCTOR'S VISIT

Endometriosis symptoms vary from one individual to the next. It is important to discuss with your healthcare provider which aspects of symptoms are most burdensome. Be graphic about the frequency and severity of your symptoms and how it affects your daily activities. If you are uncomfortable discussing this, write them down and share with your doctor.

Here are a list of things to bring along to your appointment :

- 1) Pain diary and its relation to your menstrual cycle
- 2) A list of all your symptoms
- 3) A list of your medication including over the counter medications and herbal supplements
- 4) A support person which may be your spouse, family member or friend you trust

MANAGEMENT OPTIONS

1) ANALGESIA (this includes Paracetamol as well as):

- a) Non steroidal anti inflammatories like Ibuprofen, Diclofenac, Naproxen and ketoprofen.
- b) Opioids: Such as codeine, Dihydrocodeine, morphine
- c) Neuropathic pain killers. Such as pregabalin and gabapentin which are also second line for mood changes
- d) Other Pain reliefs such as TENS Machine, Heating pads, Magnesium salt baths

2) Hormonal Treatment:

- a) A Combined oral contraception, Progesterone only pills, Implant(Nexplanon), Hormonal coil(IUCD)
- b) GnRH Analogues: Prostag (leuprorelin acetate), Zoladex (goserelin acetate), triptorelin and histrelin – Injectables

3) Other Management:

- a) Pelvic Floor physical therapy, Local Nerve blocks, Cognitive behavioral therapy

It is important to note that the latest research states that these options do not provide a cure for Endometriosis.

Also, Hormonal therapy does not stop the growth of endometriosis but in a few people may provide short term relief. It is important to weigh the risk vs benefits of hormone therapy especially on your mental health.

GnRH ANALOGUES

- These are medications that block production of certain hormones in the body, especially estrogen and androgen
- They are primarily used in the treatment of advanced prostate cancer
- They are also used to manage conditions such as Endometriosis, precocious puberty, uterine fibroids and infertility

SIDE EFFECTS :

- 1) Bone disorders: Bone and Joint aches, Thinning of bones(Osteoporosis)
- 2) Gynecological disorders: Premature menopause, Menstrual irregularities, withdrawal bleed etc
- 3) Psychiatric: Anxiety and Depression, Personality changes and hallucinations etc
- 4) Biochemical: Acute Liver Injury, Liver failure, Glucose intolerance, High calcium in blood etc
- 5) Cardiac/Pulmonary: Heart failure, blood clot in lungs, irregular heart beat, pneumonia, Heart attack
- 6) Neurological: Pins and needles, spinal cord compression etc
- 7) Physical : Alopecia, Excessive sweating, weight gain, diarrhea and constipation, leg swelling, sleep disorder, fatigue etc

Research has shown that Contraceptive Hormones and GnRH Analogues are NOT a definitive treatment for endometriosis.

TREATMENT

- 1) The only definitive treatment for endometriosis is Laparoscopic EXCISION of endometriosis lesions
- 2) By Excision, we mean, cutting out the lesion in its entirety. This is different from Ablation which burns the lesions superficially
- 3) Excision is the Gold Standard for treatment and
- 4) Laparoscopic Excision should always be considered in preference to Ablation.



QUESTIONS TO ASK YOUR GYNECOLOGIST

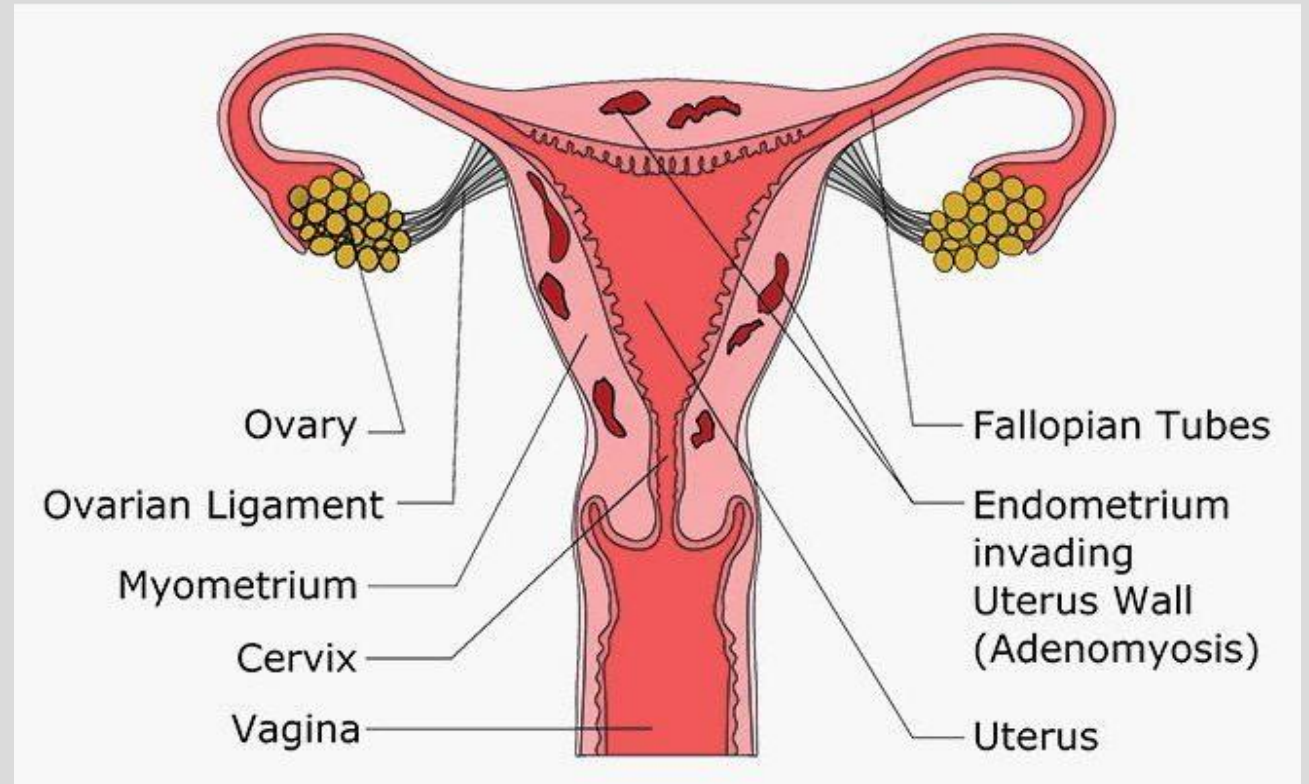
- 1) After a well detailed history and examination, a question should be put forward by the patient on what sort of management/treatment is recommended for your specific needs and why?
- 2) During your assessment with the gynecologist, the following would have been put into perspective before outlining the best course of action. This includes your Age, Fertility status, Lifestyle and activity levels, family planning goals, Symptom management, treatment efficacy and side effects as well as complications at the time of presentation both physically and mentally
- 3) Talk to your Doctor about your **fertility** options and preservations which includes both natural and assisted ways to help you, should you wish to conceive
- 4) **TEAM Approach:** You may benefit from a multidisciplinary team approach. This may include, an excision Surgeon, Endocrinologist for hormonal therapy, Gastroenterologist for gastrointestinal health, Physical therapist for pelvic floor dysfunction, Mental Health Professional for emotional, sexual, behavioral and coping skills, Nutritionist for nutritional counseling

QUESTIONS TO ASK YOUR SURGEON

- 1) What type of surgeries do you perform and why?
- 2) What kind of complex cases do you see and how do you treat them?
- 3) Do you work alone or as part of a multidisciplinary team?
- 4) What percentage of your patients require additional surgery with you or someone else?
- 5) Are you able to excise fully the lesions no matter where it is located?
- 6) Do you remove as much Gas as possible before the end of surgery to lessen referred shoulder pain, common with laparoscopy?
- 7) Do you use an adhesion barrier and/or PRP(Platelet rich Plasma therapy) intraoperatively? (An adhesion barrier/PRP accelerates the healing process, reduces pain and prevents adhesion formation)
- 8) How long will I spend in the Hospital and How best do I prepare for my Surgery?
- 9) What are the immediate and long-term complications and how do you plan to prevent that?
- 10) What is your post-surgical pain management protocol?
- 11) How Long will I be out of School or work after having my Surgery?

ADENOMYOSIS

- NHS Inform defines Adenomyosis as a condition that causes the lining of the womb (endometrium) to bury into the muscular wall of the womb (myometrium)
- As the cells respond to monthly hormonal changes, blood can get trapped in the myometrium producing a hard and enlarged uterus
- The condition is believed to affect 1 in 10 women globally, and although it is benign, Adenomyosis can have a serious impact on the patient's quality of life



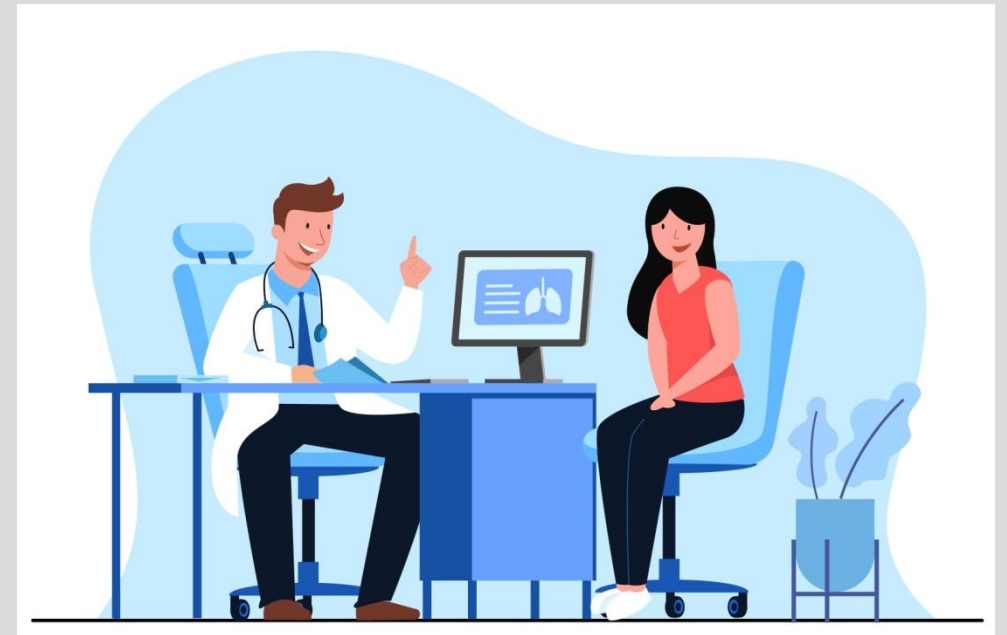
SYMPTOMS

Adenomyosis symptoms are many and varied but the most common are :

- 1) Severe Period Pain (Dysmenorrhea)
- 2) Heavy Periods (Menorrhagia) and sometimes with large blood clots
- 3) Anemia (low blood count) due to heavy bleeding
- 4) Fatigue
- 5) Pelvic Pain
- 6) Lower abdominal pressure or heaviness
- 7) Painful sex (dyspareunia)
- 8) Leg Pain due to compression on nerves
- 9) Low Back Pain
- 10) Bowel and Bladder Dysfunction

DIAGNOSIS

- 1) A pelvic physical examination is first carried out by the physician on suspicion of Adenomyosis. This may involve vaginal examination as well at the bedside with a chaperone present
- 2) An Ultrasound scan of the pelvis is ordered afterwards which may or may not show the Adenomyosis, depending on the radiographer's skills
- 3) MRI is more sensitive and specific than the ultrasound scan, in diagnosing adenomyosis
- 4) However, the Gold standard and confirmation of ADENOMYOSIS is laparoscopic hysterectomy and histology



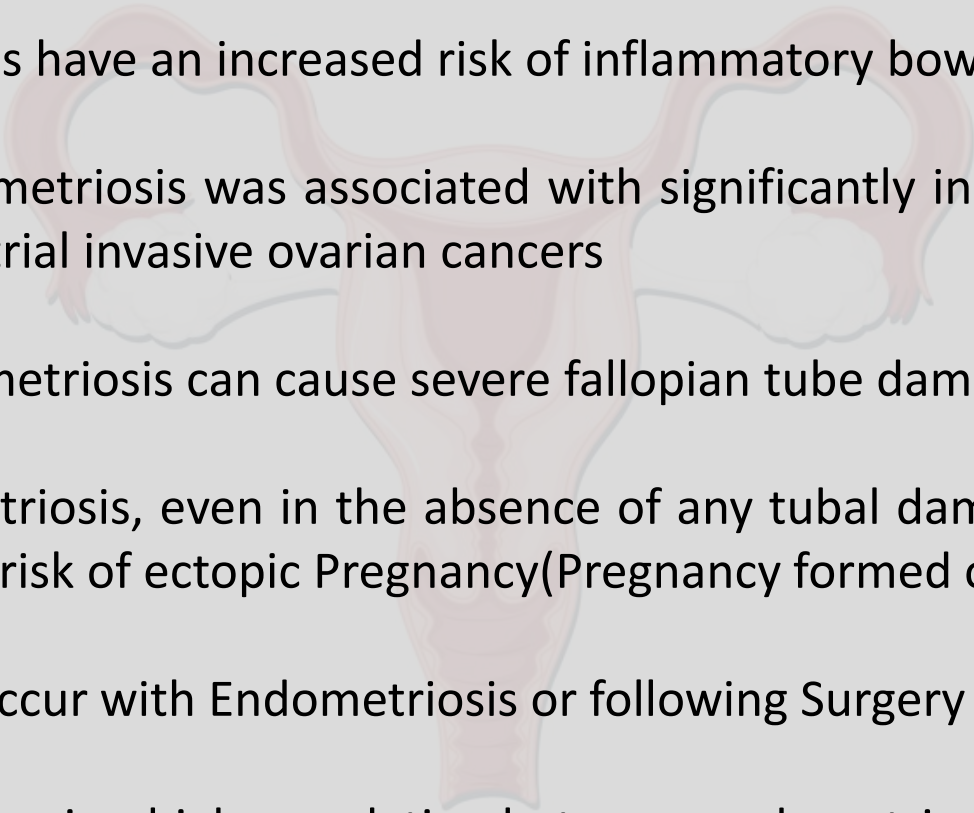
MANAGEMENT / TREATMENT

- Anti-inflammatories to relieve mild to moderate pain
- Medication to reduce bleeding; e.g. Tranexamic Acid
- Hormonal therapy such as contraceptive pill, IUCD

TREATMENT :

- 1) Hysterectomy (removal of the womb). This provides cure for Adenomyosis
- 2) Other forms of treatment are Laparoscopic Presacral Neurectomy

COMPLICATIONS

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- 1) Women with endometriosis have an increased risk of inflammatory bowel disease
 - 2) A review found that Endometriosis was associated with significantly increased risk of clear cell, low grade serous and endometrial invasive ovarian cancers
 - 3) Moderate to Severe Endometriosis can cause severe fallopian tube damage, leading to infertility
 - 4) Lesser degrees of endometriosis, even in the absence of any tubal damage are also associated with sub-fertility and increased risk of ectopic Pregnancy(Pregnancy formed outside of the womb)
 - 5) Adhesion formation may occur with Endometriosis or following Surgery
 - 6) Studies has shown that there is a high correlation between endometriosis and Autoimmune diseases

PROGNOSIS (OUTCOME OF A DISEASE)

- 1) Endometriosis is a Chronic Disease which can affect women throughout their reproductive lives and sometimes beyond Menopause
- 2) Some women with endometriosis/adenomyosis have complex needs and require long term support
- 3) Its impact on women and their productivity cannot be over emphasized as it affect every facet of their life which in turn affects the national Economy. Many of the sufferers find it difficult to create/hold jobs or have a steady source of income
- 4) Awareness of this debilitating condition is growing, however with an average diagnosis time of about eight years and a cost of an estimated £8.2 billion per year to the UK economy in terms of lost work, treatment and healthcare costs, the potential impact on work and employment is clear.(Public Health England)
- 5) Recurrence of the disease after surgery ranges from 10 – 50% @ One year and increases over time depending on the skill of the surgical team

MANAGING WORK – LIFE BALANCE WITH ENDOMETRIOSIS

- Endometriosis is a progressive Chronic illness that affects all facets of life
 - Like other chronic illnesses, stress is a trigger factor, so it is important to create a work – life balance
 - Few ways to manage endometriosis at work are as follows
- 1) Be honest with yourself – Your illness is a reality that you need to deal with. Acknowledge your limits and do not push yourself till you breakdown
 - 2) A lot of people invest more in their work than their health. This is a red flag as this can lead to worsening symptoms and emotional breakdown
 - 3) Ideally, you should not disclose your condition to any one, however if it interferes with your work, you may consider discussing this with your supervisors
 - 4) You may request for off days during peak pain cycles. You can request to work from home if permitted. Ask for adaptation and amended duties where possible. Consider asking for a day or half day off for Doctors appointments
 - 5) For the students who find themselves in this situation, consider discussing your situation with the school counselor or class teacher
 - 6) Students can join classes online from home if they are physically struggling with pain or having an emotional breakdown. There should be regular communication between the school and family
 - 7) They should be given time to take breaks in between for their medication and possibly change their pads if they are having heavy cycles

ILLUSTRATIVE IMAGES



WELLNESS TIPS

Gentle Stretching Exercise with plenty of rest; Low intensity stretches may help relieve cramps and improve bowel motility if you are constipated.

Diet: Healthy eating habits and diet may help reduce inflammation which drives pain. Your gut controls inflammation, immunity, hormone balance, sleep quality and mood. It is essential for Endo/Adeno warriors to maintain a healthy anti-inflammatory diet that includes healthy fat (avocado, olive oil, pumpkin seeds, omega 3 eggs, nut butters etc, protein (organ meat, organic bone broth, oily fish etc), fruits and vegetables (Broccoli sprouts, carrots, colorful bell peppers, green bananas, leafy vegetables including spinach, berries, cruciferous vegetables, ginger tea) etc. You may benefit from working with an Endometriosis dietician.

Balance school/work life/personal life: Maintaining a balance between your commitments and your personal life is key. It is important to plan your day with breaks in between to reduce stress. Also, consider asking for accommodations if and when needed. On the days your symptoms are particularly difficult to manage, consider taking appropriate leave or ask for the day off. If you know your worst days from keeping a diary, plan ahead.

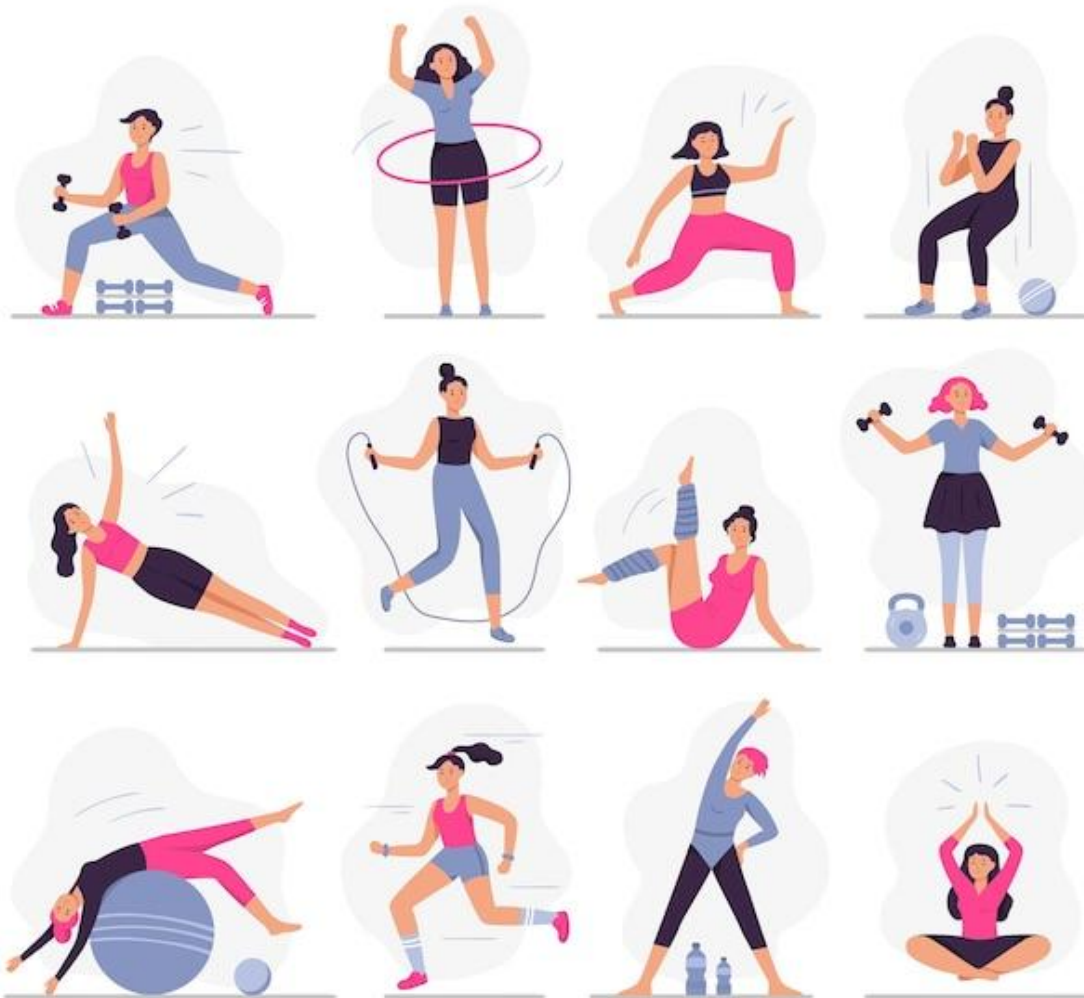
WELLNESS TIPS (cont...)

Get a support system: Create a support system you can confide in and ask for help when needed. They can help with simple chores, speaking up for you during doctor visits, help as accountability partners or give mental health support when needed.

Travel: It is advisable to schedule your trips on the least problematic days of your cycle and ensure you have enough pain killers and relaxation aids to last your trip. Having a portable Tens machine and pain relief devices to manage your pain on the go is vital. Schedule in rest days and gentle exercises.

Sexual health: It is important to talk to your partner about how you feel during intimacy. Endometriosis and Adenomyosis can cause pain or discomfort during sexual intercourse so it is important to discuss ways to make you feel comfortable. You should also discuss child bearing and family planning.

ILLUSTRATIVE IMAGES



REFERENCES

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