
The Endometriosis Summit

ENDO WORDS

BRIEF DEFINITIONS TO
HELP UNDERSTAND
ENDOMETRIOSIS

Endometriosis – clinically defined as “a systemic, inflammatory disease characterized at surgery by the presence of endometrium-like tissue found outside the uterus, usually with an associated inflammatory process. It is a spectrum disease with a variety of subtypes and clinical presentations, and pain, inflammation, infertility, development of endometriomas (“chocolate cysts”), fibrosis, formation of adhesions (fibrous bands of dense tissue), GI and other organ dysfunction, and much more are common with endometriosis” (Int’l Endometriosis Working Group, 2021)

It is systemic, often painful, whole body disease in which tissue that is similar to, but not the same as, the tissue that normally lines the inside of your uterus — the endometrium — grows outside your uterus. Endometriosis can be found anywhere in the body.

Abdomen – the part of the body the thorax and the pelvis with the exception of the back, which includes organs, muscles, ligaments, and nerves.

Ablation – a form of treatment that uses electrical energy, heat, cold, alcohol, or other modalities to destroy a small section of damaged tissue.

Adenomyosis – the presence of endometrial glands and stroma WITHIN the myometrium. The myometrium is the medical term for the muscular portion of the uterine wall. This is a uterine disease. Focal adenomyosis is an adenomyoma.

Adhesion – an abnormal union of membranous surfaces due to inflammation or injury. This union serves as a band of scar-like tissue that forms inside the body, connecting tissues or organs or areas that are not normally connected.

Agonist - a substance which initiates a physiological response when it combines with a receptor.

Appendix- (also veriform appendix); finger-like, blind-ended tube connected to the cecum. Once considered a vestigial organ (or organ with no use), it is now thought to be a reservoir for beneficial gut bacteria. Common source of endometriosis.

Bladder Biofilm- community of bacterial cells that stick together, and attach to the bladder wall or the cells of the bladder wall. Can be both bacterial or fungal. Can be complex, diverse communities of multiple pathogens. Bladder biofilm may produce a thick shield to shield itself from the antibiotics and the body’s natural defences.

Bladder and Urogenital Endometriosis -it is estimated that up to 80% of people with endometriosis have disease surrounding the ureters and the urogenital system. Bladder and urogenital endometriosis are one of the most misdiagnosed forms of endometriosis. People with endometriosis related bladder issues are often normalize their pain, thinking they just have a small bladder or that getting up at night to go to the bathroom is normal. They are often told they have recurrent infections, or that they have interstitial cystitis (IC). Similar to bowel endometriosis, bladder endometriosis is typically on the outside of the ureters or bladder

making it undetectable during a cystoscopy. Furthermore, the bladder itself is a sensory driver to the pelvis, so once pelvic pain is present bladder pain can ensue. Bladder pain and endometriosis are so common the two are thought of to be the “evil twins” of pelvis pain. Symptoms of bladder and urogenital endometriosis include (but are not limited to):

- Urinary urgency
- Urinary frequency
- Urinary burning
- Lower abdomen pain above the pubic bone
- Bloating
- Leg pain
- Constipation
- Pain with a full bladder
- Pelvic floor spasms
- Food sensitivities
- Painful sex
- Back or flank pain
- UTI symptoms with negative culture

Bowel Endometriosis- 80-90% of people with endometriosis feel some sort of bowel discomfort. Many seek out care from gastroenterologists for years with the pain attributed to IBS or have their symptoms ignored. Others have tried elimination diets and holistic measures that may help, but are not eliminating their symptoms. Unfortunately, bowel endometriosis is rarely embraced as the cause of these symptoms despite that bowel endometriosis is fairly common. Typically, bowel endometriosis will be on the outside of the bowel, not inside the lumen, making it hard to detect during colonoscopies. Additionally, bowel endometriosis can be subtle making detection on scans difficult or bowel endometriosis can be deeply invasive, creating adhesions that bind the bowel. Bowel endometriosis symptoms may worsen with the period but many experience symptoms all month long.

Symptoms of bowel endometriosis can include (but are not limited to):

- Bloating or Endo Belly
- Pain and pressure in the abdomen
- Sensitive Stomach
- Diarrhea
- Constipation
- Pelvic Floor Dysfunction
- Difficulty passing stool
- Chronic Nausea
- Food Allergies
- Abdominal cramping and pain
- Painful bowel movements
- Vomiting

Catamenial – events that have a temporal relationship with the menses. Most commonly

occurring within the three days before to the first day of menstruation.

Catamenial Pneumothorax- Spontaneous pneumothorax that occurs during menstruation or within 72 hours before or after onset of the cycle. Typically tied to Thoracic Endometriosis

Central Sensitization – a condition of the central nervous system associated with development of chronic pain which can perpetuate pain even in the absence of stimuli. It is an increased responsiveness of the nociceptors in the central nervous system to normal or sub-threshold input that may result in hypersensitivity and perpetuation of pain.

Chronic Illness – Persistent, long lasting illness or reoccurring illness that lasts for longer than 6 months.

Coccyx- boney structure at the bottom of the spine and sacrum, remnant of the vestigial tail it is three to five fused vertebrae attached to the sacrum with a fibrocartilaginous joint, which permits very limited movement between the sacrum and the coccyx.

Colonoscopy – an exam used to look for changes within the large intestine and rectum. It is procedure to see inside the colon, using a long, lighted flexible tube mounted with a tiny camera. Note: Most endometriosis is outside of the colon and cannot be spotted during colonoscopy and a negative colonoscopy is not indicative of absence of bowel or rectal endometriosis.

Colostomy – a surgical procedure that brings one end of the large intestine out through an opening in the abdomen for elimination of stool.

Cecum- a pouch within the peritoneum that is considered to be the beginning of the large intestine. The appendix is off of the cecum.

Diaphragm - the dome-shaped sheet of muscle at the base of the thoracic cavity that helps move air in and out of the lungs.

Diaphragmatic and Lung Endometriosis- the respiratory system is among the top five systems affected by extra-pelvic endometriosis Thoracic endometriosis includes endometriosis in the diaphragm and thoracic cavity. Many people with thoracic endometriosis present with catamenial pneumothorax, however many do not. Symptoms may initially be cyclical around menstruation but will progress next to during ovulation and then to all month long. Symptoms of thoracic endometriosis include (but are not limited to):

- Lung collapse
- Rib tip pain
- Burning shoulder, especially with menstruation
- GERDS or Chronic Heartburn like symptoms
- Altered oxygen saturation levels, especially during ovulation and menstruation
- Difficulty catching your breath

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- Knife like pain between the shoulders
- Pain and pressure across the bra line
- Chest pain and pressure
- Neck pain and burning C3,4,5, especially during menstruation **Dysmenorrhea** - is characterized by severe and frequent menstrual cramps and pain during menstruation.

Dyspareunia- painful sexual intercourse.

Dysuria – discomfort, pain, or burning when urinating.

Endometrioma – also known as a chocolate cyst, is a localized form of endometriosis typically within the ovary. The presence of an endometrioma indicates a more severe stage of endometriosis.

Estrogen – any of various natural steroids that are formed from androgen precursors, that are secreted chiefly by the ovaries, placenta, adipose tissue, and testes, and that stimulate the development of female secondary sex characteristics and promote the growth and maintenance of the female reproductive system.

Estrogen receptor – a group of proteins found inside cells that are receptors activated by the hormone estrogen. On the surface of these cells estrogen molecules attach.

Excision – the act or procedure of removing by or as if by cutting out especially: surgical removal or resection. With regards to endometriosis it is the surgical act of cutting out the endometriosis at its root-regardless of the tool used to perform the excision.

Erythema- hot pack or hot water bottle rash. Prolonged thermal radiation leads to nerve damage, itchiness, and a change in pigmentation on the skin.

Femoroacetabular Impingement (FAI)- condition in which extra bone (bone spur) is amongst one or both of the bones that form in the hip joint, giving the bones an irregular shape. Because they do not fit together correctly, bones rub during movement causing pain and dysfunction. Types of FAI include **pincer** which occurs because the bone extends out over the acetabulum- the socket of the hip, crushing the labrum; **cam** where the femur cannot rotate smoothly in the hip joints and **combined** where both a pincer and cam type are present. Symptoms can include pain, stiffness, limping, difficulty with load bearing activities and groin pain.

Fenestration – the creation of a new opening. From the Latin for 'the making of a window.'

Fertility Preservation- the process of saving or protecting eggs, sperm, or reproductive tissue so that a person can use them to have biological children in the future.

Fibroid - a non-cancerous tumor which can be found in or attached to the uterus. Also referred to as leiomyoma or myoma.

Fulguration- is a type of ablation that uses high-frequency electric current (diathermy) specifically to destroy tissue.

Gaslighting- psychological manipulation of a person, usually over an extended period of time that causes the person to question the validity of their own thoughts, perception of reality or memories and leads to confusion, self -doubt, loss of confidence and uncertainty of one's mental stability. Medical gaslighting is when physicians, medical professional or others dismisses or downplays a patient's physical symptoms or attributes them to something else such as a psychological condition or body weight.

Gastrointestinal tract- a continuous passageway from mouth to anus. It contains the esophagus, the stomach, the small intestine, the large intestine, and the rectum.

Genitofemoral Nerve – arising off the lumbar spine this is a nerve with two branches- the genital branch and the femoral branch. It provides sensory innervation to the upper anterior thigh as well as the skin to the mons pubis in biological females and scrotum in biological males. The nerve pierces psoas major and then splits. The genital branch continues to the inguinal canal and the femoral branch continues to the femoral canal. The genital branch accompanies the round ligament of the uterus affects the skin of the mons pubis and the labia majora. The femoral branch passes underneath the inguinal ligament and affects the upper, anterior and medial side of the thigh. Each side of the body has its own nerve.

Genitourinary System- organs of the reproductive system and the organs of the urinary system which includes in biological females: kidneys, ureters, bladder, ovaries, cervix, uterus, fallopian tubes.

Gland – any organ or tissue that secretes fluids, such as hormones, for use elsewhere in the body or as waste.

GnRH - abbreviation for gonadotropin-releasing hormone, a hormone responsible for the release of follicle-stimulating hormone (FSH) and luteinizing hormone (LH) from the pituitary gland.

GnRH Antagonist – a drug originally used to treat prostate cancer by blocking the release of luteinizing hormone that do not cause a temporary surge in testosterone. This class of drugs are now often prescribed off label in a variety of gynecological uses including treating endometriosis related pain and for fertility treatments.

Hemostasis-the process during surgery to prevent and stop bleeding, the first stage of wound healing.

Hernia – a protrusion of an organ, fat, or tissue, through connective tissue, wall, or enclosed body cavity. An example of this would be intestines protruding through the abdominal wall. A bulge is not necessary.

Hypertonic Pelvic Floor– pelvic muscles have a higher resting tone causing tense and contracted muscles. Muscle spasms can lead to pain with urination, bowel movements, sex as well as bloating and back pain.

Hypogastric Plexus- a sympathetic nerve plexus that supplies the pelvic visceral lying deep inside the body in front of the sacrum, extending down into two lateral portions. Endometriosis on or near this plexus is thought to be connected to “endo belly”.

Hysterectomy – a surgical procedure to remove the uterus. A hysterectomy may or may not include the cervix.

Hysteroscopy - is the exam of the inside of the cervix and uterus using a thin, lighted, flexible tube called a hysteroscope. The device is inserted through the vagina.

Hormone Therapy- with regards to endometriosis it is the use of hormones to halt symptoms of endometriosis. Typically tied to an origins theory of retrograde menstruation, this is a debatable intervention for people with endometriosis. Claims are that it limits growth, most believe, at best hormone therapy treats symptoms but not disease directly.

Hydronephrosis- swelling of one or both of the kidneys. Swelling can happen when urine can't drain from a kidney and builds up as a result. In regards to endometriosis, ureter endometriosis can often restrict drainage from the kidney.

Ilioinguinal Nerve – A branch of a lumbar that wraps around the abdomen as it travels anterior. It travels along the lateral border of psoas major, across quadratus lumborum and iliacus and perforates the transverse abdominals near the iliac crest between the transversus and the internal oblique muscle. In biological females it is sensory innervation to the mons pubis and the labia majora. Each side of the body has its own nerve.

Labrum- hip labrum. The acetabulum or socket of the hip joint has a ring of cartilage on it that cushions the acetabulum and completes the circle for the head of the femur to sit in. The labrum is this fibrocartilage ring. Issues with the labrum may include pain in the groin made worse by standing, sitting, walking or athletics, a locking or clicking in the hip joint and stiffness in the hip joint. Compression and high load activities may worsen this pain.

Laparoscopy – a minimally invasive abdominal surgical procedure carried out with tiny instruments inserted through small openings in the skin.

Laparotomy – an open surgical procedure where the abdominal cavity is accessed via a large opening in the skin.

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Large Intestine- also known as the large bowel, it is the last section of the GI Tract. Water is absorbed here and waste is stored prior to defecation. The sigmoid colon is the longest portion of the large intestine. The large intestine is joined to the area of the small intestine at the **ileocecal valve**. Then the large intestine continues to the ascending colon, the transverse colon and the descending colon to the rectum and ending with the anal canal.

Lesion – an infected, diseased, or wounded area of tissue.

Lichen Scelrous- chronic, inflammatory skin condition of unknown cause which can affect any body but has a strong preference for the genitals. White patches on the skin with itching, pain, dyspareunia are common. Can lead to easier bruising, cracking, tearing and peeling of the genitals.

Microbiome- collection of all microbes, such as bacteria, fungi, viruses, and their genes, that naturally live in our bodies as a community. In the human body certain microbes form a community in each body system ie vaginal microbiome, gut microbiome.

Mülleriosis – embryonic origin of endometriosis referring to a developmental defect in the differentiation or migration of any cellular component of the müllerian duct system.

Myomectomy - surgical removal of a myoma or fibroid.

Nerve- an enclosed-cable like bundle of nerve fibers (axons) that transmit electrical impulses. Part of the peripheral nervous system. There are motor nerves in which the impulse creates movement and sensory nerves in which the impulse is connected to sensation-including pain.

Nerve Block – injection of a medication into one or more nerves or nerve plexus to relieve pain.

Neurogenic Bladder- bladder malfunction caused by an injury or disorder of the brain, spinal cord, or nerves that can lead to voiding difficulties including urinary retention and urgency, and difficulty completely emptying.

Neuropelvelology- Founded by Dr Marc Possover, is concerned with the diagnosis of injuries and dysfunctions of the pelvic nerves plus the treatment of the symptoms related to such. This may include hyperactive bladder, urinary or fecal incontinence, urinary retention, neuropathic pelvic pain, genital, groin, pudendal, back, sciatic pain, spinal cord issues or sexual disorders in men and women.

Nodule – a small rounded bump or knot of tissue.

NSAID- abbreviation for nonsteroidal anti-inflammatory drug, a drug that reduces swelling and pain.

Obturator Nerve - arises from the anterior lumbar plexus, descends through the fibers of psoas major and emerges near the brim of the pelvis. It passes behind the common iliac arteries and on the lateral side of the internal iliac artery and vein. Then it runs along the lateral wall of the pelvis and to the upper part of the obturator foramen through the obturator canal and into the leg. It provides sensory innervation to the skin of the inner thigh and motor innervation to the adductors. It is not responsible for obturator internus. Compression of this nerve may be involved with hypertonic pelvic floor. Each side of the body has its own nerve.

Occult Hernia – or no bulge hernia or hidden hernia, is a mass of herniated tissue, typically fat, that compresses a nerve, typically the ilioinguinal nerve or the genital branch of the genitofemoral nerve. These hernias are often missed on exam because there is no bulge and often misses on imaging, including ultrasound, cat scan or MRI, because the fat causing the nerve compression is not a full hole through the entire peritoneum. MRI can detect if read by a occult hernia specialist.

Oophorectomy – a surgical procedure which removes one or both ovaries.

Painful Bladder Syndrome- (formerly Interstitial Cystitis) chronic long term pain condition that affects the bladder. Symptoms may include: pain or discomfort in the lower abdomen, pain worse with the bladder filling, urgency, frequency, nocturia, pain, pressure or tenderness in the bladder, urethra, vulva, vagina, rectum, pelvic floor pain, pain with sex, ulcers, sores, and or bleeding in the bladder.

Patriarchy- social system in which positions of dominance or privilege are primarily held by men. Broad social structure in which men dominate over women and children causing the exploitation or oppression of women and children. Fixates in the inherent natural differences between men and women to uphold men as the head of society.

Pelvic Floor – group of muscles that form a sling or hammock across the floor of the pelvis. Together with surrounding tissues, these muscles hold the pelvic organs in place so they can function correctly. Stabilize the core while assisting with functions like urination, defecation and penetration. They are the levator ani muscle group of pubococcygeus, puborectalis and iliococcygeus and another muscle, coccygeus.

Pelvic Floor Dysfunction - weak or spasmed pelvic floor issues that lead to pain, sexual dysfunction, genitourinary issues or gastrointestinal issues.

Peritoneum- the membranous lining of the abdominal and pelvic cavity. There are two layers and a space between each layer. The outer layer is the parietal peritoneum and the inner layer is the visceral peritoneum that wraps around the organs/visceral. There is a small space between the layers that contains serous fluid allowing the layers to glide freely over each other.

Phrenic Nerve – general motor and sensory nerve on each side of the body that arises chiefly from the fourth cervical nerve, passes down through the thorax to the diaphragm, and supplies or gives off branches supplying especially the pericardium, pleura, and diaphragm.

Piriformis- flat narrow muscle of the gluteal region lying deep to the gluteus maximus. It is an external rotator of the hip attaching to the sacrum on one end and the greater trochanter of the hip on the other. If the hip is flexed this muscle will abduct the thigh. Running beneath the piriformis muscle is the sciatic nerve and spasticity in this muscle can cause irritation to the sciatic nerve.

Pneumothorax - a collapsed lung. A pneumothorax occurs when air leaks into the space between the lung and chest wall. This air pushes on the outside of the lung and makes it collapse. A pneumothorax can be a complete lung collapse or a collapse of only a portion of the lung.

Progesterone – a steroid hormone produced by the ovaries that prepares the uterine lining for pregnancy.

Pudendal Nerve – main nerve of the perineum (not peritoneum) that has both sensory and motor components as well as a connection to the autonomic nervous system. There are three branches-inferior rectal nerve, perineal nerve and dorsal nerve to the clitoris (or penis). Supplies sensation to a small portion of the labia, clitoris, and anal canal. Motor component is the perineum, superficial pelvic floor and deep pelvic floor as well as the EXTERNAL anal sphincter and EXTERNAL urethral sphincter.

Retroperitoneum- lies between the posterior parietal peritoneum and the posterior abdominal wall. Contains the renal fascia, the psoas muscles and the great vessel compartment.

Sacrum - the large heavy bone at the base of the spine, which is made up of fused sacral vertebrae. The sacrum is located in the vertebral column, between the lumbar vertebrae and the coccyx. It is roughly triangular in shape and makes up the back wall of the pelvis.

Salpingectomy - a surgical procedure which removes one or both fallopian tubes.

Sampson's Theory – a theory that endometriosis is caused by retrograde (or backflow of menstrual blood) menstruation in which the endometrial lining spreads into the pelvis and body instead of exiting during menstruation. This theory is a source for much debate in the endometriosis community.

Sciatic Nerve - either of the pair of largest nerves in the body that arise one on each side from the nerve plexus supplying the posterior limb and pelvic region and that pass out of the pelvis and down the back of the thigh.

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Silent Endometriosis- while endometriosis commonly causes pain, up to 25% of people with endometriosis experience no overt symptoms. You can have endometriosis without heavy periods, abdominal pain and pelvic pain. Silent endometriosis bonds close to unexplained infertility. Up to 50% of those with unexplained infertility have endometriosis Many with silent infertility experience miscarriages, pregnancy loss, failed IVF cycles and pre-term labor or they cannot conceive at all. It is important to understand that endometriosis cannot be fully ruled in or ruled out by ultrasounds, blood tests, and scans. Fertility success rates increase when the disease is directly managed.

Symptoms of silent endometriosis include (but are not limited to)

- Inability to get and stay pregnant
- Inexplicable Low AMH
- Miscarriage and recurrent miscarriage
- Chocolate cysts or endometriomas
- History of bowel issues and bloating
- Back pain
- Blocked tubes
- Pre-term labor
- Pregnancy loss

While endometriosis can be silent, many people with “silent endometriosis” have normalized their painful periods, stomach issues, painful sex, or pelvic pain for years. Something you may be just accepting can be a crucial piece to the puzzle that is your infertility.

Small Intestinal Bacteria Overload (SIBO) -occurs when there is an abnormal increase in the overall bacterial population in the small intestine — particularly types of bacteria not commonly found in that part of the digestive tract.

Stroma - the part of a tissue or organ with a structural or connective role

Trachelectomy - a surgical procedure which removes the cervix.

Trauma- a response, emotional or physical, to an incident or series of distressing emotional, physical or psychological events. Trauma responses may be shock, denial, dissociation, mood swings, relationship challenges, flashbacks, and physical symptoms.

Video Assisted Thoracic Surgery (VATS) - is a type of minimally invasive thoracic surgery that can remove parts of diseased lung and/or lymph nodes. In video-assisted thoracoscopic surgery (VATS), a small tube called a thoracoscope is inserted through a small cut (incision) between the ribs.

Vulvodynia- a type of pain or discomfort of the vulva that is typically longer than 3 months of duration. A leading cause of painful sex due to the connection to the pelvic floor muscles, commonly described as burning, stinging, irritation, and rawness of the vulva. Aching, soreness, throbbing, and swelling may also be felt. Chronic vulvar pain.

10 Facts You may not know about endometriosis:

- Endometriosis, according to the International Working Group, 2021, is a systemic, inflammatory disease characterized at surgery by the presence of endometrium-like tissue found outside the uterus, usually with an associated inflammatory process. It is a spectrum disease with a variety of subtypes and clinical presentations, and pain, inflammation, infertility, development of endometriomas (“chocolate cysts”), fibrosis, formation of adhesions (fibrous bands of dense tissue), GI and other organ dysfunction, and much more are common with endometriosis

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8530702/>

- Endometriosis is not a period disease or a disease of just killer cramps. It is a whole body disease, affecting multiple systems. Cramping may be a symptom of the disease but so too is bloating, stomach issues, back pain, bladder pain, and pelvic pain.

- 200 Million Worldwide suffer from endometriosis yet, on average it takes 8-10 years to be diagnosed with endometriosis.

- For many, as the disease deepens and becomes more inflammatory, pain is all month long, not only during periods.

- 70% of teens with pelvic pain go on to be diagnosed with endometriosis

<https://pubmed.ncbi.nlm.nih.gov/21420081/>

- People with chronic pelvic pain have increased pain sensitivity even at non pelvic sites <https://pubmed.ncbi.nlm.nih.gov/24104772/>

- The only way to truly diagnose endometriosis is through surgical pathology, though there is much debate in the endometriosis community regarding this. Deeply invasive disease and endometriomas or chocolate cysts are easier to recognize radiologically, however disease presentation are varied, sometimes subtle, and not all presentations of the disease can be recognized by MRI or Ultrasound.

- Birth control pills only treats the symptoms of the disease for some, but not all with endometriosis. It does not treat the disease directly.

- Endometriosis is not a uterine disease. Adenomyosis, a cousin to endometriosis, is a uterine disease causing heavy bleeding, horrible cramping, and a often, a heaviness in the pelvis

- Staging for endometriosis has no bearing on severity of pain. Some with Stage 1 endometriosis have terrible symptoms and some with Stage 4 endometriosis have no symptoms at all.

- Endometriosis and its inflammatory nature often contributes to other driver's of pelvic pain like pelvic floor dysfunction, hernias, painful bladder syndrome, and vulvar pain.

- Delays in diagnosis, poor access to care, and pain that is typically shrouded in shame lead endometriosis to be one of the most misunderstood public health crisis.

Patients often endure years of medical gaslighting and trauma prior to finding relief.

The Endometriosis Summit is the nation's largest educational entity for endometriosis . We unite patients, practitioners, and surgeons to drive endometriosis forward.



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