

GET IN THE KNOW ABOUT

ENDOMETRIOSIS



What is Endometriosis?

Endometriosis is an estrogen-dependent chronic disease that can cause incapacitating pain, organ failure, infertility, and other severe medical consequences if inadequately treated. Clinically, endometriosis is defined as the histologically confirmed presence of endometrial-like tissue outside of the uterus. Although one rarely hears about it in the news, endometriosis is common, affecting an estimated 10 to 15 percent of women and girls (usually of reproductive age) and is a leading cause of gynecological hospitalization. Due to widespread misinformation about endometriosis, diagnostic delays continue to average up to 6-10 years. Although theories abound, the cause of endometriosis is unknown and there is no cure. For more information, visit <http://www.endomarch.org/endo-what-support-research-groups/>.

Most Common Signs & Symptoms

The symptoms of endometriosis vary widely among women and girls. However, some of the most common include:

- Severe pelvic and/or stomach pain
- Pain during or around menstruation
- Heavy bleeding during periods
- Infertility and/or sub-fertility
- Painful bowel and/or bladder symptoms
- Pain with sexual intercourse
- Chronic gastrointestinal symptoms such as nausea, vomiting, diarrhea, and constipation
- Nerve and musculoskeletal symptoms, including leg, lower back, and pudendal nerve pain

Impact of Endometriosis

- Severe chronic pain is a major factor in up to 70% of suicides
- Endometriosis is a leading cause of gynecological hospitalization
- Medications prescribed for endometriosis are associated with higher rates of heart disease, kidney disease, and strokes
- Multiple surgeries required to treat endometriosis increases risk of surgery-related morbidity and mortality
- Endometriosis can spread, invade, and cause damage to many organs and tissues beyond the reproductive system, including to the bowel, bladder, kidneys, diaphragm, nerves, muscles, and lungs
- Endometriosis costs society an estimated \$119 billion in economic loss & medical costs (D'Hooghe et. al. 2012)

Serious Diagnostic Delays

A whole range of adverse health outcomes may result from diagnostic delays, including progression of disease and preventable organ damage. Here are a few important facts:

- The length of time from the onset of symptoms to correct diagnosis averages 6-10 years
- Time.com recently recognized endometriosis as one of the top 15 diseases most commonly misdiagnosed by doctors
- As an invisible illness, those with endometriosis may look perfectly healthy, making it difficult for patients to convince health care providers of the severity of their symptoms
- Modern imaging technologies usually fail to detect endometriosis, which is a contributing factor in diagnostic delays

Debunking Myths

- Painful periods are not normal
- There is no cure for endometriosis
- A hysterectomy cannot cure endometriosis
- Pregnancy cannot cure endometriosis
- Menopause cannot cure endometriosis
- Endometriosis is not a sexually-transmitted disease
- Exercise and diet cannot prevent or cure endometriosis
- Pre-teen & teenagers are not too young to have endometriosis
- Hormonal treatments cannot prevent or cure endometriosis
- Surgical diagnosis with biopsy is the only way to definitively diagnose endometriosis

References:

Giudice LC, Kao LC. Endometriosis. *Lancet*.2004;364(9447):1789-1799.
Lebovic DI, Mueller MD, Taylor RN. Immunobiology of endometriosis. *FertilSteril*. 2001;75(1):1-10.
Mackenzie TB, Popkin MK: Suicide in the medical patient. *Int J Psych in Med*. 1987;17:3-22.
15 Diseases Doctors Often Get Wrong. *Time.com*. August 1, 2014. <http://time.com/3065882/diseases-doctors-get-wrong/>. Accessed September 18, 2014.
D'Hooghe T, Dirksen CD, Dunselman GAJ, de Graaf A, W.E.R.F. EndoCost Consortium, Simoons S. The costs of endometriosis: it's the economy, stupid. *FertilSteril*.2012; 98(3):P S218-S219.
Nezhad C, Paka C, Goma M, Schipper E. Silent loss of kidney secondary to ureteral endometriosis. *JSL5*.2012;16(3):451-455.

For more information about endometriosis or the Worldwide EndoMarch events:

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