



ENDOMETRIOSIS FACT SHEET

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Many Women and Girls Have Endometriosis:

- Endometriosis is estimated to affect approximately one in ten women of reproductive age. (source: European Society of Human Reproduction and Embryology)
- Endometriosis affects an estimated 1 in 10 women during their reproductive years (i.e., usually between the ages of 15 to 49), which are approximately 176 million women in the world.¹ (sources: *Reproductive Science* and the *Journal of Endometriosis*)

Often Called an “Invisible Illness” with Severe Consequences:

- Depression is 15-20% higher for the chronically ill than for the average person.²
- Various studies have reported that physical illness or uncontrollable physical pain are major factors in up to 70% of suicides.³
- The 2002 US Census Bureau reported that approximately 96% of people who live with an illness have an illness that is invisible. They note that these people may look perfectly healthy.

Endometriosis Causes Infertility:

- According to studies in the *New England Journal of Medicine*, endometriosis is one of the top three causes of female infertility. While it is one of the most treatable, it remains the least treated.⁴
- Up to 30% - 50% of women with endometriosis may experience infertility.⁵ (source: American Society for Reproductive Medicine)

Serious Delays in Diagnosis and/or Serious Problems of Misdiagnosis:

- Anglo-American studies have shown a delay from 3 to 11 years between the onset of pain symptoms and the final diagnosis of endometriosis.⁶ (source: National Institutes of Health; US Library of Medicine)

¹ Rogers PA, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. *Reprod Sci* 2009;16(4):335-46.; Adamson GD, et al. Creating solutions in endometriosis: global collaboration through the World Endometriosis Research Foundation. *J of Endometriosis* 2010;2(1):3-6.

<http://endometriosis.org/resources/articles/facts-about-endometriosis/>

² Rifkin, A. “Depression in Physically Ill Patients,” *Postgraduate Medicine* (9-92) 147-154.

³ Mackenzie TB, Popkin MK: “Suicide in the medical patient.” *Intl J Psych in Med* 17:3-22, 1987

⁴ <http://www.nejm.org/doi/full/10.1056/NEJM199306173282407>

⁵ http://www.asrm.org/uploadedFiles/ASRM_Content/Resources/Patient_Resources/Fact_Sheets_and_Info_Booklets/EndoDoesItCauseInfertility.pdf

⁶ <http://www.ncbi.nlm.nih.gov/pubmed/12790847>

ENDOMETRIOSIS FACT SHEET P2

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- The National Endometriosis Society claims that around 2 million women in the UK have undiagnosed endometriosis.
- Studies carried out in the USA, the UK and Australia have demonstrated that the difficulty in timely diagnosis of endometriosis is universal. **The delay in diagnosis was recorded as 9.28 years in the North American Endometriosis Association Survey (NAEAS) of 4000 members;** this includes a delay in the patient seeking help from a physician for an average 4.67 years and a delay of 4.61 years in the physician making a diagnosis of endometriosis.
- The length of time from the onset of symptoms to the definite diagnosis is often an average of 6–10 years. This delay is even longer in young patients and in severe cases.⁷ (sources: Hadfield *et al.*, 1996; Zrubek *et al.*, 1999; Ballard *et al.*, 2006; Matsuzaki *et al.*, 2006).
- A whole range of problems may result from this delay in diagnosis, including deterioration of patient's quality of life, progression of the disease, the impact of absence of an explanation of pain, and the financial burden on the budget of medical services.⁸ (source: Slack *et al.*, 2007).

Primary Care and Endometriosis

- Studies show adolescents usually turn to their primary care physician for evaluation of dysmenorrhea (painful periods) and chronic pelvic pain.⁹
- Many arguments exist to organize the clinical care for women with advanced endometriosis in centers of excellence, but continuing education of primary-care physicians also remains a priority.¹⁰
- In survey findings, 63% of general practitioners indicated they felt ill at ease in the diagnosis and follow-up of patients with endometriosis. One-half could not cite three main symptoms of the disease out of dysmenorrhea, dyspareunia, chronic pelvic pain, and infertility. Only 38% of general practitioners indicated that they perform a clinical gynecologic examination for suspected endometriosis, and 28% recommended MRI to confirm the diagnosis.¹¹

What are the Symptoms of Endometriosis?

- Pain before and during periods
- Pain during sex
- Infertility
- Fatigue
- Painful urination during periods
- Painful bowel movements during periods
- Other gastrointestinal upsets such as diarrhea, constipation, nausea.

In addition, many women with endometriosis suffer from:

- Allergies
- Chemical sensitivities
- Frequent yeast infections

⁷ <http://www.medscape.com/viewarticle/714181>

⁸ <http://www.medscape.com/viewarticle/714181>

⁹ <http://www.ncbi.nlm.nih.gov/pubmed/23817302>

¹⁰ <http://www.ncbi.nlm.nih.gov/pubmed/19804042>

¹¹ Ballard K, Lane H, Hudelist G, Banerjee S, Wright J. "Can specific pain symptoms help in the diagnosis of endometriosis? A cohort study of women with chronic pelvic pain." *Fertil Steril*. 2010;94(1):20-27; Giudice L, Evers JLH, Healy DL. *Endometriosis: Science and Practice*. Chichester, West Sussex: Wiley-Blackwell; 2012; Quibel A, Puscasiu L, Marpeau L, Roman H. General practitioners and the challenge of endometriosis screening and care: results of a survey. *Gynecol Obstet Fertil*. Epub 19 Apr 2012.

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ENDOMETRIOSIS FACT SHEET P3

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About Endometriosis (source: *The Lancet*)

Endometriosis is an estrogen-dependent disorder that can result in substantial morbidity, including pelvic pain, multiple operations, and infertility. New findings on the genetics, the possible roles of the environment and the immune system, and intrinsic abnormalities in the endometrium of affected women, and secreted products of endometriotic lesions have given insight into the pathogenesis of this disorder and serve as the background for new treatments for disease-associated pain and infertility. Affected women are at higher risk than the general female population of developing ovarian cancer, and they also may be at increased risk of breast and other cancers as well as autoimmune and atopic disorders. Clinicians should assess and follow up affected women for these and other associated disorders. There will probably be a new repertoire of approaches for treatment and perhaps cure of this enigmatic disorder in the near future.

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