

Endometriosis is a disease in which tissue similar to the lining inside the uterus (called “the endometrium”), is found *outside* the uterus, where it induces a chronic inflammatory reaction that may result in scar tissue. It is primarily found on the pelvic peritoneum, ovaries, in the recto-vaginal septum, on the bladder, and bowel. In very rare cases it has been found on the diaphragm and in the lungs<sup>1-2</sup>.

Endometriosis affects an estimated 1 in 10 women during their reproductive years (ie. usually between the ages of 15 to 49), which is approximately 176 million women in the world<sup>3-4</sup>. However, endometriosis can start as early as a girl’s first period and the menopause may not resolve the symptoms of endometriosis, especially if the woman has scar tissue or adhesions from the disease and/or surgery.

The symptoms of endometriosis include painful periods, painful ovulation, pain during or after sexual intercourse, abnormal bleeding, chronic pelvic pain, fatigue, and infertility, and can impact on general physical, mental, and social well being<sup>1,5</sup>.

A general lack of awareness combined with a “normalisation” of symptoms results in a significant delay from when a woman first experiences symptoms until she eventually is diagnosed and treated<sup>5</sup>.

There is no known cure and, although endometriosis can be treated effectively with drugs, most treatments are not suitable for long-term use due to side-effects<sup>1,3</sup>. Surgery can be effective to remove endometriosis lesions and scar tissue, but success rates are dependent on the extent of disease and the surgeon’s skills. Pregnancy may relieve symptoms but is not a cure for the disease. Hysterectomy, with surgical removal of all the disease at the same time, may relieve symptoms, but is not a “definitive cure” either. Removal of the ovaries at the same time as a hysterectomy is performed increases the chances of pain relief but also results in an immediate menopause.

There is no known cause of endometriosis but it is highly likely that certain genes predispose women to develop the disease<sup>6</sup>. Thus, women have a higher risk of developing endometriosis if their mother and/or sister(s) are also affected<sup>7</sup>. It is also likely that environmental factors influence whether a woman is affected: for example, in a few papers it has been suggested that endometriosis is caused by exposure to dioxin (an environmental pollutant), although to date there is no proven link<sup>8</sup>.

There are regular claims that women with endometriosis have a higher risk of developing ovarian cancer; however, this research is not definitive and the absolute risk is very, very small. Whereas endometriosis is not a known precursor to cancer, in *very rare isolated cases* malignant transformation has been observed<sup>9-10</sup>.

Even though endometriosis is associated with inflammation and immunological dysfunctions, it has not been proven itself to be an autoimmune disease<sup>8</sup>.

There are national support organisations in many countries now. For a complete list see:

<http://endometriosis.org/support/>

The World Endometriosis Society (WES) has organised 11 World Congresses on Endometriosis (WCE), starting in 1986. The 12<sup>th</sup> WCE takes place in Sao Paulo, Brazil, 30 April – 3 May 2014 ([www.endometriosis.ca/wce2014](http://www.endometriosis.ca/wce2014)).

The World Endometriosis Research Foundation (WERF) is the first global charity to foster research in endometriosis with an aim to improve knowledge and treatments through international multi-centre research according to standardised protocols. WERF is currently working with 30 centres in 21 countries ([www.endometriosisfoundation.org](http://www.endometriosisfoundation.org))

#### REFERENCES:

- [1] Kennedy et al, Hum Reprod 2005; [2] Guidice, NEJM 2010; [3] Rogers et al, Reprod Sci 2009; [4] Adamson et al, J of Endometriosis 2010; [5] Nnoaham et al, Fertil Steril 2011; [6] Painter et al, Nat Genet 2010; [7] Moen and Magnus, Acta Obstet Gynecol Scand 1993; [8] Guo et al, Mol Hum Reprod 2009; [9] Vigano et al, Fertil Steril 2007; [10] Wiegand et al, NEJM 2010.