

# Endometriosis facts

## The problem

Endometriosis costs the UK an estimated £2.8 billion a year in days taken off work. It affects almost 2 million women in the UK alone. A 2005 global survey, completed by 7,025 women with endometriosis (3,455 in the UK), showed an average diagnostic delay of 8 years from the time they present with symptoms. The cause of endometriosis is unknown and there is no cure.

## The disease

Endometriosis is a condition where tissue, similar to the lining of the womb (uterus), grows in other areas of the body (mainly in the abdominal cavity). This tissue responds to a woman's hormonal cycle. However, unlike a period, it remains within the body, where it bleeds and forms lesions, blood-filled cysts, and scar tissue (adhesions). This results in inflammation, pain, infertility, and can lead to other medical problems.



## The symptoms

- Pelvic pain, heavy or irregular bleeding
- Painful: menstruation, ovulation, intercourse
- Sub-fertility
- Bloating, nausea, pain on bowel movements and urination
- Fatigue
- Immune system defects, and possibly a susceptibility to develop other diseases,

## The treatments

The choice of treatment depends on the circumstances of each woman and what particular symptoms she is experiencing. The main forms of treatment are drug therapy or surgery including painkillers, birth control pills, various hormonal treatments, surgical removal and, for some, hysterectomy. For most women, side effects are associated with all of these treatments.

## The challenge

Endometriosis does not provide a visible handicap, despite its potentially serious effects, and thus is not recognised by the general public and many first line practitioners. In the survey mentioned above, 68% were initially misdiagnosed with another condition. In addition, endometriosis is shrouded in a cloud of taboos about menstruation, sexuality, infertility, and pain. The myth that "pain is part of being a woman" results in girls and women not seeking help early enough. This lack of awareness results in significant diagnostic delays. Endometriosis can be a progressive disease, so early diagnosis is vital.

## The effect

Due to the complex nature of the disease, and the fact that there is no cure, many women might have to go through a number of expensive "hit and miss" treatments, before getting their symptoms under control. Not all women, however, are fortunate enough to be treated by a physician who specialises in endometriosis. They may never become symptom-free - affecting their ability to work, their fertility and their relationships. This will have an untold impact on their quality of life.

## The impact

- 30-40% of women with endometriosis are infertile.
- 73% have had their relationships affected by endometriosis.
- 6% claim benefits due to endometriosis, which is now recognised as a disability in some countries.
- 82% of women are at times unable to carry out day-to-day activities due to endometriosis.
- 38% have had their job affected with:
  - 42% having lost their job
  - 39% have had to reduce their working hours
  - 19% have changed their job

## The cost

Not being able to finish an education, or maintain a career, have personal financial impacts on a woman and her family. For society the cost is also big: if 82% of women with endometriosis at times are unable to work for an average of 5.7 days a month, the estimated cost to society in days lost to work is £2.8 billion a year in the UK alone! This *does not include the cost of drugs, surgery, repeated hit and miss treatments, IVF, other infertility treatment, and disability compensation.*

## We need investment to

- Ensure that all women are aware of endometriosis: its symptoms and treatment options
- Ensure that all health care professionals understand what endometriosis is: its symptoms, effects, and treatment options
- Ensure that all women with endometriosis have access to fast, appropriate treatment and support
- Ensure there are adequate funds dedicated for endometriosis research.

## The investment must include funds for:

- Awareness programmes: in schools, the media, and directly to physicians
- Support group activities to make the above happen
- Legislation to ensure that women with endometriosis are treated by specialists
- Basic research into epidemiology, causal research and non-invasive diagnostic tools

## Endometriosis UK

We are the leading UK charity supporting people whose lives are affected by endometriosis. We provide key services to enable women to gain an understanding of endometriosis and take control of their lives including a free helpline, local groups, publications and campaigning for best practice.

Endometriosis UK

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