

Endometriosis can be suspected by the GP from the reported symptoms. Another pointer is if a bimanual examination is carried out to check for tenderness, pain and/or palpable nodules between the vagina and the rectum, this often suggests endometriosis in the pouch of Douglas (see diagram 4).

The development of the laparoscope (see our leaflet on laparoscopy for further details) has revolutionised the diagnosis of endometriosis and at present is the only certain way to confirm suspected endometriosis. However, if a gynaecologist who is inexperienced in the detection of endometriosis does a laparoscopy, the diagnosis can still be missed.

To obtain a laparoscopy it is necessary to get a referral from a GP to a consultant gynaecologist. If possible, get a referral to someone with an interest in the disease. All gynaecologists are not specialists in the detection and treatment of endometriosis. It is not a procedure that can be carried out in a GP surgery. It is important to give the GP a clear description of all symptoms, especially those that are cyclical (occurring every month) even if they appear to be unrelated (use our period plot chart to record your symptoms).

### **TO SUMMARISE:**

Any woman with a history of:

- **Heavy, irregular periods**
- **Pain—before, during or after a period that is not relieved by the use of simple painkillers**
- **Dyspareunia (painful intercourse)**
- **Unexplained infertility (problems with conception)**

A combination of these symptoms should alert the woman and her GP to the possibility of endometriosis leading to investigations for a proper diagnosis.

**PLEASE NOTE:** Research is being done:

- To predict which women are susceptible to develop endometriosis
- Investigating if the lining of the uterus may be different in women with endometriosis
- Investigating the theory that the “junctional” zone in the uterus could be the basis to help a non-invasive technique for diagnosis of endometriosis
- Into the effects of nutrition on the health of women with endometriosis
- Into the effects of homeopathic and herbal treatments on the health of women with endometriosis
- Into the effects of magnets on the pain of endometriosis
- Into the effects of dioxins on endometriosis
- Into the role of basal endometrium (contains stem cells) in developing endometriosis
- Into the role of associated disease including auto-immune, endocrine, allergy, plus chronic pain and fatigue disorders and endometriosis

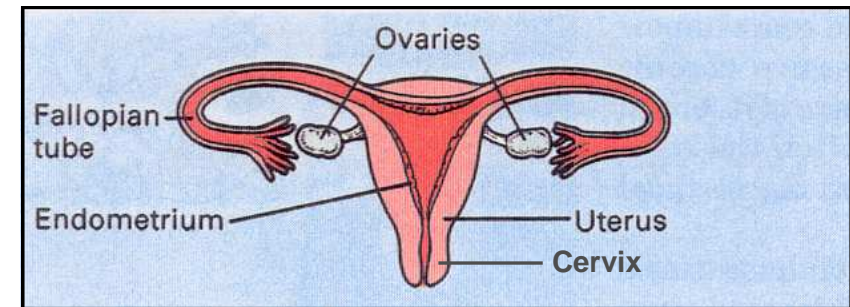
### **WHAT IS ENDOMETRIOSIS?**

“ENDO”	means inside
“METRA”	means uterus (womb)
“ENDOMETRIUM”	is a Latin word for the lining of the uterus
“ENDOMETRIOSIS”	means a problem with the lining of the uterus. The cells from this lining migrate to localities outside the uterus to sites where they are not normally found

Endometriosis means the presence of tissue similar to the endometrium growing and functioning outside the cavity of the uterus, in the muscle walls of the uterus; on the outside of the uterus; on the ovaries; bladder; bladder; and peritoneum, etc.

#### **Endometrium (lining of the uterus)**

Diagram 1



The presence of this tissue is generally referred to as ectopic endometriosis. The ectopic endometriosis responds each month (in the same way as the lining of the uterus) to the hormones oestrogen and progesterone that are produced by the ovaries.

The normal monthly cycle for a woman is 28 days. In some women this can be shorter or longer, but the first day of bleeding each month is always referred to as “day one” of the cycle. The hormones oestrogen and progesterone are responsible each month for the lining of the uterus becoming thicker in preparation for pregnancy. If no pregnancy occurs, then the lining is shed through the vagina as the monthly period.

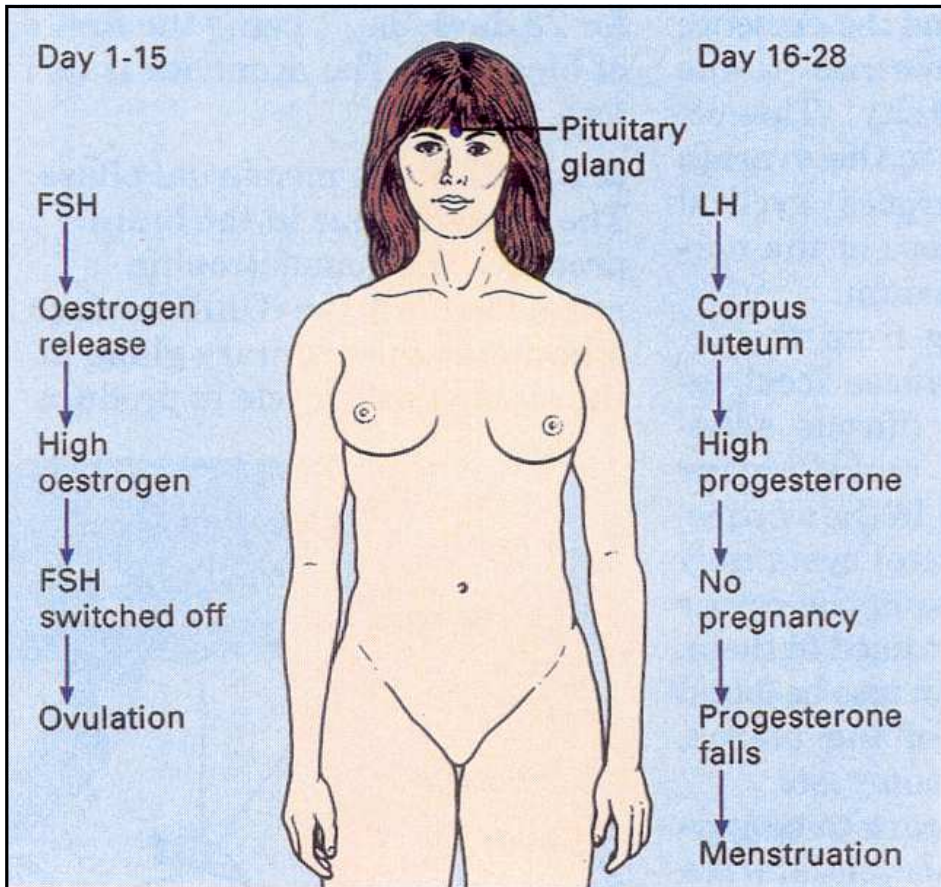
In women with endometriosis, the “shed” ectopic endometrium has no escape route. Instead the cells in the endometrium called “stroma and glandular cells” implant into or on the organs and supporting ligaments contained in the pelvis. They also implant in and on the peritoneum, which is a thin membrane like sausage skin that envelopes the organs in the pelvis. In a normal pelvis, the peritoneum allows the organs to move freely and work efficiently without causing pain. The ectopic endometrium builds up each month, in the same way as the lining of the uterus. These cells at the ectopic sites act as foreign bodies and produce local irritation and inflammation. This in turn will form cysts and create adhesions that can be filmy or thick strands of tissue that bind or stick organs together. Pain is the most frequent result of this activity and it may sometimes cause problems with fertility.

Endometriosis appears to be affected by the monthly cycle. It is a chronic and progressive condition with acute episodes. It sounds impossible to have a progressive and chronic condition and not to be aware of it, but with endometriosis, this is often the case, both for the woman and her medical practitioners. Diagnosis can sometimes be made when a woman is having treatment for some other problem such as infertility, or abdominal surgery for other reasons, and endometriosis is found even though the woman has not complained of pain. It is important that endometriosis is recognised early and that the woman receives expert treatment. The pain experienced by women is often dismissed as psychological; meanwhile the damage to the pelvic organs continues unabated and fertility may be affected.

To understand the effects and the treatment of endometriosis, it is important to understand the “monthly cycle” or “period”.

### The female hormones and monthly cycle

Diagram 2



FSH — Follicular Stimulating Hormone

LH — Luteinising Hormone

### **The most common symptoms of endometriosis are:**

- PAIN — before, during and after a period
- Deep dyspareunia (painful intercourse)
- Infertility (30 to 40% of women with endometriosis)
- Rectal pain and/or rectal bleeding at period time
- Bladder pain, irritation and/or bleeding when passing urine at period times

### **Other reported symptoms include:**

- Deep pelvic pain at any time
- Pain between periods at ovulation time, about day 14 (known as Mittelschmerz)
- Swollen abdomen and fluid retention
- Loss of stale brown blood after a period
- Prolonged heavy periods with blood clots
- Back pain
- Pain down the legs
- Pre-menstrual tension, depression, lack of sleep, nausea
- Bowel problems like IBS (Irritable Bowel Syndrome)

Other symptoms reported by some women with endometriosis are low body temperature and/or extreme fatigue.

### **Endometriosis is thought to cause pain in the following ways:**

- Bleeding into an enclosed space causing increased pressure
- Blood in the pelvis causing irritation and inflammation of the peritoneum
- If the organs of the pelvis are unable to move freely due to adhesions, the result will be pain
- Raised levels of some of the chemical compounds in the peritoneal fluid, this can cause local spasms, makes the uterus contract and can cause lack of oxygen to the tissues in the pelvis
- Endometriosis that is directly on or in an organ will cause irritation and pain

**PLEASE NOTE:** The pain experienced is not always related to the spread of endometriosis seen at surgery. Much depends on the location of the deposits as well as the depth of the deposits. Sometimes small deposits called “petechiae” produce more prostaglandins, these substances are thought to be responsible for the severity of the pain experienced.

### **WHO GETS ENDOMETRIOSIS?**

**Any female from the start of her periods (her reproductive age) can have endometriosis. Any female can suffer the consequences of endometriosis to beyond the menopause.**

Endometriosis is the second most common gynaecological condition after fibroids; it is also the most poorly understood. It is thought that 10% of all women can be affected by endometriosis to a lesser or greater degree. Women of all social classes and nationalities can develop endometriosis, until recently it was thought that it was mainly a disease of white middle-class/career women, but this has been disproved. It is now realised that these were the women who could speak out about their problems and so gain a diagnosis. Women can develop endometriosis from the onset of their periods — this means that teenagers should be taken seriously if their periods cause them to miss their education.

It is thought that endometriosis may have a hereditary factor and/or is connected to problems related to the immune system. Research is being conducted in several centres to discover the truth behind these proposals.

### **HOW IS ENDOMETRIOSIS DIAGNOSED?**

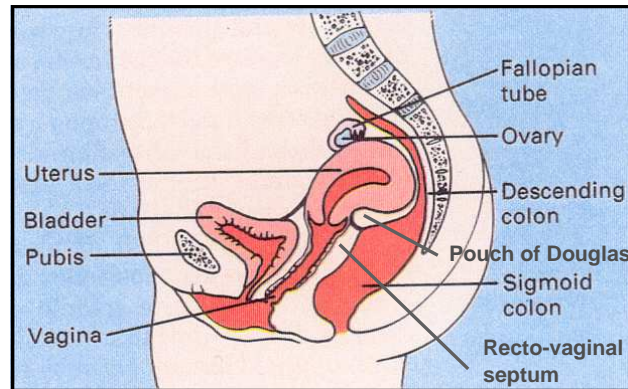
Endometriosis cannot be definitely diagnosed by your GP just listening to your symptoms, or by any examination.

Deposits of endometriosis often collect between the bowel and the uterus or the bladder and the uterus, both sites will give different symptoms—see diagrams 5 and 6 below. It is possible for both the bowel and bladder to be involved and produce quite severe symptoms. Where the ovaries and Fallopian tubes are involved, fertility can also be affected due to distortion, narrowing and impeding the progress of the ovum (mechanical effects) and fertilisation.

If the uterus becomes stuck to the bowel, the uterus gets pulled backward and is called a “retroverted uterus”. If the uterus becomes stuck to the bladder it gets pulled forward and is called an “anteverted uterus”. In some women both the bowel and the bladder can become stuck to the uterus. When the uterus becomes bound down, when the rectum and the lower part of the uterus have become stuck together by endometriosis in the pouch of Douglas, the result is generally painful intercourse, especially on deep penetration.

### **Retroverted uterus (uterus stuck to the bowel)**

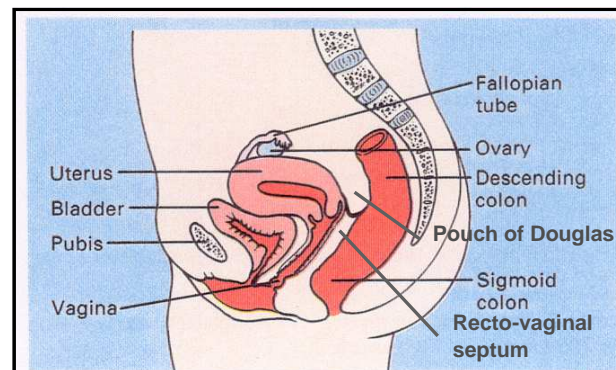
Diagram 5



**Probable symptoms due to a retroverted uterus are** — backache; dragging pains; constipation; diarrhoea and irritable bowel.

### **Anteverted uterus (uterus stuck to the bladder)**

Diagram 6



**Probable symptoms resulting from an anteverted uterus are** — bladder irritation; decreased bladder capacity (resulting in frequency); and pain (from stretching of supporting ligaments).

## **THE MENSTRUAL CYCLE**

### **Days 1 to 5 — menstrual phase (bleeding)**

During this phase (period), a gland in the brain (hypothalamus) produces a hormone called Gonadotrophin Releasing Hormone (GnRH) which stimulates the pituitary gland in the brain to produce another hormone called Follicular Stimulating Hormone (FSH). This hormone acts on the ovaries causing an ovum (egg) to start to mature and at the same time produces the hormones known as a group called “oestrogen” and the period stops.

### **Days 6 to 12 — follicular phase (follicle in the ovary develops)**

Oestrogen levels continue to increase and travel via the blood stream to the uterus where they act on the endometrium. The cells of the endometrium respond by multiplying and thickening again. FSH stops being produced by the pituitary gland after the sixth to ninth day and Luteinising Hormone (LH) is produced instead.

### **Days 13 to 15 — ovulatory phase (ovary produces and releases an egg)**

The LH triggers the maturing ovarian follicle to rupture and release the ovum into the pelvic cavity. The fimbriae (finger-like ends of the Fallopian tubes) pick up and waft the ovum through the Fallopian tube into the uterus.

### **Days 16 to 23 — luteal phase (progesterone is produced)**

The ruptured follicle in the ovary is now called the corpus luteum and it begins to produce progesterone, this prevents further follicles from developing. At the same time the progesterone prepares the endometrium in the uterus for pregnancy. If pregnancy does not occur, the corpus luteum breaks down after seven days and progesterone is no longer produced.

### **Days 24 to 28 — pre-menstrual phase (days before the period starts)**

From the 24th day, the levels of oestrogen and progesterone fall sharply, this results in the blood supply to the endometrium being reduced. The endometrium is then shed as the period. As this is happening the FSH levels rise and the whole cycle starts again at day one.

It is easy to understand why “ectopic” endometriosis can cause severe pain. However, some women with severe disease do not experience severe pain. The cause for this is not clearly understood by the answer may lie with the hypothesis that there are two endometriosis syndromes as discussed below.

Recent theories proposed by Professor Ray Garry (Human Reproduction Vol 19, No 4 pp 760 to 768 2004) suggest that endometriosis is a disease of two syndromes as it exists in two different forms that have different symptoms, signs and prognosis. Recognition of the two syndromes should improve the management of endometriosis.

### **The two syndromes:**

1. Can be defined by the presence of nodules that can be felt (palpable) deep within the pelvis. These patients, with or without associated ovarian involvement, usually have severe symptoms. There is usually a significant risk of bowel and urinary tract involvement. Such patients generally need extensive surgical intervention.
2. Can be defined when palpable nodules are not present. These women usually have the classic superficial endometriosis, visible at surgery (blisters, inflamed areas, powder burns, etc). These women generally have less severe symptoms; they do not generally develop the serious problems discussed above. Treatment is generally by medication and/or surgery to remove them (ablative surgery).

It makes the whole problem more difficult for a non-sufferer to understand when some days, a woman with endometriosis can be well and at other times be really ill and in severe pain.

## WHY DOES ENDOMETRIOSIS HAPPEN?

There have been many theories put forward since the 1930's when a doctor called Sampson first described what he thought was happening. Sampson felt that when bleeding occurred each month, some blood spilled backwards out of the Fallopian tubes and into the pelvic cavity (called retrograde menstruation). This blood contains tissue that is able to grow on the organs in the pelvis, thereby creating many of the problems experienced by women with endometriosis. If this were the whole truth, all women would have endometriosis as some retrograde menstruation happens in most women.

**Retrograde menstruation** (trans-tubal migration) - menstrual blood flows back from the uterus, through the Fallopian tubes and into the pelvic cavity. This enables "menstrual" tissue to implant onto organs and ligaments in the pelvis and may allow small deposits of tissue to be carried around the body in the blood or lymphatic fluid (a fluid that drains the glands of the body).

**Oestrogen stimulation** — some cells in the body may be stimulated by oestrogen and transform into tissue similar to the endometrium. Cells that would normally develop into endometrial cells when the fetus develops actually fail to arrive in the correct place. These cells become stimulated in the same way as the endometrium once puberty is reached.

**Genetic** — there appears to be a genetic (hereditary) factor involved. Research is starting to indicate that some families have a predisposing factor to endometriosis.

**Auto-immunity** — another theory is that there may be a fault in the woman's immune system and the retrograde bleeding is not cleared properly by the scavenger cells in the fluid that is produced by the peritoneum (peritoneal fluid). Some research is looking at the effects of dioxins on the immune system.

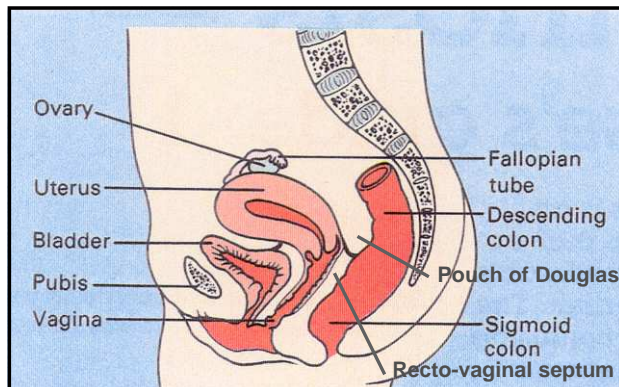
No one theory has been fully proved to-date and many researchers feel that it could be a combination of several factors. The uncertainty about the cause of endometriosis and the multifunctional ways in which it can affect women has led to endometriosis being called an "enigma" and "the disease of theories".

## NORMAL POSITION OF THE UTERUS

The pelvis holds and protects the organs of reproduction as well as the bladder, small intestine and large intestine (bowel). These organs are enveloped by the peritoneum and bathed in peritoneal fluid allowing them to move freely within the pelvis. The uterus is supported within the pelvis by strong ligaments.

### Normal position of the uterus

Diagram 3



## WHERE IS ENDOMETRIOSIS FOUND?

### **Endometriosis is most commonly found at the following "hot spots" sites:**

On the Fallopian tubes	On the ovaries
Inside/outside of the bowel	In the pouch of Douglas (see diagram 4)
In the umbilicus (tummy button)	On the outside of the uterus
Inside/outside of the bladder	In the vagina
On the ligaments that support the uterus (utero-sacral and broad ligaments)	

### **Less common sites are:**

In the cervix	On the appendix
In or on the ileum (part of the small intestine)	On the diaphragm

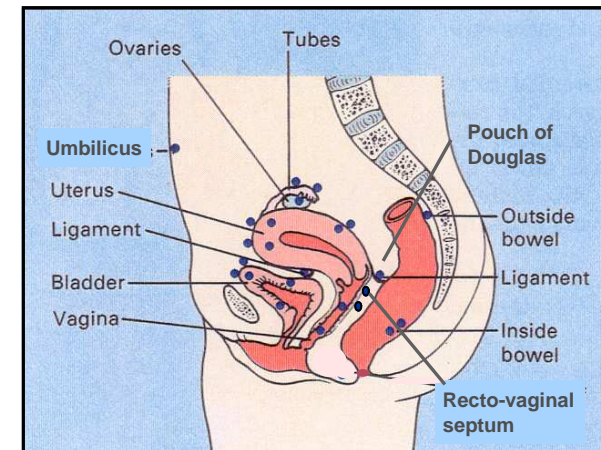
### **Rare sites are:**

In the eye	In the ear	In the gums	In the kidney	In the liver
In the gall bladder	In the lungs	In the spleen	in the brain	In skin and muscles
In joints	In the limbs	In fact almost anywhere in the body		

It is possible to develop endometriosis in previous surgical scars following such surgery as a Caesarean section, laparoscopy and episiotomy (the cut that is often made between the vagina and rectum when a baby is born).

### Endometriosis "hot spots"

Diagram 4



## WHAT ARE THE SYMPTOMS OF ENDOMETRIOSIS?

The symptoms that are experienced will vary from woman to woman and will generally depend on where the sites of endometriosis are, how deep they are (and whether they have presented as nodules according to some specialists). It must also be remembered that inexplicable as discussed previously, some women have no symptoms at all and it is suggested that in these cases, deposits are superficial or in the early stages.

As endometriosis progresses, adhesions are very likely to form due to inflammatory reactions. The adhesions can be like filmy threads that go between the organs in the pelvis and attach one organ to another. Other adhesions can become very dense like rubber bands, or solid tissue and actually stick the organs to one another. If the bowel, bladder, uterus, Fallopian tubes or ovaries are unable to move freely in the pelvis, the result is pain due to stretching and pulling of the organ involved. If the adhesions are very dense they can affect the actual function of the organs involved.