endometriosis

# Living with Endometriosis

## Real life stories, information and advice

Authorship – the medical input was provided by Caroline Overton with editorial input from Lucy Tully of Endometriosis UK. We are extremely grateful to women and their families who have shared their stories in order to support others with endometriosis.

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Please see inside front cover for full details.

Takeda

# Contents




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# What is endometriosis?

**Endometriosis (pronounced end-oh-me-tree-oh-sis) is a common gynaecological problem where cells similar to those in the lining of the womb are found elsewhere in the body.**

Each month, these cells react in the same way to those in the womb, building up then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape. This leads to inflammation, pain and the formation of scar tissue.

Sometimes there are no symptoms and it is found by chance when a woman is having an operation. However, in many women it can be a very painful condition and it is diagnosed when the symptoms are investigated. In other cases it is identified in women who are having difficulty getting pregnant. The average time from developing endometriosis to diagnosis is 11 years.

If you experience pain in your lower stomach area that follows the pattern of your monthly cycle and gets worse before and during your period, and/or you have abnormal bleeding patterns, then you might have endometriosis.

For instance, women with endometriosis often get a lot of pain the week before their period and during their period.

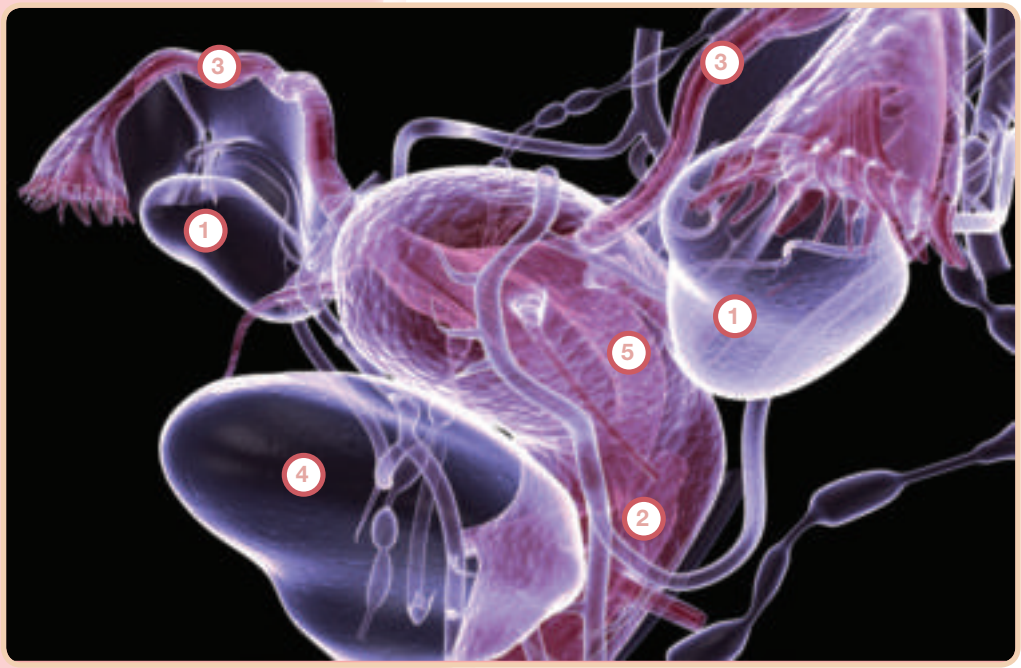
Other symptoms include: painful sex and pain in the bladder or bowels, especially when going to the toilet.

## Who gets endometriosis?

About two million women in the UK have a diagnosis of endometriosis. It can affect any woman who has started her periods.

There is an online video about endometriosis available here that you may find useful: www.youtube.com/watch?v=I-ifLNQn5AI

A glossary of useful terms is available at: endometriosis-uk.org/information/glossary.html




1. Ovary
2. Cervix
3. Fallopian tube
4. Bladder
5. Uterus

# How your body works

Most of the space below your belly button is filled by the small and large intestines (we have about 30 feet of them!). Our intestines are constantly moving as part of the digestion process (**peristalsis**).

The womb or **uterus** is about the size of a small avocado pear – surprising when it can hurt so much. The uterus connects with the **vagina** by the **cervix**. There are two **Fallopian tubes** that connect with the uterus, one on either side. The two ovaries are each the size of a walnut. These release an egg each month which is picked up by the fallopian tubes and wafted down to the uterus, where, if fertilised, a pregnancy begins.

The lining of the uterus is called **endometrium** (pronounced end-oh-me-tree-um). Each month the hormones produced by the ovaries make the lining of the uterus build up and get thicker. If the woman does not become pregnant, this lining sheds as a period.

# A woman's periods

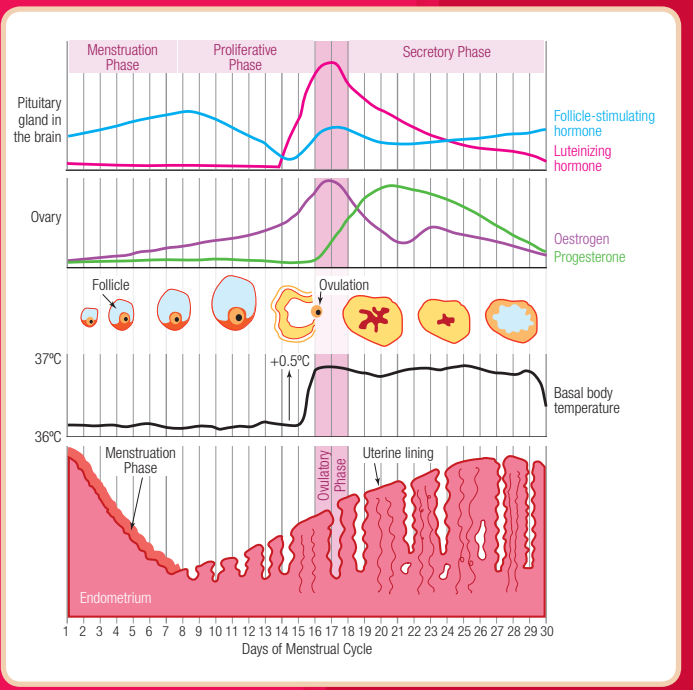
**Girls are born with their ovaries containing millions of eggs, each in a bud-like stage called a follicle. These follicles are usually just a few millimetres in size and can be seen on an ultrasound scan where they might be called 'follicular' or 'simple' cysts. No more eggs are made during a woman's lifetime which explains why women have a biological clock and men don't.**

Each month, several follicles start to develop inside the ovary. As they ripen, the egg inside matures. Usually just one of these follicles ripens fully. A mature follicle is about 20 millimetres in size and, like a blister, it 'pops' to release the egg inside. For some women, ovulation can be painful. They may also be aware of other changes that occur at the time of ovulation, such as a change in the vaginal discharge. The most fertile time to conceive is around ovulation.

The number of days between ovulation and a period starting is 14 days, give or take a day. In a shorter period cycle, ovulation happens earlier; with a longer cycle, ovulation happens later.

A normal period lasts about 3–7 days and happens every 25 to 35 days. The period blood contains iron, so very heavy periods can make you anaemic (lacking in iron). The amount of blood varies, but normal periods aren't heavy enough to make you anaemic.

If your periods are so painful that you feel you have to go to your doctor, miss work or go to A&E, this is not normal.




**ovaries**: these are where a woman's eggs develop

**ovulation**: every month, one of the eggs is released from the ovary

**ultrasound scan**: a painless test that uses sound waves to create images of organs and structures inside the body

**anaemic**: lack of iron in the blood. People with anaemia are usually pale and feel exhausted

**biological clock**: people usually refer to this when they are talking about a woman's reproductive years. Generally women are 'fertile', ie can get pregnant, from the time their periods start until they go through the menopause. It is well accepted, however, that it can be more difficult for women to get pregnant as they get older, ie beyond the age of 38

**follicles**: inside the ovary, these are where the eggs mature

# What happens when a woman has endometriosis?

**Endometriosis is where endometrium is found outside the uterus. It is most commonly found growing on the skin inside the pelvis (peritoneum), on the uterus, ovaries and ligament supports of the uterus, though it has been found in other areas of the body (in fact the only site that endometriosis has not been found is the spleen!).**

How it gets there and how it starts is not known for certain. Most of the period blood comes out through the vagina, but some blood passes down the Fallopian tubes. This is called **retrograde menstruation**. It is thought that this happens in every woman and that pieces of endometrium lining in this blood are capable of seeding and growing inside the body. What we don't know is why some women go on to develop endometriosis and others don't. There must be some other factor that we don't yet know or understand.

We do know that endometriosis is not infectious, is not caused by wearing tampons and is not sexually transmitted.

There are many myths about endometriosis. It used to be thought that endometriosis was more common in women who had never had children. It was called the 'career woman's disease' because career women tend to delay having their families until later, but we now know that this is not true.

### What does endometriosis look like?

Early endometriosis looks like spots and pimples sprinkled on the peritoneum. These are called **endometriotic implants** and may remain unchanged, become scar tissue or disappear over several months. Endometriosis irritates the surrounding skin and can produce scar tissue called **adhesions**. These adhesions can be flimsy like cobwebs or dense like superglue. These adhesions bind the uterus, tubes and ovaries together and in severe cases the bowels as well. In mild endometriosis, there may only be a few isolated implants and no adhesions.

# How can I tell if I might have endometriosis?

**The symptoms of endometriosis depend on where it is, but pain is common. Endometriosis, like the endometrium lining, builds up each month becoming more active before a period. The pain is worst in the days before a period and the period is typically very painful, often meaning days off school, college or work when all you can do is take to your bed or curl up on the sofa with a hot water bottle.**

Endometriosis is usually characterised by period-like pain in the days before the period. You may only experience the discomfort on one side. It can be painful to have sex (called **dyspareunia**) especially in the deeper positions and on just one side. (An occasional 'ouch' during sex is probably normal, however, and not necessarily an indication of endometriosis).

There is another pain typical of severe endometriosis called **dyschezia**. This is a horrible pain up the rectum when opening your bowels, typically during a period or in the days before a period when endometriosis is most active.

*Many women experience period pain, but if your pain is interfering with your everyday life - for example, it is causing you to take time off work - then you should get your symptoms checked out by a GP.*

# Will I be able to have children if I have endometriosis?

**Most women with endometriosis are able to have children without any problems. Women with mild endometriosis have the same chance of getting pregnant as women who don't have it. With more severe endometriosis, adhesions around the ovary and in the Pouch of Douglas* prevent the egg from getting down the Fallopian tube.**

If you are having difficulty getting pregnant and endometriosis has been diagnosed during the course of investigations, then surgical treatment to remove the endometriotic implants and/or release adhesions has been shown to increase the chance of getting pregnant.

Medical treatment by hormones or anti-hormones is not recommended if you are trying to get pregnant. This is because they do not improve the chance of getting pregnant; in fact they do quite the reverse: they act as contraceptives. Medical treatment is normally only prescribed to treat pelvic pain or as a treatment before or after surgery.

You can still get pregnant if you have severe endometriosis – it may just take a bit longer.

**Sara:** I had laser surgery in 2007. I had a lot of endometriosis and I know my Fallopian tubes were in a mess. I had the op, then near enough a year to the day after, I fell pregnant and now have a baby boy. We had been trying to conceive for about two years before that. I have another son, too, who was born before I was diagnosed

**Karen:** In November 2001 I had a laser op for treatment of endometriosis and was left with only one Fallopian tube functioning. My endo was very bad and I was referred for IVF treatment straight away as chances of conceiving naturally were very low according to doctors. I fell pregnant naturally around the following April and was over the moon, as before my op I had been trying with no success

***Pouch of Douglas:** the area behind the womb and in front of the rectum and lined by peritoneum

**peritoneum**: the thin tissue that covers the walls of the pelvis and abdomen on the inside, as well as the pelvic organs

# Pauline's story

I'm 39 and I first started getting really bad crampy pains 'down below' when I was 17. At first the doctor told me it was all in my head, or that I must have constipation or irritable bowel syndrome. I am quite stubborn, I mean, you know your own body, and my symptoms followed a monthly cycle: the pain just before and during my period floored me at times. I kept pushing for the right diagnosis. I changed doctors and was referred for further investigations. By the time I was 20 I was diagnosed with polycystic ovaries; it wasn't until I was 22 that endometriosis was finally diagnosed after a laparoscopy. In total I've had nine laparoscopies. Endometriosis has been found all over my womb and pelvic area, my bowel, Pouch of Douglas and my ovaries.

**Relationships and Work**

I think endometriosis did affect my emotional life. I was highly strung, snappy and short-tempered. It affected my first serious relationship: my mood swings were probably part of the reason why we split up. I was single by the time I was diagnosed and told children weren't really an option with the symptoms I had. I didn't go out: how and when would I tell a potential partner that I might not be able to have children? I met Michael nine years ago. I told him early on and he was extremely supportive. That's made all the difference. Luckily it's never affected our sex life. I've carried on working despite the symptoms but I had to reduce the number of hours at one point, which meant less pay.

**Treatment**

In 2001 I had an ovarian cyst and part of my left ovary removed. I tried a fertility drug in 2002 but it made me really ill and I didn't experience any benefits at all. I was considered unsuitable for IVF. In 2003 I had a laparoscopy and 'clean up'. In 2006 I had diathermy (spots of endometriosis removed by heat) and fell pregnant just after the operation. Sadly, I miscarried after just five weeks. In 2008 endometriosis was found on my bowel and in 2009 a consultant told me that it might be worth considering a hysterectomy. Michael and I had been through so much by then that we were at the point of agreeing but at the last minute we asked if there was any other option. The consultant said we could try diathermy again. This was in April 2009. In June I fell pregnant naturally… and to think, we had been so close to agreeing to a hysterectomy!

**Lifestyle, exercise and diet**

Endometriosis has never stopped me from doing the things I've wanted to do. I am not the type of person to give up. I've found swimming definitely eases my symptoms. In terms of diet, I find avoiding wheat and dairy seems to make a positive difference.

**Advice to other women with endometriosis**

Don't ever give up. If your doctor isn't helpful, ask to see another one; get a second opinion. I'm now 35 weeks pregnant at the age of 39 after nine laparoscopies and 22 years of living with symptoms, so there's always hope.

*"There was very little information available about endometriosis in the late 1980s. Other than a brief explanation and being told to 'go on the pill', I was left pretty much high and dry after the diagnosis."*

# What can my GP do?

**If you think that you may have endometriosis, you should make an appointment to speak to your GP about it. Keeping a diary for a few months beforehand can be an extremely useful way to show how the pain is affecting your life. It can also help confirm if there is a pattern to your symptoms, which would make a diagnosis of endometriosis likely.**

Endometriosis should be suspected if you have symptoms that get worse in the days before a period.

Your GP may suggest a vaginal examination. Your doctor may find that everything seems normal, but if endometriosis is severe he or she may be able to feel tender spots of endometriosis, an enlarged ovary or a uterus fixed in position by adhesions. Your GP may suggest a test to rule out chlamydia because this can give similar symptoms. If the test shows chlamydia, both you and your partner will need antibiotics.

Your GP may also suggest a pelvic ultrasound scan. The scan may appear normal, or it may show a cyst on one or both ovaries. Endometriotic cysts are typically blood-filled (**haemorrhagic**). Blood-filled cysts can simply be part of the ovulation cycle and so if this is your first scan, your doctor may suggest a follow-up scan after six weeks. Any haemorrhagic cyst that is still there is likely to be an endometriotic cyst. If you have bowel symptoms and an ultrasound scan is normal, your GP may suggest treatment for irritable bowel syndrome.

If your vaginal examination or pelvic ultrasound scan is abnormal, your GP may suggest referring you to a gynaecologist.

If your vaginal examination and pelvic ultrasound scan are normal but you have the typical symptoms, a diagnosis of endometriosis can be assumed and if you wish, treatment started immediately. The simplest form of treatment is the combined oral contraceptive pill and is suitable if you are not planning a family in the near future.

Endometriosis UK provides a symptom diary. You can download it here: www.endometriosis-uk.org/information/symptoms.html

# How is diagnosis confirmed?

The only certain way of confirming a diagnosis of endometriosis is by an operation called a laparoscopy (pronounced **lap-a-ross-cop-ee**). A slim telescope called a **laparoscope** is introduced into the abdomen through a small cut inside the belly button (**umbilicus**). The liver, gallbladder, stomach, appendix, peritoneum, uterus, Fallopian tubes and ovaries can all be seen in detail.

A diagnosis of endometriosis can be made by simply looking, or a small piece of endometriosis can be sent for examination (known as a **biopsy** – pronounced **by-op-see**). If fertility is important then the tubes can be checked by flushing them to make sure that they are open.

If the endometriosis is mild, it is possible to treat it at the time of the laparoscopy. It can be cut out or destroyed using diathermy or laser. How severe the endometriosis is, where it is, and what has been agreed before the operation will decide whether this can be done.

There has been intense research directed towards finding a test to diagnose endometriosis without needing an operation. Ultrasound, CT scan and Magnetic Resonance Imaging (MRI) cannot image the pelvis in sufficient detail to diagnose mild degrees of endometriosis.

There is no specific blood test for endometriosis. Once it has been diagnosed however, a blood test may be a good way of monitoring how active the endometriosis is.

Most recently research has suggested that a biopsy from the endometrium can diagnose endometriosis, but this has not been widely introduced or tested.

**diathermy**: the use of high frequency electric current to produce heat to either cut or destroy tissue or to stop bleeding

**peritoneum**: the thin tissue that covers the walls of the pelvis and abdomen on the inside, as well as the pelvic organs

**endometrium**: the cells that line the uterus (the womb); the inner layer of the uterus. This tissue is shed monthly as a period. The endometrium then grows back and slowly gets thicker and thicker until the next period.

# How can endometriosis be treated?

**Medical treatment with hormones or anti-hormones aims to suppress the endometriosis and is highly effective in treating pain. Treatment is for six months, although any improvement will hopefully last for years afterwards. It is probably best to think of treatment as a remission rather than a cure, as symptoms may recur over time.**

## Medical treatment mimics nature

Pregnancy and menopause are the two natural treatments for endometriosis. During pregnancy, there are sustained high levels of oestrogen and progesterone. During the menopause, oestrogen and progesterone levels are low.

Hormone treatments mimic pregnancy in their effects and anti-hormone treatments mimic the menopause. Both types of medical treatment are for six months and lead to improvement and healing of the endometriosis. Research suggests that both treatments are highly effective in reducing the painful symptoms of endometriosis; they differ only in their side effects. Treatment is less effective for adhesions and ovarian cysts, which usually require an operation.

Treatment is at best temporary. Once your periods start again after the treatment, the endometriosis starts to grow again, but hopefully it may be years before your symptoms are bad enough to need further treatment.

# What are the hormone treatments for endometriosis?

### Contraceptive pill

The oral contraceptive pill has been shown to be as effective as the gonadotrophin-releasing hormone agonists (see below) in relieving painful symptoms. It has the added advantage that treatment can be long-term and may delay the return of endometriosis.

The pill can be taken in the normal way (with a seven-day break at the end of each packet) or it can be taken without a break for up to three months (four packets) followed by a seven-day break (**tricycling**).

Taken continuously your periods should stop. Your GP can give you full details on this. It may slow the development of endometriosis, but the effect is temporary and symptoms may return on stopping.

If there are medical reasons why you can't take the pill, it might be worth trying the progestogen-only or mini-pill, a progestogen injection or implant. These are all similar to the natural hormone progesterone that is produced by your ovaries.

### Mirena intrauterine system (IUS)

The Mirena IUS is coil shape, but works as a hormone, releasing progesterone. The coil shape helps keep the hormone in the lining of the womb. The amount of hormone absorbed into the body is very small. It makes the lining of the womb thinner, helping make periods lighter, shorter and less painful. This may slow the development of endometriosis, but again the effect is temporary and symptoms may return when the IUS is removed. It can be fitted by your doctor and most women hardly know it is there. It is contraceptive and can be worn for five years before needing to change it.

**Danazol**, **gestrinone** and **progestogens** are all hormone treatments for endometriosis. These drugs are prescribed as tablets or injections for six months. Endometriosis and painful symptoms improve in nine out of ten women. Possible side effects include water retention, weight gain and irregular bleeding. Treatment is contraceptive, although the manufacturers advise that this cannot be relied on and barrier contraception (cap or condom) is advised for the duration of treatment.

## Does progesterone cream work?

There is no evidence that progesterone cream is effective in the treatment of endometriosis. The amount absorbed is tiny and has no effect on a woman's periods.

## Gonadotrophin-releasing hormone analogues (GnRH analogues)

These drugs are taken as a nasal spray or injection for six months. They prevent oestrogen being produced and result in temporary, reversible menopause. Endometriosis shrinks and painful symptoms improve in nine out of ten women.

Treatment is usually started during a period to be sure that you are not pregnant. It can be harmful to a developing pregnancy and so barrier contraception (cap or condom) is advised. In the first month there can occasionally be an increase in pain and you may have a period which can be heavier than normal. Periods then stop and the painful symptoms start to improve in the second month.

Side effects are those of the menopause and usually start at the end of the first month. They can include hot flushes, night sweats, mood changes, headaches, vaginal dryness and reduction in bone density. Any reduction in bone density is small and returns to near normal within six months of stopping treatment. All side effects can be reduced by taking progestogen or hormone replacement therapy without reducing the benefits of treatment.

# Gayna's story

**My first experience of endometriosis was at the age of 12, lying curled up on a sickbed at school in complete agony, pouring with blood. It would be a further 15 years before I was eventually diagnosed with the condition.**

For the next few years I got through my symptoms by taking painkillers like Feminax. Then, when I was 16 or 17 I took the contraceptive pill for a few years. It masked what was happening inside my body because it eased the symptoms a lot – the periods and the pain weren't so bad.

Over the years I tried acupuncture and consulted a herbalist but nothing worked. I went to see my doctor and said that I knew something wasn't right, but the doctor just thought it was ovulation pain. The symptoms took over my life.

In 1999, at the age of 27, I was diagnosed with endometriosis following a laparoscopy. It was all round my pelvis area. I was advised to have treatment and the plan was for me to try a class of drug called a GnRH-analogue but I had been suffering from depression (no doubt due to the endometriosis) and I had a kind of breakdown and never went back for my follow-up appointment.

In 2008 I had another laparoscopy where endometriosis was found all over my bladder and was prescribed goserelin (a GnRH-analogue) for six months. I was in immense pain, which I thought was due to the treatment, but it transpired I had a kidney stone.

*The symptoms took over my life.*

# Gayna's story continued

I moved back in with my Mum just after this and saw a new doctor: it changed my life. I was referred to the John Radcliffe hospital in Oxford where I saw an amazing consultant. She read through my notes and told me that at one point there had been plans to remove my bladder!

She recommended that we try monthly injections with a different GnRH-analogue (leuprorelin). In her experience, she said it had changed the life of 99% of women with endometriosis who had tried it. I have had very few side effects on leuprorelin. At first I had some dull headaches, but they didn't last. I found that I felt so much better that I started going to the gym but then I started to get painful knees. However, an HRT drug was added to my treatment, and my knees have been fine since then. I'm delighted to say that I've lost 8 or 9 kilos from being able to exercise.

I get some aching sensations sometimes in my pelvic area and my back from time to time, but nothing compared to before. I've got my life back. I'm even doing a sponsored 4-day trek through the French mountains this summer to raise money for Endometriosis UK. I never could have done that before!

My advice to women who have the symptoms of endometriosis is to remember that there is help out there. You have to persevere. You will get there one day. Trust what your body tells you. Find people to talk to. Try and open up to your family and friends. Go online and find a support group, through websites like Endometriosis UK or Facebook – women who know what you're going through can be a great source of advice and support.

**Can endometriosis come back after treatment?**

Surgical and medical treatments are both highly effective for the treatment of painful symptoms of endometriosis. However, as many as one in five women need further treatment within 12 months because they are getting further painful symptoms.

# When is an operation needed?

**Surgery for endometriosis is reserved for severe cases and is not undertaken lightly. This is because it is associated with a potential risk of damage to internal organs and blood vessels.**

An operation is usually carried out if examination or ultrasound scan is abnormal or if alternative treatments have been tried and haven't worked and after careful discussion between you and your consultant.

Large deposits of endometriosis need to be cut out (**excised**), particularly if close to the intestines or vagina. If attached to the rectum, a temporary colostomy* may be necessary. Adhesions can be released by cutting them with laparoscopic scissors.

Haemorrhagic cysts are inside the ovaries and are 'peeled out' using laparoscopic scissors and forceps (tweezers). Rarely, the ovary will need to be removed, either because the cyst has destroyed the ovary, because there is uncontrolled bleeding or because there is suspicion that the cyst is not entirely innocent (**benign**).

You will have between 1 and 4 small cuts on your tummy between 5 and 10mm long. One will usually be in your tummy button. It is common to think that laparoscopic surgery is minor surgery because the cuts are so small. However, it is the surgery carried out **inside** that decides whether an operation is major or minor.

***colostomy**: operation that makes it possible for stool to leave the body after the rectum has been removed

**How long will it take me to get better after an operation?**

You can go home after your operation as soon as you are well enough to get up and about, eat and drink, pass urine normally and be comfortable. You will still need to take painkillers when you go home and the normal advice is to take these regularly until you start to feel more comfortable. Check with your car insurance to see if they have any specific conditions about when you can start driving again. You should not drive for at least 24 hours after a general anaesthetic.

How soon you can go back to work depends on what was done and your recovery, but it is usually 1–3 weeks. You do not need your GP's permission to go back to work. The decision is yours.

The healing after laparoscopic surgery can give the same painful symptoms as the endometriosis itself, and it can be a full six months after the operation before the improvement in symptoms is fully appreciated.

**Before you drive you should be:**

**Free from the sedative effects of any painkillers**

**Able to sit in the car comfortably and work the controls**

**Able to wear the seatbelt comfortably**

**Able to make an emergency stop**

**Able to comfortably look over your shoulder to manoeuvre**

# Does it mean a hysterectomy?

**Some women may want to consider a hysterectomy, particularly if they have not had any success with medical treatments, have already had children or have decided not to have any. For many women it is a positive choice, but it is still a huge decision to make and deserves a lot of careful consideration.**

A hysterectomy is irreversible, and is not guaranteed to improve your symptoms (see next section), so it's worthwhile taking the time to make sure you do what feels right for you. Gather as much information as possible about the pros and cons first; talk to your doctor or gynaecologist, or contact Endometriosis UK. Remember, it is your body and your decision.

If you're in pain, you may feel like a hysterectomy is the only answer, but making the decision to have one when your symptoms are severe could lead to you regretting your choice later. If possible, work with your gynaecologist to try and find a treatment that reduces your pain, or go back on a treatment that successfully reduced it in the past, so you can make the decision as rationally as possible.

### Will a hysterectomy cure my endometriosis?

Unfortunately, there is no guarantee that a hysterectomy will cure your endometriosis.

The procedure can be done with or without removing the ovaries. If the ovaries are left in place, then endometriosis is likely to remain active (because the hormone oestrogen, produced by the ovaries, stimulates it).

The more severe the endometriosis, the higher the likelihood that further treatment will be needed if only the uterus is removed. With mild endometriosis, the chance of needing further treatment is 4 in 100 women. For severe endometriosis, the chance of needing further treatment after the same procedure is 13 out of 100 women within three years and 40 out of 100 women within five years.

Hysterectomy only treats endometriosis on the organs that are removed. If any is left behind, you may continue to experience symptoms – especially if your ovaries are not removed (see above).

Before making the decision to have the procedure, a useful 'test' to find out if a hysterectomy and oophorectomy (removal of the ovaries) will be successful for you, is a trial of one of the gonadotrophin-releasing hormone agonists (GnRHa's). This produces almost the same effect as oophorectomy. Three months treatment with GnRHa combined with HRT is enough to test that your symptoms improve and that HRT does not cause your endometriosis to return.

When both ovaries are removed a woman will experience the menopause. If this is earlier than normal, your doctor may prescribe hormone replacement therapy (HRT) to prevent premature menopause symptoms and longer term problems such as thinning of the bones (osteoporosis). It would be normal to continue HRT until the age of 50, which is the normal age for menopause.

# Are there any alternative treatments for endometriosis?

**Although complementary treatments have not been scientifically proven, many women feel that therapies such as acupuncture or reflexology help to manage their endometriosis symptoms.**

If you do decide to try a complementary treatment, remember that they are not regulated by the law in the UK (with the exception of chiropractic and osteopathy), so take special care in finding a professional practitioner that you trust. Many complementary treatments have self-regulating bodies, through which you can find a qualified practitioner – visit the Endometriosis UK website for links to these.

Certain complementary treatments involve the use of medicines, which again are not regulated. Take care to ensure that you do not take anything that will interfere with any medication that you are already taking. Many people believe that because something is 'natural' it cannot harm them, but this is not true, so inform yourself fully before trying any medication.

Some complementary therapies are widely seen as relaxing for the patient. You may find that using a treatment for this reason is beneficial enough, even if it is not directly treating your endometriosis, as feeling less stressed may help you to cope better with the condition.

Here is Emma's story, which shows how she has adopted a positive approach to living with endometriosis.

# Emma's Story

Since I was 13 I suffered with excruciating pain in my lower pelvis, lower back and down my legs for about a week before my period and during my period, too. It was a horrible, twisting sensation. I'd be unable to stand up straight and be so tired it felt like I'd been drugged. My periods were never regular, so I never knew when one was coming. I used to dread it: two weeks out of every month ruined.

I went to an all-girls school and people weren't very sympathetic when I had to take time off. A lot of girls use period pains as an excuse to get out of things they don't want to do, like PE, but I was in that much pain I was unable to exercise.

My mum and twin sister suffered with bad period pains, but for some reason mine were much worse. Then, when I was 15 or 16, I started to talk to my nan about it because she had had endometriosis and had to have an early hysterectomy.

I went to talk to my (female) GP about it. She said 'Don't you go diagnosing yourself; everyone gets period pains, and anyway, there's no point doing anything about it until you want to start a family.' She put me on the pill, and I was on it for seven years, even though it did nothing to help the pain or the heavy bleeding.

Since I was 13 I suffered with excruciating pain in my lower pelvis, lower back and down my legs for about a week before my period and during my period, too.

I saw different doctors at the same surgery, but none of them believed how bad my symptoms were. I felt like a ghost. I went to uni, although the endometriosis did have an impact on my studying and attendance. It was whilst I was at uni that I saw the first doctor who took me seriously. Just being listened to and believed made a big difference.

I had such bad pain when I was 19 it was mistaken for appendicitis. Then I was diagnosed with Pelvic Inflammatory Disease. I was also incorrectly diagnosed with sexually transmitted infections (STIs) like chlamydia, for which test results later came back negative. I felt the hospital treated me like I was diseased and it was my fault. I'd end up in A&E at times I was in so much pain, but still they couldn't find what was wrong. No pain killers, no matter how strong, could take away the symptoms.

When I was 23 I got a job in London, but I had to give it up because at times I was in too much pain to do the commute. I'd spend lunchtimes sitting in a toilet cubicle – not doing anything, just in too much pain to go anywhere.

I had scans around this time and first of all they found blood-filled cysts on my ovaries, then later they said they'd gone. This was in January 2006.

In February 2006 I wound up in A&E again. I couldn't walk, I was being sick and kept passing out. This time they found two massive cysts on my ovaries. One was the size of a cricket ball and the other had burst.

I came round in hospital. I knew I'd had an operation, but no-one would tell me what they'd actually removed for a day and a half. Eventually I was told they'd only removed the cysts but that I needed another emergency operation. As an NHS patient, this 'emergency' would have to wait three weeks, despite the fact I couldn't actually move!

My family paid for me to have the operation privately. Within a few days, the same consultant I'd seen on the NHS saved my ovaries. Extensive endometriosis was found.

I had a laparotomy (open surgery) to remove the cysts and the endometrial patches, which took a full year to recover from physically, ie being able to wear fitted waistbands, sit for any length of time and gain my energy back. However, three months after the operation the cysts returned on my right ovary. In February 2007 I was operated on again: another laparotomy, which knocked me for six again though my ovaries were saved which I'm so grateful for.

I felt my life was over, that I was just on a conveyor belt of surgery, heading for the end result of a hysterectomy and no chance of children. That was when I knew I had to find other ways of coping, getting myself healthier and physically strong so I could know that I had done everything I could for myself and any problems I did have were out of my hands.

*And with that change of mindset I changed the path of my endometriosis and my whole life by not letting it define me and it becoming a part of me.*

I was unable to work after my operation because I was unable to sit up for any amount of time. I think one of the reasons why endometriosis often goes undiagnosed for so long is that people are still uncomfortable talking about periods; it's still a bit of a taboo.

I met my fiancé when I was 17 and we got married in 2006. After my operations, sex was a no-go for a long time; every month during ovulation had always been too painful. Other times there were only certain positions that were possible, although you do get used to the discomfort.

We'd tried IVF and I had a miscarriage in June 2008, after which I had a breakdown, as the years of emotional hits had been so devastating. It's been an awful time, thinking I might never have kids. Sadly we've now decided to split up.

**Positive changes**

One of the best things I've ever done was to go and see a nutritionist, who advised me to cut out wheat and dairy: it's changed my life because I'm in so much less pain. I avoid junk food. I'm quite strict with my diet now and I accept that I have to be if I want to be able to get on with life. I also started seeing a counsellor after my breakdown. It may seem strange, but my counsellor's a man! It really works for me, though, because if it was a woman I think it would be too complicated because she might have children or she might have fertility issues herself, whereas he can look at it more objectively!! I've been for acupuncture, too, and that has really helped with my bleeding. I used to get lots of clotting, but with acupuncture I find that there are no more blockages in the flow.

I have reiki to relax me and help me think differently, too. It is a type of hands-on healing which is intended to send good energy to parts of the body that are in pain. It helps to take away negativity.

All the alternative treatments help me feel better without having to have more surgery. I hate even going near hospitals now! Another positive thing is that I have changed my GP and consultant and now feel I have people on my side, so medically I'm doing all I can, too.

My advice to someone living with the symptoms of endometriosis would be that it's really important to realise that it's not your fault: don't blame yourself. Having bad periods is not acceptable – you have a right to ask for help. It's also very helpful to have a support network. You need someone to talk to. Don't be ashamed to share what you're going through. You **can** find your own way through it as I have done. Don't be hard on yourself: you're a person, don't let the diagnosis define you. If you try something that doesn't work, keep trying different things until you discover whatever it is that helps you personally.

# What else can I do to manage endometriosis symptoms?

**Pain control is better if you stay 'ahead of the pain' by taking your pain relief medicine regularly. Anti-inflammatory drugs (such as ibuprofen) provide good pain control and can be taken with paracetamol or paracetamol and codeine.**

Exercise is a good remedy for pain – especially period pain – so if you can face getting your trainers on and getting out of the front door, this will positively help.

Endometriosis commonly co-exists with irritable bowel syndrome which can be managed by following a healthy diet with plenty of fruit and vegetables. Peppermint water or an antispasmodic bought over the counter from your chemist may help, too.

It's a great idea to get in touch with your local support group – just knowing that you are not alone can be a real help. If you aren't sure how to locate your nearest group, contact Endometriosis UK on **020 7222 2781** or visit **www.endometriosis-uk.org**. You can also find plenty of useful information and further case studies written by women with endometriosis on the website.

Try pilates for relief of endometriosis symptoms. Online video available here: http://www.ehow.co.uk/video_4961186_beginner-pilates-exercises.html?cp=1&pid=1

**Two patients share their advice for pain management...**

### Laura's Top Tips

Don't wait for pain to get unbearable before you take pain killers. Knock pain on the head as early as you can. Work out a routine if you know you experience pain on a regular basis, ie have painkillers to use in the day that do not make you drowsy, but when you're at home you can use higher strength pain relief and not worry if it makes you a bit spaced out!

Make a note of the time and dose every time you take pain relief so that you stay on top of your doses. This is especially important if your medication makes you drowsy because then it's easier to forget. Finally, don't try and be brave, and never apologise for needing a bit of help!

### Nicola's Top Tips

Find somewhere private, have a good old cry and let it out.

Getting angry will always make the pain worse; you need to be as relaxed as you can with endo, and keep telling yourself that the pain will go away soon.

Take a hot bath, get all cosy in bed with a hot water bottle, and try and sleep

# Jeff's Story

**Karen and I have been together for about six years. We had only been together a couple of months when she told me about the pain she suffers and the fact that she might have trouble having children.**

You wouldn't expect to have that conversation so early in a relationship, so it kind of hit me sideways. I didn't really understand.

I didn't quite grasp what endometriosis meant until the first time Karen had to have a laparoscopy after we got together. It was one of the more traumatic moments. The risk of surgery really dawned on me.

Endometriosis dominates Karen's life, and therefore it is ever-present in our relationship. I don't think that men can ever really understand. When she talks about the pain inside it's impossible to imagine how she's feeling.

You can listen but you can't experience it. If you tell a man a problem, he thinks he has to solve it. That's why endometriosis is so frustrating. It makes me feel helpless. I can't take it away. It's hard to make plans as a couple. We might have to cancel at the last minute, or I might have to go on my own if she's in too much pain.

Holidays are hard to plan as well, because it's so unpredictable. She also has hospital appointments, and men aren't the best at remembering dates and appointments at the best of times!

My advice to men whose partners have endometriosis is to accept that life is going to be unpredictable and be as supportive and caring as you can. Do what you can to help when she's suffering: bring her a hot water bottle or wheat bag (whatever helps her most) and offer to give her a massage, stroke her hair – whatever she likes best. There may be times when she can't face making love because of the pain. It is best if you can be open with each other about this and let her guide you as to when it's the right time to have sex, how gentle you need to be and which positions are most comfortable for her. Encourage your partner to lean on Endometriosis UK as much as possible, and to meet with her local support group – it's what they're there for.

When it seems hard to cope, or if it feels like endometriosis is taking over your relationship, focus on the woman you fell in love with and everything that attracted you to her in the first place. If you both keep up the motivation to find out what helps best with her symptoms (whether it's talking, surgery, drug treatment, alternative therapies, exercise, diet, etc), with your encouragement she will find what works for her sooner or later.

*For Karen, Endometriosis UK has been a true lifeline. It is there that she can talk to women who know exactly what she's going through. She can express herself.*

# The emotional side of living with endometriosis

**Endometriosis can be very emotional, from the difficulties in getting a diagnosis to learning to live with a long-term condition. There are many sides to it that can feel overwhelming. It is important to try and take control of your situation so that you can take an active role in managing your condition.**

**The longer you have to wait to find a cause for your symptoms, the more likely you are to be affected by self-doubt, fear, frustration, anger, isolation and depression. Without a definite diagnosis you may feel like your family, friends, employers and work colleagues are wondering if it is 'all in your mind'.**

**What you can do**

- **Keep believing in yourself. You know your body and what is normal or abnormal for you better than anyone else**
- **Get the support you need.** Endometriosis UK has a free helpline **(0808 808 2227)** and runs groups throughout the UK. Services are run by **fully trained volunteers**, all of whom have experience of endometriosis so will understand what you are going through. The helpline opening times and details of local groups can be found on the website **www.endometriosis-org.uk**, which also has extensive information about endometriosis, symptoms and treatments
- **Help your doctor.** Use a pain and symptom diary to record your symptoms. This is available from the Endometriosis UK website: **www.endometriosis-uk.org/information/publicationsform.aspx**. The more information you can give your doctor, the easier it will be for him or her to understand what is happening to you
- **Investigate your family history**. Studies have shown the possibility of a genetic link so if a female relative has endometriosis or symptoms that sound very similar to yours, please let your doctor know
- **Don't be embarrassed**. If you find it hard to discuss your symptoms, even with a doctor, or to undergo medical examinations, please remember that the doctor will have seen it all before, many times

"I knew that there was something wrong with me... After years of visiting doctors and being told my symptoms were normal, I started to question my own judgement. Was it all in my head?"

## The effect on your relationship with your partner and others close to you.

Endometriosis can have an enormous impact on your relationship with your partner in many different ways:

- The debilitating effects of the disease may change the balance of your relationship
- You may experience feelings of guilt that you are no longer 'pulling your weight' in the relationship or because you feel unable to go out and may have to cancel social arrangements at the last minute
- You may feel guilty or anxious about fertility problems
- If sex is painful it will have a lot of emotional consequences for both you and your partner, putting strain on your relationship. This could lead to feelings of anger, frustration and guilt on both sides
- If you are regularly tired or in pain, you may feel short-tempered, which can be hard for those closest to you

Endometriosis is an 'invisible' illness, making it harder for people around you to see when you are in pain, feeling low or having a 'bad day'. Other people may have their own perceptions of illness – expecting someone to be ill, get treatment and then recover. They may not understand that endometriosis is a chronic condition that cannot be 'cured', but has to be managed.

### The effect on your ability to work

Many women with endometriosis find that they have to take time off work because of the disease. Absence due to pain, other endometriosis symptoms and for surgery and medical appointments can take its toll on an employment record. The other issues surrounding endometriosis including stress, depression, fatigue and fertility issues can also have an effect on job performance.

### What you can do

- Realise that you are not alone. This is something that many women with endometriosis experience
- Try not to feel guilty. None of this is your fault
- Communicate with your manager, human resources or occupational health department. If you can let your employer know how endometriosis is affecting you, they may be able to find ways of working with you to reduce the impact that endometriosis is having on your performance. Could you discuss flexible working, eg build up 'credit hours' when you are well to be used when you need time off for medical appointments or illness or could you occasionally work from home?
- Endometriosis UK has a leaflet that explains the condition to an employer and suggests ways of working together with the employee to help reduce the impact of endometriosis in the workplace. Please call the helpline on **0808 808 2227** for a free copy or download it from the website: www.endometriosis-uk.org/information/publicationsform.aspx
- Some large organisations offer counselling or employee assistance for staff. If yours is one and you feel you would benefit from it, do try and make use of it

"I have no idea how I'm going to feel from one week to the next, so it's difficult to plan things. It's hard to get friends to understand what's going on when I say I can't do something because I'm tired. They don't see anything wrong on the outside so find it hard to believe what's happening to me."

# I've been to see my GP but I'm getting nowhere. What can I do?

**Your GP is really important because they will be your first contact when your symptoms are getting you down. They will also deal with your treatment once it has been decided and refer you if and when necessary. A good relationship with a GP who is sympathetic towards you is therefore key to getting the best possible treatment.**

Endometriosis UK has a free information pack for women who have the symptoms of endometriosis but have not yet had a confirmed diagnosis. The pack has a symptom questionnaire, advice on how to talk to your GP and information on how to get a referral.

## Useful addresses

**Endometriosis UK**
www.endometriosis-uk.org

Suites 1 & 2, 46 Manchester Street,
London W1U 7LS
Freephone helpline: 0808 808 2227

**ISSUE (National Fertility Association)**
www.infertilitynetworkuk.com

**The British Pain Society**
www.britishpainsociety.org

**Pelvic Pain Support Network**
www.pelvicpain.org.uk

**Counselling Association UK**
www.bacp.co.uk

You can find a therapist in your area if you would like an objective person to talk to

**Courses on Managing Pain**
www.expertpatients.co.uk

The production of this booklet was supported by Takeda UK. Please see inside front cover for full details.

Please note: all web addresses recommended in this booklet were correct at time of going to print. Web pages are liable to expire or be moved over time.

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