



Understanding endometriosis

It's a condition that affects millions of women, yet endometriosis often escapes diagnosis. Learn how to detect if it's causing your unexplained pain and how it can be treated



MR ASHWINI TREHAN FRCS FRCOG is a specialist in the treatment of endometriosis. He has been performing laparoscopic surgery for endometriosis for over 20 years and is responsible for pioneering total pelvic peritoneal excision surgery.

Endometriosis is a gynaecological condition that occurs when the lining of the womb, the endometrium, grows elsewhere in the body. It most commonly develops on the internal skin covering of the pelvis (the pelvic peritoneum) and over the organs in the pelvic cavity, which include the uterus, ovaries, vagina, bladder and rectum.

The disease affects 10-15 per cent of women of childbearing age, some 2 million women in the UK, most commonly between the ages of 20-40. However, it can still affect a girl of 15 or a postmenopausal woman of 65.

During the menstrual cycle, the lining of the womb responds to hormonal changes in the body that cause it to thicken and shed. But in women with endometriosis, bleeding will occur wherever in the body this lining is present, leading to inflammation and pain. This inflammation results in scar tissue, which can fuse the pelvic organs together.

What are the signs?

Symptoms of endometriosis are wide-ranging and include lower abdominal/pelvic pain and infertility. Any such pain that lasts more than six months and doesn't respond to painkillers should be investigated to rule out the possibility of endometriosis.

Getting a diagnosis

It takes an average of seven and a half years to get a diagnosis at present, with much unnecessary suffering, because women often assume pain is part of their 'normal' cycle. Endometriosis should be ruled out before treatment for IBS and recurrent cystitis is considered. The condition can't be felt on examination until it's advanced. Neither does it show up on ultrasound, MRI or CT scans. The best method is by visual inspection with a laparoscope, where a tiny camera is inserted into the pelvis.

How is it treated?

Hormone therapy: This aims to stop menstruation in the endometrial lesions, to reduce inflammation and pain. As women don't menstruate during pregnancy, after menopause or if there are high levels of male hormones in the body, the drugs used usually mimic one of these situations. All drug treatment has various side effects, on occasion debilitating, so should not be used for more than six to nine months (except for the Pill and Mirena coil). Also, it should be avoided ▶





FAST FACT: If endometriosis develops in the muscle of the womb, it is called adenomyosis.

if you're trying to conceive, as it delays and does not improve chances of pregnancy. Nor does it reduce pain in all cases; those who do find relief can find themselves back to square one when treatment is stopped.

Surgical treatment: This is more effective in terms of reducing pain and increasing fertility. Keyhole surgery should always be used, as the laparoscope magnifies the area, which allows the surgeon to survey the whole pelvis for patches of endometriosis, so it can be completely removed, which is impossible with open surgery. Two main methods are used: excision, where the endometriosis is cut away, and ablative surgery, which uses a laser to burn away the tissue. Ablative surgery is less effective, but it's more often used, as it's a quicker procedure and requires less expertise.

Advances in surgery

While excision surgery is the most effective way of removing endometriosis from the peritoneum, many women (20-40 per cent) don't see an improvement in symptoms, and 40-50 per cent see them recur in five years. This is partly because in conventional excision surgery only the tissue that appears to contain endometriosis is removed.

To improve outcome in terms of pain relief, fertility and recurrence rates, I developed a pioneering procedure: total pelvic peritoneal excision, which I've practised since 2002. With this method, all the pelvic peritoneum is removed, not just the visible endometriosis. This is because studies have shown the 'normal' peritoneum contains endometriosis, which is not visible, along with abnormal neuronal innervations, vascular changes and increased inflammation, which may cause pain. This way, all endometriosis cells, those with the potential to become endometriotic and other changes within the 'normal' peritoneum responsible for pain, are removed.

Endometriotic cysts on the ovaries require removal of the entire cyst and cyst wall, while preserving the ovary. If an ovary is removed, there's a risk that any future endometriotic cysts developing in the remaining ovary may severely affect its function.

It is a misconception that a hysterectomy will cure endometriosis. It should only be considered if your family is complete *and* the uterus is affected, and then only with excision treatment, not as standalone surgery. Unfortunately it's common, after ineffective medical and surgical treatment, for patients

to be prescribed a hysterectomy and bilateral oophorectomy (removal of both ovaries). The logic behind removing the ovaries is that you also lose the hormones they secrete, which are responsible for bleeding in endometriosis patches, and should relieve symptoms. But as other endometriosis cells remain in other parts of the pelvis, this may be ineffective, and symptoms will continue. Moreover, the loss of the ovarian hormones increases the risk of heart disease, dementia, osteoporosis, Parkinson's, decline in sexual function and psychological wellbeing, acute and aggressive menopause and a reduced life expectancy.

Women with endometriosis should have the endometriosis removed rather than their organs, especially the ovaries. If it's fully removed and recurrence is avoided, as in total excision, there's no reason to remove the ovaries. In the past decade, I've preserved the ovaries of all my patients. Surgery can provide lasting relief from symptoms. At a long-term follow up after surgery with me, on average my patients saw: a 60 per cent reduction in pain with their period; a 75 per cent fall in pelvic pain; a 70 per cent drop in painful sex; 98 per cent had an increase in quality of life from 3/10 to 8/10; and over 50 per cent with fertility issues conceived without IVF.

For further details, go to www.endometriosis-consultant.co.uk. For general support, visit www.endometriosis-uk.org.

'The affected tissue must be fully removed to prevent the symptoms recurring'



'I'M FINALLY SYMPTOM-FREE'
Frances Moule, 52, a company secretary from London, only discovered in her 40s that endometriosis was causing her painful periods

'I started my periods at 12 and they were painful from day one. I took painkillers and assumed that was my lot in life. I had my son (now 18) when I was 35. I probably had endometriosis then but, luckily, I had no problem conceiving. In my mid-40s, I started to get very painful periods - as if I'd been kicked in the stomach. My GP sent me for tests, including a laparoscopy. I had level four endometriosis, affected my ovaries, bowel and Pouch of Douglas [a small pocket between the rectum and uterus]. I was advised to have my uterus and ovaries removed. I didn't want such radical surgery, so I researched alternatives and met Mr Trehan. I had a total pelvic peritoneal excision - and kept my uterus and ovaries - four years ago, via keyhole surgery. My recovery time was minimal - and there's been no pain or recurrence of my endometriosis since. I consider myself extremely lucky.'

COMPILED BY CLAIRE LAVELLE. ILLUSTRATIONS LILY TRISTRAM, SHUTTERSTOCK