

# Diagnosis and management of endometriosis

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## Introduction

Endometriosis is rapidly becoming one of, if not the most important disease in gynaecology, due to its apparently increasing incidence and its major contribution to the problems of pelvic pain, abnormal bleeding and infertility. The actual incidence is unclear but it probably affects at least 10–20% of women and up to 50% of women who are infertile.<sup>1</sup> The incidence appears to be increasing due, in part, to more accurate diagnosis, but there is also evidence that the disease may be truly increasing in incidence and severity. There are many theories as to why this may be so. Women's bodies are undoubtedly changing. In 1941 the average woman was 1.57m tall and weighed 59kg. Now the average height is 1.62m and weight 65kg and set to grow further. The age of menarche is falling and the age of childbearing rising so that the average age of a first baby is around 30 years. Families are smaller and breastfeeding for shorter periods of time. All of these factors expose women to the cyclical highly oestrogenic environment of menstruation for far longer than in the past. There are also still controversies over environmental oestrogens such as Dioxin that may theoretically predispose to increased risk.

As far as diagnosis is concerned, it has become apparent that this disease has frequently been misdiagnosed in the past, as it may masquerade as many other conditions, including pelvic inflammatory disease, appendicitis, irritable colon, dysfunctional uterine bleeding and even pelvic malignancy in the advanced stages. The difficulties with diagnosis have been

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largely due to the lack of a suitable screening investigation and it is still the case that laparoscopy is needed to confirm diagnosis. However, there has fortunately also been a revolution in treatment options over the last 20 years with the advent of modern laparoscopic surgery (Figure 1) Also the Mirena IUCD is, hopefully, the beginning of more acceptable medical options for treatment. However the disease remains a challenge in management for many women and is the major single entity contributing to menstrual dysfunction and infertility.

## Diagnosis

Endometriosis is a disease characterised by a long delay in diagnosis. The interval between onset of symptoms and diagnosis was eight years in a group of New Zealand patients (Ascot Endometriosis Centre unpublished data). Therefore, this is a disease where suspicious symptoms must be teased out carefully to assess whether there is a need for further referral. Taking a careful history is extremely important.

## History – pain

Pelvic pain is the primary presenting symptom in 40% of women seeking a gynaecological consultation. Assessing pain may be particularly dif-

ficult in the teenager with period pain. A high percentage, up to 80%, of teenagers will complain of dysmenorrhoea. If the pain is restricting activity such as school sport or social events this is more significant. If the pill has been started but fails to relieve symptoms or relieves them initially and then the pain is breaking through, the pain is more likely to be due to endometriosis. Endometriosis is not uncommon in teenagers with chronic pelvic pain. Our centre has found 93% positive clinical diagnoses at laparoscopy in 81 teenagers presenting with pelvic pain and other studies show a diagnosis rate of 70%.<sup>2</sup> Some women regard dysmenorrhoea as normal; paradoxically this may be more so if they come from endometriosis families. Questioning these women retrospectively when unexpectedly bad endometriosis is found at laparoscopy they will admit to period pain but state that it is only the 'usual period pain that all the women in their family get'. A known family history of endometriosis is especially significant. The disease is probably linked to multiple genes and influenced by the woman's environment.<sup>3</sup> A positive family history is reported by 28% of women (Ascot Endometriosis Centre data).

However, due to the lack of a confident diagnosis in previous years, there will be considerable underestimation of a positive family history. The young woman with endometriosis will often have a mother who had an early hysterectomy for 'bleeding problems' or an aunt who had ovarian cysts. Infertility is also a less common presenting symptom in previous generations due to the much earlier age of child bearing.

Another clue to the fact that a presenting symptom of pelvic pain is likely to be due to endometriosis is the existence of other pelvic symptoms. Usually the pain is linked to menstruation but can commonly start the week before. Acyclical pelvic and abdominal pain may occur and appears to be more common in younger women. Low back pain is a common symptom and often correlates with the disease being found deeply in the utero-sacral ligaments at surgery. Therefore the back pain from endometriosis is felt in the low sacral region rather than the lumbar region. Dyspareunia may be the only, or major symptom of presentation, and again often correlates with deep cul de sac disease. The pain is thus deep and often positional.

Bowel symptoms are a common presenting symptom even in young women with endometriosis. We found that 30% of teenagers at laparoscopy have endometriotic deposits on the rectal peritoneum or less commonly in the rectal wall. The disease may mimic irritable colon and present with bloating, diarrhoea and pain which are usually maximal at menstruation. Women with deep lesions in the rectal wall or close to it in the cul de sac applying traction to the rectal wall, will often describe pain associated with defecation around the time of periods. There is a very characteristic description of the pain as building up to a peak just prior to defecation and a feeling of a sharp shooting knife in the rectal area. The pain is relieved by defecation. This pain can on occasion be severe and associated with fainting on the toilet and inability to pass a bowel motion. Rarely blood can

be present in the motions at the time of the period. Pain can relate to the bladder. It is not cystitis type of pain but again is related to traction or distension of the wall of an infiltrated bladder causing pain when the bladder is full. Endometriosis can cause cyclical haematuria and is also a cause of ureteric obstruction in severe infiltrative disease.

Endometriosis is a progressive disease, therefore, if pain is worsening over years, and especially if it is breaking through treatment with anti-inflammatories, suspicion should be raised. It is quite reasonable to treat younger teenagers with anti-inflammatories initially and to start a low dose 3rd generation oral contraceptive. But it must be remembered that the pill in particular may mask the symptoms of endometriosis whilst allowing its progression. It may be advisable to stop the pill after a year or two and assess the level of ongoing pain and the need for referral. The disease is classically thought to 'burn out' after the menopause but is not an uncommon cause of pelvic pain in women following hysterectomy and in the postmenopausal years. The deeper and larger disease deposits can become autonomous and form their own supply of intrinsic oestrogens.

### History – bleeding

Endometriosis is a cause of a number of common presentations of abnormal bleeding. It can present as menorrhagia, intermenstrual bleeding, breakthrough bleeding on the pill and even postcoital bleeding. Younger women tend to present with breakthrough bleeding on the pill and postcoital bleeding and older women with menorrhagia. This symptom in particular can be due to the manifestation of adenomyosis, which is the presence of endometrial glands and stroma in the myometrium. It is commonly associated with endometriotic peritoneal disease. The combination of any abnormal bleeding and significant pelvic pain should immediately suggest endometriosis as the most likely diagnosis.

Figure 1. Evolution of surgical treatment

<b>1970s</b>	Delay in diagnosis Laparotomy removal of organs
<b>1980s</b>	Diagnostic laparoscopy Medical therapy
<b>1990s</b>	Laparoscopic diagnosis and treatment

Figure 2.

### Endometriosis may present as:

- Painful periods
- Acyclical pelvic pain
- Deep dyspareunia
- Back pain – sacral
- Midcycle pain
- Irritable bowel
- Pain on defecation
- Acute pelvic pain (appendicitis)
- Abnormal bleeding
  - Menorrhagia
  - Intermenstrual bleeding
  - Postcoital bleeding
  - Breakthrough bleeding on the pill

### Diagnosis – investigations

It is important for the patient to realise that the disease cannot be diagnosed by ultrasound. Ultrasound may be useful as a screening test as it may detect the presence of cystic change on the ovary and sometimes deep rectovaginal disease and or adenomyosis.

Small endometriomas may be easily confused ultrasonographically with follicles or corpus lutea, but larger endometriomas are usually accurately detected as abnormal. Endometriomas are often a marker for more advanced pelvic sidewall and cul de sac disease as they generally develop late in the disease process.<sup>4</sup> Measurement of Ca125 is occasionally helpful as it can be raised if there is proliferative peritoneal disease or endometrioma but is usually normal in deep disease and the early stages. It is not suitable as a screening investigation.

### Treatment – laparoscopic surgery

Laparoscopy is the gold standard for diagnosis and treatment. The disease can justifiably be regarded as a be-

nign tumour as the endometrial cells attach, proliferate, invade and form significant fibrotic plaques and adhesions in the later stages. Therefore optimal treatment is to excise the disease if that is technically possible. Laparoscopy must be performed by surgeons experienced in finding and diagnosing the disease. It can be missed in up to 20% of diagnostic laparoscopies.<sup>5</sup> Once diagnosed the deposits of the disease can be excised or ablated by diathermy or laser. Excision has the advantage of dealing with the invasive nature of the more serious disease that can be largely retroperitoneal and more deeply invasive than it may appear. Also excisional surgery done in an 'en bloc' technique will remove a lot of smaller disease foci surrounding larger more obvious areas and increase clearance rates. Surgery for more severe disease, especially with bowel involvement is best done in a small number of centres with access to multidisciplinary teams as the risk of complications to bowel and ureter are significant. The disease characteristically obliterates planes between the organs with fibrotic and invasive plaques and thick adhesions. Excising these is a major technical challenge with three to five hour procedures being common in Grade 4 endometriosis. However the results of surgery appear to justify the risks with initial long-term studies showing 70–80% of patients not needing further treatment.<sup>6,7</sup> If re-operation is required endometriosis is not always found,<sup>7</sup> confirming the paradoxical relationship that the degree

of pain has to the degree of disease in some patients. Fertility seems to be significantly improved by ablative surgery of mild to moderate disease in infertile women with endometriosis.<sup>8</sup> Although there are as yet no randomised controlled trials in more severe disease, good pregnancy rates follow radical surgery for severe disease with up to 50% of women achieving a pregnancy following surgery.<sup>9</sup>

### Treatment – medical therapy

A variety of hormonal agents can be used to suppress the growth of endometriotic deposits with the consequence of relieving pain and symptoms. As expected, symptoms usually return after cessation of the medication. However they can be useful in women in whom surgery is not appropriate or postoperatively, especially if full clearance of the disease is not possible. There is still a significant rate of true recurrence even after full excisional surgery so the search for an ideal medical treatment as an adjunct to surgery continues. The choice between the combined oral contraceptive, progestagens, danazol and GnRH agonists depends principally upon their side-effect profiles because they relieve pain associated with endometriosis equally well.<sup>10</sup> After surgery many younger women tricycle the pill to avoid menstruation and use non steroidal anti-inflammatory drugs if necessary.

The Mirena IUCD is looking very promising as a method of treatment, as an alternative to surgery, to treat suspected adenomyosis and/or where

there is significant menorrhagia associated with endometriosis and also postoperatively to reduce recurrence of symptoms.<sup>11</sup> There is no role for medical therapy with hormonal drugs in the treatment of endometriosis associated infertility.<sup>10</sup>

### Treatment – supportive therapies

Many women with endometriosis will benefit from lifestyle changes to increase exercise and improve nutrition to help with pain management. If the bowel symptoms of the disease are predominant or if there is confusion over the coexistence of irritable bowel, disease referral to a nutritionist can be very helpful to some women. Evidence for any specific diet to follow is lacking, but anecdotal evidence of benefit is frequent, especially with avoidance of wheat and fibre.

### Summary

Endometriosis is the commonest cause of chronic pelvic pain in teenagers and in women of all ages. Vigilance is necessary to reduce the unacceptable delay in diagnosis that historically, and to the present day, characterises this disease. A careful history will elucidate a group of women to refer for laparoscopy. Full excisional surgery, removing the disease not the organs, will relieve pain and preserve and restore fertility in a majority of patients. Despite optimal treatment there will still remain a small difficult group of women in whom the disease remains chronic or there is such severe damage to the pelvis that there is continuing pain.

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