

# **Endometriosis: Case Studies for Education**

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## **Abstract**

This paper examines the gynaecological condition of endometriosis and uses the example of UK case studies as illustrations of the condition and as a vehicle to describe the medical and pedagogic care that was available to the case study patients. The first case study is told from the point of view of the lead author, who was the case study's tutor at the time. The second case study gives an indication of how the material was used in the lead author's teaching sessions, with the case study patient's full consent.

## **Introduction**

The endometrium is the inner membrane of the mammalian uterus and prevents adhesions between the opposed walls of the myometrium. Endometriosis is a growth of endometrial tissues outside the uterus, which is subject to the normal cyclic changes. The condition is associated with infertility in 30-40% of women who leave childbirth to after the age of 30. The incidence is 1-7% and it is not associated with lifestyle. The average age of onset is around 28 but the condition has been seen in an age range of 10-83 years. Worldwide it is estimated that 176 million women are affected; there is no racial preference, and the cause remains unknown.

Endometriosis can occur in a variety of sites, including the uterosacral ligament, the ovary, the Pouch of Douglas, the bladder, the rectum, the sigmoid colon, the round ligament and the appendix. In rare circumstances it can also occur in the umbilicus, brain, retina, lungs, breasts, joints and nasal cavity. Theories surrounding its occurrence include those of reflux menstruation, the cell transportation of endometrial cells, embryological displacement due to a deficiency in the immune system, and toxins and environmental pollution.

A patient suffering from endometriosis might present with signs and symptoms including dysmenorrhoea (pain during menstruation), pelvic pain, cramps, heavy periods, irregular bleeding, abdominal bloating, pre-menstrual tension, and pain during sexual intercourse. Furthermore, she might experience a lack of energy, anaemia and/or depression, as well as a cycle of less than the normal 28 days, with periods lasting longer than five days. Further complications include adhesions and scarring, organ dysfunction, cystic formations on the

ovary, and diarrhoea and/or constipation. The condition might be treated with hormonal treatments, or with aspirin and/or ibuprofen; or alternatively with relaxation techniques and therapies including hypnosis (for some patients).

### **Case Study: Surrinder**

(For this case study, the name has been changed to protect confidentiality. Permission to use this case study has been given. It is written from the point of view of this paper's lead author.)

I met Surrinder when she was completing her midwifery training; she was already a trained nurse. She was my personal student and for this reason I became aware that she would have two or three days off each month. In order to determine if there was anything wrong, or there was anything that we should know about, I asked to see her. Initially she did not want to disclose what her problem was so I offered an appointment with Occupational Health. After talking about other aspects of her progress, she told me that she had endometriosis, according to her GP. The severe pain that the condition caused was the reason why she needed to take two or three days off each month. I suggested that she asked her GP to make an appointment with a Gynaecological Consultant.

Her date arrived and Surrinder was required to stay in hospital for two days; the reason for this was because if it *was* endometriosis he would do an ablation of the endometrium, which would help with the heavy periods. These heavy periods were contributing factors to why Surrinder needed so much time off work. She asked me if I would visit her, which I did. The diagnosis was confirmed and the condition was both in and outside the uterus. After her six - week appointment we met; Surrinder was extremely anxious, and during our conversation she told me that the consultant had said that she needed a hysterectomy and that there was no other satisfactory treatment. To me this sounded rather drastic. I suggested that before she decided that a hysterectomy was the only way forward, she should go and meet a person from Endometriosis UK and to ask her GP to refer her to an expert in endometriosis at [X] Hospital in [Y]. Surrender was only 23 and had no partner or boyfriend, so accepting that there was no alternative but to say yes to a hysterectomy was too drastic: it would determine her reproductive future.

As a result of Surrinder's visits, she was put on the continuous pill. There were certainly a few side effects but these she managed well. During this time she also recovered from the anaemia that had affected her while she was in hospital. She completed her training and took a post as a staff midwife in a local unit. We kept in contact and later I met her husband-to-be. She had explained about her endometriosis to him, but because she was so well I think he considered it to be little more than a cold. Six months later she was married; and some time after this her husband rang me and asked if he could see me... but not with Surrinder. Although his request sounded rather odd, we made an appointment for him.

When he arrived a week later he looked anxious and upset; it was difficult to describe his persona. Once the niceties were over, he told me they were hoping for a family. I knew immediately that what he wanted to know was how to help her through these bouts of pain. He said he had no idea that she would suffer so much in order to become pregnant. So I

explained the pattern of endometriosis. We discussed how he could support her until she became pregnant. I did feel sorry for him as he had only seen her happy and healthy, so this was a complete shock despite having been told by the consultant that this would happen. What he said was, although he had heard and understood what he'd been told, it had not prepared him for Surrinder's distress, and he was not sure he could manage until she became pregnant. At the end of nine very long months, Surrinder became pregnant. Her pregnancy progressed very well and she had a son. After six weeks she went back on the pill and was very well.

During the next two-and-a-half years, all was well. She visited me quite unexpectedly as her Consultant had said that if she wanted any more children she needed to consider it in the next two years. She did want a second child but her husband did not want to see her in such pain again. (This is a frequent problem and it is hard to support a wife while she hopes to become pregnant.) We discussed the options that were available which could reduce the pain. One of these is hypnosis, which enables the person to relax at the time of pain. After many sessions she was competent to self-induce her hypnosis. Pregnancy seemed to evade her and she became a little distressed, so her Consultant told her that endometriosis can affect fertility. It is possible that she became a little more relaxed while waiting to start her fertility treatment, and I can guess this because she became pregnant. This was diagnosed during an ultrasound scan at the beginning of her treatment. There was great joy at the birth of her daughter.

After this delivery it was discovered that Surrinder had some displaced cells in her elbow and the pain was incapacitating and more of a problem as she had children to look after. Her Consultant was so helpful over this period, and after three months he agreed for her to go back on the pill, but asked her and her husband to consider bringing on an early menopause. Obviously this was a very big decision, and they wisely took time to consider their options. Two years later they agreed to go ahead. She had some of the side affects but these were easier to copy with after all the pain and other problems that she had had before. Surrinder sailed through this time easily. At the end of this time her husband's firm wished him to relocate to Norway for four years. Surrinder was worried that she would not be able to see that Consultant whom she had such faith in; however, he said that she could email him whenever she felt she needed any help. This eased her mind. They moved and are now settled in [NORWEGIAN CITY].

Surrinder considers she was very fortunate to have a good Consultant who treated her as a partner in her care and did not dictate her future. Her second link was Endometriosis UK who gave her knowledge in relation to the condition and enabled her to consider her options before she met with her Consultant. Surrinder's story indicates the quality care management that is not always available to everybody.

### **Case Study: Ann**

(For this case study, the name has been changed to protect confidentiality. Permission to use this case study has been given. It is written from the point of view of reflections on lesson

notes and reflections on material provided in a lesson. If there is time at the conference, these prompts will be used as conversation points.)

Ann, 17, was admitted to the Gynaecological ward with heavy painful periods and pain that had lasted for six months. *What could be her diagnosis?* The consultant discussed the situation with Ann and her parents and the decision was made to do a laparoscopy, to see if she had endometriosis. (A laparoscope is an instrument through which structures within the abdomen and pelvis can be seen. A small surgical incision is made in the abdominal wall.)

Ann asked to go home and return later to have the investigation; her reason for asking this was that she needed time to think through the procedure and the consequences. While talking to Ann, several nurses intuited that she wanted to look it up (on the Web or in a medical resource book) so that she could understand what exactly it was. Despite having these conversations, Ann did not understand her condition fully. *How would you describe endometriosis to a teenager? Where would you put the emphases?*

Ann returned four weeks later for a laparoscopy, as a day case. *Since the laparoscopy indicated that the endometriosis was only in the uterus, what treatment could be offered?*

The treatment that could be offered is as follows:

- Combined oral contraceptive pills.
- Progestogens (e.g. norethisterone), which can shrink endometrial tissue. (Progestogens have the function of maintaining pregnancy, although they are also present at other phases of the oestrous and menstrual cycles.)
- Antiprogestogens (e.g. danazol), which are hormones that cause an artificial menopause by decreasing oestrogen and progesterone production.
- Gonadotropin-releasing hormone (GnRH) analogues, which are hormones that cause an artificial menopause by decreasing oestrogen production.

Ann was offered an ablation of the uterus. *How would you describe this procedure and how long might she stay well?* An endometrial ablation is a simple day case treatment which aims to destroy as much of the lining as possible so that less will grow each month, making periods lighter in about 90% of patients.

She had an ablation two weeks later. On her six week clinic visit she was very well. A further appointment was made and at this appointment she too was well. A year on she began to have her symptoms return. *What point do you need to know before you suggest any further treatment?*

She had a further ablation and again remained well for a further eighteen months. During a routine appointment she asked if she could go on the pill as she had now a boyfriend. This was offered. *What advice would you give her now that she has chosen this option?*

Ann was 23 when she returned for a yearly appointment and said that she was getting married in six months' time. She was asked to make an appointment for nine months later. *Do you know why?*

Ann reached 25 before she wanted a child. Initially all went well, but by the seventh month she felt her endometriosis had returned. She and her husband saw the medical staff and the family planning staff as her husband had never seen her so distressed. *What help could be offered?* Some of the ways of managing the symptoms were by diet, exercise, and pain control.

Ann became pregnant when she was 27 and was about to consider fertility treatment. *Given her medical history, is this a common problem?* The pregnancy went well and Ann delivered a baby boy. While she breastfed she was well. *Is there a link between the breastfeeding and Ann's condition?*

Nine months after the birth of the baby, Ann's endometriosis began to be more trouble, despite the fact that she was on the pill. She visited the family planning clinic, where it was suggested that she should have a three month injection. *How do these injections work, and are there any downsides?*

At the age of thirty, she and her husband wanted to try for a second child. She was advised of several factors. Over time, an accumulation of scar tissue can cause pain if it occurs close to nerve fibres. When impacting the fallopian tubes, endometriosis can also negatively impact fertility and the outcomes of infertility treatments. Ovulatory dysfunction is the single most frequent cause of infertility.

Ann did not become pregnant so her ovulatory function was checked. The results indicated some dysfunction, so she commenced hormonal treatment. *What would be offered?* On the third cycle she became pregnant, but she miscarried at twelve weeks; there appeared to be no reason for this. It was suggested that she wait six months before she considered trying again. These months, both Ann and her husband found difficult because of the return of the endometriosis. *What help would be available?*

At 32 she became pregnant without any treatment and gave birth to a girl. Ann asked for a hysterectomy after the birth. *Would she be offered one? Or what could she be offered?* The consultant suggested she had an induced menopause, and apart from some minor problems, all went well. Five years later she had a hysterectomy. Since then her life has been symptom-free.

What she said was that it had been a hard journey, made a little easier by having people to speak to about her option, before she met the medical staff on her visits.

## **Conclusion**

Using a case study approach enables the exploration of an aspect of health which is often referred to in textbooks as if it is a minor problem or nuisance. For the person living with it, endometriosis is far from a minor problem or nuisance, and it can dominate a woman's life.

Teaching in this way can be achieved well in the classroom and via on-line conferencing. Discussion produces active learning which is more substantive than some other methods. The

learning can be enhanced if you have asked for a tape from the person and you play it at the end, as this will provoke more discussion. It is an underused method, in our opinion.