

Thousands of women have it, but don't know it. The symptoms range from painful periods and painful sex to the inability to conceive. "It" is endometriosis, the scourge of the womb ... a condition whose treatment has been a long time coming

Story **Caroline Baum** Illustration **Kaz Cooke**

the enemy within

■ **QUESTION:** WHAT DO MARILYN MONROE, RAELENE Boyle and cartoonist Kaz Cooke have in common? **Answer:** endometriosis, a mysterious illness often inaccurately described as "career woman's disease", about which little is known and for which there is, at present, no real cure. Or is there?

Endometriosis first came to my attention when I found two friends talking in the kitchen with their T-shirts rolled up, apparently comparing their belly buttons. In fact, they were showing each other their wounds: scars from a laparoscopy, the surgical procedure necessary to diagnose endometriosis.

Endometriosis is a condition in which some of the lining of the uterus, or endometrium, instead of being expelled in the menstrual fluid, moves to and grows in locations outside the uterus, usually on the

ovaries, where it forms cysts. It can also be found on the bowel, bladder and ligaments, and in the Pouch of Douglas (the area between the uterus and bowel). In really extreme and highly unusual cases, it has been known to find its way into the lymph system, the lungs, thighs, eyes and nose.

The label "career woman's disease" is, thank goodness, on the way out. It arose in the 1930s when leading gynaecologists noted the condition among women who were: white, middle-class, intelligent perfectionists, obsessive, overambitious and underweight, in their 30s or 40s, with a stressful career, and who had deliberately delayed child-bearing because of their professional commitments.

No-one is entirely sure why endometriosis occurs. Symptoms range from painful periods and in-▶

says Wood, who will be attending the 3rd World Congress on Endometriosis in Brussels in June.

"Interferon [the anti-viral drug much publicised because of its success rate in arresting some some forms of cancer] may be a possibility, but there is not enough evidence yet and it also has bad side-effects."

But Dr Robert Jansen, who is the medical director of Sydney IVF and is researching the causes of endometriosis at the University of Sydney, says: "The immune deficiency theory could be a red herring, in that it may be a result of endometriosis rather than a cause."

Meanwhile, other research suggests that women with endometriosis have a higher incidence of allergic conditions, particularly food sensitivities and hay fever, while another study has found that women who exercised regularly were less likely to develop endometriosis. This advantage was limited to women who had begun regular

exercise before the age of 26 and who exercised for more than two hours a week. It is thought that, usually, vigorous exercise lowers the oestrogen levels in the body, oestrogen being the hormone which encourages the growth of both the endometrium and any endometrial cysts. Ironically, women who already suffer from endometriosis often find vigorous exercise painful, but stretching and relaxing exercise, such as walking, yoga and tai chi, are recommended.

What appears to be beyond dispute is that there is a heredity factor involved in the disease. Says Robert Jansen, "If a mother has endometriosis, her daughters are five times more likely to get it."

A modern girl's dilemma

KAZ COOKE, cartoonist and author of *The Modern Girl's Guide to Safe Sex*, is another sufferer. "I thought I was well ▶



Chinese herbalist Lily Jiang Lui uses herbs, massage and acupuncture to treat endometriosis.

tercourse, through to low energy levels and constant tiredness, to infertility. But the symptoms are frequently misdiagnosed: one woman with persistent pain and vomiting had her appendix removed only to find her symptoms recurring a month later — the surgery had been pointless because she was suffering from endometriosis, not appendicitis. Treatment by conventional Western medicine is extreme, involving dosages of hormones with powerful side-effects or the radical step of a total hysterectomy.

Documentary film-maker Pat Fiske, an American living in Sydney, is preparing a film about endometriosis. Fiske did some research into the condition, and found the few existing statistics frightening. American research suggests the disease affects 10 per cent of women of child-bearing age; 45 per cent of women on the Australian IVF program have it; but most sufferers don't know what it is they've got. "They may simply think they have painful periods," says Fiske. "Many gynaecologists will tell women to put up with pain as it's their lot in life. Trouble is, the longer you wait before getting a proper diagnosis, the more damage the disease can do, because it grows — fast."

When Fiske and her producer, Glenys Rowe, who are both endometriosis sufferers, approached health organisations to sponsor their project, they were turned down. "They refused to believe the figures," says Fiske, who now has funding from Film Australia.

To select the case histories for the documentary, Fiske contacted the Endometriosis Association, a national organisation formed in Victoria by two sufferers, Lorraine Henderson and Ros Wood, and sent a questionnaire to their members. She was flooded with letters, many of them so desperate and tragic that they reduced her to tears of anger and frustration. Among the descriptions of pain, some mentioned a feeling of a balloon ready to pop in their stomach, or a knife being thrust into the vagina, a feeling "like passing glass when urinating" or of the pelvis being on fire, stabbing shooting pains from thighs to breasts, and a sensation of being impaled with a steel rod up the rectum.

Fiske discovered she had endometriosis when she developed a nagging pain on her left side while jogging. "The first person to suggest what it might be was Dr Fred Hollows, who I run with. My gynaecologist suggested a laparoscopy, but wrongly diagnosed the problem as pelvic inflammatory disease and put me on antibiotics. It took seven years for the disease to be properly identified.

"Meanwhile, the symptoms were really extreme: I had terrible mood swings because of the way the disease plays with your hormones and confuses your body. I took Danazol, which is a weakened form of the male hormone testosterone and has some pretty unpleasant side-effects — it can make you put on weight or grow facial hair or cause your voice to drop permanently.

"The first course of Danazol made me feel euphorically healthy, although I wanted to eat red meat all the time. As soon as I came off the drugs after an eight-month course, the symptoms returned. A second course felt less effective, but Danazol is not a long-term solution: as a steroid, it

may damage the liver. So I investigated other options: now I have a Chinese herbalist and have no more problems."

Cause and effect

THERE ARE several theories about what causes endometriosis. The most widely accepted is that of retrograde menstruation, or menstrual backflow, which seems to explain the majority of cases.

When most women menstruate, some menstrual fluid from the uterus flows backwards through the Fallopian tubes into the pelvic cavity and is deposited into the surrounding organs and tissues. The menstrual fluid contains not only blood, but fragments of endometrium.

The problem occurs when, in some women, these fragments implant themselves on the surface of organ tissue, where they grow, either as "spot and dot" endometriosis, which may be as small as a pinhead, or as cysts, which can measure up to 15cm, but are more commonly between 2cm and 5cm, and which sometimes cause organs to adhere to one another.

Adhesions can hinder conception in a number of ways. Those around the ovary make it difficult for the ovum to be expelled. If the Fallopian tubes are bound by adhesions,

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the egg can't reach the tube for fertilisation, while adhesions in the tube may obstruct the passage of the egg to the uterus for implantation.

According to the authors of a new book, *Explaining Endometriosis* (see footnote) endometriosis is one of the most common causes of infertility in women over 25. It is thought that 30 to 40 per cent of women with endometriosis are infertile, compared with 15 per cent of women generally. The likelihood of conceiving depends on its severity. The good news is that at least 50 per cent of infertile women with endometriosis do finally conceive.

Endometriosis is active all the time, growing as oestrogen levels rise in accordance with the female cycle. But, in most cases, symptoms are only evident at certain times, such as ovulation or menstruation. The pain associated with the disease is caused partly by the endometrial growths themselves and partly by the presence in the pelvic area of a mix of blood and endometrium which irritates organs and has nowhere to go.

Endometriosis is a benign disease because it does not invade the body in the same way as cancer. It is simply the growth of normal tissue in an abnormal place.

Professor Carl Wood, a pioneer in the field of infertility and the chairperson of the department of obstetrics and gynaecology at Monash University, believes that this happens to women with some kind of unidentified immune deficiency. "I believe we won't find a cure for endometriosis until the immune factor is fully understood,"

informed about my body, but I'd never heard of this," says Cooke. "I've had period pains ever since they started when I was 14. I went to my doctor and he told me I'd be all right as soon as I had a baby — very helpful advice at that age. The pain made me throw up every month and I felt at war with my body, which seemed to be rebelling and betraying me."

Cooke is now 29 and was diagnosed correctly only last year — a gap of 15 years, which is not uncommon among sufferers. She says: "After my first diagnostic laparoscopy, the surgeon told me there was not much endometriosis there and said he thought I probably had a teratoma. I went home and looked it up: I found the root of the word is Greek and means monster — it's a cyst that grows hair and teeth. I was horrified and had visions of a voodoo cyst like something out of *Alien!*"

"Then my flatmate took me to a Chinese herbalist who asked me all the right questions, like what was the colour of my menstrual blood. She adjusts my medication every few weeks and has put me on a diet, so I no longer have ciggies and Coke for breakfast. As a result, I had my first pain-free periods in more than 10 years. But I have not totally rejected conventional medicine when it comes to getting rid of the endometriosis which is already there. I am using a herbalist method as a preventative measure. I've also had a second laparoscopy, which revealed that my left ovary was stuck to my uterus, that my uterus was stuck to my pelvis, that I had two endometrial cysts and the whole thing looked like a Labor Party pre-selection meeting: blood everywhere! The surgeon lasered everything and put sheets of cellulose, called Interceed, in between my organs to stop them from adhering to each other again. The whole operation really knocked me about. My surgeon has now suggested that I could have another laparoscopy in six months and go on Provera [a drug that is frequently prescribed for endometriosis] in the meantime.

"I have decided to refuse that option and stay with the herbs, but, in a very encouraging step, my surgeon has decided to co-operate with the herbalist by writing her a report of my operation and assisting her in my treatment.

"It has taken me countless GPs, several gynaecologists, two surgeons and one herbalist to work out something

that has really helped me and it has cost a fortune, with no Medicare rebate for the one thing that has really worked — the herbs."

More open-minded members of the medical profession are prepared to admit that Chinese medicine has a high success rate in the treatment of endometriosis. The surgeons involved in establishing Australia's first endometriosis clinic in Melbourne, in conjunction with the Endometriosis Association, have included Chinese herbalists in their team of consultants.

The Chinese diagnosis of endometriosis is that it is linked to stagnation of the blood in the liver and is related to emotional stress. Beijing-trained herbalist Lily Jiang Lui, who specialises in gynaecological disorders, explains: "When the blood circulates poorly, especially around the time of menstruation, it causes blockages, which manifest as symptoms of feeling either very cold or having a very hot sensation in the uterus. I treat this by relaxing the organs, clearing the liver meridian [energy zone], which passes through the uterus, and mobilising the blood."

Liu uses hundreds of herbs as well as massage and acupuncture, "but the herbs are the most effective because they are the deepest treatment". They may be boiled up as

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tea or administered as a ready-mixed medicine to be taken several times a day. After several months, Liu claims that the herbs not only alleviate symptoms, but actually soften and dissolve cysts. "The problem with laser treatment is that it actually creates more scar tissue, which in turn requires more surgery to remove," says Liu.

Patients are also advised on how to modify their diet and lifestyle appropriately: "It's not an old wives' tale that you shouldn't swim in cold water when you have your period. Cold water is a shock to the system, as are cold drinks, ice-cream and [hot] coffee."

Most naturopaths treating endometriosis recommend a low-fat, low-sugar diet such as that undertaken by sufferers of yeast allergy/thrush/candida, which can in turn

Research undertaken by the Endometriosis Association reveals that most women are diagnosed as having the disease between the ages of 24 and 35. The average number of years between the onset of symptoms and the diagnosis is 6.1 years. More disturbing is the evidence that women who reported their symptoms to a doctor before the age of 20 waited an average of 8.8 years to get a correct diagnosis, while those in the 30-34 age

bracket received an accurate diagnosis only 1.4 years after symptoms were first reported.

The society's findings also suggest that when the medical profession says that endometriosis is rare in teenagers and uncommon in women under the age of 25, it's because endometriosis is not generally diagnosed in women of this age group simply because they have never had a laparoscopy.

Often, the only clue that a woman is

suffering from endometriosis may lie in her inability to conceive, which is not something that always concerns women in their 20s. They are less inclined to explore reasons for infertility than they are in their 30s.

For further information, contact the Endometriosis Association in your state: ACT (06) 286 2742; NSW (046) 55 2928; Qld (07) 831 2217; SA (088) 32 2264; Tas (002) 48 9413; Vic (03) 879 1276; WA (09) 417 2382.

be symptomatic of endometriosis. An advantage of the naturopathic approach seems to be that it works on the hormone system naturally, encouraging it to rebalance itself without disrupting the menstrual cycle as the drugs offered by conventional medicine do.

But Sydney IVF's Dr Jansen categorically rejects any suggestion that Chinese herbalists may have the answers to the causes of and cures for endometriosis. "You might as well believe in Father Christmas. Those alternative health people don't have a clue what they're doing, there are no trials for their treatments and no systematic controls. All reports of improvement are merely anecdotal."

Jansen believes that the most important progress made towards a cure for endometriosis is the ICI-developed drug Zoladex, recently trialed in Australia. Zoladex is a GnRH agonist, a modified version of a naturally occurring hormone which helps control the menstrual cycle. GnRH agonists work on endometrial implants by suppressing ovulation and oestrogen secretion. The resulting low levels of oestrogen in the body mean that the endometrium is no longer stimulated to grow and break down each month; instead, it eventually degenerates and wastes away. Most women stop ovulating and menstruating during treatment (as they do with most drugs prescribed for the condition), but begin again within a couple of months of completing treatment.

Danazol is currently the most often prescribed drug for endometriosis. Zoladex does not share its side-effects but it may cause osteoporosis if used over a long period of time, as well as hot flushes and loss of libido. It is also extremely expensive, at \$400 for a monthly injection over six months. It is still awaiting federal government approval for commercial sale, although it is available in the United Kingdom and United States. It is hoped that Zoladex will become available in Australia within the next year. Other drugs frequently prescribed include Duphaston, Provera and Depo-Provera (Provera is administered in tablet form while Depo-Provera is administered as an injection — its unapproved use as a contraceptive in developing countries was controversial), as well as Primolut N and the Pill.

The laser surgery which Kaz Cooke underwent during her second laparoscopy is still relatively uncommon in Australia due to the high cost of laser equipment.

If drugs and/or alternative health remedies fail to provide consistent relief and a woman is confident that she has completed child-bearing, hysterectomy may be considered as a last resort if symptoms are chronic (such as persistent bleeding) and the pain has become intolerable. Hysterectomy is often said to be the only "cure" for endometriosis apart from menopause. However, it does not always eradicate endometriosis, especially if the ovaries — which produce oestrogen — are not removed.

The keys to overcoming endometriosis are prompt diagnosis and finding a doctor who takes the condition seriously. Joining the local branch of the Endometriosis Association will put you in touch with other sufferers. ■