

Chapter 1

The Lowdown on Endometriosis: A Quick Run-Through

In This Chapter

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People generally don't understand endometriosis very well. Until recently, you didn't even hear about it — unless you were at a gynecology convention! But new research and better publicity have brought endometriosis to the public's attention, making many women wonder whether this is the nameless disease they've had since puberty.

In this chapter, we talk about the little-known disease of endometriosis: what it is, who it affects, and why it's received so little attention (despite the fact that it costs millions of dollars a year in lost wages and productivity). We also include a self-test to see whether you may have this disease.

Defining Endometriosis

If you tell someone you have endometriosis, you probably get a blank look in return. Unfortunately most people are pretty clueless when it comes to this disease. (Check out the nearby sidebar, "The roots of endometriosis," for some background on the word itself.)

The roots of endometriosis

Endometriosis (en-doe-meet-ree-*oh*-sis) has six syllables, but don't let its size intimidate you. Just put the accent on the *oh* and you'll impress your gynecologist. (Maybe he'll even warm the speculum for you next time.) The roots of

the syllables break it down — in Greek, *Endo* means *inside*, and *metros* means *uterus*. So *endometrium* essentially means *inside the uterus*. The *-is* suffix means *an abnormal state*, like gastrit*is*, cystit*is*, and sinusit*is*.



So what *does* having endometriosis mean? The following basics can give you a better grasp of it:

- ✓ Every woman has a uterus with an *endometrium* (the uterine lining).
- ✓ When this lining implants outside the uterus, the abnormal condition is called *endometriosis*.
- ✓ Endometriosis consists of *endometrial tissue* (pieces of endometrium) containing glands (just like sweat glands and saliva glands) and *stroma* (supporting tissue) growing where it doesn't belong — anywhere *outside* the endometrial cavity.

Sounds fairly clear so far, right? However, endometriosis isn't quite so simple. This section looks a bit closer at the complexities of endometriosis, including how endometriosis moves to different parts of the body and why it hurts.

Figuring out why endometriosis moves

You think you're starting to understand endometriosis, but you may be wondering how pieces of a uterus get into places they don't belong. After all, parts of your nose or ears don't wander to other places in your body, so why do parts of your uterus travel around to lodge in your lungs, intestines, bladder, ovaries, or even your brain?

Unfortunately, the simple answer is this: Doctors and researchers still don't know. In Chapter 4, we delve into the mysteries of endometriosis and some theories of why it travels to strange places.

Understanding why endometriosis hurts

Endometriosis is painful because the endometrial tissue in other locations behaves just like the endometrium inside your uterus. The endometrium normally becomes thicker during your menstrual cycle and then sheds off the

wall, flowing out through the cervix and vagina as menstrual bleeding. (See Chapter 5 for a more detailed description of the menstrual cycle.)

The endometrial tissue in your ovaries or fallopian tubes also bleeds during your cycle, but the blood has no place to go. The trapped blood irritates nearby tissue by stretching the lining (like a pimple stretches the skin), making it tender. In addition, localized inflammatory factors, such as prostaglandins, interleukin, and tumor necrosis factor (we talk about these in detail in Chapter 4) also irritate tissue. These inflammatory factors can cause severe, painful reactions even when very small areas are involved.



But wait, we're not done. Irritation and inflammation month after month can lead to *nodules* (or cysts) that form on ovaries or other organs. Over time, these nodules can turn into *adhesions* (scar tissue) that cause organs and tissue to stick together, also causing pain. And when the misplaced endometrial tissue releases chemical irritants over long periods of time, a chronic irritation develops, forming extensive scar tissue and — you guessed it — chronic pain. In other words, every month *is* a vicious cycle of pain or other symptoms.

Endometriosis lesions, or *implants*, range in size from too small to see with the naked eye to as large as a grapefruit. Most implants are fairly small, the size of a pencil eraser or smaller. The implants can grow throughout the pelvis and may be singular (rare) or number in the hundreds (also rare). In Chapter 3, we cover the most and least common areas for endometriosis to occur, along with the consequences for each location.

Another factor that makes endometriosis difficult to understand is the amount of endometrial tissue versus the amount of pain a woman feels. For example, you may have a neighbor who has just a few spots of endometriosis but experiences a lot of pain each month, but your sister, who was diagnosed with many endometrial implants during an appendectomy, may have no pain at all.



It's never too late for endometriosis

A 40-year-old patient came to my office because her family practitioner had tested her and diagnosed a cyst in her left ovary. (Her symptoms had been pain with bowel movements.) Because she was in her 40s, my initial concern was cancer. This woman had never had any symptoms related to endometriosis; she had no painful periods and no pain with sex,

and she had delivered three children without any problems. What did we find? Stage III (we define staging in Chapter 9) endometriosis with a large chocolate cyst (see Chapter 3 for more on these not-so-yummy cysts!). No doctor would ever consider endometriosis from her history. And that's the problem — endometriosis isn't always the obvious diagnosis.

Going Public: Why Don't People Know About Endometriosis?

With endometriosis being one of the most common gynecologic problems that women face, you would expect everyone to know about it. So why don't you see ads about endometriosis on television and national telethons to raise money for research?

This section covers some of the reasons for the relative anonymity of endometriosis. Sadly, some of these reasons are all too familiar to many women.

Endometriosis is a women's disease

Even though women have come a long way, baby, they haven't come all the way. Gynecologic diseases, especially non-life-threatening ones, don't get the respect, research dollars, or media play that other diseases do. Is this somewhat puritan? Yes. Unfair? Absolutely. Remediable? Of course, but change takes public awareness.

Simply put, government agencies, insurance companies, and even pharmaceutical companies shortchange female problems. Consider the dozens and dozens of blood pressure medications, diabetes treatments, cold remedies, and, yes, erectile dysfunction treatments (men must be men!), but modern science provides few therapeutic options for most female problems. One reason? The United States is still male-dominated. As a result, according to documented studies, medical research and treatment for women receive far fewer dollars than they do for men.

Endometriosis symptoms are "all in your head"

Guess what — the naysayers are partly right. Endometriosis really *may* be in your head — and in your lungs, appendix, and ovaries, too! But for years, health professionals have ignored or minimized the symptoms of endometriosis due to a variety of misunderstandings. For example:

- ✓ They thought the symptoms were mere exaggerations of the monthly menstrual cycle.
- ✓ They thought the woman was a hypochondriac, depressed, or simply seeking attention.

- ✓ They thought that women were meant to suffer in silence, especially with traditionally taboo topics, such as menstrual pain.
- ✓ Too many women believed (because their moms said so) that all women suffer during their periods, so they didn't bother their doctors with their symptoms.

In fact, many women who seek help for infertility often have a long history of painful periods, irregular periods, painful sex, and so on (all signs of endometriosis). But, too often that history includes a doctor who ignored the patient's symptoms or made her feel that the symptoms were normal. (Check out Chapter 7, which discusses the relationship between endometriosis and fertility.)

Endometriosis is invisible until you have surgery

When a disease has obvious signs (markings on the skin, abnormal EKG, and so on), the patient usually has confidence in the diagnosis. Unfortunately, endometriosis has no outward signs and no accurate diagnostic test. As Chapter 9 discusses, an accurate diagnosis occurs only when a doctor can visually observe the endometriosis during surgery or through a biopsy.

However, some doctors are hesitant to put patients under the knife for diagnostic purposes. Because surgery has risks even under ideal conditions, a doctor may decide some symptoms don't justify the risk (see Chapter 11 for more on surgery and endometriosis). This decision is especially true with young patients, who often have other problems that can mimic endometriosis. (Chapter 14 has more on teens and their symptoms.)

Endometriosis isn't glamorous

The symptoms of endometriosis aren't dire enough or intriguing enough to draw the media attention — or big funding dollars — that support the more socially acceptable diseases. Women's diseases certainly don't make the cover of national magazines, and no movie star has broadcast that she has endometriosis — it's just not glamorous or popular.

Add to the mix that men don't *usually* get endometriosis (yup, you heard me right) and that it's not contagious, and you have a formula for widespread disinterest. So endometriosis remains in the background — a disease that today's society just doesn't bother to promote or treat.



Speaking of sex . . .

I can't count the number of patients over the years that have refused to discuss sex in medical terms. I try to inquire about their sex lives, orgasms, pain, lubrication, and basic enjoyment, but most women are too embarrassed to talk even with a gynecologist about these issues. Most times I hear, "It's okay," or "If my husband/boyfriend wants it. . . ." In addition,

most women have very little understanding of their sexual and reproductive organs. Because of this taboo against discussing sex and genitals, too many women have a hard time bringing up the symptoms of endometriosis, even when a doctor encourages them to. No wonder this disease and its symptoms often go undiagnosed.

Who Gets Endometriosis?

Does endometriosis find its way to all countries in equal numbers, or is it more of an industrial society's problem? Obviously, in developing countries, where women need to worry more about their family's next meal than mid-cycle bleeding, endometriosis isn't a high priority to diagnose or treat. In addition, endometriosis is less common in women who have many children and at a young age (which is also more typical in third-world societies).

This section takes a look at the number of people endometriosis affects worldwide, and it discusses age and pregnancy — two of the important factors in determining the total number.

Counting the women with endometriosis

How many women have endometriosis? The numbers may surprise you. Because determining the number of women with endometriosis can be difficult, estimates worldwide range from as little as 2 to as much as 40 percent. Based on a relatively conservative estimate then, endometriosis affects one out of every ten women of childbearing age.



So what women have endometriosis? The following facts provide some insight:

- ✓ More than 5.5 million women in North America alone suffer from endometriosis.
- ✓ Race and socioeconomic status don't seem to influence the incidence of endometriosis in any meaningful way.

- ✓ Women with lower socioeconomic status (regardless of race) are less likely to be diagnosed.
- ✓ Women with more education and a higher socioeconomic status generally seek medical care sooner, read more, ask their doctors more questions, and, therefore, are more likely to be diagnosed with endometriosis. And, because they're more likely to delay childbearing until later in life, these women have more time to develop severe symptoms, including infertility.
- ✓ Around 50 percent of women with new onset of severe menstrual cramps have endometriosis.
- ✓ At least one-third of infertile women have endometriosis.

Many women don't know they have endometriosis until they have surgery for another condition, such as a Cesarean section or tubal ligation. And this incidental diagnosis complicates the numbers issue by raising the following questions:

- ✓ How many other women who never have surgery have undiagnosed endometriosis?
- ✓ If these undiagnosed women have none of the typical endometriosis complaints, should they be part of the total number of women suffering from endometriosis?
- ✓ If a woman doesn't have pain, does she still have endometriosis?
- ✓ Is endometriosis without pain the same disease that causes so much pain in other women?



The total number of women with endometriosis is difficult to estimate because of these great variabilities in symptoms and diagnoses. An accurate diagnosis of endometriosis is possible only through a visual confirmation during surgery or by biopsy.

Looking at age and endometriosis

Women between the ages of 23 and 35 are most likely to be diagnosed with endometriosis. The average age at diagnosis in North America is 27. Table 1-1 shows data by the Endometriosis Association of more than 3,000 women with endometriosis. The percentage for each group represents the amount of women who had endometriosis symptoms begin at that age.

Is endometriosis becoming more common throughout the world?

According to a recent World Congress on endometriosis, the disease hasn't increased over the last 30 years. However, doctors are diagnosing it earlier and more effectively, probably because more medical personnel are looking for the disease. Also, because of smaller instruments, better optics, and vast improvements in anesthesia (even local anesthesia), more gynecologists feel comfortable using surgery to diagnose the disease (we talk more about surgery in Chapter 11).

Even in third-world countries, where basic surgery tools aren't available and surgery is a major risk, many doctors are treating women for endometriosis and could treat more of them if the resources were available.

Endometriosis is clearly a worldwide disease, and the estimated number of women suffering from it is at least 15 million. Nevertheless, endometriosis is still more likely to be diagnosed in industrialized countries for reasons that reflect varying social systems. For example:

- ✔ Cultural norms in some countries discourage women from complaining about pain, especially pain related to the reproductive system.

- ✔ Women in industrialized countries put off childbirth longer and have fewer children.
- ✔ Women in poorer countries and third-world countries tend to have children earlier and more often.
- ✔ Women in poorer countries don't live as long — they may even die before puberty.
- ✔ Techniques for diagnosing endometriosis aren't easily available or may be dangerous.
- ✔ The attitude may exist that, if treatment isn't available, why bother to diagnose it?
- ✔ Medical knowledge of the disease may be lacking in some areas.
- ✔ Women in industrialized countries are more likely to be exposed to toxins and hormones.

Even with the greater likelihood for it to be diagnosed in industrialized countries, endometriosis is everywhere. Medical journals of Europe, Japan, and Australia all have numerous articles on the topic. So the disease is present, but the real challenges are looking for it and diagnosing it.

Table 1-1 Age When Endometriosis Symptoms Begin

Age When Symptoms Began	Percentage
<15 years old	14.9
15–19 years old	25.9
20–24 years old	19.6
25–29 years old	23.3
30–34 years old	12.5
35–39 years old	4.0

Endometriosis through the ages

Endometriosis isn't a new disease, although it hasn't always had the same name. Daniel Shroen first described the symptoms in 1690 as sores throughout the stomach, bladder, and intestines as well as broad ligaments that had a tendency to form adhesions. In 1769, Arthur Duff described the intense pain of endometriosis,

and it was first seen microscopically in the late 1800s. In 1921, Dr. John Sampson was the first person to hypothesize that retrograde menstruation contributed to endometriosis. (See Chapter 4 for more about the retrograde menstruation theory.)

The ages of 23 to 35 coincide with the period when many women consider pregnancy and regularly visit the gynecologist. A woman may have a problem conceiving, or she may share her symptoms with her doctor, or her physician may find a problem during the pelvic exam. Any of these scenarios may lead the doctor to suspect endometriosis (although a myriad of other problems may also cause these problems). As we note in Chapter 7, there's no law against having other diseases *and* endometriosis!

This age range also coincides with the time women work outside the home on a regular basis. At this age, the symptoms of endometriosis can alter a woman's lifestyle for the worse. For example, women who work full time may have symptoms that cause them to miss work, or they may have bad days that detract from their performance. They may now have a boss who doesn't understand why they're bent over in their chair, leave early, come in late, and miss a couple of days a month due to their recurring symptoms.

The incidence of endometriosis decreases in the 35 to 39 age range, and problems are rare for women in their 40s, unless they had severe endometriosis at a younger age. In contrast, one study found that 50 percent of younger women (teenagers especially) who had pelvic pain, bloating, painful periods, irregular periods, and other symptoms were diagnosed with endometriosis. This high percentage may be due to the aggressive nature of the disease in teens. (Check out Chapter 14 for more on treating teens and preteens with endometriosis.)

Linking pregnancy and endometriosis

Parity refers to the number of pregnancies a woman has had, so women who have never been pregnant are *nulliparous*, and women who've had at least one pregnancy are *multiparous*.

Can men ever have endometriosis?

Even though a uterus seems like a basic requirement for endometriosis, a few men have developed lesions that appear to be

endometriosis after exposure to high-dose estrogen treatments for prostate cancer. The lesions developed in the prostate.

Endometriosis is

- ✓ Most common in women with no children.
- ✓ More common in women with fewer children.
- ✓ Least common in women with more children.

Linking pregnancy to endometriosis may be a chicken-egg relationship. In other words, do women who have endometriosis have fewer children because endometriosis can contribute to infertility, or do they develop endometriosis because they've had fewer pregnancies? Pregnancy does seem to have a protective and therapeutic effect on the disease (we discuss the effects of pregnancy in Chapter 4). In fact, pregnancy was one of the oldest treatments for endometriosis — but, then again, not being able to get pregnant may be part of the problem!

Furthermore, endometriosis is less common in women

- ✓ Whose first pregnancy occurred at a younger age
- ✓ Who have had multiple pregnancies

When women have their first pregnancy early and then have several children, their uterus and ovaries have longer *quiet* times — without the steady supply of irritants from the menstrual cycle, the endometriosis simply burns out.

Calculating the Cost of Endometriosis

Endometriosis literally costs millions of dollars. How ironic is it that a disease that can't be seen and doesn't kill you can still cause so many problems? Consider this: The main symptom of endometriosis is pain during your menstrual period, which shows up every month. So endometriosis is a disease that recurs, almost like clockwork, once every three to four weeks.

This pattern means that every three to four weeks endometriosis is affecting your life, maybe preventing you from going to work, probably adding to your medical bills for pain relief, and definitely challenging your relationships. This section totals some of those high costs of endometriosis.

Eying the economic costs

Being in pain once every three to four weeks may not seem bad, but that week that you're lying on the couch and taking pain relievers by the handful means you're not at work and you're not contributing to the economy. One large British study determined the following rather startling statistics on endometriosis:

- ✓ Sixty-five percent of women in the study indicated that they had initially been misdiagnosed with another condition.
- ✓ Seventy-eight percent missed an average of five days per month from work due to endometriosis.
- ✓ Thirty-six percent said that endometriosis had affected their job performance, and of this group
 - Forty-one percent had lost or given up their jobs entirely.
 - Thirty-seven percent had reduced their hours.
 - Twenty-three percent had changed jobs.
 - Six percent went on disability.

All this sick time and the resulting decreased performance cost the economy dearly. When you miss work for several days, you aren't productive. Either your company pays someone else to take your place or no one does the work. If you reduce your hours or quit, then your personal economy takes a big hit — and the government may end up paying unemployment or disability.

Furthermore, if the pain is severe, you may have major surgery. Women are typically out of work at least six weeks after such surgery, and this time off places an even greater burden on the economy. Often a woman who has major surgery (such as a hysterectomy) doesn't return to full productivity for several weeks or even months. (Some women never get back to full-time work.)

Common complications (wound infection, urinary tract infection, excessive blood loss, adhesions, bowel complications, and so on) can extend the recovery time even further. When major complications occur (and they do in a small percentage of cases, no matter how good the surgeon), the result is prolonged periods of reduced work, absence, or permanent loss of productivity.

Considering the diagnostic and treatment costs

In addition to its effect on the economy, endometriosis (its diagnosis and treatment) is hard on the wallet too. Considering the vast numbers of women with the disease, the total cost for even conservative treatments, pain

medication, hormonal therapies, and the like, is enormous. One common prescription for endometriosis is more than \$400 per month per woman! This amount of money is staggering to treat a disease we can't see and know so little about.

The total cost of diagnosis, surgical interventions, and extensive treatment is billions of dollars annually. For example, of the nearly 600,000 *hysterectomies* (removal of the uterus and one or both ovaries) in the United States each year, around 20 percent (100,000) are for reduction of endometriosis-associated symptoms. The hospitalization, medications, and other fees for these surgeries cost the healthcare system tens of millions of dollars — each year.

Looking at the cost on relationships



The cost of endometriosis extends far beyond money. Endometriosis is hard on relationships. Chronic illnesses, especially ones that affect sexual relations, can be a huge strain. The British study mentioned earlier in this section reported the following statistics:

- ✓ Seventy-two percent of the women studied reported they had problems with relationships due to endometriosis.
- ✓ Ten percent said that endometriosis had caused a split in a relationship.
- ✓ Thirty-four percent said it caused significant problems with their partner.
- ✓ Eleven percent said they had trouble taking care of their children.

How can you even put a price on these problems? No one can estimate a monetary number to compensate for loss of life's pleasures and love. These emotional and social problems can cause other problems. When a disease puts a strain on a relationship, any number of psychological troubles can surface. For example, depression is common for people with a chronic disease. Women can be anxious or paranoid, and they can lose self-esteem. A woman may shut herself off from other people and become reclusive. These side effects and other relational problems are all difficult to address.

Furthermore, surgeries such as hysterectomies and *oophorectomies* (removal of the ovaries) can be psychologically damaging, leading to depression and perceived loss of sexuality. Although placing a value on life's pleasures is next to impossible, the emotional and psychological costs of these losses (along with the many short- and long-term complications of major surgery) are substantial and may be more devastating to a woman and her family than the symptoms directly related to the disease.



One woman's story: The high cost of endometriosis

One patient, Jane, had had 10 or 11 laparoscopies over the years for recurrent endometriosis. She'd have relief after each one for a year or two, but then the pain returned. When she couldn't function at work or socially, she'd have another laparoscopy. Jane had also tried all the conservative medical therapies (GnRH agonist, NSAIDs, and hormones — we cover all these in detail in Chapter 10) with either no relief or too many side effects. Finally, she demanded a hysterectomy and removal of the ovary that kept hurting, and she did feel better afterwards. Unfortunately, when the other ovary became a problem a couple of years later, she had several conservative

surgeries to try and save it. Eventually it had to come out, and she is now symptom-free!

This story isn't typical, but it illustrates the great difficulty in assessing the cost of endometriosis and its effect on a woman's life. What was the total cost to treat Jane, and what was the cost of all the lost work days and life's pleasures while she was suffering? I don't even want to hazard a guess — it's staggering!

Of course, for every story like Jane's, another story exists of a woman who continues to suffer in silence or who has major surgery and then always wonders whether it was the right choice.

We're not saying that major surgery is always bad. Many women opt for this course when the more conservative approaches have failed, and the majority of women do well (see Chapter 11 for more info on the different types of surgeries). In fact, most patients who eventually have major surgery are ready for it *and* happy with the results.

Do You Have Endometriosis: A Self-Test

Statistics are interesting, but you're probably more concerned about whether you have endometriosis than about the statistics. Although only your doctor can diagnose endometriosis, the following questions help answer the question: Do I have endometriosis? You don't have to answer all the questions with a "yes" to have endometriosis, but more than one or two "yes" answers is a good reason to make an appointment with your doctor sooner rather than later.

Questions

1. Do you have a family history of endometriosis?
2. Do you have painful periods?
3. Do you have pain during sex?

4. Are you having trouble getting pregnant?
5. Did you start having periods at a younger age than the norm?
6. Do your periods last longer than four to five days?
7. Do your periods come more often than every four weeks?
8. Do you have heavier than normal menstrual periods?
9. Do you have allergies or autoimmune diseases such as asthma?
10. Do you have painful urination during your period?
11. Do you have tummy troubles, such as diarrhea, constipation, or pain, during your period?
12. Are you taller and thinner than average?

Answers

The following information provides some explanations for each question:

1. Endometriosis is more common in women whose close female relatives have endometriosis.
2. Painful cramping during menstrual periods is the most common symptom of endometriosis, although many women with cramps *don't* have endometriosis.
3. Endometriosis in the pelvis can make sex painful.
4. Thirty to forty percent of infertile women have endometriosis (see Chapter 7 for more info).
- 5–8. Any factor that causes more menstrual bleeding over the course of your lifetime is a risk factor for endometriosis. Women whose periods start at a younger age and who have longer than normal periods, heavier than normal periods, or periods closer than every four weeks are all more likely to develop endometriosis.
9. Women with endometriosis are also more likely to have allergies or other autoimmune diseases.
10. Endometriosis in the urinary tract can cause pain and bleeding.
11. Endometriosis in the intestines can cause pain, cramping, diarrhea, constipation, or rectal bleeding during your period.
12. Women who are taller and thinner than average are more likely to have endometriosis.

This test is just a starting point. If you're concerned that you may have endometriosis, don't hesitate. Make an appointment with your gynecologist.

