

# ***Endometriosis*** FOR **DUMMIES®**

**by Joseph W. Krotec, MD**

Former Director of Endoscopic Surgery at Cooper Institute  
for Reproductive Hormonal Disorders

**and Sharon Perkins, RN**

Coauthor of *Osteoporosis For Dummies*



Wiley Publishing, Inc.



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# *Dedication*

To all the women with endometriosis we've known and treated and to all the women who've suffered without knowing why.

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—Joseph Krotec

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—Sharon Perkins

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# Introduction

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**E**ndometriosis is a chronic disease that, until recently, didn't get the attention it deserves. In fact, not too long ago, medical personnel and laymen often dismissed the symptoms of endometriosis as being more psychological than physical in origin. Fortunately, times are changing, and interest in endometriosis research has never been higher.

But the more researchers uncover about endometriosis, the more complicated this disease seems to be. For example, some researchers believe that endometriosis isn't one, but several different diseases. And many researchers believe that endometriosis is closely related to autoimmune disease.

If you're one of the millions of women suffering from endometriosis or if you suspect your symptoms are from endometriosis, you may not care much about research; you just want your symptoms to go away! We want you to feel better too, but we also look forward to the day when researchers discover what causes endometriosis — so they can figure out how to cure it.

Endometriosis is far more than just cramps. Millions of dollars are lost in the workplace each year because of absences and surgeries related to endometriosis. Endometriosis symptoms can cause everything from headaches to chest pain — in addition to the more common symptoms of cramps, painful sex, and abnormal bleeding. Many women with endometriosis have suffered for years without realizing they had a serious disease (and may have been called *malingers*, fakers who use illness to avoid work) because their disease wasn't visible! Too often these women have given up on getting help.

We hope you read *Endometriosis For Dummies* saying, "That's me! I never knew endometriosis caused that!" In addition, we hope to help you find ways to live a more pain-free life. If you want kids, we want to show you that pregnancy and endometriosis aren't mutually exclusive. To sum up, we want to show you that endometriosis doesn't have to rule — or ruin — your life.

## About This Book

We wrote this book realizing that many women never know that their pain and suffering (often dismissed as *all in the head* by family, friends, and doctors alike) stem from a real disease with symptoms so diverse that it sometimes defies diagnosis. Our goal is to inform you about endometriosis and to help you understand what it is and how it affects many body systems, not just your reproductive organs. We also want to show you how to live with endometriosis as painlessly as possible and how to modify the effect endometriosis has on your life.

We cover all the bases in this book, starting with the basic information on what endometriosis is, what the symptoms are, and who gets it. If you don't know much about endometriosis or about the reproductive system in general, start at the beginning of the book and read straight through. After the basics, we delve a little deeper into how endometriosis affects specific areas of your life and discuss the treatments for endometriosis. We also help you decide whether medication, surgery, or alternative medicine options are best for you.

## Conventions Used in This Book

In this book, we use the following conventions to help make the information consistent and easier to understand. The last thing we want to do is confuse you!

- ✓ All Web addresses appear in `monofont`.
- ✓ **Bold** text indicates key words in bulleted lists and highlights the action parts of numbered steps.
- ✓ *Italics* identify new terms that are beside easy-to-understand definitions.

## What You're Not to Read

Although we hope you, our dear reader, cherish every word in this book, we know better. Sometimes you're just looking for quick answers, but other times you want to discover everything possible about endometriosis, even the technical stuff. We've designated some information as *interesting-but-not-essential-to-read*. Feel free to read it, but if you skip it, you're not missing anything vital. Optional sections are

- ✔ **Text in sidebars:** This text is in shaded boxes that appear throughout the book. The information in sidebars may be anything from personal stories to technical information. The common denominator is that the information isn't essential to understanding or dealing with endometriosis.
- ✔ **Anything with a *Technical Stuff* icon attached:** This information is interesting, but not essential — unless you're planning on doing your doctorate thesis on endometriosis. (For more information on icons, check out "Icons Used in This Book" later in this Introduction.)
- ✔ **The stuff on the copyright page:** The attorneys require that we have this information. Unless you're an aspiring lawyer, feel free to skip it.

## *Foolish Assumptions*

We assume that you're reading this book because you want to know more about endometriosis. We also assume that you want to

- ✔ Understand the basic biology of what endometriosis is and why it develops
- ✔ Understand how endometriosis affects different body systems
- ✔ Discover what medical options are available for treating endometriosis
- ✔ Be up-to-date on the latest surgical treatments for endometriosis
- ✔ Find out how you can get pregnant if you have endometriosis
- ✔ Figure out how to manage the pain of endometriosis

Endometriosis doesn't have to mean the end of a good life for you; you can figure out how to manage pain, minimize symptoms, and keep endometriosis from taking over your life. Our greatest hope is that this book takes the clout out of endometriosis and gives you the tools to live your life as symptom-free as possible.

## *How This Book Is Organized*

*Endometriosis For Dummies* is divided into six parts. As with every *For Dummies* book, this one is designed to help you find the information you need quickly and easily, without having to read the book cover-to-cover. The following explanations can help you find the information you need with a minimum of effort.

## ***Part I: Endometriosis: What It Is and Isn't***

What exactly is endometriosis and what causes it? Who gets endometriosis and why? In these chapters, we explore the mysteries behind endometriosis, its typical symptoms, the biology behind it, and the most common risk factors for developing it.

## ***Part II: Digging Deeper into Endometriosis***

In these chapters, we look at how endometriosis affects various body systems, such as the menstrual cycle, digestive system, and the urinary tract. We also delve into the complicated relationship between endometriosis and infertility and describe the tests that determine whether you really have endometriosis or another disease. Finally, we help you find a doctor who's willing to treat you as an equal partner and make a diagnosis based on your symptoms.

## ***Part III: Treating Endometriosis***

You may already know you have endometriosis. Now the big question is, "How do you treat it?" These chapters describe numerous treatments, from traditional to alternative, from medications and surgeries to massages and acupuncture. We also talk about the way endometriosis affects teens and preteens and how their treatment differs from that of adults.

## ***Part IV: Living with Endometriosis***

Life goes on, even when you have a chronic disease such as endometriosis. In these chapters, we talk about how to cope with work, family, and friends when you're in pain. We also give you suggestions for changing your lifestyle to minimize the impact of endometriosis, including how to eat better, exercise more, and avoid toxins. Finally we provide a chapter specifically for your friends and family that helps them better understand you and your disease.

## ***Part V: The Part of Tens***

We have nothing long-winded in the Part of Tens chapters — they're short and sweet, giving you a lot of information in little bites. These chapters dispel some of the most common myths about endometriosis, give some insight into the future of endometriosis diagnosis and treatment, and list some quick ways to decrease pain when you're down and out with endo.



## Part VI: Appendixes

This section contains two appendixes. The first is a glossary that defines all the undecipherable (and unpronounceable!) Latin medical terms as well as other terms in this book that may be unfamiliar to you. The second appendix is a list of resources to help you find out more about endometriosis, support groups, and online information sources.

### Icons Used in This Book

Icons are the strange-looking symbols that appear occasionally in the margins next to the text. We include them to let you know that a topic or information is special in some way. *Endometriosis For Dummies* includes the following icons:



This icon identifies information that's helpful and can save you time or trouble.



This icon highlights key points in the section you're reading.



This icon stresses information that describes potentially serious issues, such as side effects to medication or other dangerous problems. Pay attention to warnings — they can keep you out of trouble!



This icon signals information that's interesting but not essential to understanding endometriosis, unless you're a scientist or medical student.



This icon shows up when a situation requires you to — you guessed it! — notify your doctor. The situation can include symptoms or side effects.



This icon appears next to information straight from the doctor's mouth — in this case, from Dr. Krotec. You can find personal stories and suggestions here from his years of treating patients with endometriosis.

## *Where to Go from Here*

Enough talk about the book — time to read it already! If this were a novel, you'd start at Chapter 1 and read straight through. But it's not a novel, and it's not a textbook, where each chapter builds on the one before. You can open this book at any point and be able to understand the information there.

For example, you may suspect you have endometriosis, but you're not sure. Turn to Chapter 2 to read about the most common symptoms of endometriosis. Feeling a little technical today? Turn to Chapter 3 for an in-depth look at the biology behind endometriosis.

The point is, you don't have to read everything (although you certainly can, and you may discover something you never knew before)! Just flip to the Table of Contents or Index, find a subject that interests you, and turn to that chapter. It's not essential to read everything — just what interests you and helps you.

*Endometriosis For Dummies* is a resource, a guide that presents the practical information in a fun, easy-to-read-and-understand format. Read a chapter a day or a chapter a year, or keep it in the bathroom for frequent browsing. But however you choose to use this book, we hope it's helpful.

# Part I

## Endometriosis: What It Is and Isn't

The 5<sup>th</sup> Wave

By Rich Tennant



"The pain you're experiencing is normal. It's as normal as walking down the street with say, an inflated truck tire in your pelvis."

## *In this part . . .*

**E**ndometriosis is a long word derived from Greek, as many medical words are, but what is it? In this part, we look at the complicated disease of endometriosis: what it is, what the typical symptoms are, and how common it is. We cover some biology to give you a good understanding of how all your inner parts interrelate. And we look at the reasons some women get the disease and others don't.

## Chapter 1

# The Lowdown on Endometriosis: A Quick Run-Through

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### *In This Chapter*

- ▶ Understanding endometriosis basics
  - ▶ Educating the public about endometriosis
  - ▶ Knowing who's who in endometriosis
  - ▶ Counting the real costs of endometriosis
  - ▶ Answering the big question: A self-test
- 

**P**eople 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 *gastritis*, *cystitis*, and *sinusitis*.



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