

Living with Endometriosis

**How to Cope
with the Physical and
Emotional Challenges**

Kate Weinstein



1990年3月21日



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ADDISON-WESLEY PUBLISHING COMPANY, INC.

Reading, Massachusetts Menlo Park, California Don Mills, Ontario

Wokingham, England Amsterdam Bonn Sydney Singapore

Tokyo Madrid Bogotá Santiago San Juan

Weinstein, Kate.

Living with endometriosis.

Includes bibliographies and index.

I. Endometriosis—Popular works. I. Title. [DNLM:

I. Endometriosis—popular works. WP 390 W424L.]

RC483.E53W45 1987 618.1'42 86-28779

ISBN 0-201-19810-X

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Cover design by Copenhaver Cumpston

Text design by Diana Eames Esterly

Set in 10 point Cheltenham by DEKR Corporation

ABCDEFGHIJ-DO-8987

First printing, June 1987



Foreword

Endometriosis is one of the most common gynecologic disorders of the reproductive years, and its incidence appears to be on the increase. It is diagnosed in about 25 percent of abdominal operations performed by gynecologists and is second only to uterine fibroids as the most frequent cause of surgical procedures in premenopausal women. Although seldom life-threatening, endometriosis typically causes severe, progressive, and often incapacitating pain, infertility, repeated hospitalizations and surgeries, and prolonged medical treatments. Yet the symptoms and clinical findings of endometriosis vary from patient to patient and may mimic other gynecologic disorders. This makes office diagnosis difficult and often unreliable. Prior to the advent of laparoscopy, physicians learned to depend on clinical observations and impressions describing physical, psychological, and even racial and socio-economic characteristics of a "typical patient profile." These observations and impressions, however, were never subjected to rigid scientific scrutiny, and many have been subsequently placed in the realm of myths and misconceptions.

Laparoscopy has greatly improved our diagnostic abilities, especially in the earlier stages of endometriosis. Yet it appears that even laparoscopy may be inadequate for evaluation of the microscopic lesions. Endometriosis, through unknown mechanisms, interferes with the reproductive function of the woman, yet it is the function of the ovaries that stimulates the development and spread of the disease. It is not known why some women acquire endometriosis, but it is generally accepted that its persistence and spread are stimulated by the cyclic secretion of ovarian hormones.

The unknown cause of endometriosis precludes development of curative treatment. All current therapeutic methods offer only a temporary resolution. The only method of treatment that prevents recurrence is hysterectomy with oophorectomy. However, as new strides are being made in almost every corner of the medical field, there are also new developments in the area of endometriosis. New research, especially in the field of reproductive immunology, is especially promising. It is likely that, within the not too distant future, pathophysiology of

endometriosis will be clarified and noninvasive diagnostic techniques will become available. This should bring us significantly closer to the development of effective preventive measures and therapeutic techniques.

In the meantime, controversies, contradictions, and disagreements among the medical profession on the subject of endometriosis are not conducive to dissemination of adequate and objective patient information. At a time when the practice of medicine is undergoing rapid changes and patients are playing a larger and more active role in the management of their diseases, there is a clear need for a comprehensive, in-depth review on the subject of endometriosis. Kate Weinstein did an excellent job in this respect. Her book should be easily understandable even to those not familiar with the medical jargon. The review is thorough, clear, and objective and should serve as both a guide and a resource to women who suffer from this disease. Patient histories and quotations enliven the text, making it more personal and appealing. Women suffering from endometriosis should find sections on the emotional aspects and the management of pain and stress especially helpful, since these subjects are seldom covered by physicians who treat endometriosis. The book also contains a wealth of comprehensive information on the physiology of menstruation and the reproductive cycle which healthy women may find educational as well.

W. Paul Dmowski, M.D.
February 1987

Dr. Dmowski is Professor of Obstetrics and Gynecology and Director, Section of Reproductive Endocrinology and Infertility at Rush-Presbyterian-St. Luke's Medical Center in Chicago, Illinois.



Preface

Endometriosis—the presence of endometrial tissue outside of its normal location lining the uterus—remains a word unfamiliar to many, yet its signs, symptoms, and complications have confounded researchers and clinicians for more than a century. Since 1860, when the disease was first described in the medical literature, medical writers and researchers, in several thousand case reports and research studies, have attempted to describe, define, analyze, and demystify this perplexing malady.

Despite this, basic knowledge of endometriosis has advanced little since the term was coined in 1921. Alongside a dearth of facts stands a profusion of myths, misconceptions, and unknowns. Causes and cures continue to elude investigators, and even its chief symptoms—pain and infertility—have yet to be fully explained.

Ultimately, the study of endometriosis has led to virtually only one fact about which all agree: it is a poorly understood disease that has generated considerable speculation and controversy concerning all of its aspects, from its etiology to its treatment.

The conventional wisdom about the disease is derived in large part from clinical observation and impressions handed down from decade to decade without benefit of rigid scientific scrutiny. Hence, the popular and medical literature is riddled with contradiction; researchers try to piece together the puzzle, but many are beginning to conclude that the pieces they have been working with simply don't fit.

As a result, the most basic convictions concerning endometriosis are continually being challenged, if not by scientific method, then by the indisputable experience of women afflicted.

Just as there is little consensus on the part of physicians and researchers concerning the nature and effects of the disease, each woman with endometriosis will tell a different story. There is no "textbook" case, no classic experience of the disease. For some women, the disease poses few difficulties. For others, it thoroughly impairs their ability to live normal, productive, and satisfying lives.

It's tempting to present the research findings as a neatly wrapped package. But

endometriosis defies such a presentation. Women with the disease must recognize the controversies and the gaping holes in the research, and realize that there is no unified viewpoint from which to comprehend the disease. To prepare themselves for the uncertainties and challenges that endometriosis may pose, women need to understand that their decisions may have to be based on possibility and probability, the half-known and the unknown. There will not always be satisfactory answers to their questions.

Therefore, to reflect the divergence of medical opinion concerning the nature of the disease, as well as the variety of women's experiences, I have tried to leave intact the ambiguities, the controversies, and the unknowns and to gauge the ways in which they, along with the symptoms and effects of the disease, greatly challenge, and sometimes exhaust, patients' coping abilities.

The contents of this book should not be construed as medical advice nor used in lieu of medical consultation. Medical information is provided to form a background against which the emotional aspects of the disease can be better understood. Treatment options are neither endorsed nor opposed; nor are some of the "alternative" therapies not yet subject to scientific investigation. They, like the more conventional therapies, are options to be carefully investigated and considered in consultation with your health care providers.

Living with Endometriosis provides you with the tools, strategies, and resources you need to increase your ability to cope with the disease. Part 1 sets the stage, with an overview of information on the reproductive system and menstruation and a discussion of some of the myths regarding the latter. Current medical knowledge of endometriosis is provided—its characteristics, development, and prevention; its sites, symptoms, and complications; and finally its diagnosis, description, and classification.

Part 2 takes you through the maze of treatment options, exploring the risks and benefits of each, from aspirin for pain relief to definitive surgery. Part 3, the emotional aspects, guides you through five stages, or phases, of adaptation, from initial crisis through resolution.

Awareness, however, is only the first step. The next is to devise strategies for coping with the various stages of the disease and its problems and challenges: gathering information, building support, managing pain and stress, and simply knowing where and how to ask for help when you need it. These important tools, as well as some alternative therapies, are provided in Part Four. Finally, at the end of the book, are the resources: organizations, publications, and glossaries.

I have addressed this book to women who have, or who suspect they have, endometriosis. My hope is that it will be shared with family, friends, and lovers, as well as with health care practitioners, so that they all may better understand the emotional needs of women with endometriosis.

The experiences of women with endometriosis were culled from (1) responses to 100 questionnaires, designed specifically for this book and sent by the Endometriosis Association to a random sampling of its members; (2) responses to a notice in the *Endometriosis Association Newsletter* requesting contact from members; (3) the correspondence files at the Endometriosis Association headquarters in Milwaukee, Wisconsin; (4) the databank of the Endometriosis Association located at the Medical College of Wisconsin in Milwaukee; (5)

interviews with women who have endometriosis; and (6) interviews with a sampling of association support group leaders, chapter officers, and board members.

Medical and psychological information was drawn from (1) an extensive review of the scientific literature concerning endometriosis and related issues (see Appendix D); (2) professional conferences and symposia; and (3) interviews with gynecologists, infertility specialists and counselors, mental health professionals, sex therapists, and alternative practitioners.



Acknowledgments

Many individuals contributed their time, expertise, suggestions, and support to this manuscript. I'm particularly grateful to the following who consented to be interviewed: Dr. Pierre Asmar, reproductive endocrinologist in private practice in Alexandria, Virginia, advisor to the Washington, D.C. Endometriosis Alliance; Dr. Veasy Buttram, Jr., director of the division of reproductive endocrinology and fertility, Baylor College of Medicine, Houston, president of the American Fertility Society; Dr. Margaret Davis, assistant professor of obstetrics and gynecology, George Washington University Medical Center, Washington, D.C.; Dr. Charles Debrovner, gynecologist in private practice in New York; Dr. W. Paul Dmowski, professor of obstetrics and gynecology, director of reproductive endocrinology and infertility at Rush Medical College, Rush University, Chicago; Dr. Richard Falk, chief of reproductive endocrinology and fertility, Georgetown University Medical School and Columbia Hospital for Women in Washington, D.C.; Dr. Elizabeth Herz, associate professor of obstetrics and gynecology and psychiatry, director of the psychosomatic obstetrics and gynecology program at George Washington University Medical Center; Dr. Laura Hitchcock, psychologist in private practice in Bethesda, Maryland; Dr. Jennifer Jacobs, a Seattle homeopathic physician; Dr. Linda Kames, clinical psychologist and assistant professor of psychology, University of California, Los Angeles; Dr. Milton Kline, director of the Institute for Research in Hypnosis and Psychotherapy, New York; Dr. Burt Littman, assistant professor of obstetrics and gynecology, George Washington University Medical Center; Dr. David Meldrum, associate professor of reproductive endocrinology and chief of female infertility at the UCLA Medical School; Dr. Deborah Metzger, chief resident, Duke University Medical School, Durham, North Carolina; Dr. Suzanne Pratt, gynecologist in private practice in Rome, Georgia; Dr. David Redwine, gynecologist practicing at the Mountain View Women's Clinic in Bend, Oregon; Dr. John Rock, associate professor of obstetrics and gynecology, director of reproductive endocrinology at the Johns Hopkins University School of Medicine, Baltimore; Dr. Andrea Shrednick, a Los Angeles

infertility counselor and sex therapist; Catherine Tuerk, a Washington, D.C. therapist; Dr. Anne Ward, gynecologist in private practice in Chicago; Dr. Benny Waxman, professor of obstetrics and gynecology, George Washington University Medical Center; and Wanda Wigfall-Williams, clinical psychologist in private practice in Great Falls, Virginia.

I owe special thanks to Mary Lou Ballweg, president and co-founder of the Endometriosis Association, Milwaukee, Wisconsin; to the staff and volunteers of the Association and to the following members and officers: Linda Barbarotta, Marilyn Beggs, Randy Beggs, Jean Foos, Georgette Gerben, Khristine Lohr, Kate Shaughnessey Low, Suzanne McDonough, Jennifer Jean Yoell, and Joanna Brown; and to Alisa Irving of the Endometriosis Society in London. I'm also grateful for the assistance and information provided by Claudia Dominitz, Medical Center Public Relations, The George Washington University; Mark Stern, News and Information, The National Institutes of Health; the reference staffs at the UCLA Biomedical Library, the National Library of Medicine, and the Dahlgren Library at Georgetown University Medical School; and to the following organizations: the American College of Obstetricians and Gynecologists, the American Fertility Society, the Center for Communications in Infertility, the East West Foundation, Resolve, Inc., Tambrands, Inc., and Winthrop-Breon Laboratories.

I'd also like to thank Tim Moriarty, editor of *Feeling Great*, for giving me the initial opportunity to explore endometriosis in an article from which this manuscript grew; Dan Winter of Emerson Braxton & Co., for providing the illustrations; my editors at Addison-Wesley: Robin Manna, for involving me in the project; Genoa Shepley, for getting me started; and most particularly Cyrisse Jaffee, not only for pushing me across the finish line, but also for her vision, clarity, and sensitivity, which shaped the manuscript, and her vast reserves of patience. I'm also indebted to Perry McIntosh, production supervisor at Addison-Wesley, for extraordinary grace under pressure. I'm continually appreciative of the friends and family members who offered support and encouragement in countless ways, especially: Michelle LaSane; Rick Lesser; James and Mary Proth, Wesley and Irma Schneyer, Herman Silver, Louis Weinstein, Wanda Wigfall-Williams, Laura Wiggins, Peggy Willens, Dr. Lee Winston, Mark, Penne, Katie, and Bo Winston, Helen Zeilberger, Joan Ziemba, and, most certainly not least, Mollie B. Zion.

Finally, to the men and women who shared with me their experiences in hope that others might benefit, I'm grateful.



Note to Readers

In a book written to empower women to take charge of their own health care, and to encourage them in asserting their rights (within a medical system that often neglects those rights), I particularly regret the perpetuation of sexist language. However, since the medical professions continue to be male dominated, and in order to clearly distinguish between doctor and patient while avoiding the cumbersome and repetitious *he/she*, I have used feminine pronouns for patients and masculine pronouns for medical professionals.



Introduction

There is probably no other benign condition in gynecology that has remained so long misunderstood, misdiagnosed, and refractory to effective obliteration as pelvic endometriosis.¹

To be sure, it is rarely a fatal disease, but rather the great gynecological crippler.²

Endometriosis is not yet a household word; still, as many as nine million women may suffer its common consequences: pain, sexual difficulties, menstrual irregularities, and infertility. Despite the fact that it is a leading cause of infertility in women over twenty-five, and the underlying component in as many as half the cases of severe menstrual cramps, endometriosis frequently goes undetected and untreated.

Although theories abound, the precise cause of the disease remains unknown. A variety of treatments—medication, hormonal therapy, conservative surgery—provide little more than a temporary remission of symptoms. Definitive surgery—the removal of the uterus, cervix, fallopian tubes, and ovaries—offers the greatest promise of a permanent cure. Thus, when more conservative treatments fail to bring sustained relief, women severely afflicted by endometriosis must decide whether to continue to live with pain or to forfeit their reproductive organs and the potential for childbearing.

Once the reproductive organs are removed, unless a woman takes replacement hormones, she may face the symptoms of "surgical" menopause: hot flashes, vaginal dryness, osteoporosis, and increased risk of heart disease. And, for some, even definitive surgery is not the end of the line. Although very uncommon, endometriosis can recur or persist following even such radical treatment.

For many women, this "cure" exacts too great a penalty and arouses too many fears. Therefore, to alleviate as much pain as possible, while preserving or attempting to restore their fertility, it is not unusual for women to proceed from one treatment to another, following courses of hormonal therapy with repeated conservative surgery, waiting, hoping, and wondering whether each will be the last.

Faced with these uncertainties, women are reassured that the disease is at least not life threatening. But it can be devastating, not only physically, but emotionally, sexually, and financially as well.

Determined to understand the confounding medical facts and to find a cure, patients and physicians alike often pay little attention to the serious emotional repercussions that occur along the way: that is, the psychological stress that is caused by the disease and its chronicity. In many cases, physicians are unwilling or unable to offer practical coping strategies, and patients are too preoccupied with treatments to deal with the day-to-day problems the disease poses. Beset by pain, disability, anxiety, and fear, often isolated and confused, many women are unable to make critical treatment decisions. They cannot sustain the energy and clear thinking they need to cope with various changes in lifestyle and life goals the disease may bring.

When physicians and other professionals are unable to help with the emotional aspects, they often advise women to "live with it." Seldom, however, do they provide the tools and strategies to do so.

The single most important thing you can do to improve your ability to live with the disease is to face head-on the unpleasant fact most women go to great lengths to avoid: endometriosis will probably be with you for a very long time. It may come and go, it may get better or it may get worse, but it is unlikely that it will disappear completely. Although it seems a dismal and discouraging prospect, this fact actually offers you a measure of control. You are forced to see that you must deal not only with the physiological effects of the disease, but also with its impact on your life plans and goals, because a cure may never come.

As you turn your energies from pursuit of a cure to management of the disease, you soon realize that you are not helpless, that endometriosis needn't always be the focus of your life, that definitive surgery is *not* inevitable, and that there is much you can do to make living with endometriosis easier.

Aptly described as "making the best of a bad bargain,"³ coping—learning to live with chronic illness with a minimum of that which holistic thinkers term *dis-ease*—means cutting your losses and moving on. It takes an enormous amount of motivation, determination, resources, and support. Frustrations and disappointments are all too common. But as you learn to gather information and make use of coping strategies, you will soon discover that you have been empowered to regain and sustain the energy and clear thinking you need to take charge of your life as you face the continuing challenges of endometriosis.

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PART I

Endometriosis: Medical Aspects

To effectively cope with a disease as puzzling, complex, and unpredictable as endometriosis, women will need many different kinds of information. Those who suspect they have endometriosis need to learn as much as possible about its signs and symptoms as well as the methods by which it is detected. Those who already have been diagnosed and who now approach treatment decisions need to learn more about the ways in which the disease is believed to develop in order to understand the ways in which it is combatted. Whatever stage you are in, it's important to become familiar not only with the facts, but also with the theories and myths associated with endometriosis and to learn to distinguish one from the other. To make appropriate decisions, you need access not to only one point of view or interpretation of the disease, but to a variety of viewpoints. And, in order to understand these various viewpoints, a solid background of fundamental medical information is necessary.

Part I provides an overview of the basic medical knowledge concerning endometriosis, drawn from many sources and representing a broad spectrum of opinion. It begins not with endometriosis, however, but with a detailed exploration of reproductive anatomy and physiology. While you may be eager to delve directly into a discussion of endometriosis, realize that a firm grasp of the reproductive cycle is an essential prerequisite to an understanding of the disease. Without this knowledge, you cannot comprehend the rationales behind the various treatments discussed in Part 2 or the complex and mysterious ways in which endometriosis affects fertility.

Chapter 1, therefore, explores the complexities of the female reproductive cycle from menarche—the beginning of the reproductive years, to menopause—the cessation of menstruation and the end of reproductive life. At the same time, this chapter looks into those myths surrounding menstruation and menopause that hinder women's ability to differentiate normal from abnormal characteristics of the cycle.

Chapter 2 investigates the nature of endometriosis: what it is and what it is not, who gets it, what its consequences are, how it develops, and how it may be prevented. Of particular importance to women who merely suspect that they have endometriosis, Chapter 3 details the sites and symptoms of endometriosis, while Chapter Four illustrates the methods by which the disease is detected and discusses the many obstacles to a rapid and accurate diagnosis.

With this background, you will be able to grasp the various treatment methods discussed in Part 2 and more confidently approach treatment decisions.

Medical Aspects

To effectively cope with a disease as puzzling, complex, and unpredictable as endometriosis, women will need many different kinds of information. Those who suspect they have endometriosis need to learn as much as possible about its signs and symptoms as well as the methods by which it is detected. Those who already have been diagnosed and who now approach treatment decisions need to learn more about the ways in which the disease is believed to develop in order to understand the ways in which it is controlled. Whether you are in the important to be one familiar not only with the facts, but also with the theories and myths associated with endometriosis and to learn to distinguish one from the other. To make appropriate decisions, you need access not to only one point of view or interpretation of the disease, but to a variety of viewpoints. And in order to understand these various viewpoints, a solid background of basic medical knowledge concerning endometriosis. Part 1 provides an overview of the basic medical knowledge concerning endometriosis, of your own body, and representing a broad spectrum of opinion. It begins with endometriosis, however, but with a detailed explanation of reproductive anatomy and physiology. While you may be eager to dive directly into a discussion of endometriosis, realize that a firm grasp of the reproductive cycle is an essential prerequisite to an understanding of the disease. Without this knowledge, you cannot comprehend the theories behind the various treatments discussed in Part 2 or the complex and mysterious ways in which endometriosis affects fertility.

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