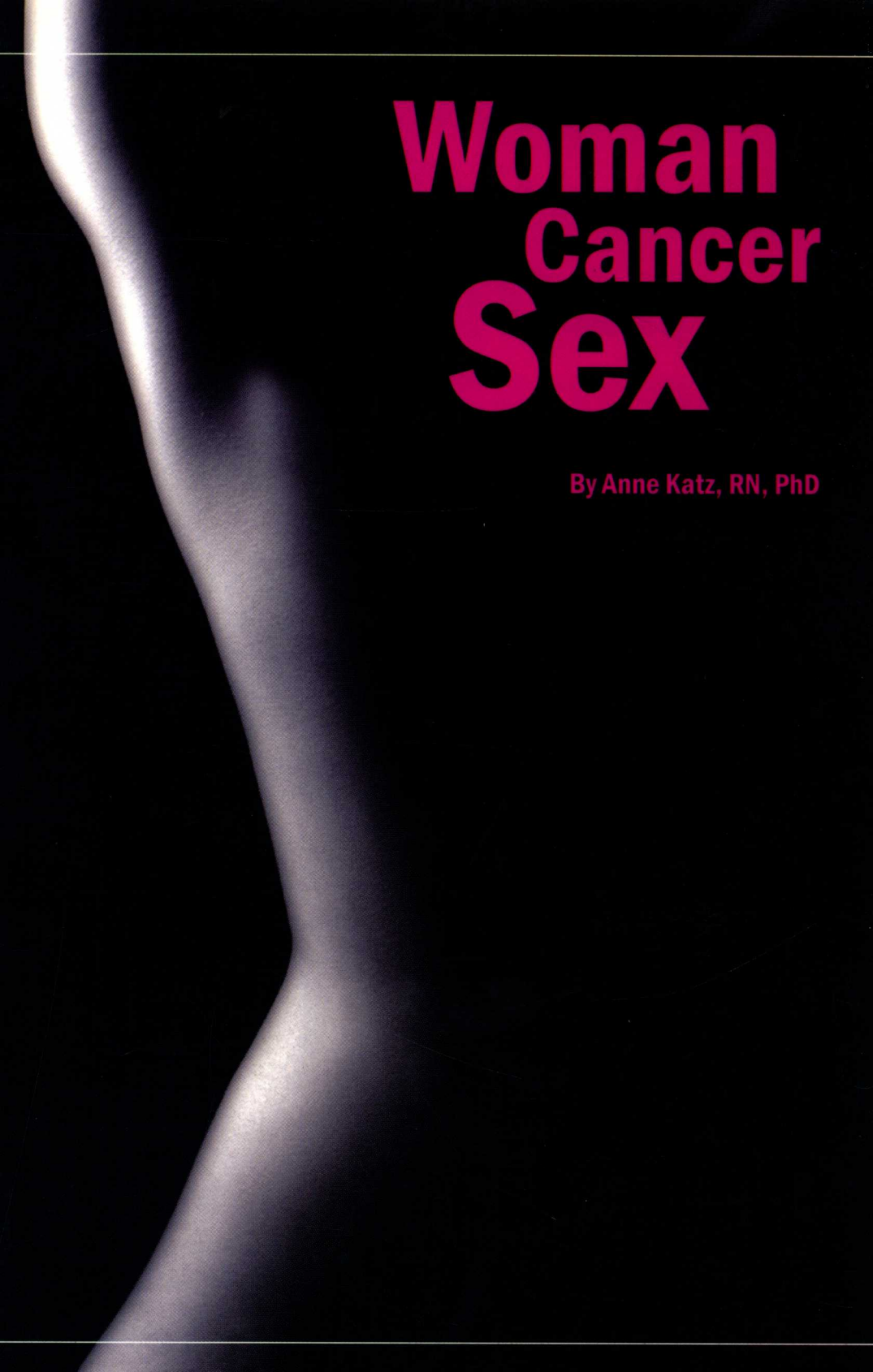
Woman
Cancer
Sex
By Anne Katz, RN, PhD

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For my Mouse
I carry you over my heart
To the n^{th}

With grateful thanks to Jen Hellwig
for ideas

Preface

I have worked with many women over the years in my practice as a sexuality counselor for people with cancer. Some have had breast cancer; others have had cervical or uterine cancer. There have been women with lymphoma or leukemia, and some with melanoma, a skin cancer, that many healthcare providers never would have thought could have sexual problems related to its treatment.

All these women dealt with their illness and its consequences in different ways. All of them coped, but many were really sad at the changes in their lives and relationships. All of these women touched me and challenged me. I laughed with many (humor is a great healer) and cried with many, even if they didn't see the tears on the outside.

But those were the ones who were lucky enough or brave enough to get help from me, a professional who specializes in this area. What about the many millions of other women who have cancer or who have survived cancer and who have problems but are too far from a specialist to get help? Or who are too scared to ask their healthcare provider for a referral? What about the women who try to talk to their healthcare provider and are told that what they are going through has nothing to do with cancer or treatment?

This book is for these women and for the men and women who love them.

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PART ONE

Understanding the Basics

Why is sex important to us as individuals and as couples? How do we become sexual beings, and what influences it? This introductory chapter will set the stage for the rest of the book by describing the anatomy of the sex organs and how things work.

CHAPTER 1

Introduction

Sex and sexuality are important aspects of life for women in the 21st century. We all are aware of ourselves as sexual beings, whether we express that with a partner or alone, frequently or infrequently, proudly or with conflicted feelings.

So what's the difference between sexuality and sexual functioning? *Sexuality* has been defined as the way we experience and express ourselves as sexual beings. This begins in infancy and persists through old age and is influenced by the norms of our families, communities, and society as a whole. It includes our awareness of ourselves as female and male and is an essential part of who we are and how we interact with others, irrespective of whether we actually engage in sexual activity or not. Our sexuality persists even when we're faced with challenges; it's not based in our breasts or genitalia but rather in our hearts, minds, and souls. We may feel pleasurable sensations in our genitals, but we experience those sensations in our heads and hearts, too. Part of our sexuality embraces how we seek out pleasure, intimacy, and connectedness with our partner, as well as how we experience erotic thoughts and feelings. Our sexual orientation, or with whom we choose to be sexual, is an intrinsic part of sexuality. For some of us, procreation or reproduction is the expression of our sexuality. All of this occurs in the context of our religious, cultural, and ethnic beliefs and practices. Many of us have strong feelings about what's right and wrong and what's acceptable or not acceptable about sexuality, sexual expression, and sexual activity. This, too, is influenced by our family of origin, our education as children, teens, and adults, and the experiences we've had as we have matured.

On the other hand, *sexual functioning* describes what we do as sexual beings. There is a whole language around this phrase. Most people have their own language for sexual functioning and use euphemisms to describe what they do. For example, many couples talk about their "intimate life," which comprises their "sexual activity" as well as the feelings of connectedness that flow from that. Or they may use that phrase because they're embarrassed to say the words "sexual activity" or "sexual intercourse." Many people refer to "making love," which may be, to them, a more acceptable way of saying that they engage in sexual activity. The phrase *sexual activity* is confusing in many ways; for some people it means having intercourse, while for others it may mean masturbation, alone or with a partner. For others, it may involve only oral sex without genital penetration.

The importance that we, as individuals and couples, place on sexual functioning tends to ebb and flow throughout our lives. At the beginning of a relationship, sex is often of high importance, and most of us can recall with fondness those first few months of a new relationship where every kiss, touch, and glance made our pulses race. But when raising a young family, many women find that sex takes a backseat to the myriad other roles and responsibilities they have. This can cause stress in a relationship when members of the couple have different levels of sexual desire. Menopause also presents changes to sexuality and sexual functioning at a time when a woman's partner may be experiencing his or her own changes. Acute or chronic illness poses another challenge, and some couples choose to ignore their sexual needs and desires in the face of health challenges for fear of causing damage or pain to their partners.

Cancer and Sexuality

Some people may think that these two words—sexuality and cancer—don't go together. This is probably because they haven't experienced cancer or because they have an image of sexuality as being related to the more sensationalized images we see in the media or to reproduction. If sexuality is the expression of ourselves as human beings, then it's important to consider that cancer and its treatments don't take away the experience of being a sexual person. Cancer may change the way we see ourselves as sexual beings but not necessarily in a negative way. Today, the success or failure of cancer treatment is not judged solely on the basis of cure but also on how it affects quality of life for patients, their partners,

and their families. Cancer can have a profound effect on all aspects of quality of life, including physical, psychological, and social dimensions.

The physical location of the cancer can profoundly affect how a woman sees herself as a sexual being. Gynecologic cancer affects a woman's reproductive organs, which also are her sexual organs. Breast cancer affects a part of the body that represents femininity to many women, and alterations to the structure of the breast can profoundly affect her self-image and body image. Other cancers may seem less likely to affect sexual functioning, but because the heart, mind, and soul, as well as the body, play a part in sex, *any* cancer experience can affect how women perceive themselves and how they act out their sexuality and sexual feelings.

The Stages of Illness

As with all other illnesses, cancer has its own unique stages. Sexuality and sexual functioning are affected at every stage of the cancer journey. The time surrounding diagnosis is usually one of crisis. When multiple tests are being done to diagnose a particular cancer, a woman may find that she's under too much stress to enjoy sexual thoughts or sexual activity; yet, other women may find that sexual activity is a distraction and a way to connect with themselves and their partner in a pleasurable way and put aside fears and uncertainties. When the cancer diagnosis is made, life is forever changed, and a woman must learn a whole new way of being as she works with the healthcare team to develop a plan for care and treatment. For many, a diagnosis of cancer initially presents a very real threat to life, and thoughts of death are very real. Many women find that even thinking about sex seems contradictory. Others find solace and comfort in the arms of their partner. Touch and sensation may take on new meaning in the face of this threat to life.

Cancer treatments can have significant effects on sexual feelings and expression. The most common treatments for cancer—surgery, radiation, chemotherapy, and hormonal manipulation—all have the potential to affect how the body works. The impact may be temporary, long-lasting, or even permanent. Treatments can affect nerves, blood vessels, muscles, skin, bones, and hormone levels. The mind, too, can be affected, and the psychological and emotional impact of the treatments may persist for many months or even years. Some women put sex on the back burner and, over time, might not "revisit" themselves as sexual beings. Other women mourn the changes in their lives and try to stay connected to their

partners and their own bodies through whatever means they can find, depending on their health and the severity of treatment side effects.

When treatment is over, the "chronic" phase of cancer begins. Many women find that over time, the body heals and returns to something resembling normalcy. But this can be a time of great uncertainty, when altered sensations can cause panic that the cancer is back. Some women do experience recurrence, and once again there is a crisis as expectations or hopes are crushed and a transition to quality versus length of life may need to be made.

But thanks to dramatic advances in cancer detection and treatment, more and more people are surviving cancer. According to the American Cancer Society (2008), at least 10.5 million Americans with a history of cancer were alive in 2003, and between 1996 and 2002, survival rates were up 51% over previous decades. There are many myths associated with cancer survival, including the myth that once treatment is over, a woman should go back to life as it was before and also should return to her precancer sense of self, including sexual functioning. The reality is that some women return to their previous levels of sexual functioning, and others don't. Some find that the alterations they needed to make during treatment or recovery from treatment have opened up a new world, and they incorporate these changes as permanent features of an expanded or different sex life. For some women, the cessation of sexual activity during acute treatment is never addressed, and they don't attempt to return to their previous activities. For some, this may be a relief—perhaps sex wasn't important or enjoyable to them, and the cancer was a welcome excuse to avoid it. Others don't know that there's help available to assist them in finding solutions to problems they encounter with treatment or recovery. Some women's healthcare providers never even ask patients if they have any questions or need help dealing with changes in their sexual functioning. If you've experienced sexual problems during or after cancer, you're not alone. Almost half of all cancer survivors report ongoing problems with sexual functioning; these problems are physical, emotional or psychological, and social.

What Can You Expect From This Book?

I'm a passionate believer that all people who experience cancer—patients and their partners—deserve to have their issues with sexual functioning addressed and

resolved in the best way possible. Every day, I counsel patients and their partners experiencing these very problems. This book explains the changes that many women with cancer experience and offers practical advice on how to handle these changes. Each chapter describes the experience of a woman with a particular kind of cancer. But the experience isn't applicable only to women with that kind of cancer. Even if you've experienced a different kind of cancer, you'll find yourself relating to that woman's feelings and her experiences with a variety of problems, including loss of libido, physical pain during and after treatment, and struggles communicating with a partner. So make sure you read every chapter of this book even if you think it doesn't apply directly to you, because all chapters include information that applies to different types of cancer. And ask your partner to read it, too. Why is this important? Because there are some universal experiences for those who have cancer that are not different by type of cancer. For instance, fatigue is a universal response to many treatments, and body image is something that many women are very concerned about and is almost always affected by cancer.

This book has three parts. The first deals with sexual functioning and describes "how things work," so that you'll be able to better understand the terms commonly used in talking about sexuality and sexual functioning. The second part highlights the different feelings—physical and emotional—that women with cancer may experience. These include changes in body image, loss of sexual desire, alterations in arousal, changes in orgasmic response, pain, and the emotional responses to these changes. There's also a chapter on how to communicate with a potential partner about a sensitive and often emotionally laden topic. Issues facing lesbians with cancer are addressed, as well as the interaction between fertility and sexuality. The third part presents specific strategies for the woman with cancer, including drugs and other therapies used to treat sexual problems, communication strategies and exercises, and additional resources for where to find help. Because the partners of women with cancer experience their own individual issues, there's also a chapter in this section for the partner of the woman with cancer.

Today, most women who receive a cancer diagnosis will go on to survive, and in time, the memory of cancer and its treatments will fade. Sexuality is a part of life, and women deserve to continue to express themselves as sexual beings in loving relationships. This book gives you the information and tools you need to reclaim your sex life after the challenges of cancer.

Reference

American Cancer Society. (2008). *Cancer facts and figures, 2008.* Retrieved November 26, 2008, from http://www.cancer.org/docroot/STT/content/STT_1x_Cancer_Facts_and_Figures_2008.asp

CHAPTER 2

How Do Things Work?

To talk about sex, we need to know about the parts and processes involved in sexual activities. We know quite a bit about the parts: the female and male reproductive organs. And we know something about how they work, but even in this area, we are learning all the time. Do we know how diseases like cancer affect sexuality? Yes, in part, we do. But there is still lots to learn. So let's start at the beginning with the female (and for completeness) the male sexual organs.

Sexual Anatomy

Women have breasts, and below the waist are the pubic mound (or mons), the vulva (made up of the clitoris, the labia majora and minora [inner and outer lips], and the entrance to the vagina), and then internally the vagina and cervix. The cervix connects to the uterus and uterine (fallopian) tubes. The ovaries lie in the abdomen and produce the hormones that influence sexual functioning.

The breasts grow and develop during the years of puberty. They are described as secondary sex characteristics. The breasts are mostly fat and a special tissue called mammary glands. The mammary glands produce milk after a baby is born, and the fat gives breasts their size and shape. Each breast has a nipple on it that is surrounded by a colored area of skin called the areola. The nipples and areolae have many nerve endings that are very sensitive and play a role in sexual arousal.

The genital organs in the woman have external and internal parts. On the outside is the pubic mound, or mons. It is a fatty pad that lies over the pubic bone and after puberty is covered with hair. Lying below the mons are two fleshy

folds of skin (called the labia majora) that run backwards to the entrance to the vagina. These also usually are covered with hair. They lie over the inner lips (the labia minora). The inner lips surround the opening of the urethra (which carries urine from the bladder) and the entrance to the vagina. This area also has a lot of nerve endings and a rich blood supply. During sexual arousal, the whole area will swell and grow darker in color.

Where the inner labia meet in the front, just below the mons, is the clitoris. This organ has the highest number of nerves in the human body, even more than the number supplying the male penis. It used to be thought that the clitoris was a small organ, about the size of a pea. Many medical textbooks still show it that way. But we now know that the clitoris has a large part of itself hidden under the skin of the labia; in fact, there is clitoral tissue as far back as the entrance to the vagina on each side. Just a small part of the clitoris is visible on the outside, and it is partly covered by a hood.

The entrance to the vagina lies between the urethra in the front and the anus in the back. The vagina is a tube about three to five inches in length. The walls of the vagina are covered in mucosal tissue that also is richly supplied with blood, but this area does not contain many nerve endings. This is probably a good thing when you think about a 9-pound baby coming through the vagina! There are more nerves in the lower third of the vagina, near the entrance. In its normal resting state, the walls of the vagina touch each other. These walls have many folds, and the mucosal cells secrete a fluid to keep the vagina moist.

The cervix lies at the top of the vagina and serves as the entrance to the uterus. The cervix makes a fluid that lubricates the vagina. On either side of the cervix are two large groupings of nerves and blood vessels that supply the sexual organs. The uterus is a muscular organ, roughly the size and shape of a pear. The uterine tubes (also called the fallopian tubes) extend from each side of the uterus toward the ovaries. The ovaries produce eggs (ova) and sex hormones: estrogen, progesterone, and testosterone.

Let's briefly talk about the male sex organs. Externally are the penis and the scrotum. The scrotum contains the testicles, which produce the sex hormone testosterone. The penis consists of the shaft and the head (or glans), which may be covered by a foreskin. Some parents opt to have the foreskin removed when their sons are babies (referred to as circumcision). Running through the penis is the urethra, which carries urine and ejaculate to the outside. The internal organs

are the vas deferens, which carries sperm to the prostate gland, the seminal vesicles, which make the fluid portion of the ejaculate; and the Cowper's glands, which produce a liquid during sexual arousal. An important internal organ is the prostate, which lies underneath the bladder and surrounds the urethra. The prostate makes fluid that forms part of the ejaculate and also aids in the process of expulsion of semen during ejaculation.

Hormonal Influences

The hypothalamus and pituitary gland in the brain control the secretion of hormones by the ovaries and testicles. These hormones (estrogens, progesterone, and testosterone) are important for various aspects of male and female sexuality and sexual functioning. Another hormone, prolactin, also is important for libido, and oxytocin is produced after orgasm. Women have higher levels of estrogen and progesterone than men but lower levels of testosterone.

Estrogen is involved in the maturation of sexual organs, the development of the breasts and body hair, and the regulation of the menstrual cycle. Estrogen also is called the hormone of arousal because it increases the secretion of lubrication in the vagina.

The Sexual Response Cycle

The brain often is described as the biggest sex organ, in part because of the role that the brain plays in sexual thoughts and fantasies, sexual desire, and the interpretation of sensations. Our modern understanding of human sexuality comes originally from the work of Masters and Johnson in the 1960s. They developed a model of human sexual functioning comprising four parts. These stages (excitement, plateau, orgasm, and resolution) were described as the same for men and women and were thought to occur in a linear fashion with one stage following the other. These stages essentially are made up of episodes of increased blood supply to sexual organs, as well as muscle contractions.

The Excitement Stage

In this first stage, the heart beats faster and blood pressure increases. Blood flows into the tissues of the sexual organs, causing swelling. The breasts increase