

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