

# CHAPTER 1

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## Why Sex Matters

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Why is sex important for us as individuals and as couples? How do we become sexual beings, and what influences this? This introductory chapter will set the stage for the rest of the book by defining sex and sexuality in the context of human development across the life span.

Sex, sex, sex—we hear so much about this every day and in every way. Sex sells cars and vacations and clothing. Many men think that they are not having enough sex and that everyone is having more sex than them. We learn how to be sexual from many different sources: parents, peers, school, religious institutions, and the media. What we learn as we grow from childhood into old age (and this learning should and does continue along the life span) may affirm that sex is a good and pleasurable thing if we are lucky or may be less positive if we are not.

The media tend to portray men as testosterone-driven, unfeeling and uncommunicative, stupid and bumbling characters similar to Homer Simpson. Men are portrayed as sexual machines, ready and able to have sex no matter what the circumstances (even with bombs falling around one's ears) or the situation. Many men have integrated these images and are worried when they seem to fall short of them. When illness happens, particularly a life-threatening illness such as cancer, many men don't know what will happen to them sexually.

### **Sexuality Across the Life Span**

#### **Adolescence**

As you will learn in the following chapter, sexual development is under the influence of hormones, mostly testosterone for boys. During adolescence, a period

of physical growth and development, the boy/young man begins to experience changes to his body that eventually lead to the typical size, shape, and structures of the adult male. The penis and testicles enlarge, hair grows seemingly all over, and the voice deepens. The shoulders grow broader and the hips narrow, leading to the typical inverted triangle shape seen in adult men. The young man grows in height and by the end of adolescence is usually the height he will be as an adult.

Emotional maturation happens during this time, too. The peer group becomes more important in the life of the young man. Many young men are physically mature but lack the emotional and social maturity of adults. Their thinking may still be quite immature, and this often leads to mistakes and lack of judgment, which can get them into trouble. Adolescents are usually very aware of the need to conform to the norms of their peer group and may be preoccupied with how they look, what clothes they are wearing, and how popular they are. Adolescence can be a very difficult time if the young man thinks and feels that he is different. If his peers see him as being different, he may be isolated, teased, and ridiculed, and this can have lifelong consequences, with low self-esteem as the usual result. Low self-esteem can lead to risky social and sexual activities, as well as feelings of inadequacy that influence occupational and relationship choices.

But most young men negotiate this passage into adulthood just fine. Somewhere along the way, they discover who they are attracted to and usually act on that attraction. Young men who are attracted to women often have their hearts broken many times on the road to a lasting relationship. Those who are attracted to men must negotiate a world of stigma and marginalization where homosexual attraction is still seen as different and not legitimate. Confusion about sexual attraction is common during adolescence, but the negative societal messages about same-sex attraction further compound the issue.

The major tasks of adolescence that must be accomplished before adulthood are separation from family and achievement of independence, as well as finding a vocational goal. The adolescent must be able to control his impulses and deal with frustration in a constructive way, and he must also learn to delay gratification of his wishes. And to round out this challenging list of tasks, the adolescent must develop a healthy and realistic sense of self and reach a mature level of sexuality.

Most young men masturbate, and this solitary sexual activity usually persists into adulthood. Even though it is universally practiced, many young men feel

guilty about this, and in parts of our society it is still a taboo topic, and not much is said about it by parents or other adult authorities. Some religious and cultural institutions still frown upon masturbation, and many young men struggle with the drive to do it, the pleasure that results from it, and the subsequent feelings of shame and guilt.

Young men often feel pressure to become sexually active. There is a great deal of boasting about sexual experience among young men, and the facts are often quite different from what they tell their friends. This persists into adulthood where men often don't speak honestly about sex—their feelings and experiences—but rather inflate their stories and never talk about their true emotions. Young men also receive conflicting messages about sex: “Get all you can” versus “Don't take advantage,” or “Sex is the greatest” versus “Don't get into trouble.” Much of the information that appears in the media is also contradictory. On the one hand, sex is shown as something that is highly pleasurable, and those who have sex are cool and manly, but on the other hand, sex is also dangerous, as it leads to sexually transmitted infections and pregnancy. Adolescents commonly are thought of as viewing themselves as immortal, invulnerable, and immune and are treated accordingly by their parents and teachers. Therefore, the messages they receive are about preventing themselves from getting into trouble and not about how to be a sexually healthy young person.

When an adolescent gets cancer, everything changes. The young man may be more dependent on his parents for help with activities of daily living; this may lead to an inability to achieve the developmental task of independence. The adolescent may miss extended periods of school, and the social consequences of that may affect his ability to make and keep peer relationships in the future. Treatment for cancer may cause physical changes, and for a young person who is trying to look like everyone else, this can be a significant challenge. He may avoid social situations because he is embarrassed by scars from surgery, weight gain or loss from chemotherapy, or other side effects of medications or radiation therapy. Some treatments interfere with normal growth and development, including sexual development, so the young man may look many years younger than he really is.

In short, a life-threatening illness like cancer challenges the notion of adolescents as immortal, invulnerable, and immune. However, 80% of children and adolescents treated for cancer now survive the disease and grow into adulthood.

But their lives are fundamentally changed by the disease and the experience. Some may be infertile, which may affect their decision to enter a permanent relationship in adulthood. On the other hand, others may assume that they are infertile and so may not use contraception and then go on to father children when they don't want to or with the wrong person.

### **Young Adulthood**

Young adulthood is the period between ages 20 and 40 and is a time of great social and emotional growth. Physical growth does not really occur at this time; however, some young men do gain some height in their early 20s. In these two decades, most people decide whether to get married and whether to parent. This is also a time when many men build their careers or at least settle down in a career for the future. Cancer in this period presents some unique challenges.

One of the most significant challenges for men who have had cancer is how to tell a new or prospective partner that they have had cancer, that they may not be able to father children, or that they are missing a body part, or have an ostomy bag, or many scars. When do you tell someone, and what do you do if that person rejects you? For the man who is partnered when the diagnosis of cancer is made, this relationship usually proves to be a source of strength and comfort. Most couples report that the cancer experience brought them closer and enhanced their commitment and the depth of their emotions for each other.

A young adult dealing with cancer or its aftermath may have a very different attitude toward life compared to his peers. He may be more serious or perhaps a greater risk taker. The cancer treatments will affect him not only physically but also emotionally and socially, and he may have to delay some of the important tasks of young adulthood, such as establishing a career, because of extended periods in the hospital or time spent recuperating from chemotherapy. This can also affect his ability to form romantic relationships and to establish a strong social peer group. The illness may mean that the man has to remain in his parents' home instead of moving out, and he may be physically and financially dependent on them far beyond the time his peers move out and make their own way in the world.

Fertility issues usually become important for men in these decades, although some men may wish to start their family when they are past 40 years of age. For the childhood cancer survivor who reaches young adulthood, this may be

the first time that he has to deal with this issue. When cancer is diagnosed in childhood, decisions about treatment usually are made in a great hurry, and most parents are concerned only about the survival of their precious child. Delaying treatment to think about fertility far in the future is not something that most would even consider. But the treatment may render the young man infertile, and it is in young adulthood that this is discovered. Some men may be angry that nothing was done to preserve their fertility back then or that no attempts were made to freeze sperm. This is, of course, dependent on the sexual development of the child in the past, as development of sperm occurs during puberty; so, if the cancer occurred in early childhood, nothing can be done. But the man may not understand this and may be regretful about decisions that he was not part of in the distant past.

## **Middle Adulthood**

Middle adulthood covers the years from age 40 to about age 65. This is usually a time of secure primary relationships, well-established careers winding down into retirement, and parenting responsibilities becoming less intense as children grow and form their own families. Ill health is more common during this period, and men in this age group may experience medical diseases such as high blood pressure, raised cholesterol, and diabetes. The later years of middle adulthood are also the years when a diagnosis of cancer is most common.

This is also the period when some men notice that their sexual functioning changes. The most common challenge to men in these years is the onset of some difficulties with achieving and maintaining erections. This may be linked to the onset of cardiac disease or diabetes and often causes distress to the man and his partner. During this same time, the female partner of the man may be going through the menopausal transition, and her sexual interest may wane, causing more or less distress to the couple. Some men also notice a decline in their level of sexual desire coupled with a change in body fat and loss of muscle mass. This is probably caused by slowly declining levels of testosterone but may also be associated with decreased physical activity.

The focus of society is on youth and strength, and loss of both in combination with ill health may affect the man not only physically but also in the way he sees himself as a man and a member of society. This can be a time when the losses associated with cancer cause significant challenges for the man. Loss of a partner

to cancer means that the older man may be seeking social and emotional support at a time when he is not confident in his ability to attract someone new. He may not want to feel like a burden to his adult children, and he may be lonely.

### Older Adulthood

Older adulthood is a time when physical changes are inevitable. However, they do not necessarily mean the end of vibrancy and enjoyment of life. It is also a time when illness and disability are more common, and the loss of friends and one's partner is a reality.

In our youth-obsessed culture, it is often assumed that older adults, those age 65 and older, are not sexual. In fact, this is one of the last social taboos that we hardly talk about. However, recent surveys suggest that partnered older adults continue to enjoy regular sexual activity that they find satisfying. Older adults have the same needs for physical and emotional love and support, and many will seek new relationships after the loss of a long-term partner or spouse to avoid the loneliness of being single in their later years.

### The Words We Use

With all this talk about sex, sex, sex, it is important to understand the difference between some of the terms used throughout this book and in our daily conversations about this important topic. The two major terms are *sexuality* and *sexual functioning*. *Sexuality* means how we express and experience ourselves as sexual beings. This is a lifelong process that begins in infancy and remains a vital part of our lives until death. It encompasses our image of ourselves as men (and women) and how we interact with others of both sexes, and is essentially a process that takes place in our brains. Sexuality is influenced by the messages we received from our family as children and from our peers and society as a whole. Our sexuality encompasses our sexual orientation and where and how we seek sexual pleasure. It is strongly influenced by religion, culture, and ethnicity, as well as education and experience. It is not a rational process but rather an innate characteristic. And our expression of sexuality is not dependent on being in a relationship; as single and partnered individuals, our sexuality is a unique part of ourselves.

On the other hand, *sexual functioning* is what we *do* as sexual beings. Sexual behavior is something that is learned over the years. This learning is influenced by

experimentation with what feels good for our own bodies and what brings pleasure to others when we touch them. Curiosity leads to further experimentation, and pleasure reinforces these activities. However, social taboos and restrictions seek to limit what is regarded as normal and healthy, and this is something that changes over time. As such, it should be viewed within the context of history, culture, and time. There has always been wide variation in sexual practice across societies, cultures, and geography; no single one is right or wrong, acceptable or deviant.

Most of us have our own language for what we think and do regarding sexuality and sexual activity. We even have our own language for our body parts, and men are much more likely than women to have an affectionate name for their genitals. This may have something to do with comfort as well as the visibility of the male genitalia. Some of the language used with regard to sexual activity tends to be euphemistic (for example, describing sexual intercourse as *intimacy* instead of using the word *sex*). Sexual activity itself has many meanings: It may describe sexual intercourse, oral sex, or masturbation alone or with a partner. This can cause all kinds of confusion when trying to explain what you want or what you did, or what you don't want to do! Euphemisms tend to make us feel more comfortable but can obviously lead to problems when the meanings aren't clear.

Our sexual behaviors may change over time and under the influence of many different factors in our lives. Being partnered for some men means having regular sex, while for others it may mean having less sex than when they were single. Sex may be more or less important at different stages of our lives and for many different reasons. Male sexuality also contains many myths, many of which men believe themselves. A good example of this is that male sexuality is simple, like a light switch. Men are either turned on or not, and it is easy to get turned on under any circumstances.

In fact, male sexuality is a complex phenomenon comprising biologic factors (the body, sexual drive, erectile capacity and ejaculation, and sexual satisfaction), and these are under the influence of hormones and blood and nerve supply, as well as personal health behaviors. A second factor is that of psychological influences (cognition [thoughts], behaviors, and emotions). A relationship dimension also exists that reflects the man's way of interacting with a partner and how he is able to empathize and support the partner. Societal norms play a role in how

men react and interact. And finally, psychosexual skills (one's sexual response and knowledge) are an integral part of a man's sexuality and sexual life. No simple light switch there!

### **Sexuality and Cancer**

For many people, these two words just don't go together. For many years, talking about cancer was a big taboo, and at the same time, sex was not discussed either. Both were secretive subjects that were talked about in private, if discussed at all. Things are different now: Cancer is seen in a different light, and we are much more open about sex. Sex and cancer can and do go together, because cancer is beatable and sex is part of life. According to the American Cancer Society, 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. People with cancer are living longer and better. They are returning to work and social life, and they and their partners continue to have sexual wants and needs. Quality of life after cancer has become an important part of how we view the success (or failure) of cancer treatment. And sexuality is an important part of quality of life affecting physical and emotional aspects.

The site of the cancer may have a lot to do with the sexual consequences of both the cancer and its treatments. For example, a man with prostate cancer will be expected to have some problems with erections following both surgery and radiation because the erectile nerves are found on the outside of the prostate gland. But with other cancers, the sexual consequences are not that clear and may be much more subtle. For example, surgery for cancer may leave a man with a large scar on his body. How this affects his body image can affect how he sees himself as a sexual being. The man with a colostomy bag may feel sexually unattractive and may avoid his partner out of fear of being rejected. His partner, in turn, feels rejected because the man no longer seems to want contact with him or her. This book describes in detail what these changes are and how they can affect the individual and his partner.

The stages of the cancer experience also play a role in when and how sexuality is affected. The time of diagnosis usually is one of crisis and anxiety. The person has to undergo many different tests, and there sometimes are extended periods of waiting for test results and doctor's appointments. All of this causes uncertainty,

and human beings usually don't do well with uncertainty; we prefer to *know* what is happening. Once we know that it is cancer, life is never the same again. For most people, a diagnosis of cancer presents a life-threatening challenge. Everything is thrown into chaos: Will I live? What will happen to my family? How bad are the treatments going to be? Am I going to make it? How this affects sexuality and sexual functioning is as different as people are different. Some men find that during this period, their desire for sex disappears. They don't think about it and don't seem to care about it. This is a natural reaction to an extremely stressful event. Others seem more interested in sex and may be more demanding of their partner or masturbate more. This is also a normal reaction because sex brings comfort and pleasure and is a great way to distract oneself from the harsh reality of a new diagnosis. It is also a way of connecting with one's partner and seeking support and love. Many people report that at this time sex takes on a new meaning and brings with it a poignancy and sense of pleasure unique to the couple.

The period when treatment takes place can stretch over many weeks or months. The most common treatments for cancer—surgery, radiation, and chemotherapy—may be given alone or in some combination. Every year new treatments become available, such as immunotherapy and agents that prevent blood from reaching tumors. All of these can affect sexuality in one way or another. Cancer treatment can alter levels of hormones and can disrupt nerve and blood supply to sexual and adjacent organs. The treatment can also affect mood and how we see ourselves as sexual beings. These changes may be temporary or may last for many years after treatment.

The active treatment phase is usually one where sexual activity is not a priority for the patient, but everyone is different. For some men, being sexual in the face of disease is one way of showing the cancer who's the boss and refusing to give in. For others, the side effects of treatment (such as nausea, pain, fatigue, and dizziness) preclude even the thought of anything sexual being possible. And still others want to experience the pleasure that sexual activity brings as a way of comforting themselves and their partner. There really is no right or wrong way to be during treatment.

But one day, the treatment will be over, and the person moves into the more chronic stage of the illness. This is an extended period of time when life begins to go back to normal, but thoughts of the cancer and fear of recurrence are common. Many people regard this phase as the survivorship phase, and some say that

once you have had cancer, you are forever changed and are, from that time on, a cancer survivor. Others don't like the term and prefer to put the cancer behind them and try not to think about it. It is often in this stage when couples resume sexual activity, and so it is during this time that they notice something is not as it used to be. Men may notice that things are different in the quality of their erections independent of sexual activity or may notice that they no longer have erections upon wakening in the morning. They may also notice changes when masturbating, which can affect when and if they try to resume partnered sexual activity. Some men experience little or no disruption in their sexual lives, and some report that after getting through the treatment, sex is even better than before because they are more in touch with their bodies and want to embrace life with a new intensity. Once again, any and all of these experiences are perfectly normal.

### Talking About It

Although men often laugh and joke about sex, having a serious conversation about it is something else. Most of us have some difficulty finding the right words to say when it comes to this topic. And it is particularly difficult to talk to healthcare providers about this. Often the appointment is rushed and you only have the opportunity to ask when the doctor has his hand on the door and asks you if there is anything else you'd like to talk about. (This is called the *doorknob syndrome* and is recognized as a barrier to communication.)

Research has shown that healthcare providers are willing to talk about sexual issues with patients if the patient brings it up. And the same research shows that patients wait for the healthcare provider to ask about it. The result is silence, with both parties waiting for the other to go first. The reasons why this happens are similar for both patient and provider: embarrassment and not wanting to ask about or discuss a private part of life. There are some differences, however. Many healthcare providers have received very little education about human sexuality and are afraid of being seen as lacking knowledge on the subject if the patient asks. At the same time, some patients are afraid that they will seem stupid for asking a question. Some healthcare providers think that it is someone else's responsibility and that their primary goal is to cure the cancer and leave all the other "stuff" to someone else, whoever that may be. And patients may not know who to ask, because no one on the healthcare team has ever asked if they have any concerns or questions. What a mess!

It can also be difficult for one man to talk to another man about sexual difficulties. This may represent some sort of symbolic weakness and may also be why men tend to joke about sex a lot. Your healthcare provider may be much older or much younger than you, and age can sometimes present a significant barrier. Young people find it difficult to talk to older people about sex (because older people aren't having it and don't know anything about it!) and vice versa.

That is why I wrote this book. I believe that all people—man or woman, young or old, partnered or single, gay or straight—have the right to ask questions about sexuality and sexual functioning and to have those questions answered in a way that they understand and that makes sense to them. I have done this in three different ways. First, I wrote a textbook for healthcare professionals called *Breaking the Silence on Cancer and Sexuality: A Handbook for Healthcare Providers*. This book provides a comprehensive overview of cancer and the sexual consequences of treatment. Then, I wrote a book for women with cancer called *Woman Cancer Sex*. And now there is this book for men and the women and men who love them.

## **What Can You Expect From This Book?**

This book is divided into three parts. This chapter and the one following provide some basic information about how things work and why. This is important information and shouldn't be skipped over, because understanding this forms the basis of understanding how cancer affects sexuality.

The second section of the book contains the stories of 10 men, all of whom have or have had cancer. Each man experiences some sort of sexual difficulty, and his story is told in the chapter, along with explanations and suggestions for how to get help or help yourself. The chapters cover everything from loss of interest in sex to changes in body image, problems with erections, and pain with orgasm. There is a chapter about what happens to the partner of a man with cancer. It is important to read all these chapters even if you don't have the same kind of cancer. There is information in each chapter that will be of interest and use to you, no matter what kind of cancer you had or how long ago it was, or if you are older or younger than the man whose story is told in the chapter. And ask your partner to read it too. Or, if you don't have a partner now, sometime in the

future this book may help a new partner understand some of what you went through or may still be dealing with.

The final part of the book has two chapters. One addresses the important topic of communication with your partner, and the very last chapter has useful resources to help you find your way to additional help and information.

Most people diagnosed with cancer today will go on to live for many years, hopefully with good quality of life. And sexuality is a part of that quality of life. This book was written to help you access the information and tools to reclaim sexual health after the fight for life has been won.