

# INTRODUCTION

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**C**ancer survivors are a growing population. The latest estimate is that almost 12 million Americans, almost 4% of the total population, are living after a cancer diagnosis. About 65% of adults diagnosed with cancer are alive five years after their diagnosis, and more than one million survivors are alive 25 years or more after diagnosis. This is something to celebrate, so if you are one of those 12 million, take a moment and congratulate yourself on your membership in this amazing group. If you are a family member of someone with cancer, pat yourself on the back too. As you will see throughout this book, cancer survivorship includes family and friends who provide the essential support, love, and encouragement to those with cancer, and they couldn't do it without you. If you are a healthcare provider, you have likely played an important role in treating and caring for many survivors from the beginning of their cancer journey.

## DEFINING CANCER SURVIVORSHIP

So who is a cancer survivor? No mention of cancer survivorship existed in the medical and nursing literature until the

1980s. In 1985, cancer survivor and physician Fitzhugh Mullan described three “seasons” of survival in a landmark article in the prestigious *New England Journal of Medicine*. The first season is that of *acute survival*, which begins with diagnosis and continues to the end of active treatment. The second season, *extended survival*, begins at the end of treatment and continues through the period of disease remission and is seen as a period of watchful waiting. The third season is described as *permanent survival* or *cure*.

These seasons of survival have been further elaborated upon. A season of *transitional cancer survivorship* is suggested to occur when the person moves from the period of active treatment to one of careful observation and when adaptation to the physical, emotional, and social changes happens. Extended survivorship (the second season) is now seen to embrace three groups of survivors: those who are alive and living with cancer but require ongoing treatment for recurrence or advanced disease, those in complete remission who require ongoing treatment, or those in complete remission with a favorable prognosis. Some of the survivors in this second season will live long lives, whereas others will experience progression of their disease. Permanent survival is now thought of as comprising four subgroups:

- Those who are cancer free but not free of cancer, as their lives are irrevocably changed
- Those who are cancer free but live with significant challenges physically, emotionally, financially, legally, and socially
- Those who go on to develop secondary cancers unrelated to their primary cancer
- Those who develop cancers secondary to their treatments.

But much has changed since the 1980s when Mullan described his view of cancer survivorship. Many cancers, such as prostate and breast, are now diagnosed at a relatively early age. Treatments have improved, and as a result, many more people are living past diagnosis and treatment. The side effects of some treatments are now better controlled and even prevented, allowing for a reduction in the numbers of people dying from these effects. New and emerging therapies allow some cancers to be treated effectively where before there was little hope. Bone marrow and stem cell transplantation has evolved dramatically, providing greater hope and even remission or cure for cancers that were immediately lethal in years past. However, these changes have downsides, too: More survivors live long enough after initial diagnosis and treatment to develop secondary cancers related to their initial treatment or new cancers. And many cancer survivors now live long enough to experience the effects of aging that are compounded by late effects from treatment.

Today cancer survivorship has many different definitions, and researchers and oncology care providers often don't agree on the "best" or "most accurate" definition. The Office of Cancer Survivorship at the National Cancer Institute considers cancer survivorship to start at the time of diagnosis and to continue for the balance of the person's life. They include family, friends, and caregivers as survivors too because they are also affected by the diagnosis. In 2004, the President's Cancer Panel defined cancer survivorship this way:

Among healthcare professionals, people with a cancer history, and the public, views differ as to when a person with cancer becomes a survivor. Many consider a person to be a survivor from the moment of di-

agnosis; in recent years this view has become increasingly prevalent. Some, however, think that a person with a cancer diagnosis cannot be considered a survivor until he or she completes initial treatment. Others believe a person with cancer can be considered a survivor if he or she lives five years beyond diagnosis. Still others believe survivorship begins at some other point after diagnosis and treatment, and some reject the term “survivor” entirely, preferring to think of people with a cancer history as fighters, “thrivers,” champions, patients, or simply as individuals who have had a life-threatening disease. A considerable number of people with a cancer history maintain that they will have survived cancer if they die from another cause.

Do any of these definitions matter? Perhaps to policy makers and researchers who have to plan programs and studies, knowing who can access the services or studies is important. But to the person who has been diagnosed with cancer, life after cancer does not have to fit into certain parameters. For people living with cancer and its aftermath, life has changed. Life with cancer has both positive and negative aspects, and although everyone’s experience is unique, some experiences seem to be universal.

## TRANSITIONING FROM ACTIVE TREATMENT

Life during treatment is a very controlled one; you attend appointments for chemotherapy or radiation daily or a couple of

times a week or every month. Your healthcare providers tell you what to do and where to be. They are efficient and caring, and they make you feel important and cared for. In many ways, you are controlled by your treatment. As human beings, we like to think we are in control. Cancer has probably taught you that, in fact, we have very little control. You may have done everything right before the cancer—you ate healthily and exercised and didn't smoke or drink to excess—and yet you still got cancer!

And then, once treatment ends, that controlled environment is no longer a part of your every day or week. You are on your own, picking up the pieces of your life after a significant interruption. Your family and friends may celebrate this milestone—your treatment is over, you can get back to living your old life, and things will be back to normal. Many myths are associated with the end of treatment, such as the following.

- The end of treatment is a time to celebrate and forget the cancer.
- Recovery should occur soon after treatment ends.
- You should quickly go back to your “old” self.
- You don't need support after treatment is over.

What?! Sure you can celebrate the end of treatment, but many people are just too sick and tired to do much besides rest and try to figure out what just happened. And you may never be able to forget what you have gone through. Recovery can take many months, and there is no timetable for feeling better or stronger or more energized. You may never go back to the way you were; physical and emotional changes may make you better than you were before, stronger and wiser but not the same. And we all need support, perhaps even more so when treatment ends.

So how do you make the transition from active treatment to recovery and survivorship? It may be helpful to think of this transition as one that involves three stages: (a) endings, (b) a neutral zone, and eventually (c) a new beginning. When treatment ends, so too do the intense relationships you had with your oncology care providers and the safety they represent. You have to give up being the patient. Although it was a forced and reluctant role, it provided one with attention, reassurance, and support. Leaving that behind can be frightening and lonely. When treatment ends, you move into what has been called the *neutral zone*, which is characterized by feelings of chaos, loss, and confusion. Where are you? What comes next? For many, a new beginning emerges in its own time, when the survivor has resolved the issues from the end of treatment and the questions from the neutral zone.

Transitioning from active treatment is stressful. Not only have you lost the intense contacts and monitoring of your health, but now that treatment is over, you may begin to worry about the cancer coming back. You may not be clear on what comes next, how your health will be monitored, and whether you will recognize signs of things going wrong or will know what to do if that happens. You may be feeling at your very worst as the side effects of chemotherapy or radiation are at their most intense. And you may not know how you are going to go back to being what you were before—a parent, a family member, a worker, a “normal” person.

## BEING “CANCER FREE”

What does it mean to be *cancer free*? Are you ever cancer free? Some would suggest that for the person who has had cancer,

though there may be no evidence of the disease after treatment, one is never free of the cancer. Not only are there lingering long-term effects, such as fatigue and perhaps changes to both body image and functioning, but there also may be abiding worry about the cancer coming back.

We know that cancer survivors are resilient and can teach the rest of us important lessons about strength and courage and humor. Many survivors say that cancer changed their lives for the better, that ironically something that most of us fear can have a silver lining. Many cancer survivors come through treatment with a sense of mastery and self-esteem. They have faced something terrible and traumatic and yet have grown emotionally and spiritually and have found meaning in their lives from the experience.

Cancer survivors commonly report improved relationships with family and friends and experiencing a deeper love for their partner or spouse and close family members. They often find that they want to invest more time and energy in these relationships, which in turn deepens and improves the relationships even more. Cancer survivors also report that they cope better with whatever life throws at them; they are more likely to accept things as they come and to cope more effectively with stress. And the cancer experience tends to imbue survivors with greater compassion for others and a better outlook on life.

But some do not cope with the cancer or adapt to the new reality of life after cancer. Many factors can negatively affect what happens after cancer. These include more advanced disease, less social support, poor relationships with oncology care providers, rigid coping styles, being a natural pessimist and

having a helpless and hopeless outlook on life, and being in a difficult spousal or partner relationship.

## SO WHAT HAPPENS NEXT?

The answer to this important question, in part, lies in the rest of the book. At least I hope it does! In the next 10 chapters of this book, you will read about 10 important features of cancer survivorship. Why 10? Why *these* 10? For the past 10 years in my role as a sexuality counselor in a large cancer center in Canada, I have worked with cancer survivors experiencing sexual difficulties. In working with these cancer survivors and their partners and spouses, I became increasingly interested in the challenges they face in their daily lives, outside of their sexual difficulties. I began to read about this phenomenon called *cancer survivorship*, and as I read and thought and digested the information I was reading, I saw some trends emerge from my readings. It became apparent to me that cancer survivors face 10 key issues, and in the following chapters, I describe these challenges and what to do about them.

**Chapter 2. Sometimes a Cough Is Just a Cough:** The number-one fear of most cancer survivors is of the cancer coming back. Every ache and pain, cough, or sneeze sends the survivor into panic mode: Is the cancer back? This chapter will address this fear of recurrence, which for some survivors can be overwhelming. It can also be an issue for loved ones who may watch the survivor like hawks, terrified that it will all happen again. This chapter will provide strategies to help survivors and

their loved ones cope with this fear, helping to keep it in balance while maintaining vigilance.

**Chapter 3. Battling the Blues:** Many cancer survivors find that after all the activity and attention during the treatment phase, they are depressed. Often their family and friends do not understand why this is happening and tell the survivor to just be happy to be alive. Depression is common among cancer survivors and has been linked to a risk of recurrence. This chapter will address this important topic with tips on how to manage depression with medication and other nonprescription interventions.

**Chapter 4. Walking Through Mud:** Cancer survivors often assume that once treatment is over, they will feel “normal” again. They may be surprised when side effects linger for a long time. Fatigue is one contributor to feeling this way. Many factors affect energy levels, and these will be described in this chapter along with suggestions to combat them.

**Chapter 5. Moving Right Along:** Treatment for cancer can ravage the body, and it is important to eat well and exercise to regain strength and heal the body. But these kinds of lifestyle changes are very difficult to make and sustain. How do you find the motivation to exercise when all you want to do is rest? With all the hype about what foods are good to eat and what can “prevent” cancer, what is the survivor to do? This chapter will provide evidence-based answers to these questions and more.

**Chapter 6. On High Alert:** Cancer survivors must monitor their health, especially for recurrence or secondary cancers. But how do you know what to look for? When should you see your oncologist, and when should you schedule tests and in-

vestigations? What should you tell other healthcare providers who are not part of the cancer team? One way of keeping all this straight is to have a survivorship care plan, a carefully laid out document of what to look for, what tests to have, and how often, as well as a detailed description of the treatments you received.

**Chapter 7. Protection for Life:** Many of the treatments for cancer result in long-term complications or side effects. Examples of this include weak bones (osteoporosis), hot flashes, and increased risk for the development of diabetes. This chapter will describe the most common late and long-term side effects and will offer suggestions for early recognition as well as coping.

**Chapter 8. In a Fog:** Cancer-related cognitive changes (called *chemobrain* in the past) are one of the more significant and scary challenges of life after cancer. These changes can interfere with memory, language, and other activities involving the brain. These changes are not only related to chemotherapy but also may be the result of radiation or the diagnosis itself. This chapter will describe and explain this frightening phenomenon and make suggestions for how to cope with these changes, for both survivors and their loved ones.

**Chapter 9. Being a Part of It All:** Many cancer survivors want to or have to go back to work after treatment, but this is not always easy. Changes to tasks and responsibilities may have to be made. This chapter will highlight some of the challenges and opportunities in creating a back-to-work plan for cancer survivors.

**Chapter 10. Up Close and Personal:** Sexual and relationship changes are a common challenge after cancer treatment. Af-

ter the many months of treatment, it is usually in the survivorship phase of the cancer trajectory that couples start to think about being sexual again. All cancer treatments affect sexuality in some way, and it often is difficult to ask for help. This chapter will provide strategies to address this sensitive topic with partners and healthcare providers.

**Chapter 11. Empty Nests:** Many cancer survivors have not started or completed childbearing when the diagnosis of cancer is made. This can present some significant challenges. Couples who are dealing with infertility are twice as likely to be depressed than those who are able to conceive easily. A great deal of misinformation and inaccurate promises exist about fertility treatments. This chapter will provide the latest evidence about fertility after cancer treatment in a caring and compassionate manner.

**Chapter 12. Resources:** This chapter provides print and Web-based resources for information about life after cancer. It also contains detailed explanations of some of the techniques mentioned in the other chapters of the book.

**Bibliography:** Here you will find some selected papers and books that I have used in the research for this book. They are mostly academic papers that can be found through college and university libraries, online, or even at your local public library.

## RING THAT BELL!

Many cancer centers have a bell for patients to ring the day they have their last treatment. The bell signals to staff and other patients that someone has ended treatment, that someone

has reached a milestone in the cancer journey that at one time seemed to be just a distant dream. For some, ringing the bell means the beginning of cancer survivorship, a new phase in the journey, a passage from patient to something else.

But what does it mean to be a cancer survivor? Are your worries over? Will side effects of treatment magically disappear and life go back to what it was before? Take a deep breath, turn the page, and start to read. Your journey is not over—there is more to learn and experience. Bon voyage!