Handbook of Cancer Survivorship Care serves as a practical and concise guide for the multidisciplinary management of cancer survivors. Nearly all the chapters are written by a team working in a survivorship clinic, including a seasoned oncologist who specializes in the specific cancer disease and an experienced practitioner who provides direct patient services. Chapters reflect the importance of interdiscplinary collaboration and cover the high-yield pearls and clinical applications that lead to quality patient care outcomes. Part I discusses the basic concepts of survivorship care, models of care, and clinical tools while addressing late and long-term effects of treatment, screening methods for secondary or recurring tumors, and prevention of disease relapse. Part II includes chapters on cancers commonly seen in community practice, such as breast, prostate, lymphoma, and colorectal. Chapters in Part II provide clinical pearls and disease-specific background, a guide to disease surveillance, instructions for monitoring late effects, early detection tips, and information on psychosocial health, all to better direct clinical assessment and management. With cancer survivors an increasing segment of the healthcare population and survivorship care rapidly evolving, it is paramount that oncologists and other care providers are up-to-date on the clinical strategies, interventions, and recommendations for follow-up care. As a pocket-sized, quick reference, Handbook of Cancer Survivorship Care is an indispensable resource for any healthcare provider seeing patients in remission; it covers the must-know points of clinical management and successfully carries over cutting-edge expertise into clinical practice whether it is used at the bedside or in the clinic.

KEY FEATURES:
- Includes practical guidance on challenging areas such as addressing psychosocial issues, establishing screening and prevention strategies, and managing late effects in cancer survivors
- Easy-to-read outline format makes referencing in the clinical setting quick and convenient
- Practical clinical vignettes with self-assessment Q&A accompany chapters in Part II
- Clinical pearls highlight survivorship guidelines and their application
- Provides management guidelines and detailed disease surveillance strategies for site-specific cancers
- Includes digital access to the ebook
Handbook of Cancer Survivorship Care
Handbook of Cancer Survivorship Care

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For Figures 10.1, 10.2, 10.3, 11.1, 11.2, 12.1, 13.1, 14.1, 14.2, 16.1, and 16.3, the cancer survivorship algorithms have been specifically developed for MD Anderson using a multidisciplinary approach and taking into consideration circumstances particular to MD Anderson, including the following: MD Anderson’s specific patient population; MD Anderson’s services and structure; and MD Anderson’s clinical information. These algorithms are provided as informational purposes only and are not intended to replace the independent medical or professional judgment of physicians or other healthcare providers. Moreover, the algorithms should not be used to treat pregnant women.

Medicine is an ever-changing science. Research and clinical experience are continually expanding our knowledge, in particular our understanding of proper treatment and drug therapy. The authors, editors, and publisher have made every effort to ensure that all information in this book is in accordance with the state of knowledge at the time of production of the book. Nevertheless, the authors, editors, and publisher are not responsible for errors or omissions or for any consequences from application of the information in this book and make no warranty, expressed or implied, with respect to the contents of the publication. Every reader should examine carefully the package inserts accompanying each drug and should carefully check whether the dosage schedules mentioned therein or the contraindications stated by the manufacturer differ from the statements made in this book. Such examination is particularly important with drugs that are either rarely used or have been newly released on the market.

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Preface

Survivorship is now recognized as a critical and separate phase of the cancer care continuum (1). The Institute of Medicine (IOM) report, *Lost in Transition*, increased awareness that coordinated follow-up care can enhance the overall health and quality of life for cancer survivors (2). Since the IOM report, notable advances have been made in the care of survivors who have completed curative treatment, including development of clinical algorithms and guidelines, emergence of survivorship care plans, progress in health policy initiatives, and increase in clinical education for healthcare professionals caring for cancer survivors. The IOM report identified four domains as core concepts in providing comprehensive care to survivors. They included surveillance for new/recurrent cancers, management of late or long-term effects, risk reduction/prevention, and monitoring psychosocial functioning.

To address the growing needs of cancer survivors, in 2008 the Cancer Survivorship Program at MD Anderson Cancer Center launched a robust clinical program that provided tailored care designed for long-term cancer survivors. In response to the various advances and changes in survivorship care and the desire to provide high-quality survivorship care, the Cancer Survivorship Program added educational and research components. In 2018, there are 12 different disease-specific survivorship clinics delivering care to adult survivors of the most common cancers such as breast, prostate, colorectal, and gynecological cancers. However, clinics have been added for other cancers, including thyroid, head and neck, lymphoma, and our most unique stem cell transplants. The clinics were and continue to be based on a multidisciplinary model of survivorship care, which includes the principles set forth in the seminal IOM report. These core elements are embedded in our institutional clinical care program, practice algorithms, and survivorship care plans. These domains serve as the foundation for the delivery of multidisciplinary care for survivors.

In our experience, one notable gap continues to contribute to the unmet needs of cancer survivors—the limited availability of educational resources for healthcare professionals, particularly those in primary care, which focus on this unique population. To provide coordinated care and appropriate care plans, practitioners must have educational resources that focus on the complex and unique management of cancer survivors. Despite the widespread recognition of their value, there are few, if any, published handbooks to educate practitioners about the complex nuances of survivorship care.

Clinical handbooks covering the basics of survivorship care are one way to provide up-to-date strategies to the oncology workforce, that is, oncologists and other primary care providers. Such resources must be concise, user-friendly, and easy to access for practitioners in diverse and busy clinical settings. *Handbook of Cancer Survivorship Care* addresses, in detail, the current and practical management of long-term cancer
survivors. The content in this handbook is written in a manner that can be easily applied in a variety of clinical settings and practices.

CONTENT

This text consists of 16 chapters that are organized into two sections. The handbook serves as a practical and useful guide for the multidisciplinary management of long-term cancer survivors.

Part I: General Principles of Survivorship Care covers basic principles of survivorship that aid the clinician in the assessment and management of survivors’ care. The goal of this section is to help establish the foundation for content covered in Part II. Chapters 1 and 2 introduce the reader to core concepts of survivorship; provide a review of the IOM’s core domains; and present a definition of cancer survivorship and long-term cancer survivors. Chapter 3 provides a detailed discussion of the basic concepts of surveillance, late effects, and prevention of new or secondary cancers. Chapter 4 outlines the psychologic challenges that often accompany the survivorship experience. Strategies for cancer screening and prevention are discussed in Chapter 5, with application to the needs of long-term cancer survivors. Chapters 6 and 7 focus on the complex care of older survivors, older than or equal to 65 years, and provide a useful discussion of late effects and comorbid conditions that create a confluence of special needs for this population.

Part II: Management of Site-Specific Cancers contains everything needed by clinicians to provide quality care to cancer survivors. Chapter 8 discusses the role of integrative medicine in addressing some of the late effects of cancer and its treatment. The handbook is designed for care of the adult survivors; however, Chapter 9 addresses the burdens faced by adolescents and young adults who are survivors of cancer. This section also focuses on cancers selected by the editors because they were the sites with the largest number of survivors seen in the clinics or are considered the most common in long-term survivors. Readers will discover that Chapters 10 to 16 in Part II offer guidance on surveillance, prevention, late effects, and psychosocial issues encountered by cancer survivors. The outline format provides evidence-based, easy-to-use information that can be integrated at the point of care regardless of clinical setting or specialty. The handbook features a concise overview of a specific type of cancer with a discussion of the clinical tools, that is, survivorship algorithms available for the practitioner.

Nearly all the chapters are written by a team working in a survivorship clinic, including a seasoned oncologist who specializes in the specific cancer disease and an experienced practitioner who provides direct patient services. By using a team approach, we combine the clinical expertise of experienced practitioners with an expert oncologist who has a broader understanding of the theory and research of that particular cancer.

Brief clinical vignettes illustrate the application of the clinical practice algorithm(s) and survivorship care plan developed for each type of cancer. An outline format gives the reader concise and easy access to the survivorship guidelines and other information to support their application.

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We believe this practical, concise, and easy-to-read handbook will become the go-to book on cancer survivorship for practitioners in diverse clinical settings. Each chapter will contain useful and state-of-the-art information on the application of clinical algorithms and personalization of survivorship care plans for specific subgroups of survivors. The handbook’s size and availability of the ebook format will also increase its appeal to trainees, oncologists, and other providers.

AUDIENCE

Handbook of Cancer Survivorship Care is a practical and useful resource for a widely diverse number of audiences within the spectrum of oncology, primary care, family medicine, nursing, and other important specialties. There are other groups who will also benefit from this clinical handbook. The first are hospitals or academic centers who offer training programs to residents, fellows, or other trainees in various subspecialties. The second are practitioners in community-based hospitals caring for cancer survivors who have returned to their local communities for follow-up care. The third are academic institutions preparing the future oncology workforce. This market group includes schools of medicine, nursing, osteopathy, pharmacy, and other similar academic institutions.

Maria Alma Rodriguez and Lewis E. Foxhall

REFERENCES

Acknowledgments

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Handbook of Cancer Survivorship Care
General Principles of Survivorship Care
Defining Cancer Survivorship

Maria Alma Rodriguez
Paula Lewis-Patterson

CANCER SURVIVOR DEFINITION

The Institute of Medicine’s (IOM; now the National Academy of Medicine) landmark report, *From Cancer Patient to Cancer Survivor: Lost in Translation*, raised awareness of the need to address the specific issues that cancer survivors encounter after completing their cancer treatment (1). In 1986, the National Coalition for Cancer Survivorship introduced one of the first definitions of *cancer survivor* by stating that a patient who has had cancer is a cancer survivor from the time of diagnosis through the remainder of his or her life (2). This broad definition takes into account the entire spectrum of the cancer journey—diagnosis, treatment, remission, surveillance, after-cancer care, and end of life. The cancer journey affects caregivers, family members, and friends; therefore, all of these people also are recognized as survivors. The National Cancer Institute (NCI) customized the definition of survivorship, stating that it is the “health and life of a person with cancer post treatment until the end of life” (3). Survivorship encompasses the physical, psychosocial, and economic issues of cancer beyond the diagnosis and treatment phases. Survivorship involves issues related to the ability to obtain healthcare and follow-up treatment, late effects of treatment, second cancers, and quality of life (3). The focus of this chapter is the care of adult survivors who have completed their curative treatment. This handbook’s authors acknowledge NCI’s definition and recognize survivorship as a distinct period that commences after treatment is complete and the time during which recurrence most likely has passed. Healthcare providers in all types of clinical settings and practices need to prepare to care for growing numbers of cancer survivors. This chapter introduces basic concepts used in the specialty of cancer survivorship such as risk stratification and survivorship care models that transition survivors from treating oncologists to providers who specialize in survivorship care. A clinical vignette demonstrates how survivorship concepts, models, and risk stratification can be integrated into routine clinical practice.

SURVIVORSHIP STATISTICS

According to statistics from the Surveillance, Epidemiology, and End Results (SEER) database, approximately 15.5 million cancer survivors resided in the United States in 2016 (4,5). SEER data estimate this number will increase to 20.3 million by 2026.
By age distribution, 74% are 60 years of age and older, 21% are 40 to 59 years old, 4% are 20 to 39 years old, and fewer than 1% are younger than 20 years old (4,5). Approximately two-thirds of patients with cancer live at least 5 years after receiving their diagnosis, with many survivors living 15 years or longer after diagnosis (Figure 1.1). The most common cancers for men are prostate, colon, rectum, and melanoma, whereas breast, uterine corpus, and colorectal cancers are the most common cancers for women (6).

**FORCES DRIVING SURVIVORSHIP CARE**

In 1985, Fitzhugh Mullan, a physician and cancer survivor, published “Seasons of Survival: Reflections of a Physician with Cancer” (7). This article chronicled his personal cancer story and launched a movement in which patients with cancer shared their concerns related to life after cancer treatment (7). Dr. Mullan’s work and the IOM report gave cancer patients a forum in which to voice their concerns regarding the impact of symptom management (physical and psychosocial) after treatment, the onset of late effects, and poor coordination of medical care attributed to a lack of communication among providers (1,7). Other factors contributing to the increase in cancer survivors include an aging population, early detection, and improved treatment modalities (8).

In 2013, the IOM published a second report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, which called for a dramatic shift in the broken, cost-prohibitive cancer-care delivery system. This care model defined
survivorship as a distinct cancer care phase (9) and described a patient-centered, evidence-based approach to care; a system for sharing of critical patient information; and ways to cultivate collaborative practice among all caregivers. Organizations such as the Centers for Disease Control and Prevention, NCI, and the American Cancer Society continue to highlight the need to recognize and address cancer survivors’ long-term needs. The Commission on Cancer, an accrediting body, has published quality measures focused on improving cancer care (10). The measures mandate that an all-inclusive treatment summary and follow-up plan be provided to patients who complete curative cancer treatment. Chapter 2 provides a detailed description of these critical documents and their role in survivorship care.

DOMAINS OF SURVIVORSHIP CARE

The premise of survivorship care is to shift patient care from a model of illness to one of wellness. Typically, patients are transitioned to a survivorship clinic after surviving beyond the interval during which risk is highest for recurrence of their primary malignancy. The IOM outlined four domains for the delivery of survivorship care: surveillance, monitoring for late effects, preventive services, and psychosocial health (1). These domains are listed in Figure 1.2.

<table>
<thead>
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<td>• Psychosocial support services to maintain healthy relationships and restored life</td>
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**FIGURE 1.2** Core domains of survivorship care as recommended by the Institute of Medicine.

Surveillance is conducted to detect recurrence of the primary malignancy and assess for the likelihood of any second cancer. Prevention counseling is provided to encourage lifestyle changes including but not limited to smoking cessation, healthy living, energy balance, and dietary changes. The body of knowledge regarding the late effects of cancer treatments comes predominantly from studies of childhood cancer survivors. Children who received anthracycline during treatment and are now in their 40s and 50s are experiencing accelerated coronary artery disease (11–13). The body of knowledge regarding late treatment effects for adults with cancer continues to grow. Other cancer-treatment modalities such as radiation may increase risk for other symptoms and conditions (11). Therefore, screening for late effects based on the specific treatment received is essential. The psychosocial and economic consequences of surviving cancer treatments are as important as the physical late effects. Patients and their families often face many challenges, including economic stress, loss or disruptions of relationships, and emotional distress that may last or manifest long after therapy is completed.

SURVIVORSHIP CLINIC MODELS

The University of Texas MD Anderson Cancer Center has three types of survivorship clinics that can serve as models of care for cancer survivors:

1. In the first model of care, survivorship patients transition from their primary disease treatment site to a cancer prevention center with multidisciplinary healthcare providers. Clinical leaders in cancer prevention provide operational oversight of these clinics. Included in this model are patients with breast, thyroid, and colon cancers.
2. A second model is one in which disease-specific clinics, such as genitourinary, melanoma, and sarcoma clinics, provide survivorship care within each of their each disease-specific centers. A steering committee with representation from each primary oncology discipline (radiation, surgical, and medical) within the center governs the operation of each clinic. The primary oncology discipline refers patients to clinics in which care is delivered based on the four domains of survivorship care.
3. A third model is referred to as a comanagement model and is used in MD Anderson’s hematology malignancy clinics. Patients who have received a stem-cell transplant schedule visits with a survivorship provider when they see their stem-cell transplant physician. Clinical operations are governed through an internal operations leadership team.

THE INTERDISCIPLINARY SURVIVORSHIP TEAM

The emergence of survivorship as a distinct phase of cancer care carries with it established and new knowledge regarding care delivery, practice, and technology. To address these issues, MD Anderson has developed survivorship practice algorithms. Each disease-specific algorithm defines patient eligibility, surveillance, late effects, risk reduction and prevention, and psychosocial function. A discussion regarding algorithms as clinical tools appears in Chapter 2 of this handbook.
Individuals’ responses to treatment and the threat of recurrence are contingent on the type and stage of a primary malignancy. A risk stratification approach can help to address each survivor’s unique, complex needs. McCabe and colleagues described risk-based care as “a personalized systematic plan of periodic screening, surveillance, and prevention relevant to the cancer experience” (14).

MD Anderson has developed an interdisciplinary team approach that is the foundation of algorithms for cancer survivors. This model of care addresses each patient’s treatment response and recurrence threats that are contingent upon the type and stage of the primary malignancy. Age, sex, and overall health status primarily influence treatment type and may affect responses to treatment received.

Care for cancer survivors should be tiered based upon risk factors and degree of care required. Figure 1.3 provides an example of each tier.

- **Tier 1**: Patients in this group are at low risk for complications or recurrence. The aims of care are symptom management, smoking-cessation counseling, energy balance, and healthy living
- **Tier 2**: These patients are at risk for late effects of treatment; they have received combined-modality therapies including chemotherapy, radiation, and surgery. This subgroup is at higher risk for secondary cancers, and primary care providers and oncologists should comanage follow-up care
- **Tier 3**: Patients in this category are at high risk if they experience a cancer recurrence or late effects from their treatment. Patients who undergo stem-cell transplantation, for example, fall into this tier. These patients should be followed closely by an oncologist and primary care provider to manage comorbid conditions and health issues

As providers in a major comprehensive cancer center with 12 disease-specific clinics, clinicians at MD Anderson have established survivorship care from a unique perspective.
perspective. Clinical, educational, and research aspects are combined to provide high-quality survivorship care. Care for long-term survivors must be tailored to each patient. Models of care delivery can vary in their operational structure but must be clinically designed to optimally address complication risks and include the key IOM domains for the delivery of survivorship care: surveillance, prevention, monitoring for late effects, and psychosocial health. Healthcare providers must deliver care based on individual survivor needs.

The number of cancer survivors continue to increase. The aim of survivorship care is to address the impact of cancer care and its therapies in an effort to improve survivors’ health and quality of life. Therefore, care for long-term survivors must be tailored to each patient. Models of care delivery are most optimal when they address complication risk while including the key domains of surveillance, prevention, monitoring of late effects, and psychosocial health.

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