Survivorship

Focus on Female Cancers

THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS
WOMEN'S HEALTH CARE PHYSICIANS
1951

Survivorship

Focus on Female Cancers:

Cancer Survivorship: The Transition from Cancer Specialist to the Women's Health Care Provider

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This initiative was generously supported by the New York State Department of Health

Compiled April 2009

Dear Women's Health Care Provider,

On behalf of the American College of Obstetricians and Gynecologists, District II (ACOG), we are pleased to provide you with the third chapter of Focus on Female Cancers, a resource guide offering relevant cancer education for health care providers. This chapter's content focuses on the unique health concerns of a female cancer survivor transitioning from oncology care back to her primary health care provider.

Improved access to appropriate and technologically advanced health care has transformed cancer, once a deadly disease, into a sometimes survivable but chronic condition. Today, there are more than 12 million cancer survivors in the United States. Women who have survived breast or gynecologic cancers make up approximately 33% of this group. Long-term survivors often transition from oncology services back to their primary care provider. Therefore, the challenge of maintaining effective lifelong surveillance for cancer survivors has become a new and increasingly frequent responsibility of women's health care providers. In order to maximize the overall health and quality of life for these patients, a thorough understanding of cancer survivorship and oncology follow-up care is needed.

We would like to extend our sincere appreciation to the task force of medical experts who offered their expertise throughout the creation of this resource guide chapter. Their knowledge and dedication to this project are invaluable.

The Cancer Survivorship resource guide chapter is the third installment in a series of comprehensive education and resources on cancer and women. The first two chapters addressed cervical cancer and hereditary breast and ovarian cancer. ACOG will continue developing additional chapters, which will be added to the resource guide throughout 2009. If you have any questions regarding the resource guide or ACOG's cancer initiatives, please contact the ACOG District II office at info@ny.acog.org or (518) 436-3461.

Sincerely,

Scott D. Hayworth MD, FACOG
Chair, ACOG District II

Maureen Killackey, MD, FACOG, FACS
Chair, Cancer Survivorship Task Force

Introduction

Project Overview

In 2008, ACOG District II formed a task force of experts in the field of cancer survivorship in order to address the many special health concerns of cancer survivors returning to their primary care provider. Ultimately the goal of this initiative is to maximize the health and quality of life for cancer patients after treatment.

According to the National Coalition for Cancer Survivorship, the National Cancer Institute's Office of Cancer Survivorship and the Institute of Medicine, an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life. However, for the purposes of this resource guide, we will focus only on the post-treatment period for individuals free of disease.

As advances are made in cancer screening, early detection and treatment, more people with cancer are surviving five, ten or more years beyond their diagnosis and treatment. Current estimates of the growing population of cancer survivors predict a shortage in the number of physicians who are appropriately trained in oncology to support this group. Subsequently, the need to train current women's health care providers in oncology follow-up care is clearly evident.

More than two-thirds (71%) of all female cancer survivors had breast, colorectal, and/or gynecologic malignancies. Survivors of these cancers often experience unique physical, psychosocial, economic, and legal issues in the post-treatment period. These may include impaired physical function, early menopause, sexual dysfunction, financial dilemmas and challenges to psychological well-being. Studies have shown that by utilizing a collaborative approach between primary care providers and oncologists, patients are more likely to receive the highest proportion of recommended services for health care issues facing cancer survivors.

While this chapter provides up-to-date medical information, it is also important for health care providers to remain current with new advances in their field. This resource guide chapter is aimed at addressing the needs of women's health care providers by increasing knowledge of cancer survivorship and the unique challenges patients face after cancer treatment. The content of this chapter was developed by a panel of nationally recognized experts in women's health and cancer survivorship.

While this chapter serves to guide best practices, the most essential best practice includes an individualized approach to the evaluation of each patient and the delivery of care based on sound clinical judgment. With this in mind, it is our hope that this chapter provides a foundation upon which women's health care providers can deliver optimal quality patient care.

Communicate effectively with patients' oncology teams to coordinate optimal survivorship care.

Resource Guide Overview

Effective lifelong surveillance of cancer survivors has become a new and increasingly frequent responsibility for primary care physicians.

This cancer survivorship chapter contains clinical information on the unique health care challenges facing survivors of breast, colorectal, gynecologic and other common cancers in women. In addition, relevant resources for both providers and their patients have been identified throughout the chapter.

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Objectives

This guide is designed to enable participants to:

- Communicate effectively with patients' oncology teams to coordinate optimal survivorship care;
- Become familiar with the most common cancer sites among female cancer survivors;
- Understand and be sensitive to the long-term and late effects that may result from cancer treatment, and how to appropriately care for patients experiencing these effects (including referring to other health care providers when appropriate); and
- Become aware of cancer survivorship resources available in your area for referral.

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Overview

BACKGROUND

Improved access to effective screening, diagnosis and treatment, combined with significantly improved therapeutic modalities has transformed cancer into a survivable but chronic condition. Today, there is a new generation of cancer survivors, estimated to include more than 12 million people in the United States. According to the National Cancer Institute, women who are survivors of breast and gynecologic cancers make up the largest group of cancer survivors in the U.S. (approximately 33%).

Although there are many different definitions of cancer survivorship, this resource guide will use the Institute of Medicine's definition, and the information covered will focus on the post-treatment period for individuals free of disease. While the term free of disease accurately denotes the absence of any remaining malignancy, many survivors still require lifelong surveillance because of an increased risk for secondary cancers. They are also at risk for a diversity of late and long-term health effects of surgery, radiation and chemotherapy. These may present early during the treatment course and persist or occur many years after the completion of therapy. Today, long-term survivors often transition from the care of their oncology team back to the care of their primary care provider. Thus, the challenge of maintaining effective lifelong surveillance of cancer survivors has become a new and increasingly frequent responsibility for primary care physicians. To maximize the overall health and quality of life for these patients, a thorough understanding of cancer survivorship is required. Enhanced communication between providers during the transition from active cancer treatment to post-treatment care is an essential part of developing an anticipatory risk-based care plan. Similarly, eliciting a risk-based history update from the survivor at regular visits is an invaluable surveillance tool.

WHAT YOU SHOULD KNOW

- Definition of cancer survivorship according to the National Coalition for Cancer Survivorship, the National Cancer Institute's Office of Cancer Survivorship and the Institute of Medicine: **"An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life."**
    - While the experiences of patients' family members, friends, and caregivers are also important and greatly impact the patients' survivorship experience, *the focus of this resource guide will be the post-treatment period for individuals free of disease*
- Physical and psychological concerns of cancer survivors after treatment can include problems such as depression, anxiety, fatigue, chronic pain, cognitive dysfunction, physical impairment, and sexual and reproductive dysfunction (among many others)
- The basics of optimal cancer survivorship care include:
    - Prevention
    - Surveillance
    - Intervention
    - Coordination
- Barriers facing providers to giving optimal cancer survivorship care may include:

By utilizing a collaborative approach between primary care providers and oncologists, patients are more likely to receive the highest proportion of recommended services.

    - Lack of education and training on survivorship care
    - Lack of survivorship standards of care
    - Difficulties in communication with patients' various health care providers
    - Fragmented U.S. health care delivery system which can make coordination of survivorship care difficult
    - Non-compliant patients
- Barriers facing patients in obtaining optimal cancer survivorship care may include:
    - Lack of understanding of the importance of survivorship care
    - Perceptions of cost of survivorship care
    - Fear of recurrence
    - Patient denial

WHAT YOU SHOULD DO

- Become familiar with the components of optimal cancer survivorship care
- Coordinate with your patients' specialists to ensure that all health needs are being met, including obtaining a survivorship care plan provided by your patients' oncologists, when available. An example of a survivorship care plan is included in Section IV of this chapter
- Maintain a patient-centered approach when delivering cancer survivorship care
- Empower your patients to take control of their health and health care needs by recommending educational opportunities in your community and online and by referring patients to appropriate resources for information

What You Need to Know

Survivorship Care: Defined

According to the National Coalition for Cancer Survivorship, the National Cancer Institute's Office of Cancer Survivorship and the Institute of Medicine, an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

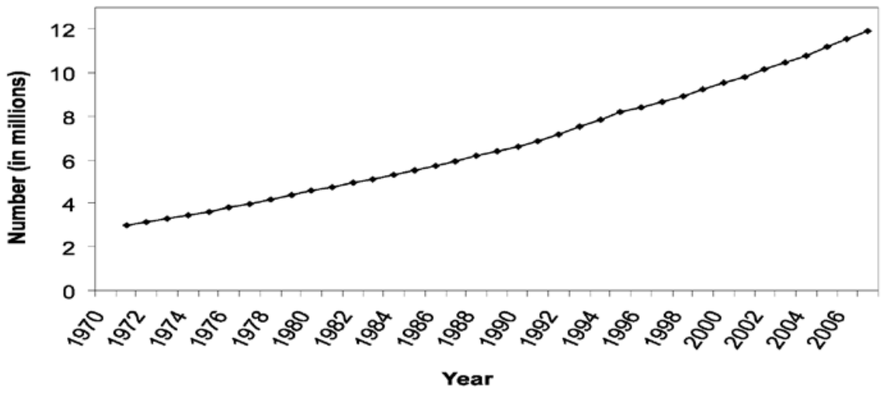
Although there are many opinions and definitions of who may be considered a cancer survivor, for the purposes of this resource guide, the definition above will be used, and the information covered will focus on the post-treatment period for the individual free of disease.

History of Cancer Survivorship Care

It is estimated that in 2008, there were over 12 million cancer survivors living in the United States. This number is expected to dramatically expand with the anticipated growth of the U.S. population and the aging of the baby boomers. As the number of cancer survivors has increased, a survivorship advocacy community has emerged to demand increased funding for research and has focused attention on the identification and recognition of the unique physical, psychosocial, economic, and legal issues facing cancer survivors.

According to the National Cancer Institute, the most frequent primary invasive cancers among all cancer survivors are breast (22%), uterine corpus (10%), and colorectal cancers (10%). About 62% of survivors had their cancer diagnosed within the previous 10 years, and females are more likely to be long-term cancer survivors; 19% of female cancer survivors were diagnosed 20 or more years ago. See Figure 1 for the gradual increase of cancer survivors in the United States over the past 30 years.

Figure 1: Estimated number of cancer survivors in the United States from 1971 to 2007.



National Cancer Institute, 2008

Issues Facing Cancer Survivors Post-Treatment

The post-treatment period for many cancer survivors can present a host of physical, psychological, social, and economic problems. These may include impaired physical function, disturbed sleep patterns, fertility issues, challenges with relationships, cognitive dysfunction, early menopause, sexual dysfunction, financial dilemmas, and challenges to spiritual and psychological well-being. While many of these issues may be temporary, some become persistent or permanent long-term changes. Others may present as late-onset effects, many years after the completion of acute cancer treatment. These will be discussed in greater detail later in this chapter.

It is important to remember that not all effects that cancer survivors experience are negative. Survivors often will rate their quality of life more favorably than patients of other medical conditions, and identify many positive aspects of life as a result of their cancer experiences. Many survivors report feelings of gratitude, a new sense of self-esteem, and positive spiritual growth. This often creates a new appreciation for life.

Optimal Cancer Survivorship Care

The basics of optimal cancer survivorship care include:

- Surveillance for cancer recurrence and second cancers
- Intervention for consequences of cancer and its treatment (i.e., medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress and concerns related to employment and insurance)
- Cancer screening
- Recommendations for healthier lifestyle including diet, exercise and smoking cessation
- Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (i.e., health promotion, immunizations, screening for both cancer and noncancerous conditions, and the care of concurrent conditions)

A patient-centered approach is crucial to delivering optimal cancer survivorship care. This may include responsiveness to your patients' needs, effective communication, counseling on adopting healthy lifestyles, and referral to community support services.

Although all individuals who have been treated for cancer should receive survivorship care, specific services delivered vary among patients and by type of disease. For example, a cancer survivor who experienced limited treatment may require very minimal follow-up care, while survivors who have been treated more intensely, with combinations of surgery, chemotherapy, radiation, and hormone therapies may require long-term rehabilitative and supportive care. Because each survivor had a unique disease with an individualized combination of treatments, care and support for each survivor should be personalized. Regardless of the intensity of treatment or severity of disease, remaining sensitive to each patient's needs and other comorbidities is essential to the provision of quality survivorship care. In addition, developing a specific familiarity with the unique needs and health risks of cancer survivors enables the health care provider to practice proactive and anticipatory risk-based care. This approach facilitates the early recognition of the onset of secondary cancers, as well as late effects or progression of long-term effects. Thus, definitive care for these problems can be initiated promptly, increasing the probability of a satisfactory outcome.

Survivorship care should be delivered until recurrence, a second cancer, or death occurs. Many survivors have several different providers throughout the course of treatment. Therefore, it is extremely important to stay informed and connected with other specialists involved in your patient's care. Studies have shown that by utilizing a collaborative approach between primary care providers and oncologists, patients are more likely to receive the highest proportion of recommended services. If available, an organized survivorship care plan from the survivor's oncology team can be a useful tool in this effort. An oncology team often includes professionals from a wide spectrum of fields including oncologists, social workers, psychiatrists, nurses, rehabilitation specialists, and other medical specialists who provide the highest level of care for cancer patients.

Utilizing a Survivorship Care Plan

At the present time, cancer centers throughout the country are developing survivorship care plans to encourage improved communication between treating oncology teams and primary health care providers. The implementation of an individualized plan has been proposed as an excellent way to communicate specific details of a patient's diagnosis, treatments used and patient response, and plan for the survivorship period. Such plans clearly communicate the patient's medical history and summary of treatments to better prepare the health care provider to assume the continuation of follow-up care. While several survivorship care plan models are available, at a minimum, a survivorship care plan should include the following:

- Cancer type and treatments delivered
- Timing and content of recommended post-treatment surveillance and cancer screening
- Information on possible late and long-term effects and symptoms of treatment
- Information on the possible signs of recurrence and second tumors and cancers
- Recommendations on preventive practices and how to maintain a healthy lifestyle
- Support services provided and those available within the community
- Full contact information for treating institutions and individual providers

A survivorship care plan is of crucial importance to women's health care providers since they can better predict what specific types of late or long-term effects might occur in the future. These plans link the primary care physician to the oncology team and ensure improved continuity of care. A copy of a survivorship care plan has been included at the end of Section IV.

Barriers to Optimal Survivorship Care

There are many barriers to optimal care for survivors including a lack of awareness of the late and long-term effects of cancer and its treatment and barriers in communication between the patient and provider. In the difficult and stressful time following a cancer diagnosis and making treatment decisions, patients may not be aware of or retain complete information regarding late effects. As survivors are sometimes in denial of the possibility of subsequent risks (i.e., second cancers), they are often late in getting yearly mammograms or following guidelines for Pap tests and colorectal cancer screenings. It is important for the health care provider to address denial and self-imposed amnesia among cancer survivors.

In addition, many patients may lack important health literacy skills needed to help understand the health care system and their own medical care plan. This can certainly contribute to communication problems between patients, providers and the medical institutions at which they receive their care. In addition, some studies have shown a patient's expectations and a physician's perceptions of cancer follow-up may be very different, resulting in patients feeling uninformed. Misunderstandings can undermine the success of even the most comprehensive survivorship care plans.

The coordination of appropriate survivorship care may not always be easily accomplished. Often after a cancer diagnosis, other preventive, non-cancer care may be missed during the duration of a cancer patient's treatment, leaving survivors not only to cope with the ongoing effects of cancer but also to catch up with other necessary, routine care. Cancer patients also see multiple specialists during their cancer treatment including surgeons, medical oncologists, and radiation oncologists. A primary care provider may feel disconnected from the care patients received from specialists and less prepared to address the long-lasting effects during survivorship. A lack of communication and continuity of care may decrease the chances of a survivor receiving optimal survivorship care.

Providers also face barriers to delivering optimal, coordinated cancer survivorship care, including little training and education on survivorship, the absence of standards or guidelines of survivorship care, difficulty navigating multiple health insurers' regulations, and the communication issues addressed above including a non-compliant patient. Each of these problems presents unique difficulties to providers who are attempting to care for cancer survivors.

While serving as a patient advocate and providing the best survivorship care for their patients, providers may feel overwhelmed in the host of issues that surround survivorship care. Fortunately, there are many resources available for health care providers. Refer to Table 1 and the Resources section at the end of this chapter for possible solutions in addressing these barriers to optimal survivorship care.

Table 1: Possible Barriers to Optimal Survivorship Care and Helpful Resources

Barriers	Resources
Providers' lack of awareness of late and long-term effects of specific treatments	• Children's Oncology Group: Long Term Follow Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers http://www.survivorshipguidelines.org/pdf/LTFUGuidelines.pdf • American Society for Clinical Oncology Survivorship Guidelines http://www.asco.org/ASCO/Quality+Care+%26+Guidelines • National Comprehensive Cancer Network: http://www.nccn.org
Barriers to communication between patient and provider	Set up an account with www.languageline.com or call 1-800-752-6096
Non-compliant patient	Suggest the patient is accompanied by a family member or close friend to all appointments
Fragmented health care system	Survivorship Care Plan, Section IV
Communication between providers/specialists	Survivorship Care Plan, Section IV
Little training and education on survivorship	See Provider Guidance and Educational Opportunities in Section VI of this chapter
Lack of consensus for agreed upon standards or guidelines of survivorship care	Ongoing research
Difficult navigation of health insurance policies and procedures	New York State Attorney General's Healthcare Bureau: 1-800-428-9071 http://www.oag.state.ny.us/bureaus/health_care/about.html

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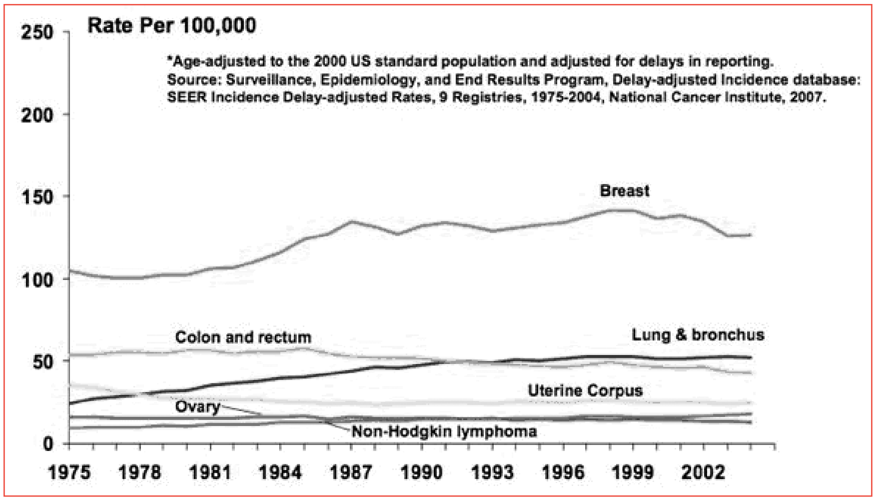
Overview

BACKGROUND

In 2008, it is estimated that 692,000 women were diagnosed with cancer and 271,530 women died of cancer in the United States. Between 2001 and 2005, about 411 out of every 100,000 women were diagnosed with cancer annually.

For the first time in a decade, both incidence and death rates for all cancers are decreasing. For women, incidence rates have decreased for cancers of the breast, colon/rectum, uterus, ovary, cervix, and oral cavity but increased for cancers of the lung, thyroid, pancreas, brain/nervous system, bladder, and kidney, as shown by Figure 1 below.

Figure 1: Cancer Incidence Rates* Among US Women, 1975-2004



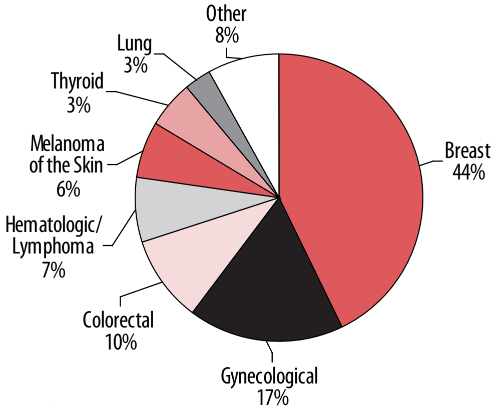
*Age-adjusted to the 2000 US standard population and adjusted for delays in reporting.
Source: Surveillance, Epidemiology, and End Results Program, Delay-adjusted Incidence database: SEER Incidence Delay-adjusted Rates, 9 Registries, 1975-2004, National Cancer Institute, 2007.

National Cancer Institute, 2007

As advances are made in cancer screening, early detection, and treatment, more people with cancer are surviving five, ten or more years beyond their diagnosis and treatment. The percentage of survivors from each type of cancer depends on the incidence, detection rate, and success of treatment for each cancer. For females, breast, colorectal, and gynecologic malignancies comprise about two-thirds (67%) of female cancer survivors. See Figure 2 for the distribution of female cancers in the U.S.

> *Most female cancer survivors (71%) are those who have had breast cancer, colorectal cancer, or gynecologic cancers.*

Figure 2: Distribution of Female Cancer Survivors by Site, 2005



National Cancer Institute, 2005

Cancers of different organ systems present unique challenges and considerations for each woman as she moves into the survivorship phase of care. This section will take a closer look at the most common types of cancer sites among female cancer survivors.

Please refer to Table 1 on page 19 for incidence, mortality, and survival rates for the different cancer types. This table helps put in perspective which cancers are the most common and which are the most deadly among women in the U.S.

WHAT YOU SHOULD KNOW

- Most female cancer survivors (71%) are those who have had breast cancer, colorectal cancer, or gynecologic cancers
- The top female cancer incidence rates are breast (126.1), lung and bronchus (52.6), colon and rectum (43.8), uterine corpus (23.4), Lymphomas (18.8), and ovary (13.3)*
- The leading sites of cancer death in women are lung and bronchus (26%), breast (15%), and colon and rectum (9%)
- Ovarian cancer accounts for 6% of cancer deaths while cancer of the uterine corpus accounts for 3% of cancer deaths among women
- Cancers of different organ systems present unique challenges and considerations for each woman as she moves into the survivorship phase of care

WHAT YOU SHOULD DO

- Become familiar with basic cancer statistics including the incidence and mortality of common female cancer types
- Be aware of how common cancers are screened for, evaluated and managed
- For your patients who are cancer survivors, assess individual risk for recurrence or second primary cancers as well as hereditary cancer syndromes based on age, prior cancer and treatment, as well as family history
- Counsel patients with modifiable risk factors for specific cancers about prevention, early detection and risk reduction
- Address survivorship issues with each patient, taking into consideration the unique challenges she faces based on her type of cancer
- Coordinate with your patients' specialists to ensure that all health needs are being met including obtaining a survivorship care plan from their oncologists, when available. A sample survivorship care plan is included at the end of Section IV of this chapter

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**Rates are per 100,000 and age-adjusted to the 2000 U.S. standard by 5-year age groups.*

Overview of Cancer in Women

Cancers of different organ systems present unique challenges and considerations for each woman as she moves into the survivorship phase of care. This section will take a closer look at the most common types of cancer among cancer survivors.

The field of oncology is constantly changing and therefore, therapies are always evolving. Please visit www.nccn.org for more detailed and specific diagnostic information and treatment guidelines.

For providers or patients looking for a gynecologic-oncologist in their area, please visit the Gynecologic Cancer Foundation's "Find a Gyn-Onc" website at http://wcn.org/findadoctor.

Breast

Incidence & Mortality

Breast cancer is the most common of all cancers in women and the second most deadly (after cancer of the lung and bronchus). See Table 1 on page 19 for incidence, mortality, and survival data.

Prevention

Several factors have been identified that influence a woman's risk of developing breast cancer. Factors associated with increased risk of breast cancer include:

- Familial Predisposition/Genetic Mutations: Women who inherit gene mutations (i.e., BRCA 1 and 2) or who have a strong family history of breast and ovarian cancers are at increased risk. See the Hereditary Breast and Ovarian Cancer (HBOC) chapter of this resource guide for more information
- Hormone Replacement Therapy (HRT): Combined estrogen/progesterone hormone replacement therapy is associated with an increased risk of developing breast cancer. The evidence concerning the association between estrogen-only therapy and breast cancer incidence is mixed. The benefits may outweigh the risks in the limited use of HRT for menopausal symptoms in some patients, and is best discussed on an individual basis with the health care provider
- Obesity: Obesity is associated with an increased breast cancer risk in postmenopausal women who have not used HRT. It is uncertain whether reducing weight would decrease this risk
- Ionizing Radiation: Exposure of the breast to ionizing radiation is associated with an increased risk of developing breast cancer, starting eight years after exposure and persisting lifelong (i.e., Hodgkin's disease and thyroid cancer survivors who have received chest wall or mantle radiation need additional and earlier screening studies). Risk depends on dose and age at exposure, with the highest risk occurring during puberty
- Alcohol Consumption: Alcohol consumption is associated with an increased breast cancer risk in a dose-dependent fashion. It is uncertain whether decreasing alcohol exposure would decrease the risk of breast cancer
- Oral Contraceptives: Oral contraceptives are not associated with a long-term risk of breast cancer, but may be associated with a short-term increased risk while a woman is taking oral contraceptives. The risk of breast cancer declines with time since last use

Factors associated with decreased risk of breast cancer include:

- Healthy Lifestyle: Maintaining a healthy weight, exercising strenuously for more than four hours per week, eating a low-fat diet, and limiting alcohol are all associated with a decreased risk of breast cancer
- Lactation: Women who breast-feed have a decreased risk of breast cancer
- Age at First Full-Term Pregnancy: Women who have had a full-term pregnancy before age 20 have a decreased risk for breast cancer
- Premenopausal Oopherectomy/Ovarian Ablation: There is a decreased risk of breast cancer, especially in women with increased risk due to hereditary or genetic mutations

Screening

Breast Cancer Screening Guidelines

- Mammography every one to two years for women aged 40-49 years and annually thereafter
- All women should have clinical breast examinations annually as part of the physical examination. Although randomized controlled trials do not confirm a reduction in overall breast cancer mortality in women performing breast self-examination, awareness of normal breast findings and changes from these findings may lead to early detection for some women and can be recommended
    - Clinical breast exam and self-examination alone are not sufficient for *primary* breast cancer screening
- Ultrasonography is an established adjunct to mammography in evaluating inconclusive mammographic findings, evaluating palpable masses, evaluating young patients, and women with dense breast tissue
- MRI can be useful as an adjunct to diagnostic mammography in high-risk women, but cost, time, and contrast injection prohibit its use as a routine, population-based screening technique
- For BRCA1 or BRCA2 mutation carriers, the Cancer Genetics Studies Consortium recommends education regarding monthly breast self-examination, and annual or semiannual clinical breast examination and annual mammography beginning at age 25-35 years. These women may also be considered for additional screening tests such as ultrasound or MRI. For more information on hereditary breast and ovarian cancer, see the HBOC chapter in this guide

Symptoms & Diagnosis

The most common symptom of breast cancer is a lump found in the breast tissue. Other signs or symptoms may include clear or bloody nipple discharge, nipple retraction, flattening of the skin over the breast, or redness or pitting of the skin. Breast abnormalities may be detected on a clinical breast exam, mammography, ultrasound, or MRI. Biopsy samples may be extracted by fine-needle aspiration, core needle biopsy, stereotactic biopsy, wire localization, or surgical biopsy. Other tests include estrogen and progesterone receptor tests, molecular markers and other radiologic tests which may be utilized to determine the best treatment plan for each patient. Guidelines for diagnostic methods are constantly updated.

Guidelines and algorithms are available at the National Comprehensive Cancer Network website: www.nccn.org.

Treatment

The surgical, radiation, chemotherapy and hormonal options for each woman based on cancer grade, type, stage, biomarkers and co-existing medical conditions are best discussed at the time of consultation. Breast cancer treatments are continually developing, but often fall into one of the following categories:

- Surgery: The plan may include surgery (lumpectomy, partial or segmental mastectomy, simple mastectomy, or modified radical mastectomy) and sentinel lymph node biopsy, or axillary lymph node dissection
- Radiation: Radiation therapy is also used when there is breast conserving surgery or extensive disease after mastectomy
- Chemotherapy: Chemotherapy is often recommended based on tumor size and stage. A variety of agents are used including cyclophosphamide, adriamycin, 5-fluorouracil, methotrexate, capecitabine, docetaxel and paclitaxel
- Hormone Therapy: Hormone therapy may include selective estrogen receptor modulators (SERMs) such as tamoxifen or aromatase inhibitors such as anastrozole, letrozole and exemestane as well as GNRH-analogs such as goserelin and leuprolide. Recent interest in androgen receptor status in the breast tumor may result in additional hormonal treatment options
- Biologic: Biological therapies have been approved for use in breast cancer and include trastuzumab, bevacizumab, and lapatinib

There are many therapeutic options that offer effective treatment, but this is best discussed with a cancer specialist with an interest and expertise in breast cancer. Second opinions and referral for clinical trials should always be considered.

Lung and Bronchus

Incidence & Mortality

Cancer of the lung and bronchus is the second most common malignancy in women (after breast cancer) and is the most lethal. See Table 1 on page 19 for incidence, mortality, and survival data.

Prevention

Cigarette smoking (or exposure to cigarette smoke) is the primary risk factor for developing lung and bronchus cancer. Smoking avoidance results in decreased mortality from primary lung cancers, and smoking cessation results in decreased incidence of lung cancer and of second primary lung tumors. Heavy smokers who take pharmacological doses of beta carotene have an increased lung cancer incidence and mortality that is associated with taking the supplement. Exposure to radon and asbestos also increases lung cancer incidence and mortality.

Screening

Unfortunately, there are no recommended screening procedures for lung cancer.

Symptoms & Diagnosis

Lung and bronchus cancer typically does not cause signs and symptoms in early stages. When the disease is advanced, symptoms may include a new or worsened cough, hemoptysis, dyspnea, angina, wheezing, or hoarseness. Lung cancer is definitively diagnosed and staged histologically with a biopsy or cell sample.

Treatment

Treatment plans vary by type and stage of lung cancer.

- Small Cell Lung Cancer: Without treatment, small cell lung cancer (SCLC) has the most aggressive clinical course of any type of pulmonary tumor, with a median survival from diagnosis of two to four months. Patients with SCLC tend to develop distant metastases prior to diagnosis; therefore, localized forms of treatment (surgical resection or radiation therapy) rarely improve long-term survival. The addition of chemotherapy may improve short-term survival rates. The overall survival at five years is five to 10%. Most of the improvements in the survival of patients with SCLC are attributable to clinical trials. These patients should be offered research studies when possible
- Non-Small Cell Lung Cancer: Non-small cell lung cancer (NSCLC), the more common type, is classified by histology (epidermoid, squamous carcinoma, adenocarcinoma, and large cell carcinoma). Patients with resectable disease may be cured by surgery with or without adjuvant chemotherapy. Local control can be achieved with radiation therapy in a large number of patients with unresectable disease, but this is usually not curative. Patients with advanced metastatic disease may achieve improved survival and palliation of symptoms with chemotherapy. It should be noted that there is a subset of NSCLC in female non-smokers, often Asian, that shows a significant response to some targeted chemotherapy agents. These patients should be identified and may also benefit from referral to clinical trials

Patients who are diagnosed with lung cancer should be assisted in their tobacco cessation efforts by all of their health care providers.

Colon and Rectum

Cancers of the colon and rectum are often referred to as colorectal cancer, or CRC. For more information on CRC, please see the Colorectal Cancer chapter of this resource guide (to be released in 2009).

Incidence & Mortality

CRC is the third most common cancer in women (after breast and lung cancer) and the third most lethal (after lung/bronchus and breast cancers). See Table 1 on page 19 for incidence, mortality, and survival data.

Prevention

- Removal of adenomatous polyps reduces the risk of CRC
- There is inadequate evidence that the use of nonsteroidal anti-inflammatory drugs (NSAIDs) reduces the risk of CRC, but research into these and other chemopreventive agents is ongoing
- Postmenopausal estrogen plus progesterone hormone use decreases the incidence of CRC, but this benefit is not applicable to estrogen alone use. It is important to note that postmenopausal combined estrogen plus progestin hormone use is associated with increased risk of breast cancer, coronary heart disease, and thromboembolic events

Screening

Colorectal Cancer Screening Guidelines

- Colonoscopy every 10 years starting at age 50 *is the preferred method of screening*
- Other appropriate methods include:
    - Fecal occult blood testing or fecal immunochemical testing every year
    - Flexible sigmoidoscopy every five years
    - Fecal occult blood testing or fecal immunochemical testing every year plus flexible sigmoidoscopy every five years
    - Double contrast barium enema every five years

Screening for women at increased risk:

- Women at increased risk of colorectal cancer may need to begin screening between ages 40-45. Those who may be at increased risk are those who have:
    - A first-degree relative younger than age 60 with CRC or colon polyps
    - Two or more first-degree relatives of any age with CRC or colon polyps
    - Had CRC themselves
    - Had colon polyps
    - Had inflammatory bowel disease (IBD), chronic ulcerative colitis, or Crohn's disease
    - Diagnosed with endometrial cancer at a young age (< 50 years old)
- It is also important to note that African Americans experience higher incidence and mortality from colorectal cancer. The American College of Gastroenterology recommends that African Americans begin screening at age 45
- Women who carry certain genetic mutations or whose family members carry mutations are also at increased risk of CRC. Known syndromes that predispose women to CRC include:
    - Hereditary nonpolyposis colorectal cancer (HNPCC or Lynch syndrome)
    - Adenomatous polyposis syndromes: FAP, AFAP, and MYH-associated polyposis
    - Syndromes in which secondary manifestations can include CRC: Bloom syndrome, Cowden, Li-Fraumini, Peutz-Jegher, and Juvenile polyposis

Symptoms and Diagnosis

Symptoms of CRC may include a change in bowel habits, blood in the stool, persistent abdominal discomfort, pain with bowel movements, weakness, fatigue, or unexplained weight loss. Generally, a colonoscopy is performed to visualize polyps and biopsy suspicious lesions for histological examination and diagnosis.

Treatment

Specific treatment recommendations depend largely on the cancer stage (see the NCCN guidelines at www.nccn.org). The three primary treatment options include:

- Surgery (open or laparoscopic colectomy and resection of regional lymph nodes)
- Chemotherapy
- Radiation (more commonly for rectal cancer than colon cancer)
- Combination of all three
- Biologic agents

Recent advances in the use of molecular markers will further aid in determining which patients will respond best to various treatment protocols (i.e., targeted therapies).

GYNECOLOGIC CANCERS

Gynecologic cancers include malignant neoplasms that arise in the female genital organs; uterine corpus, ovary/fallopian tube, cervix, vulva, and vagina. This section will include information on the cancers that appear in survivors most frequently: uterine, ovarian and cervical.

Uterine Corpus

Incidence & Mortality

Endometrial cancer is the most common cancer of the uterine corpus and is also the most common of all gynecologic cancers. See Table 1 on page 19 for incidence, mortality, and survival data. Uterine sarcomas are less common, more aggressive, and have a worse prognosis.

Prevention

- Estrogen + Progestin: The use of combination oral contraceptives (estrogen plus a progestin) is associated with a decreased risk of developing endometrial cancer
- Weight Loss: There is inadequate evidence to determine if weight reduction alters the incidence of endometrial cancer

Screening

There is inadequate evidence that routine screening in average-risk asymptomatic women by ultrasonography (transvaginal ultrasound (TVU) or endovaginal ultrasound) or endometrial sampling (biopsy) reduces the mortality from endometrial cancer.

Symptoms & Diagnosis

Most cases of endometrial cancer are diagnosed because of symptoms such as postmenopausal bleeding, spotting or cramping or persistent irregular bleeding at any age. These symptoms are usually investigated early, and therefore lead to high survival rates. Other symptoms may include abnormal, nonbloody vaginal discharge, pelvic pain, dyspareunia, or unintended weight loss. Diagnostic procedures may include transvaginal ultrasound, endometrial biopsy, sonohysterography, and dilatation and curettage.

Treatment

- Surgery: Surgery is the most common initial treatment for endometrial cancer (hysterectomy usually with bilateral salpingo-oophorectomy, removal of lymph nodes plus full surgical staging)
- Combined Modalities: Women with disease that is high risk for recurrence or metastasis may require adjuvant radiation, hormone therapy (high dose progestin or gonadotropin-releasing hormone agonists), chemotherapy or a combination of these treatments

Ovarian

Incidence & Mortality

Ovarian cancer is the second most common of gynecologic cancers, following cancer of the uterine corpus. See Table 1 on page 19 for incidence, mortality, and survival data.

Prevention

- Oral Contraceptives: Oral contraceptive use is associated with a decreased risk of developing ovarian cancer even in women with familial predisposition or genetic mutations. However, estrogen/progestogen oral contraceptive use is associated with an increased risk of venous thromboembolism. Oral contraceptives are not associated with a long-term increased risk of breast cancer but may be associated with a short-term increased risk while a woman is taking oral contraceptives. The risk of breast cancer declines with time since last use
- Prophylactic Removal of Fallopian Tubes and Ovaries/Tubal Ligation: Prophylactic bilateral salpingo-oophorectomy (complete removal of fallopian tubes and ovaries) as well as bilateral tubal ligation are associated with a decreased risk of ovarian cancer. Peritoneal carcinomatosis has been reported following prophylactic removal of the ovaries. Prophylactic salpingo-oophorectomy is generally reserved for women at high risk of developing ovarian cancer, such as women who have a deleterious mutation in the BRCA1 or BRCA2 genes

Screening

Ovarian Cancer Screening Guidelines

- There are no screening tests for ovarian cancer that have proven effective in screening low-risk asymptomatic women (including measurement of CA 125 levels and pelvic ultrasonography)
- Hereditary ovarian cancer is estimated to represent 5-10% of all ovarian cancers. There are no data demonstrating that screening improves early detection in women who carry BRCA1 or BRCA2 mutations, however these women should begin screening for breast cancer at an earlier age and be referred to genetic counseling. For more information on hereditary breast and ovarian cancer, see the HBOC chapter of this resource guide

Symptoms & Diagnosis

Symptoms of ovarian cancer are nonspecific and often mimic those of other more common conditions. Common misdiagnoses include irritable bowel syndrome, gall bladder disease, stress, or symptoms may be attributed to menopausal changes. The key to recognizing ovarian cancer is identifying persistent and/or worsening signs and symptoms. These may include:

- Abdominal pressure
- Fullness
- Swelling

- Bloating
- Urinary urgency
- Pelvic discomfort or pain

Additional symptoms for ovarian cancer may include:

- Persistent indigestion
- Changes in bowel habits
- Early satiety
- Dyspareunia
- Fatigue
- Low back pain
- Changes in menstruation

Diagnostic tests may include CA 125 levels, ultrasound, computerized tomography (CT), PET-CT, and MRI. Since the definitive diagnosis of ovarian cancer is usually not made until surgery, a laparoscopy may be performed to visualize the ovaries or collect tissue, or a laparotomy to remove the ovaries for the histological diagnosis.

It is essential that patients with suspected ovarian cancer be referred to a gynecologic oncologist when possible. It has been well-established that women with ovarian cancer whose care is managed by a physician with advanced training and expertise in the treatment of gynecologic cancer, such as a gynecologic oncologist, have improved overall survival rates as compared with those treated without such collaboration.

To find a gynecologic-oncologist in your area, please visit the Gynecologic Cancer Foundation's "Find a Gyn-Onc" website at http://www.wcn.org/findadoctor/.

Treatment

- Surgery: Women with ovarian cancer often require extensive surgery that includes removing both ovaries, fallopian tubes, and the uterus as well as nearby lymph nodes and omentum and removal of all visible tumors (cytoreduction or debulking surgery)
- Chemotherapy: Following surgery, chemotherapy including carboplatin and paclitaxel is often used. Chemotherapy may be delivered through the intravenous (IV) or intraperitoneal (IP) routes, or combined IV and IP treatments depending on the findings and effectiveness of surgical cytoreduction. Many other agents are effective and can be used initially or after recurrences are detected
- Radiation: Radiation is generally not considered for initial treatment of ovarian cancer

Referral to clinical trials may be encouraged since many of the advances in treatment and increased survival from ovarian cancer have resulted from such research studies.

Cervical

Incidence & Mortality

Cervical cancer is the third most common of the gynecologic cancers, mostly due to effective and improving cancer screening and technology. See Table 1 on page 19 for incidence, mortality, and survival data. For more information on ovarian cancer, see the Ovarian Cancer chapter of this resource guide (to be released in 2009).

Prevention

The human papillomavirus (HPV) is the most common sexually transmitted infection in the U.S. with approximately 6.2 million people newly infected per year. It is thought to be the cause of virtually all cervical cancers. Co-factors for HPV infection that increase the exposure to, susceptibility to, and/or the progression of cancer include multiple sexual partners, cigarette smoking, HIV and other immunosuppressive conditions, multiparity, and oral contraceptive use. Patients can now be protected against the two most common oncogenic strains of HPV through vaccination. Please see the Cervical Cancer chapter of this resource guide for more information.

Screening

For women who have precancerous lesions detected through a Pap test, the survival rate is nearly 100% with appropriate evaluation, treatment, and follow-up. Cervical cancer screening technologies, evidence-based screening guidelines, as well as management of abnormal Pap findings are thoroughly covered in the Cervical Cancer chapter of this resource guide.

Symptoms and Diagnosis

Early cervical cancer is usually asymptomatic. As the cancer progresses, symptoms may include vaginal bleeding after intercourse, between periods, or after menopause, watery, bloody vaginal discharge, and pelvic pain or dyspareunia. Although a Pap test may be helpful, the optimal evaluation of these symptoms is with colposcopy and histologic specimens.

Treatment

The type and combination of treatments depend on cancer stage. Treatments may include surgery, radiation, and chemotherapy, or a combination of these. During pregnancy, no therapy is warranted for preinvasive lesions of the cervix, including carcinoma in situ, but ideally these patients should be managed by those providers experienced in colposcopy. Treatment of invasive cervical cancer depends on the stage of the cancer and gestational age at diagnosis.

Lymphomas

Incidence & Mortality

Hodgkin's Disease (Hodgkin's lymphoma) is most common in early adulthood (age 15-40) and late adulthood (after age 55). About 10-15% of cases are diagnosed in children and teens.

Non-Hodgkin's lymphoma (NHL) is the fifth most common cancer in men and women in the United States (not counting skin cancers). The American Cancer Society estimates that over 30,000 women in the United States were diagnosed with NHL in 2008. See Table 1 on page 19 for incidence, mortality, and survival data.

Prevention

Currently there are no known ways to prevent Hodgkin's OR non-Hodgkin's lymphoma. However there are some known risk factors for both:

- Infection with the Epstein-Barr virus is associated with Hodgkin's lymphoma
- Factors associated with NHL include HIV infection, organ transplants, and prior cancer treatments

Screening

There is currently no recommended screening test for Hodgkin's or NHL.

Symptoms & Diagnosis

- Non-Hodgkin's Lymphoma: Symptoms may include enlarged lymph nodes in the neck, armpits or groin, weight loss, fever, night sweats, pruritis, dyspnea, or a tender, painful and/or swollen abdomen
- Hodgkin's Lymphoma: Enlarged lymph nodes in the neck, armpits, or groin are often the only sign of non-Hodgkin's lymphoma in its early stages. Other symptoms may include fever, night sweats, fatigue, weakness, intense pruritis and dyspnea

Work-up for Hodgkin's or non-Hodgkin's lymphoma may include blood tests, imaging studies, and biopsy. The diagnosis is confirmed histologically.

Treatment

- Hodgkin's Lymphoma: Standard, first-line therapy includes radiation for most early-stage lymphomas or a combination of chemotherapy and radiation. Later-stage lymphomas are primarily treated with chemotherapy; radiation may be used to control bulky disease. Biologic therapy is also now being used in some cases
- Non-Hodgkin's Lymphoma: Treatment of NHL depends on the histologic type, stage, age, and overall medical condition. Many of the improvements in survival rates for NHL have come from clinical trials. Options for treatment include:
    - Chemotherapy
    - Radiation (early stages of low-grade lymphomas)
    - Stem cell transplantation (generally used for intermediate- or high-grade lymphomas that relapse after initial, successful treatment)
    - Biologic therapy (rituximab/Rituxan)
    - Radioimmunotherapy (ibritumomab [Zevalin], tositumomab [Bexxar])
    - Combination of above

Table 1: Overview of the Most Common Cancers in Women

Cancer Type	Incidence		Mortality		5 Year Survival Rate (%)		Survival Rates by Stage (%)			
	Median Age at Diagnosis (in years)	Incidence* (per 100,000 females)	Median Age (years)	Death Rate** (per 100,000 females)	White Females	African-American Females	Localized	Regional	Distant	Unstaged
Lung and Bronchus	71	53**	72	39	18	15	53	24	4	9
Breast	61	124**	69	25	90	78	98	84	23	58
Colon and Rectum	71	43**	77	16	66	57	91	70	11	38
Gynecologic Cancers:										
Uterine	62	23**	73	4	85	61	96	67	18	56
Cervical	48	8**	57	2	72	61	92	58	17	57
Ovarian	63	13**	71	9	46	37	94	73	28	27
Lymphomas:										
Hodgkins Lymphoma	38	3**	64	0.4	87	87	90	91	75	82
Non-Hodgkins Lymphoma	67	16	77	6	70	64	81	71	57	65

National Cancer Institute; SEER Data

*Based on cases diagnosed in 2002-2006 from 17 SEER geographic areas.

**Based on cases diagnosed in 2001-2005 from 17 SEER geographic areas.

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Overview

BACKGROUND

As survival rates for cancer patients increased markedly during the last few decades, the concept of cancer as a deadly disease has slowly transformed. It is now evident that many cancers are chronic diseases, similar to diabetes or heart disease. If detected early, patients with cancer can often be effectively treated and restored to a disease-free state. Even patients with more advanced tumors can experience longer survival with greater quality of life than in previous decades. However, as is true with other chronic diseases, ongoing management and surveillance are necessary throughout the remainder of the patient's life. With longer periods of disease-free survival becoming more common, cancer survivors today can eventually "graduate" from the intensive cancer services they received from their oncology team and transition back to their primary health care provider. Effective surveillance requires knowledge of specific late and long-term effects as well as an efficient approach for eliciting important history from the patient.

WHAT YOU SHOULD KNOW

- Definitions of late and long-term effects (Aziz and Rowland):
    - Late Effects: Late effects may not appear until months, or even years after the completion of treatment. They refer specifically to unrecognized toxicities that are absent or subclinical at the end of therapy and become manifest later with the unmasking of hitherto unseen injury because of any of the following factors: developmental processes, the failure of compensatory mechanisms with the passage of time, or organ senescence
    - Long-Term Effects: Any side-effects or complications of treatment for which a cancer patient must compensate; also known as persistent effects, they begin during treatment and continue beyond the end of treatment
- Psychological late and long-term effects can include a lingering state of vulnerability, anxiety, anger, sadness, depression and overwhelming fatigue
- Social late and long-term effects can include concerns associated with employment, financial crisis related to medical costs, and strained relationships
- Some late and long-term effects are site-specific depending on the patient's cancer diagnosis

WHAT YOU SHOULD DO

- Be familiar with the late and long-term effects of various cancer treatments
- If needed, consult with the patient's oncology team to confirm suspicion of late and long-term effects
    - Coordinate with your patients' specialists to ensure that all health needs are being met. If you did not receive a survivorship care plan from your patient's oncologist, you should request one. This document should include a brief but thorough review of the patient's course of treatment, and recommendations for future care and proactive surveillance. A sample of a survivorship care plan which you can provide to the oncologist is included at the end of Section IV of this chapter
- Be familiar with your community's resources to make appropriate patient referrals
- Refer to www.nccn.org for the National Comprehensive Cancer Network's guidelines and algorithms. These resources are continuously updated

Late and Long-Term Effects of Cancer Treatment

Psychological and Social Late and Long-Term Effects

Persistent and late-occurring effects of cancer and cancer treatment often include the following problems. These issues, which can sometimes be persistent, can undermine a survivor's quality of life:

- Lingering state of vulnerability
- Fear of recurrence
- Anxiety
- Anger
- Sadness
- Depression* (Cancer patients and survivors experience major depression and depressive symptoms approximately four times more frequently than the general population.)
- Overwhelming fatigue

* Major depression can be disabling and interfere with a survivor's ability to fulfill ordinary activities of daily life. For example, depression can cause insomnia which contributes to chronic fatigue and an inability to perform even simple tasks. Depression may also contribute to dietary disruption. Severely depressed individuals may also forget or neglect to take their prescribed medications, which could complicate physical symptoms as well as other comorbidities.

Physical, social, and other effects of cancer treatment can sometimes intensify the above symptoms. Factors that have been shown to enhance the above feelings include:

- Chronic pain
- Loss of function
- Loss of independence
- Loss of employment
- Financial crisis related to medical costs
- Inadequate or poor nutrition

Some cancer survivors suffer from recurring, intrusive thoughts or avoidance behaviors which are suggestive of post-traumatic stress disorder (PTSD).

HOW CAN I HELP?

Resources available to the patient having problems with job loss, family/medical leave, insurance issues, or needing medical legal support related to their cancer experience include:

- **National Cancer Institute: Resources for Cancer Survivors**
  http://www.cancer.gov/cancertopics/life-after-treatment/page9
- **American Society of Clinical Oncology**
  http://www.cancer.net/patient/Survivorship
- **The Legal Aid Society in New York City**
  www.legal-aid.org
- **Albany Law School: Health Law Clinic**
  http://www.albanylaw.edu/sub.php?navigation_id=66
- **New York State Attorney General's Healthcare Bureau**
  1-800-428-9071
  http://www.oag.state.ny.us/bureaus/health_care/about.html

Also, many social support services available in communities across the state can act as great resources for cancer survivors. These resources can provide a wide range of information from legal services to nutrition counseling. Many of these support groups are listed in the Resources section of this chapter, however it may also be beneficial to become familiar with local cancer centers in your area.

It is important for the health care provider to ask about and observe patients for signs of psychological and social struggles, since very often these are issues that she may neglect to volunteer. Being aware of these problems makes it possible for the health care provider to intervene. Referring the patient to a psychiatrist or psychologist, or linking the patient to appropriate support groups or social services can help ameliorate her psychosocial distress.

Common Specific Late and Long-Term Effects

When assessing for late and long-term effects of cancer survivors, it is important to avoid overlooking their concerns about common health issues. Some concerns, although seemingly minor, may be related to cancer treatment and therefore warrant referral. However, many of these effects may gradually resolve in the long-term, and their intensity may be lessened by the incorporation of lifestyle changes such as eating properly and being more active. Some common symptoms reported to women's health care providers include fatigue, chronic pain, premature menopause, issues with fertility and sexuality, osteoporosis, and others detailed below. For treatment-specific effects, refer to Tables 1 and 2, beginning on page 25.

Fatigue

Severe fatigue is common. Reportedly, more than 30% of all cancer survivors suffer from profound fatigue not only during their cancer treatment but also long after the treatment is completed. A study published in 2006 revealed that 34% of breast cancer patients complained of fatigue five to 10 years following diagnosis and treatment. Factors which may contribute to fatigue are persistent pain, depression and insomnia. Additionally, patients who have received combined therapy (such as radiation plus adjuvant chemotherapy) are at higher risk for severe fatigue. Treatment approaches include improving pain control, and treating depression and insomnia. Educating the patient about the importance of lifestyle changes such as improved diet, increased exercise and taking regularly scheduled naps during the day can also help alleviate chronic fatigue. If severe fatigue persists, the patient should be examined for other contributing health problems.

Chronic Pain

There are many varied reasons for chronic pain. It may be associated with surgically or radiologically induced scarring or adhesions. Survivors may complain of a pulling sensation, tightness, or sharp, knife-like stabbing or shooting pains at the site of the scar. Successful pain management is one of the most important goals in survivorship care and is crucial to improving quality of life. Additionally, integrative medicine approaches, such as meditation and massage, can be very helpful for recovery.

Premature Menopause

Premature menopause may be induced not only through planned surgical interventions, but also as a result of damage to the ovaries caused by chemotherapy or radiation. Premature menopause usually causes severe hot flashes, night sweats, irritability, bladder discomfort, vaginal dryness and sexual dysfunction (dyspareunia and/or diminished desire). Low dose anti-depressants can relieve hot flashes and irritability, and lubricants and vaginal estrogens may improve vaginal and bladder symptoms. Additionally, premature menopause may lead to early onset osteoporosis, dementia, and other illnesses associated normally with advanced age. The short-term use of hormone replacement therapy (HRT) in appropriately selected and informed patients may delay some of these issues. Regular surveillance with DEXA scans and treatment with Vitamin D3, calcium and biphosphates is recommended for osteoporosis. Any cognitive changes or evidence of other chronic diseases usually associated with advancing age would be appropriate for referral for consultation.

The use of HRT, either systemic or local (i.e., vaginal estrogen), should be given careful consideration. While it is true that HRT can be used for a limited period of time in women who have entered menopause naturally, the use of systemic hormones in survivors of hormone responsive cancers may not be advisable. Also, vaginal estrogen should be used with caution in patients with estrogen-dependent tumors. However, for survivors of cancers that were not determined to be estrogen-responsive, treatment with hormone replacement for a limited time could significantly improve quality of life.

Younger cancer survivors may be disturbed by the resulting infertility that premature menopause causes. Ovarian failure may be an unfortunate consequence of exposure to lifesaving chemotherapeutic treatments or pelvic radiation therapy. It has been observed after treatment for many different forms of cancer and is often reported in association with treatment for breast cancer, childhood cancers and Hodgkin's lymphoma. Even if continuing ovarian function occurs following the conclusion of the cancer treatment, premature menopause may still present years later as a result of depleted ovarian follicles.

Fertility and Sexuality

Due to improved cancer survival, many younger patients express concerns about potential loss of fertility. Several approaches to fertility preservation have been developed and include:

- <u>In Vitro Fertilization and Embryo Cryopreservation</u>: Since this process requires 10-14 days of ovarian stimulation, it is not advised for breast cancer patients
- <u>Ovarian Transposition (oophoropexy)</u>: The surgical repositioning of the ovaries to move them out of the field of planned radiation
- <u>Trachelectomy</u>: Uterine preservation during cervical resection for early stage cervical cancer
- There are several other approaches such as ovarian tissue freezing, that are under investigation

Typically, oncologists do not encourage initiating conception immediately after the conclusion of cancer treatment. Rather, it is preferred that the patient wait one to two years. This time frame coincides with the period when the patient is at the highest risk of recurrence, is still recovering from the immediate effects of treatment, and before the transition back to the care of the primary health care provider. Therefore, these providers should be prepared to encounter cancer survivors who are interested in becoming pregnant and who will subsequently require obstetrical services.

Sexuality is a major concern to many women who have undergone treatment for various female cancers. Patient concerns and requests for advice should be addressed. A proactive approach from the women's health care provider during which the patient is asked about sexual health and concerns could provide a much appreciated opportunity for patients to discuss an otherwise difficult or embarrassing topic. Such an approach is highly recommended.

A specific issue which contributes to sexual dysfunction is poor body image (which may result from disfiguring scars and alterations of feminine body contours as a result of surgery). Additionally, abdominal and pelvic surgery may result in the formation of adhesions which place painful traction on the

(continued on page 26)

Table 1: Examples of Possible Late Effects of Radiation Therapy, Chemotherapy, and Hormonal Therapy Among Survivors of Adult Cancers

		Chemotherapy/Hormonal Therapy	
Organ System/ Tissue	**Radiation Therapy Late Effects**	**Late Effects**	**Agent Responsible**
All tissues	Second cancers	Second cancers	Steroids, alkylating agents nitrosureas, topoisomerase inhibitors, anthracyclines
Bone and soft tissue	Atrophy, deformity fibrosis, bone death	Bone death and destruction, risk of fractures	Steroids
Cardiovascular	Scarring or inflammation of the heart, coronary artery disease; scarring of heart sac (pericardium)	Inflammation of the heart, congestive heart failure	Anthracylines, high-dose cyclophosphamide, cisplatin herceptin, taxanes
Dental/oral health	Dental caries, dry mouth	-	-
Endocrine-pituitary	Various hormone deficiencies	Diabetes	Steroids
Endocrine-thyroid	Low thyroid function, thyroid nodules	-	-
Endocrine-gonadal	Sterility, premature menopause	Women: Sterility, premature menopause	Alkylating agents, Procarbazine hydrochloride, nitrosureas
Gastrointestinal	Malabsorption, intestinal stricture	Motility disorders	Vinca drugs
Genitourinary	Bladder scarring, small bladder capacity	Hemorrhagic cystitis (symptoms include urinary frequency, urgency, bleeding and pain)	Cyclophosphamide, ifosfamide, transplant therapy
Hematologic	Low blood counts function, myelodysplastic syndrome and acute leukemia	Myelodysplastic syndrome and acute leukemia	Alkylating agents, nitrosureas, topoisomerase inhibitors, purine analogs, any high-dose therapy with autologous transplantation
Hepatic	Abnormal liver function, liver failure	Abnormal liver function, cirrhosis, liver failure	Methotrexate, carmustine (BCNU)
Immune System	Impaired immune function, immune suppression	Impaired immune function, immune suppression	Steroids, anti-thymocyte globulin (ATG), methotrexate, rituximab, alemtuzumab, purine analogs, and any high-dose therapy with autologous transplantation
Lymphatic	Lymphedema	-	-
Nervous system	Problems with thinking, learning memory; structural changes in the brain; bleeding into the brain	Problems with thinking, learning, memory; structural changes in the brain; paralysis; seizure Numbness and tingling, hearing loss Numbness and tingling	Methotrexate, multiagent chemotherapy, bortezomib Cisplatin Vinca alkaloids, taxanes, oxaliplatin
Ophthalmologic	Cataracts, dry eyes, visual impairment	Cataracts	Steroids, cytarabine
Pulmonary	Lung scarring, decreased lung function	Lung scarring, inflammation Potentiation of radiation therapy effects (gemcitabine)	Bleomycin sulfate, carmustine (BCNU), methotrexate Actinomycin D/ doxorubicin (Adriamycin)
Renal	Hypertension, impaired kidney function	Impaired kidney function, delayed-onset renal failure	Cisplatin, methotrexate, nitrosoureas

Table 2: Examples of Possible Late Effects of Surgery Among Survivors of Adult Cancers

Procedure	Late Effect
Any procedure	Pain, cosmetic, psychosocial, impaired wound healing
Surgery involving neurologic structures (brain, spinal cord)	Impairment of cognitive function, motor sensory function, vision, swallowing, language, bowel and bladder control
Head and neck surgery	Difficulties with communication, swallowing, and breathing; cosmetic; damage to muscles affecting movement
Removal of lymph nodes	Lymphedema
Abdominal Surgery	Risk of intestinal obstruction, hernia, altered bowel function
Pelvic surgery	Sexual dysfunction, incontinence, hernia, risk of intestinal obstruction
Removal of spleen	Impaired immune function, increased risk of sepsis, hernia
Amputation; limb-sparing procedures	Functional changes; cosmetic deformity; psychosocial impact; accelerated arthritis in other joints; post-surgical, phantom, and/or neuropathic pain
Lung resection	Difficulty breathing, fatigue, generalized weakness
Oophorectomy	Premature menopause and infertility
Ostomy	Bowel obstruction, constipation, nausea, vomiting, loss of appetite, fatigue, poor body image

vagina and pelvic soft tissues during intercourse. Premature menopause results in vaginal atrophy with drying of the vaginal mucosa and shortening and narrowing of the vagina. These conditions contribute to dyspareunia. Topical hormonal treatments may be effective for enhanced libido as well as the disturbing physical manifestations of menopause (vaginal dryness). Gentle attempts at vaginal dilation with a dilator are recommended for these patients. Over-the-counter vaginal moisturizers and lubricants may also be somewhat helpful. Encouraging the patient to experiment with her partner with different sexual positions may also help her find techniques that create less tension within the lower pelvis. Additionally, if the patient is deeply troubled by the appearance of her surgically altered body, the health care provider can recommend consultation with a plastic or reconstructive surgeon.

Osteoporosis

This is one of the most common sequela of cancer treatment. It results from bone depletion caused by some chemotherapeutic agents, steroids (prednisone and dexamethasone), aromatase inhibitors, and premature menopause. Careful surveillance using bone densitometry, and treatment with calcium, vitamin D supplements, and bisphosphonates are important components in survivorship care. Osteoporosis can also be minimized by regular exercise. It is important for health care providers to inquire about a survivor's exercise level and to offer reminders and encouragement at each visit.

Cognitive Impairment (sometimes referred to as "Chemo Brain")

Some cancer survivors are troubled by short-term memory loss, confusion, disorganization and diminished attention, focus and concentration. This may occur following any treatment modality but is often associated with chemotherapy. It is commonly referred to by patients as "chemo brain". Cognitive impairment following chemotherapy may be related to central neurotoxicity. Medications which have been associated with central neurotoxicity include methotrexate, cytarabine (cytosine arabinoside) and ifosfamide. Radiation therapy to the brain may also have an impact on cognitive function. Current studies show that cognitive deficits are often subtle, although when observed consistently in a proportion of patients, may be durable, and can be disabling. They may be relatively mild (i.e., forgetfulness regarding keys, eyeglasses, etc). However, more serious symptoms of short-term memory loss, confusion and disorientation may disable and even endanger the survivor.

It is important for the treating physician to inquire about any cognitive changes that are occurring since they may be caused by other processes, such as:

- Stress
- Anxiety
- Depression
- Poor nutrition
- Comorbidities such as thyroid disease and diabetes

These other causes of cognitive problems may often be promptly corrected with appropriate interventions. Mild cognitive deficits can be monitored by the primary health care provider, but more severe or progressive symptoms should be evaluated by a neurologist.

Lymphedema

Lymphedema may occur after lymph node biopsies or dissection, after radiation therapy, or a combination of both. It can appear early in the survivorship period, although sometimes does not appear until 10 or 15 years after the completion of the cancer treatment. While swelling and warmth of the affected limb are the usual signs of lymphedema, the condition may present as a sensation of fullness or heaviness in the limb in the absence of any overt findings. A patient suffering from this problem will benefit from referral to a lymphedema specialist (PT or OT), to learn the proper way to apply compression bandages, as well as effective exercises to address the problem.

Cardiovascular Disease

Various elements of cancer treatment may occasionally be associated with cardiac complications. This includes radiation to the chest delivered during treatment for cancer of the left breast, or mediastinal irradiation associated with lymphoma. Specific chemotherapeutic agents associated with cardiotoxicity include the anthracyclines, 5-fluorouracil, capecitabine, cisplatin, taxanes (paclitaxel and docetaxel) and also the monoclonal antibody, trastuzumab. If cardiotoxicity is noted during the active treatment period, many survivors will already have had cardiac evaluation and management. However, late-onset evidence of cardiotoxicity may occur many years after the completion of cancer treatment. Therefore, it is recommended that the health care provider continue to monitor the cancer survivor for signs and symptoms of late-onset cardiac disease and readily refer for cardiac evaluation if identified.

Neurotoxicity

Peripheral neuropathy has been associated with some chemotherapeutic agents such as vinca alkaloids, taxanes and cisplatin, and may manifest with the following symptoms:

- Numbness
- Tingling
- Burning
- Muscle cramps
- Muscle weakness
- Pain in the distal extremities

Management of peripheral neuropathy includes rehabilitation for restoration of function and symptomatic treatment. Supportive measures such as orthotics, canes, walkers, and physical therapy are important. Various pharmacologic treatments have been attempted including analgesics, antidepressants, anticonvulsants, calcium and magnesium infusions, glutamine, glutathione, nerve growth factor and others. However, the effectiveness of these medications has not been proven. For the treatment of neuropathic pain, analgesics, antidepressants and anticonvulsants are effective. It would be reasonable to refer the patient with peripheral neuropathy to a neurologist or physiatrist for evaluation and further management. Since diabetes contributes to the severity or progression of peripheral neuropathy in cancer patients and survivors, it is essential for women's health care providers to encourage glycemic control in diabetic cancer survivors. The glycosylated hemoglobin (HA1c) should be checked and should optimally be less than 7% in diabetics. The fasting blood sugar should also be regularly checked and should be maintained in the range of 90 to 130 in diabetic patients. Diabetic cancer survivors who have difficulty maintaining glycemic control should be referred to a diabetic specialist.

Pulmonary Disease

Pulmonary damage may result from irradiation to the chest, from exposure to chemotherapy or a surgical reduction in lung volume. Radiation pneumonitis results in pulmonary fibrosis and can progress to respiratory failure. This may present as early as six months following radiation, and it can progress for months to years. Symptoms include:

- Dyspnea (on exertion or at rest)
- Nonproductive or minimally productive cough
- Chest pain
- Fever
- Malaise
- Hemoptysis

If radiation pneumonitis or pulmonary fibrosis is suspected, the patient should be referred for consultation with a pulmonologist. While there is no definitive treatment for radiation pneumonitis, corticosteroids may help to reduce symptomatology and supportive therapy such as oxygen may be useful.

There are many chemotherapeutic agents which have been associated with lung toxicity. Alkylating agents, antibiotics such as bleomycin and mitomycin C, antimetabolites, nitrosoureas, the vinca alkaloids, taxanes and etoposide have all been implicated as etiologic agents of lung injury. Interstitial pneumonitis with fibrosis is one form of pulmonary toxicity associated with chemotherapy that can result in permanent pulmonary changes. With exposure to bleomycin, this condition usually begins within one to six months after treatment. However, with busulfan, cyclophosphamide, chlorambucil and the nitrosoureas, the interval between exposure to the drug and onset of pulmonary symptoms can be quite long, sometimes more than 10 years after therapy. Late onset carmustine lung injury has even been reported after 16 to 20 years. Signs and symptoms of onset of lung injury are nonspecific and may include an insidious onset of dyspnea, dry cough, fever, tachypnea, rales, and some changes with pulmonary function testing. Chest radiograph may show reticular densities at the bases and peripherally and there may be consolidation as well. Consultation with a pulmonologist for further evaluation and management is advisable.

Gastrointestinal

Late gastrointestinal effects of cancer treatment may include diarrhea, constipation or a combination of both. Bowel and rectal strictures, fistula formation (rectum, bowel), and bowel obstruction with or without perforation may result from any of the treatment modalities. Prompt referral to a gastroenterologist, colorectal surgeon, or the surgical oncologist that operated on the patient is advised.

Ototoxicity

Platinum-based chemotherapeutic agents, such as cisplatin, are among the most effective antineoplastic agents for many gynecologic cancers. Unfortunately, they can be associated with various toxicities including neurotoxicity, nephrotoxicity and ototoxicity. Ototoxicity is caused by damage to the hair cells in the cochlea which results in permanent sensorineural hearing loss. Patients may also complain of tinnitus as well as dizziness or vertigo. Survivors complaining of any of these symptoms should undergo an evaluation by an audiologist to determine the extent of hearing loss and to be fitted with hearing aids, if deemed appropriate. While there is no known effective treatment for tinnitus at this time, there are pharmacological approaches to the treatment of vertigo. These include meclizine or compazine, lorazepam and/or a transdermal scopolamine patch. The differential diagnosis for "dizziness" includes many other common causes, and a thorough evaluation for this complaint should be performed in the usual manner.

Nephrotoxicity

Multiple chemotherapeutic agents such as cisplatin, carboplatin, cyclophosphamide, methotrexate and mitomycin C may cause acute, short-term renal effects, as well as chronic renal dysfunction. Chemotherapy can indirectly affect the renal system as a result of tumor cell lysis with rapid release of large volumes of intracellular ions and metabolites. While the primary health care provider may not encounter late-onset renal toxicity in cancer survivors, it is important to remember that a survivor's care plan may already include ongoing management with a renal specialist for the long-term manifestations of renal toxicity.

Stomas

Surgery such as abdominoperineal resection or radical pelvic surgery for gynecologic malignancies may result in the creation of a colostomy. Patients who have undergone these procedures are usually followed by an enterostomal nurse immediately following surgery. Ongoing stomal issues continue to be addressed by the surgeon and the enterostomal nurse. However, it is important for the health care provider to recognize the special needs and concerns of survivors with stomas. In particular, stoma patients may seek advice regarding sexual function. It is useful to be familiar with stoma care products in order to help them adjust. For example, the use of a small stoma cap during times of intimacy can greatly improve a stoma patient's self-confidence regarding body image and may improve sexual function. A recommendation for a stomal pouch antibacterial deodorant (such as Ostofresh-Triad Medical, or M9-Hollister) can greatly improve personal care issues. Insurance coverage for these products is often available if a physician's prescription accompanies the order. Small interventions and recommendations such as these contribute to a greatly improved quality of life and will be profoundly appreciated by the survivor who has a stoma.

Educating the patient about the importance of lifestyle changes, such as improved diet (high protein, low fat) and increased physical activity (muscle strengthening exercises, taking short walks), can help the survivor assume some control over several of these late effects of cancer treatment.

Site-Specific Late Effects

Though late and long-term effects may occur in all cancer survivors, symptoms and other effects may also be unique to the specific cancer site and intervention used. The following section includes site-specific late effects of breast, endometrial, cervical, ovarian, and colorectal cancers. Making up the majority of the female cancer survivors, Tables 3 and 5 highlight possible site-specific late effects of breast, gynecologic, and colorectal cancers.

Breast Cancer

With more than 2.5 million women in the U.S. who have survived a diagnosis of breast cancer, this comprises the largest group of cancer survivors in the world. Many of these women are long-term survivors, living well past 20 or 30 years from the date of their diagnosis. Because of improved screening techniques, more cancers are detected at an earlier stage when the tumor is smaller and has less likelihood of distant spread. Therefore, the contemporary approach to breast cancer treatment involves less radical surgery which results in less post-operative sequelae. However, even for early stage breast cancer, breast conserving surgery is followed by a course of radiation intended to eradicate any remaining cancer cells. Adjuvant chemotherapy and hormonal therapy are often administered as well. Each of these treatment approaches has been associated with the potential for the development of late effects. While the combination of different treatment modalities is appropriately intended to improve and extend a patient's survival, investigators have found that adjuvant chemotherapy in addition to surgery and radiation, tends to worsen a survivor's quality of life. Possible late effects experienced among breast cancer survivors are highlighted in Table 3, page 29.

Cancer of the Uterine Corpus

Endometrial cancer is the most common cancer of the female reproductive organs, with over 40,000 cases diagnosed each year. Since irregular vaginal bleeding, staining or pelvic cramping often occur early in the growth of the tumor, this cancer is frequently diagnosed at an early stage. Patients who are diagnosed and treated when their tumor is Stage IA (endometrium only) or IB and IC (endometrium and myometrium) have a 90-95% five-year survival rate. Therefore, there is a large population of women in the United States (more than 550,000) who are survivors of endometrial cancer.

The most common form of treatment for early stage endometrial carcinoma is surgical staging, total hysterectomy and bilateral salpingo-oophorectomy (TAH-BSO). The use of minimally-invasive, laparoscopic-assisted or robotic

(continued on page 30)

Table 3: Possible Late Effects Among Breast Cancer Survivors

Late Effect	Population at Risk	Risk	Interventions
Cancer recurrence	All women with a history of breast cancer	Varies by stage and tumor characteristics	Mammography, physical examination
Second primary cancer	All women with a history of breast cancer	Varies by treatment, age, and genetic predisposition (women with BRCA mutations are at higher risk)	Mammography, colorectal cancer screening, pelvic examination, general physical examination, patient education
Psychosocial distress	All women with a history of breast cancer	Approximately 30 percent experience distress at some point; distress declines overtime	Assessment for distress, referral for psychosocial interventions which may be effective in reducing distress
Arm lymphedema	Women who had axillary dissection and/or radiation therapy	Across treatments and time since treatment, approximately 12 to 25 percent of women develop lymphedema	Massage and exercise (manual lymphatic drainage), use of elastic compression garments, complex decongestive therapy, referral to PT/OT lymphedema specialist
Premature menopause and related infertility and osteoporosis	Women who received adjuvant chemotherapy (e.g., alkylating agents such as cyclophosphamide) Women with BRCA mutations who elect oopherectomy	Risk depends on the chemotherapy regimen, the cumulative dose, and patient age (see details below)	New reproductive technologies for infertility Diagnostic and preventive strategies for osteoporosis Assessment of sexual function
Symptoms of estrogen deprivation (e.g., hot flashes, sweats, vaginal discharge)	Women taking endocrine therapy	More than half report symptoms, although mild in most cases	Promising nonhormone treatments include antidepressants, dietary changes, and exercise
Weight gain (associated with poorer prognosis)	Women who had adjuvant chemotherapy and experience menopause	Roughly half report weight gain of 6 to 11 pounds; one-fifth report weight gain of 22 to 44 pounds	Diet/exercise interventions
Cardiovascular disease	Women receiving specific therapies (e.g., anthracycline chemotherapy, trastuzumab [Herceptin]) Premenopausal women with ovarian failure following chemotherapy	Congestive heart failure develops in 0.5 to 1 percent of women Increased risk of atherosclerosis	Symptomatic women should have a symptom-directed cardiac work-up; routine screening of cardiac function is not recommended Preventive strategies for heart disease
Fatigue	Women with breast cancer	Reported in one-third of survivors 1 to 5 years after diagnosis. Prevalence similar to that seen in women in the general population of same age. A subgroup of survivors has more severe and persistent fatigue	Exercise programs appear promising
Cognitive impairment	Women who received adjuvant chemotherapy	Estimates vary, but up to one-third of women with Impairments. New evidence suggests onset may precede chemotherapy treatment	Evidence Lacking
Risk to family members	All survivors	An estimated 5 to 10 percent of women with breast cancer have a hereditary form of the disease	Genetic counseling Refer to Chapter 2, "HBOC"

hysterectomy is becoming more widespread. Patients who are candidates for this surgery often experience an improved post-operative course with fewer post-operative problems. Late effects from surgery include pelvic adhesions which may contribute to bowel and bladder dysfunction. Although the median age for endometrial cancer is 65, it is still possible that a premenopausal woman might require treatment for endometrial cancer. Thus, concerns about surgically-induced menopause and subsequent infertility might still be expressed by this group of younger women.

For patients that have advanced stage endometrial carcinoma, a combination of chemotherapy and radiation may be offered. Late effects may therefore include radiation-related effects involving the bowel, rectum and urinary tract system as described earlier in this section. Consultation with their gynecologic oncology surgeon, surgical oncologist, colorectal surgeon, or urologist is recommended.

Cervical Cancer

In the United States there are about 230,000 survivors of invasive cervical cancer. Approximately 63% (more than 145,000) are long-term survivors with more than 10 years since diagnosis. Since the median age of cervical cancer patients is younger than most other gynecological cancers (47 years for cervical cancer, compared with 59 and 65 years for ovarian cancer and endometrial cancer, respectively), concerns regarding sexual function and preservation of fertility are particularly challenging.

The treatment for cervical cancer involves surgery, radiotherapy and/or chemotherapy. Lymphedema occurs in about 3.6 – 4.9% of patients after surgery and can increase to 7-20% of patients with pelvic node dissection. It can also occur as a result of pelvic radiation. Cellulitis is a late and often recurrent effect that may occur in areas of lymphedema.

Radiation therapy can result in damage to other local pelvic organs, including fibrosis and necrosis of rectal, genitourinary tissues, and bowel and bladder.

Adjuvant chemotherapy, using cisplatin, may also result in other late effects, such as neuropathy, nephrotoxicity, ototoxicity and severe fatigue.

Ovarian Cancer

While early stage ovarian cancer responds well to treatment and is associated with survivals of greater than 80%, less than 20% of patients are diagnosed with disease confined to the ovaries. About 75% of patients are diagnosed after the cancer has spread beyond the ovary, at which time, the five-year survival rate drops dramatically. There are approximately 175,000 women in the United States who are survivors of ovarian cancer. Since many of them had advanced stage tumors at the time of diagnosis, they face a high likelihood of having a recurrence at some time in the future. Therefore, surveillance for recurrence is of primary importance during the survivorship period since 80 to 95% of women with Stages III and IV will recur.

The most common treatments for ovarian and other gynecologic cancers and their associated late effects are highlighted in Table 4.

Table 4: Possible Late Effects Among Gynecologic Cancer Survivors

Treatment	Late Effects
Surgery (including surgical debulking, unilateral and bilateral salpingo-oophorectomy, hysterectomy, endoscopic)	Menopausal symptoms, infertility, effects on bladder function, effects on bowel function
Chemotherapy	
• Cisplatin	Neurotoxicity, neuropathy, ototoxicity with permanent sensorinerual hearing loss, cardiotoxicity
• Carboplatin	
• Taxanes (paclitaxel and docetaxel)	May be associated with Leukemia later in life Cardiotoxicity, neurotoxicity, osteoporosis
Radiation Therapy	Infertility, fibrosis and stenosis of the vaginal canal, fibrosis and stenosis of the bladder, colitis, enteritis, proctitis, fistula formation, intestinal obstruction

Ideally, women who have been treated for ovarian and other gynecologic cancers are also under the care of a gynecologic or medical oncologist. Management of treatment sequelae are best addressed with this team.

Colorectal Cancer

According to the 2005 statistics from the U.S. National Cancer Institute's Surveillance Epidemiology and End Results (SEER) database, there are approximately 598,000 women who are survivors of colorectal cancer. This includes some survivors who were diagnosed 20 to 30 years ago. Over that time period, treatment modalities have dramatically improved for this disease, and even greater survival can be expected for future decades.

Surgical approaches differ depending on the location and the stage of the tumor. Survivors who have undergone traditional open laparotomy procedures sometimes complain of progressive discomfort in the region of the midline scar, which may be exacerbated by exertion or straining. Incisional herniation may not be apparent or symptomatic in the early post-surgical period, but may appear later on. This is especially true as patients age, become more sedentary, and gradually develop more attenuated abdominal muscles. Long-term survivors may no longer be seeing their general surgeons for regular follow-up, and therefore may depend upon their women's health care provider for recognition of the problem and referral back to their surgeon.

Adjuvant chemotherapy, and occasionally radiation may be utilized in the treatment of colorectal cancer even in the setting of hepatic or distant metastases. These interventions have resulted in long-term survival (10 years or greater), even for some patients who were diagnosed with Stage IV colon cancer. Despite long-term survival from cancer, these patients are still at risk for developing late and long-term effects of cancer treatment. Since women who are long-term survivors of colorectal cancer may no longer be seeing their surgeon or oncologist, it is wise for the health care provider to become familiar with some of the late presenting effects of colorectal cancer treatment. Possible late effects among colorectal cancer survivors are highlighted in Table 5, page 32.

Adult Survivors of Childhood Cancers

Advances in the approach to the treatment of childhood cancers have achieved dramatic improvements in survival rates. Today, children diagnosed with cancer have an 80% overall likelihood of becoming a long-term survivor. As they reach adulthood, they may naturally transition from their pediatrician to a primary care provider who focuses on adult care. Knowledge of the patient's previous cancer treatment is essential to women's health care providers in order to provide optimal and anticipatory risk-based care.

Radiation therapy and chemotherapy are frequently used in the successful eradication of childhood cancers, however, they are also damaging to healthy developing tissues. Cardiotoxicity with lifelong cardiovascular consequences may occur. Neurocognitive dysfunction is not uncommon and psychosocial issues may also follow the childhood cancer survivor into adulthood. Ongoing surveillance for these problems will continue to be a significant part of the health care for the life of these patients. Referrals to appropriate specialists are advised to obtain help and guidance with the management of these problems. For women's health care providers, issues related to breast health, osteoporosis, sexual and reproductive dysfunction are among the main concerns of young women who are long-term survivors of childhood cancer.

Breast cancer is the most common secondary cancer among childhood cancer survivors which explains the importance of maintaining a heightened surveillance for its onset. It is particularly common after treatment for Hodgkin's lymphoma. In recent studies, women treated for childhood Hodgkin's disease were found to be 37 times more likely than others to develop breast cancer. Although there is not yet a complete understanding of the pathophysiological processes which lead to late onset breast cancer, a history of thoracic irradiation is believed to be an important risk factor. According to the American Cancer Society, women who had radiation therapy to the chest when they were between the ages of 10 and 30 years should be considered at high risk for breast cancer. For most women at high risk, screening with MRI and mammograms should begin at age 30 years and continue for as long as a woman is in good health. However, because the evidence is limited regarding the best age at which to start screening, this decision should be based on a discussion between patients and their health care providers, taking into account personal circumstances and preferences.

The ovaries are sensitive to radiation throughout childhood and adolescence. Studies have revealed that more than 70% of women who had been treated with 2,000 cGy or more of ovarian irradiation developed ovarian failure. Additionally, doses of ovarian irradiation less than 1,000 cGy have also resulted in ovarian failure if the patient had also been treated with an alkylating agent such as cyclophosphamide. Total body irradiation (TBI) used prior to stem cell transplant also carries a very high risk of acute ovarian failure.

While the ovaries in childhood are generally less sensitive to chemotherapy-induced damage, high-dose myeloablative therapy (as with busulfan, melphalan, thiotepa or cyclophosphamide) prior to stem cell transplant, is associated with a high risk for ovarian failure. Patients who do not develop ovarian failure may have diminished ovarian reserve resulting in earlier menopause. Decreased numbers of antral follicles per ovary are associated with ovarian irradiation as well as with treatment with alkylating agents. Cranial irradiation during childhood can also result in infertility due to the effect of irradiation on the hypothalamic-pituitary axis altering gonadotrophins.

The consequences of premature menopause in survivors of childhood cancers include early onset of osteoporosis, as well as sexual dysfunction and body image issues. Use of hormone replacement therapy in selected, informed patients, in consultation with their oncologist should be considered.

Clearly, an existing knowledge of the survivor's cancer treatment history would enable the health care provider to anticipate specific high risk outcomes, and identify them at an early stage, when management could be optimally effective.

Table 5: Possible Late Effects Among Colorectal Cancer Survivors

Late Effect	Population at Risk	Risk	Interventions
Cancer recurrence	All survivors	40 percent among those treated with local or locally advanced cancer	Follow-up imaging recommended. Periodic testing for carcino-embryonic antigen (CEA) may be indicated for some survivors in the first few years after diagnosis
Second primary cancer	All survivors	Increased risk of cancers of the colon, rectum, small intestine, cervix, uterus, and ovary	Follow-up colonoscopy recommended
Psychosocial distress	All survivors	Higher rates of depression have been reported	Assessment for distress and referral Evidence on the effectiveness of psychosocial interventions among survivors of colorectal cancer is limited
Bowel dysfunction: diarrhea and fecal leakage incontinence, constipation, bowel obstruction, pain	Variable	Hemicolectomy can lead to loose stools that usually improve over time. Surgery can also lead to adhesions. Rectal cancer patients are at higher risk of fecal incontinence. Radiation may lead to small bowel scarring and bowel obstruction	Dietary counseling, use of over-the counter medications (e.g., fiber laxative, stool softeners, antidiarrheals), and anal sphincter biofeedback training
Colostomy	Rectal cancer survivors who had tumors located in the lower part of the rectum	Approximately 15 to 25 percent of survivors will have permanent colostomies	Enterostomal nurses provide education, training, and counseling
Sexual Function	Rectal cancer survivors	Painful coitus in women. Infertility, abnormal bowel function can affect sexual functioning	Assessment for sexual function: vaginal dilatation, over-the-counter lubricants. Effective options for fertility preservation in women are limited. Ovarian pexy, pinning the ovaries up out of the radiation field at the time of surgery, may preserve ovarian function, but the uterus will be damaged
Peripheral neuropathy	Survivors who received oxaliplatin	Numbness or painful sensations	Prescription medications (i.e., vitamin B6, amitriptyline, gabapentin)
Risk to family members	All survivors	Most colorectal cancer is sporadic and relatives are not at higher risk. Family history and clinical characteristics of the cancer may suggest a genetic etiology	Genetic counseling; in addition, those at high risk are counseled to begin colonoscopy 10 years before the earliest colorectal cancer in the family (or age 50, whichever comes first). Genetic tests are commercially available for some genetic disorders (e.g., hereditary nonpolyposis colorectal cancer [HNPCC], familial adenomatous polyposis [FAP])

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Effective surveillance requires knowledge of specific late and long-term effects as well as an efficient approach for eliciting important history from the patient.

Notes:

Overview

BACKGROUND

As growing numbers of female cancer patients emerge from the period of active treatment and embark upon a new and long lasting phase of survivorship, the ongoing medical care of this large population becomes the responsibility of the primary care provider. The size of this population is expected to increase to more than 18 million people by the year 2020. However, current estimates predict a shortage in the number of physicians who are appropriately trained in oncology to support such a patient volume. Subsequently, the need to train current women's health care providers in oncology follow-up care has become evident. The medical community recognizes that cancer survivorship has become an evolving clinical opportunity for a multidisciplinary approach and research.

Due to these growing numbers of cancer survivors, quality of life issues are becoming increasingly important. A patient's quality of life is dependent upon many factors, as well as her personal perception of how those factors impact her ongoing purpose and obligations in life. These factors include the basic physical functions which impact her ability to accomplish the activities of daily life, maintain autonomy and achieve satisfaction. Physical and psychosocial qualities contribute to the perception of independence, control and self-esteem. Women's health care providers are uniquely positioned in their ability to oversee and maximize these qualities and strengths.

WHAT YOU SHOULD KNOW

- Definition of quality of life: an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale quality of life can be viewed as including all aspects of community life that have a direct and quantifiable influence on the physical and on the mental health of its members
- Quality of life changes may impact the physical, psychosocial, spiritual and sexual aspects of a survivor's life
- Communication and coordination between specialists and primary care providers are essential to the delivery of high quality health care which can optimize quality of life for long-term survivors
- A patient-centered approach is essential to survivorship care. This may include not only monitoring their physical well-being, but also encouraging the adoption of healthy lifestyles, providing assistance in accessing community support services, and acting as an advocate for continued funding for treatment, psychosocial support and research
- Cancer survivorship care is a relatively new concept. The availability of information and resources regarding cancer survivorship care is increasing. Continuing medical education courses (live or online) are also more common. Several physician resources are outlined in this section, as well as in the Resources section of this chapter

WHAT YOU SHOULD DO

- Educate yourself on the basics of cancer survivorship care. Several educational opportunities and information resources are outlined in this section as well as the Resources section
- Facilitate open communication with your patients' specialists and other health care providers. A survivorship care plan sample template is included at the end of this section to aid this process
- Become familiar with the community support services available to cancer survivors in your area and make appropriate referrals
- Become familiar with the quality of life issues that your patients may be experiencing
- Facilitate conversation with patients regarding the importance of sharing personal cancer history with their families

Current estimates predict a shortage in the number of physicians who are appropriately trained in oncology.

Quality of Life After Cancer / How Can I Help?

Quality of Life

The term "quality of life" (QOL) is difficult to define since it is based on an extremely subjective and variable perception of one's well-being, functionality, independence, fulfillment and satisfaction with life. The CDC defines it as "an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, QOL can be viewed as including all aspects of community life that have a direct and quantifiable influence on the physical and on the mental health of its members."

Even among patients who have similar treatments and post-treatment outcomes, major differences may exist in their perceived QOL. For example, a bowel resection with an ostomy can be perceived as a catastrophic outcome by a 35 year-old woman who was essentially in good functional health until her acute intestinal obstruction secondary to colon cancer. Her post-operative QOL may be dismal, even if her ostomy may be surgically reversed in the future. Yet, for a 35 year old woman with colon cancer associated with severe inflammatory bowel disease who has suffered many years of debilitating gastrointestinal symptoms, a bowel resection and ostomy (even a permanent one) may provide tremendous relief resulting in greatly improved QOL. However, it is important for providers to remember that even for this patient, who seems overtly satisfied with her post-operative state, there continues to be challenging QOL issues that must be addressed. These may include frequent dehydration and fatigue, stomal inflammation and pain, poor body image and femininity issues, sexual dysfunction, and even stomal odor. The patient, who recognizes that this surgery saved her life, may feel ashamed and reluctant to confide these seemingly "less important" concerns with her providers. Therefore, it is important for providers to encourage open discussion regarding patients' concerns.

Specific Quality of Life Effects After Cancer

It is unrealistic to expect that quality of life after cancer will return to the pre-cancer status. Inevitably, as one progresses through the trauma of a cancer diagnosis and subsequent treatment, some permanent changes will occur. These changes may impact the physical, psychological, social, spiritual, and sexual components of one's life. Interestingly, the alterations may not necessarily cause deterioration in QOL, but rather, may enhance the individual's perception of her life. The patient may gain enlightening insights spiritually and her social relationships may strengthen as she and her loved ones develop renewed appreciation for each other. She might also experience a physical improvement if, in the pre-treatment phase, her illness had already begun to interfere with normal physical functioning.

QOL may be negatively impacted by any one of the following factors:

- Fear of cancer recurrence
- Persistent pain
- Chronic fatigue
- Poor body image
- Anxiety
- Depression
- Significant financial problems
- Loss of employment and income
- Weakened social relationships
- Physical disabilities due to the primary cancer, the treatment or the manifestations of late-onset sequelae

It is essential that the health care provider identify these issues and offer compassionate and effective guidance and care.

Comorbidities

Since many cancer patients are older than 65 years of age, it is important to remember that they may also have other illnesses such as diabetes, hypertension, cardiovascular disease, hypothyroidism, and more. All of these chronic illnesses have their own associated constellation of possible symptomatology, which may potentiate the deterioration in QOL. Thus, all physical findings and troublesome issues reported by the patient throughout the survivorship period should be carefully noted and evaluated. These may not only be early clues to the appearance of treatable late-onset problems, but may also signal the deterioration of QOL factors.

Improving the level of communication between the patients' many caretakers, including the oncologist, primary care provider, internist and other health care providers may facilitate an improvement in the patients' quality of care and ultimate quality of life.

Predictors of Positive and Negative Influence Upon Quality of Life

Knowledge of specific factors which may influence the ultimate QOL for cancer survivors is a valuable tool not only for oncologists, but also for the primary health care provider.

Predictors of Negative Influence

A review of current literature has provided the following information regarding factors which may negatively influence the QOL in cancer survivors. Provider awareness of the following factors may help improve the provision of resources and referrals to improve your patients' QOL:

- General factors:
    - A history of psychological disease (particularly depression, anxiety)
    - A history of other serious medical conditions
    - Poor social support
    - Low socioeconomic status:
        - Low income (less than $45,000 annually)
        - Low level of education (less than 12th grade-level)
    - Lack of religious beliefs
    - Young age at diagnosis (survivors of pediatric cancers may have very different and significant problems related to QOL and studies have found the younger the patient was at diagnosis, the more negative affect it can have on their QOL)
    - Advanced stage of disease at time of diagnosis
    - Cigarette smoking
- Post-treatment factors:
    - Uncertainty about the future
    - Depression
    - Pain
    - Fatigue
    - Neurotoxicity
    - Poor sexual function
    - Comorbid disease
    - Difficulty controlling bowels
    - Presence of stoma
    - Having had adjuvant chemotherapy for breast cancer

HOW CAN I HELP?

For patients suffering from many of the above symptoms, the websites below have several useful resources which may help them know what to expect as a cancer survivor, and ways to improve their QOL.

- http://www.cancer.net/patient/Survivorship
- http://www.mdanderson.org/topics/survivorship/Having had radiation therapy rather than surgery for cervical cancer

Predictors of Positive Influence

Studies have shown that the following factors may have a positive influence on a cancer survivor's QOL:

- Strong social support
- Eating a healthy, low-fat diet
- Doing more physical exercise
- Weight loss
- Smoking cessation
- Being comfortable talking about their cancer
- Taking vitamins
- Relaxation techniques (i.e., meditation, yoga)
- Stress reduction strategies
- Positive imagery
- Participation in activities related to spirituality (i.e., existing religious beliefs, increased involvement in religious activities)
- Older age (older than 60-65 years of age)

Complementary Therapy

The use of complementary therapies in conjunction with standard medical care can focus the cancer survivor on healing and wellness. It is very important to distinguish these modalities as being a complement to medical care, as opposed to a substitute or alternative for cancer care and adequate follow-up surveillance in the post-treatment period. As identified above, massage, relaxation techniques, meditation, yoga, Tai Chi, acupuncture and other modalities can be quite useful to recover a sense of well-being and improved QOL.

Please Note: The use of herbs and supplements is very prevalent and it is important that providers obtain an accurate list that includes supplements as well as prescribed medications when obtaining a health history. There are potential interactions and some herbs and supplements have known contraindications for cancer survivors. An excellent resource for the evaluation of supplements is Memorial Sloan Kettering's *About Herbs, Botanicals & Other Products* website: http://www.mskcc.org/mskcc/html/11570.cfm.

Issues to Consider When Providing Survivorship Care

Monitoring the survivor for local or regional recurrence of cancer, evidence of metastatic disease, or the appearance of a new primary malignancy is one of the main, ongoing objectives of survivorship care. Encouraging the continuation of ongoing therapy is also important.

Menopausal symptoms may still be problematic for long-term survivors, although they usually begin to improve after the first year or so. Nonetheless, there may still be a need to treat symptoms such as hot flashes, irritability, and early onset of osteoporosis and cognitive decline. Other menopausal symptoms such as genitor-urinary discomfort may worsen over time and require treatment. Fertility is another issue of concern, particularly for younger survivors. Those who have undergone fertility preservation procedures may be interested in conception by the time they transition into the care of the primary provider. Therefore, helping them fulfill this goal will become part of the health care provider's role when treating cancer survivors.

Chronic pain can be a debilitating issue for some cancer survivors and may be a management challenge. In this situation collaboration with the oncology team or a pain management specialist for that aspect of care may be appropriate. Evaluating for any comorbidities such as diabetes, hypertension or cardiovascular disease is equally important. In addition, patients should always be counseled about the importance of a healthy diet, tobacco avoidance and exercise.

It is also important to have a reliable list of resources for the patient to help with specific problems. Resources to be aware of include:

- Psychiatrists or psychologists
- Plastic surgeons
- Dermatologists
- Cardiologists
- Pulmonologists
- Otorhinolaryngologists or audiologists
- Gastroenterologists
- Urologists
- Enterostomal care nurses
- Home care nurses, aids and services
- Genetic counselors
- Social support networks
- Legal services

In addition, the importance of having office staff who are sensitive to the specific needs of cancer survivors is crucial. Having nurses or medical technicians who are specially trained as survivor care professionals (when possible) facilitates patient care.

Inquiring about the well-being of the patient's family members is extremely important. A cancer diagnosis in one family member generally impacts all members of the family. The benefits of family counseling can be emphasized with the patient who reports difficulties with her family. Referrals should be made to community education and resources for survivors' family members as needed. Also, encouraging realistic optimism throughout the survivorship period is helpful for the patient as well as her family. Emphasizing aspects of good progress is reassuring and motivates a survivor to continue to overcome her challenges. In addition, it is extremely important to encourage your patient to discuss her cancer experience with her family. Not only does being open and comfortable about talking about her cancer improve her quality of life, but members of her family should be aware of their potentially increased cancer risk.

Finally, as cancer survivors live longer, they experience greater challenges and increasing medical needs, as well as supportive requirements financially and socially. In order to provide survivors with all that is necessary to ensure a good quality of life, advocacy must continue for funding for treatment, psychosocial support and research.

> *The medical community recognizes that cancer survivorship has become an evolving clinical opportunity for a multidisciplinary approach and research.*

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Cancer Diagnosis, Treatment Plan and Follow-up Care

Date: ____________

Patient Name: ______________________________ DOB: __________ MR#: ______________

Cancer Type/Location: ______________________ Stage at Diagnosis: ____________ histo/grade: __________

Diagnosis/Surgery Date: ______________________ Hospital: ______________________

Surgeon: ______________________ Phone #: ______________________

What surgery was performed: ______________________ None or: ______________________

Radiation: Y or N Facility: ______________________ Dates: __________ Rad Onc Name: ______________

Radiation Field: ______________________________ Dose: ______________

Side effects: ____

Chemo: Y or N Facility: ______________________ Dates: __________ Heme/Onc Name: ______________

Regimen 1 Drugs: ____

Regimen 2 Drugs: ____

Side effects ____

Follow-up Care: Next appointment and frequency of visits

Medical Oncology visits: ______________________ Radiation Oncology: ______________________

Surgeon: ______________________ Internist: ______________________

Gynecologist: ______________________ Radiology Testing: ______________________

Laboratory Testing: ____

Referrals provided/needed:

Dietician

Genetic counselor

Endocrinologist

Smoking cessation counselor

Psychiatrist/therapist

Nutritionist

Physical therapist

Social worker

Sex therapist

Exercise specialist

Fertility specialist

Financial assistance counselor

Cancer Screening: Date last completed and frequency

Colorectal: ______________________ Breast: ______________________

Prostate: ______________________ Cervical: ______________________

Other: ____

Cancer Survivorship Resources

Many local cancer centers have websites with survivor resources specific to their region and can be a valuable resource.

Cancer Survivorship Resources

Resources Featured in Section I:

For providers

American Society for Clinical Oncology Survivorship Guidelines
http://www.asco.org/ASCO/Quality+Care+%26+Guidelines

Children's Oncology Group: Long Term Follow Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers
http://www.survivorshipguidelines.org/pdf/LTFUGuidelines.pdf

Language Line Services: 1-800-752-6096
www.languageline.com

National Comprehensive Cancer Network
http://www.nccn.org

For providers and patients

New York State Attorney General's Healthcare Bureau, 1-800-428-9071
http://www.oag.state.ny.us/bureaus/health_care/about.html

Resources Featured in Section II:

For providers

National Comprehensive Cancer Network
www.nccn.org

For providers and patients

Gynecologic Cancer Foundation's "Find a Gyn-Onc" website
http://www.wcn.org/findadoctor/

Resources Featured in Section III:

For patients

Albany Law School: Health Law Clinic
http://www.albanylaw.edu/sub.php?navigation_id=66

American Society of Clinical Oncology
http://www.cancer.net/patient/Survivorship

National Cancer Institute: Resources for Cancer Survivors
http://www.cancer.gov/cancertopics/life-after-treatment/page9

New York State Attorney General's Healthcare Bureau, 1-800-428-9071
http://www.oag.state.ny.us/bureaus/health_care/about.html

The Legal Aid Society in New York City
www.legal-aid.org

Resources Featured in Section IV:

For patients

Cancer.Net from the American Society of Clinical Oncology, for Cancer Survivors
http://www.cancer.net/patient/Survivorship

MD Anderson Cancer Center, Cancer Survivorship
http://www.mdanderson.org/topics/survivorship/

Memorial Sloan Kettering - About Herbs, Botanicals & Other Products
http://www.mskcc.org/mskcc/html/11570.cfm

General Websites:

American Cancer Society
www.cancer.org

American College of Obstetricians and Gynecologists
www.acog.org

Centers for Disease Control and Prevention
www.cdc.gov

Gynecologic Cancer Foundation
www.thegcf.org

National Cancer Institute
www.cancer.gov

National Coalition for Cancer Survivorship
www.canceradvocacy.org

National Comprehensive Cancer Network
www.nccn.org

National Institutes of Health - Cancer Survivorship Research
http://cancercontrol.cancer.gov/ocs/research-survivorship.html

Society of Gynecological Oncologists
www.sgo.org

Women's Cancer Network
www.wcn.org

Other Provider Education and Resources:

Institute of Medicine and National Research Council, Committee on Cancer Survivorship: Improving Care and Quality of Life and the National Cancer Policy Board. From Cancer Patient to Cancer Survivor: Lost in Transition. Hewitt M, Greenfield S, Stovall E, eds. Washington, DC: National Academy of Sciences; 2006.

Conferences, seminars and on-line web-based CME courses are one way to become more familiar with the various characteristics and late effects of cancer and its treatments. Such courses are frequently offered through organizations such as:

- American Cancer Society
  www.cancer.org
- American Society for Clinical Oncology
  www.asco.org
- Live Strong: Lance Armstrong Foundation
  www.livestrong.org
- American Psychosocial Oncology Society (APOS)
  www.apos-society.org

Specific examples of provider educational opportunities include:

- Cancer Survivorship: A Distinct Phase of Cancer Care; Harvard Medical School Department of Continuing Education Online course; 2 AMA/PRA Category 1 credits. $40.00
- OB/GYN 1108: Online course includes a segment on: "Reproductive and Sexual Function in Long-term Ovarian Cancer Survivors After Platinum-based Chemotherapy", 2 AMA/PRA Category 1 credits. $20.00
  http://www.cmeweb.com/gcourse_view.php?course_id=67899

Other Patient Education and Resources:

Many local cancer centers have websites with survivor resources specific to their region and can be a valuable resource. It may be beneficial to look up the specific cancer resources in your area, in addition to those listed below.

- Regional Cancer Resource Directories: Capital Region Cancer Services Consortium. Capital Region Cancer Community Resource Guide. February, 2009.
- Adirondack Region Cancer Services Guide
    - Both of the above resource guides are available at the following website: www.nyscancerconsortium.org/resources/resources_documents.aspx

Clark, EJ, ed. Teamwork: The Cancer Patient's Guide to Talking with your Doctor. National Coalition for Cancer Survivorship. 2006. Available at: http://www.canceradvocacy.org/resources/publications/teamwork.pdf.

Facing Forward: Life After Cancer Treatment, National Cancer Institute
www.cancer.gov/cancertopics/life-after-treatment

Facing Forward: Ways You Can Make a Difference in Cancer, National Cancer Institute
www.cancer.gov/cancerinfo/make-a-difference

Facing Forward: When Someone You Love Has Completed Cancer Treatment, National Cancer Institute
www.cancer.gov/cancertopics/Facing-Forward-When-Someone-You-Love-Has-Completed-Cancer-Treatment

Gilda's Club
http://www.gildasclub.org

LiveStrong: Lance Armstrong Foundation. Strength as a Survivor: Living After Cancer Treatment brochure series (Resources for different ethnicity groups). 2006. http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661751/k.933B/Brochure_Series.htm

Living Fully with Cancer Conference; MD Anderson Cancer Center; held annually. Call: (800) 345-6324 or (713) 792-2553 for information.

Siga adelante: La Vida Después del Tratamiento del Cáncer, National Cancer Institute
www.cancer.gov/espanol/vida-despues-del-tratamiento