Red Flags in Caring for Cancer Survivors

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Introduction

The 13.7 million cancer survivors in the United States (American Cancer Society, 2013) today are living longer and experiencing many issues in their "new normalcy" of living post treatment. They are living longer because of the many advances in diagnosis and with treatment and their numbers are projected to grow to ~18 million by the year 2022 (American Cancer Society, 2013). Cancer survivorship numbers are also increasing internationally with 2012 estimates of the global number of cancer survivors within five years of diagnosis being 32.6 million (International Agency on Cancer Research, 2013). No matter the location, cancer survivors face many challenges, including at home and in the work place. Not all survivors are able to advocate for themselves; family members, caregivers, nurses, or others become their advocates. Patients with cancer and their families often try to learn all they can about their illness and its treatments. Once they enter the survivorship period, they may not know what questions to ask and who to ask.

The focus of cancer care today continues to be on cure, rather than the recognition that for many patients, cancer is a chronic disease. Current treatment options and improvements in medical care mean that patients are living longer and must contend with ongoing effects of cancer and its treatments. The paradigm must shift from *illness* to *optimum wellness*. A management model designed for improving outcomes for those living with chronic conditions can be used for cancer survivorship plan of care, as well (Improving Chronic Illness Care, 2004). The six elements of this model are (Improving Chronic Illness Care, 2004):

1. "Mobilize community resources to meet needs of patients.
2. Create a culture, an organization, and mechanisms that promote safe, high-quality care.
3. Empower and prepare patients to manage their health and health care.
4. Ensure the delivery of effective, efficient clinical care and self-manage support.
5. Promote clinical care that is consistent with scientific evidence and patient preferences.
6. Organize patient and population data to facilitate efficient and effective care."

Background

In July 2004, the Institute of Medicine (IOM) Committee on Cancer Survivorship came together to discuss how to improve and best serve cancer survivors in the United States, thereby improving survivors' health care and quality of life. They also reviewed the consequences of cancer and its treatment and concluded that they are substantial. In 2006, the IOM report on cancer survivors *From Cancer Patient to Cancer Survivor: Lost in Transition* was published. The IOM report includes further need for research and development of clinical practice guidelines for follow up, surveillance and management of treatment-related sequelae.

Evidence suggests that people who are diagnosed at advanced ages or with late-stage disease (e.g., lung cancer, pancreatic cancer) are not well-represented within the cancer survivorship support community. Screening tests influence the composition of the survivorship population and those living long-term with preclinical and treatable early-stage disease (Institute of Medicine, 2006).

The IOM report noted the four essential components of survivorship care are (Institute of Medicine, 2006):

1. Prevention and detection of new cancers and recurrent cancer
2. Surveillance for cancer spread, recurrence, or second cancers
3. Intervention for consequences of cancer and its treatment
4. Coordination among specialists and primary care providers (PCPs) to ensure that all of the survivors health needs are met (e.g., health promotion, immunizations, screening for cancer and noncancerous conditions, care of concurrent conditions)

Survivorship Care Needs

It is imperative that survivorship care is patient centered. Patients as survivors need to be heard, listened to, encouraged, taught, and instructed with up-to-date information with the goal of optimal wellness. Survivors need assistance and resources in accessing community support services. The IOM report states that "Optimal survivorship care is characterized by an organized plan for follow up that is shared with patients so they can take responsibility for their care" (Institute of Medicine 2006, p. 194).

Survivorship care can be provided by either a specialist or a PCP. Every patient needs a survivorship care plan following cancer treatment. This care plan should be developed and given to the patient by the time primary treatment ends. Today, many of the larger medical centers throughout the United States are using survivorship care plans. Some of these include Stanford Hospital and Clinics (Stanford, California), City of Hope National Medical Center (Duarte, California), The University of Texas MD Anderson Cancer Center (Houston, Texas), Memorial Sloan-Kettering Cancer Center (New York, New York), Dana-Farber Cancer Institute (Boston, Massachusetts), and Yale Cancer Center (New Haven, Connecticut).

With the National Comprehensive Cancer Network (NCCN) guidelines, more institutions are developing survivorship care plans and are offering survivorship clinics as part of their healthcare services for cancer survivors.

Survivorship care planning is also an integral part of several quality measures. In support of the importance of survivorship care planning, the American College of Surgeon's Commission on Cancer added Standard 3.3 to their accreditation standards, requiring cancer centers seeking

accreditation to "develop and implement a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment" (American College of Surgeons, 2013). The American Society of Clinical Oncology (ASCO) also includes survivorship quality indicators as part of their Quality Oncology Practice Initiative (QOPI) quality assessment and improvement program (American Society of Clinical Oncology, 2013c).

Resources such as National Cancer Institute (NCI) literature, CDs and downloadable resources, National Coalition For Cancer Survivorship (NCCS) Cancer Survival Toolbox, and the Lance Armstrong Foundation LIVESTRONG produce popular resources that have been widely distributed and published throughout the United States in major cancer centers, local regional hospitals, clinics, and oncology offices. These materials provide the necessary education, communication tools, and resources to assist cancer survivors in navigating the next phase in their journey.

Barriers to Effective Survivorship Care

Cancer survivors may face barriers that can affect their ongoing health and quality of life. Today's cancer survivors, as well as anyone else with a chronic disease, seek care in a fragmented delivery system. They face many challenges in obtaining medical care that is appropriate, efficient, and effectively meets their needs. The challenges faced are not just physical, but emotional, spiritual, and financial. One Canadian study found that more than one-third of cancer survivors surveyed after completion of treatment were not sure which physician was in charge of their cancer follow-up care (Miedema et al., 2003).

During a three-day nursing conference convened in 2005 to discuss the State of the Science concerning long-term impact of cancer treatments, much discussion was held on barriers that exist for cancer survivors (Houldin, Curtiss, and Haylock, 2006). These include:

- A fragmented delivery system: Patients with chronic conditions face obstacles in obtaining medical care that meets their needs.
- The lack of awareness of late effects of cancer and its treatments. Patients may not know what questions to ask or what to report to their PCPs as possible late effects. Some of the examples of this lack of awareness barrier include:
    - Female adult survivors of Hodgkin lymphoma treated at a young age with mantle irradiation are at high risk for subsequent cancer, but only 47% reported having had a mammogram in the past two years. As many as 40% of women were unaware of their increased risk.
    - Breast cancer survivors report knowing little about lymphedema before developing it, and physicians report not routinely giving counsel or any written information about lymphedema prevention.

    - Breast cancer survivors often do not recall discussing the reproductive health impact of their treatment, and many report their concerns are not adequately addressed.
    - Twenty-two percent of colorectal cancer survivors could identify risk indicators for recurrence, but most (64%) agreed that they would like to be told what to look for.
- Paucity of information about adult cancer survivors. More is known about the awareness of late effects among survivors of childhood cancer. The Childhood Cancer Survivorship Study looked at long-term effects of cancer treatments received as children. In this study, 635 adult survivors of childhood cancers were asked if treatments received in childhood could cause serious health problems in later life. Thirty-five percent answered affirmatively, 45% answered negatively, and 19% did not know (Kaden-Lottick et al., 2002). Only 15% stated that they received a written statement of their diagnosis and treatments to keep as a reference for the future.
- Barriers to communication between patient's expectations and physician's or healthcare provider's perceptions of cancer follow up. When follow up is done, not all components of survivorship care may be addressed. An added barrier exists if English is not the patient's primary language.

Barriers to optimal care for cancer survivors also exist and include (Houldin, Curtiss, and Haylock, 2006):

- Knowledge deficits on part of the health care professional.
- Knowledge deficits on the part of cancer survivors.
- Lack of awareness about survivorship issues on the part of the general public.
- Lack of nursing research to inform practice, education, and policy.
- Failure of society to value outcomes other than cure.
- Lack of clarity about roles and responsibilities for management of care.
- Lack of funding for survivor care.
- Lack of funding for survivorship research.

It has been only in the past six or seven years that cancer survivors have been increasingly informed and educated about symptom management, long-term effects, and what to report to their providers. More data about management of short- and long-term effects of treatment, quality-of-life and other survivorship issues are being collected by major cancer centers, the NCI and by the Centers for Disease Control and Prevention (CDC). Evidence-based guidelines are much needed, as is a national database for tracking the health of cancer survivors, identifying their needs, and providing education for providers, the public, and policy makers. Research is needed in this area in clinical practice outcomes, education, and policy.

Other gaps in survivorship research include effects in older adults, minorities, and other underrepresented populations, and the effects of culture and language on survivorship issues.

Survivorship Cost

The cost of both cancer care and survivorship care is a major factor in how they are delivered. Cancer is expensive. The National Institutes of Health (NIH) estimates the overall cost of cancer in 2010 was $263.8 billion dollars. According to the U.S. Census Bureau, 46 million Americans were uninsured in 2008; lack of health insurance prevents many from receiving optimal cancer care. Medicaid and Medicare continue to face cuts, further limiting access to care. Budget cuts affect everyone: the private and public sectors, clinicians, and consumers. The major research centers such as NCI, NIH, and the CDC have had their funding decreased as well. Survivorship research must compete with projects focused on curative treatments.

There is substantial work to be done. A national database will improve cancer care and outcomes for generations to come. Survivorship issues are in the hot seat and are finally being recognized! We as clinicians need to roll up our sleeves and educate ourselves as well as our patients, advocate for them, and involve ourselves in the political arena to influence policy making and funding.

Back to the Basics: What Is Cancer?

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not "contained" or stopped, it can result in host death. Normal cells go through a process of cell death due to DNA damage, which is called apoptosis. However cancer cells often do not have this built in mechanism. Cancers are then able to continue to grow and metastasize (spread).

Cancer may be caused by environmental or biologic factors. Environmental factors include tobacco or alcohol use, certain infectious organisms [e.g., hepatitis B or C, human papillomavirus (HPV), HIV, and *helicobacter pylori*, exposure to certain chemicals or ionizing radiation]. There is good evidence that obesity is a risk factor for the development of cancers of the colon, breast (postmenopausal), endometrium, kidney, and esophagus. Some studies have also reported links between obesity and cancers of the gallbladder, ovaries, and pancreas (National Cancer Institute, 2004). Biologic factors include inherited mutations, hormonal factors, immune conditions, and mutations that occur during cell division. These factors may act in concert to promote carcinogenesis, but not all those with risk factors will go on to develop cancer. People who have a strong family history of cancer are at higher risk for developing cancer than the general population, even if they may not have a known genetic mutation. About 5% of all cancers are strongly hereditary (National Cancer Institute, 2010).

The number of people in the United States with a history of a cancer diagnosis continues to rise. As stated previously, 2012 estimates shows 13.7 million Americans to be living with a history of cancer. Cancer is the second most common cause of death in the United States, exceeded only by heart disease. About 1,660,290 new cancer cases are expected to be diagnosed in 2013. The 5-year relative survival rate for all cancers diagnosed between 2002-2008 is 68%, which is up from 49% in 1975-1977. The improvement reflects both progress in diagnosing certain cancers at an earlier stage and improvements in treatment (American Cancer Society, 2013).

Currently, one in four deaths in the United States is due to cancer; however, death rates due to lung, breast, colorectal, and prostate cancers are decreasing. Lung cancer in men and breast cancer in women each account for more than one-third of the sex-specific decreases in cancer death rates. The decrease in lung cancer death rates is due to the reduction in tobacco use over the past 50 years. The decrease in deaths due to female breast cancers, colorectal, and prostate cancers is largely due to improvements in screening, early detection, and treatment (American Cancer Society, 2013).

Regular screening examinations are vital for early detection and prompt treatment of cancer. Health promotion interventions aimed at smoking cessation and abstinence from alcohol and other substances of abuse can reduce the risk of developing lung, liver, and other cancers. Immunizations for hepatitis B protect against hepatocellular cancers whereas immunization for HPV protects against cervical, anal, and some head and neck cancers. Infection with *Helicobacter pylori* have been implicated in the development of gastric mucosa-associated lymphoid tissue lymphoma, eradication of the infection may be the only treatment needed. Many skin cancers may be prevented by use of sunscreen and avoiding tanning bed use.

Lifetime risk refers to the probability that an individual over the course of a lifetime will develop or die from cancer. In the United States, men have a slightly less than a 1 in 2 lifetime risk of developing cancer (44%); for women, the risk is a little more than 1 in 3 (38%). Relative risk is a measure of strength of the relationship between risk factors and a particular cancer (American Cancer Society, 2013).

Survivorship

The definition of cancer survivor has changed over time. Historically, few types of cancer were considered curable; most of these “cures” were in childhood leukemia and Hodgkin lymphoma. In the first edition of the textbook *Cancer Nursing: Principles and Practice*, patients were considered cancer survivors if they had remained free of disease for five or more years after diagnosis (Groenwald, 1987). Advances in early detection and treatment mean that more cancers are curable. Others, while not curable, can be controlled and have become chronic illnesses.

Cancer survivorship is now defined as the period from the time of diagnosis until the end of life (National Cancer Institute, 2013). The National Coalition for Cancer Survivorship definition is very similar and is as follows: “From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor” (2013).

More patients are long-term survivors of cancer. The most recent data available from the American Cancer Society indicates that 64.8% of cancer survivors have lived five or more years after their cancer diagnosis (American Cancer Society, 2013). The most common diagnoses among cancer survivors are breast, prostate, and colorectal cancers. Long-term survivors face many challenges as they transition from active treatment to living the rest of their lives. Being a cancer survivor means finding a “new normal” that is often vastly different from life before cancer.

Cancer Myths

It is important to acknowledge the cancer myths that patients and their families encounter because these myths can hinder the transition from patient to survivor. Many people believe they have done something to cause their cancers. The links between smoking and lung cancer and HPV and cervical cancer are well researched, but other causative factors are not as well defined. It is important to remember that not all patients with risk factors for the development of these cancers actually develop them. Here is a list of common cancer myths (American Society of Clinical Oncology, 2013a):

- Cancer is contagious.
- Deodorants and antiperspirants cause breast cancer.
- Artificial sweeteners cause cancer.
- The number of people diagnosed with and dying from cancer is increasing.
- Cancer is a death sentence; people always die of their cancer.
- Children of a patient with cancer will develop cancer, too.
- Hair dyes cause cancer.
- People who develop cancer have weak immune systems.
- Positive thinking will cure cancer.
- The medical establishment is hiding the cure for cancer.
- Older adults cannot get cancer treatment.
- Sugar makes cancer grow faster, so patients with cancer must avoid sugar.
- People being treated for cancer must be hospitalized to receive treatment.
- Only smokers get lung cancer.
- Dark skinned people never develop skin cancer.
- Children and young people do not develop cancer.

The Early Survivorship Period

The early survivorship period encompasses the period from diagnosis through the end of active treatment. During this period, patients often focus on two main concerns: (a) cancer recurrence and (b) ongoing effects of treatment. The risk of cancer recurrence for solid tumors, such as breast cancer is highest in the first two to three years after treatment and remains higher than that of the general population for several more years. Indolent lymphomas and chronic leukemia, although not curable, respond to treatment and are stable diseases for varying periods of time before requiring retreatment. Patients may also develop second and higher order primary cancers. These may be due to treatments or other factors, which led to the development of the initial malignancy. Screening for recurrence and secondary malignancies will be discussed in a later section.

After Effects of Treatment

Cancer survivors and their families are often surprised by the magnitude and duration of treatment side effects. Many patients describe themselves as healthy prior to their cancer diagnosis, which may seem to have come "out of the blue". Their prior illness experience is often with time-limited illnesses that resolve fairly quickly and without sequelae. The cancer experience is vastly different from this: it is life-threatening and includes unfamiliar treatment modalities (such as chemotherapy and radiation therapy) that have significant short-term and long-term effects.

Acute effects are those that happen during treatment or shortly thereafter. Many cancer survivors are familiar with chemotherapy side effects, but may not realize that other treatment modalities may have significant acute side effects. Some treatment side effects become chronic, lasting long after the completion of treatment. Some effects do not become apparent until long after treatment ends; these are referred to as late effects. Table 1 outlines some of the common acute, chronic, and late effects of various treatment modalities.

TABLE 1. Acute, Chronic, and Late Effects of Cancer Treatments

Body System	Chemotherapy Effects	Endocrine Therapy	Biotherapy Effects	Radiation Effects	Surgical effects
Hematopoietic	Neutropenia, anemia, thrombocytopenia, bone marrow suppression	Anemia	Neutropenia, anemia, thrombocytopenia	Same	Blood loss
Endocrine	Hot flashes, premature	Hot flashes,		Hypopituitarism,	Sexual dysfunctio

	menopause, osteoporosis, infertility	irregular menses, testicular atrophy, adrenal insufficiency		hypothyroidism hot flashes, premature menopause, osteoporosis, infertility	n or loss of function, surgical menopause
GI	Nausea, vomiting, taste changes, mucositis, constipation, diarrhea	Nausea, vomiting, diarrhea, liver injury or liver failure	Nausea, vomiting, diarrhea, GI bleeding, elevated transaminases, anorexia	Nausea, vomiting, dry mouth, taste changes, swallowing problems, enteritis, proctitis	Short bowel syndrome, ostomy, dumping syndrome, adhesions,
Skin/Integument	Dry skin, nail changes, pigment changes, hand-foot syndrome, alopecia, radiation recall	Injection site pain	Rash, hives, pruritus, dry skin,	Burns, pigment changes, thickening of tissues, alopecia in radiation field, lymphedema	Scars, Infections, lymphedema
Cardiovascular	MI, CHF, cardiomyopathy, coronary artery disease	MI, CVA, DVT, PE, edema, elevated cholesterol	CHF, cardiomyopathy, thromboembolism, hypotension, hypertension,	Atherosclerosis, conduction abnormalities	
Respiratory	Pulmonary fibrosis, interstitial lung disease, hypersensitivity	Shortness of breath	Dyspnea, bronchospasm, hoarseness,	Radiation pneumonitis, pulmonary fibrosis	Loss of lung volume after lung resection

	pneumonitis, pulmonary edema				
GU	Cystitis, renal failure, impotence, infertility, irregular menses, decreased libido	Irregular menses, vaginal bleeding, loss of libido, impotence, hot flashes, breast pain or tenderness	Proteinuria, renal failure, renal insufficiency	Cystitis, enteritis, proctitis, vaginal stenosis, fistulas, fibrosis of ureters	Altered sexual functioning
Musculoskeletal	Weakness, fatigue,	osteopenia, osteoporosis, osteonecrosis of the jaw, bone or joint pain, arthritis, increased fracture risk	Fatigue, asthenia, bone or muscle pain,	Decreased function due to induration/scarring	Amputations, scarring, altered body image, phantom limb pain
Nervous system	Peripheral neuropathy, chemo brain,	Depression, mood swings, insomnia	Peripheral neuropathy	Cognitive problems with brain irradiation	Acute postop pain, post-mastectomy pain, neuropathic pain
Special senses	Hearing loss, conjunctivitis, tear duct	Cataracts		Vision loss if eye in radiation field	

	stenosis				
Other late effects	Second or higher order cancers		Leukemia, myelodysplastic syndromes	Second cancers	
Note. Based on information from the American Society of Clinical Oncology, 2013b.					

The Post-Treatment Phase of Cancer Survivorship

This period starts when treatment has ended and the patient has recovered from acute treatment effects; it lasts for the remainder of the patient's life. The risk for recurrence for many cancers is highest in the first two or three years after treatment, and lessens with the passage of time. The oncology practice performs screening for recurrence for the first few years after treatment ends. The interval between appointments is short during the first year and gradually lengthens over time. Patients may see their oncologist yearly once they reach the fourth or fifth year after treatment. It is important to remember that patients remain at risk for recurrence for a number of years after treatment, depending on the particular cancer involved.

Surveillance and Screening

Surveillance for cancer recurrence includes an interval patient history and physical and symptom review at each visit. It may include laboratory tests or imaging studies; such as computed tomography (CT) or positron emission tomography/CT scans. The surveillance procedure varies, depending on the type of cancer, its stage, and institutional policies. The American Society of Clinical Oncology (ASCO) and NCCN have published guidelines for surveillance; these are available online.

Patients and their families often ask for laboratory tests and imaging studies to reassure themselves that the cancer has not returned. Testing at intervals has a role for surveillance for some types of cancer, but not for all. For example, routine monitoring of CA-125 in ovarian cancer survivors is now considered optional because women with relapsed ovarian cancer who receive chemotherapy based on a rising CA-125 level only do not live any longer than those women whose treatment was delayed until they developed symptomatic disease (Salani et al., 2011). It is important to educate patients and families regarding the risks and benefits of these tests. Imaging tests may give false positive results, necessitating further testing and increasing anxiety. Imaging studies also expose patients to radiation; unnecessary studies increase both cumulative radiation exposure and risk to the patient without clear benefit (Desch et al., 2005; Khatcheressian, 2006). Table 2 lists recommended laboratory and imaging for common cancers.

TABLE 2. Recommended Laboratory and Imaging Tests for Surveillance for Selected Cancers

Type of Cancer	Tests	Frequency
Breast	H & P Mammogram	Every 4-6 months for 5 years, then annually Yearly
Lymphomas (varies among specific lymphoma types)	H& P with CBCD, LDH CT, PET/CT	Every 3–6 months for 5 years, then annually No more than every 6 months for 2 years, then no more than annually for total of 5 years, then as clinically indicated
Colorectal	H&P with CEA Colonoscopy CT chest/abdomen/pelvis PET/CT	Every 3–6 months for 2 years, then every 6 months for total of 5 years 1 year after completion of treatment (in 3–6 months if no preoperative colonoscopy done due to obstructing lesion)with additional procedures based on findings Yearly for 5 years if high risk for recurrence Not routinely recommended
Lung, Non-small cell	H & P with CT chest +/- contrast	Every 6-12 months for 2 years, then annually

	PET / MRI	Not routinely recommended
Prostate, after initial definitive treatment Node-positive or metastatic	H&P with PSA DRE H&P with PSA	Every 6–12 months for 5 years, then annually Every year but may be omitted if PSA undetectable Every 3–6 months
Ovarian	H&P CA-125	Every 2-4 months x 2 years, then 3-6 months for 3 year, then annually for total of 5 years Optional (Salani et al., 2011) Every visit if initially elevated (NCCN)

CA—cancer antigen; CBCD—complete blood count with differential; CEA—carcinoembryonic antigen; CT—computed tomography; DRE – digital rectal exam; H&P – history and physical examination; LDH—lactate dehydrogenase; MRI – magnetic resonance imagery; PET—positron emission tomography; PSA—prostate-specific antigen

Note. Based on information from Salani et al., 2011; National Comprehensive Cancer Network, 2013a; National Comprehensive Cancer Network, 2013b; National Comprehensive Cancer Network, 2013e; National Comprehensive Cancer Network, 2013f; National Comprehensive Cancer Network, 2013g; National Comprehensive Cancer Network, 2013h; National Comprehensive Cancer Network, 2013i.

Other Components of Survivorship Care

Survivorship care includes much more than surveillance for recurrence; it also includes surveillance for and management of lasting physical and psychosocial effects of cancer treatments, screening for new cancers in both the patient and family, and health and wellness promotion. This type of care requires an alliance among PCPs and a variety of others healthcare teams, including oncology, nursing, physical and occupational therapy, social work, and mental health. PCPs are often involved in management of many of the long-term side effects of cancer treatment, but may not be entirely comfortable with this (Bober et al., 2009). It may be difficult to tease out which complaints are treatment-related and which are not. The reader is referred to a summary of late effects of cancer treatments from the Institute of Medicine 2005 report *From Cancer Patient to Cancer Survivor: Lost in Transition*. Psychosocial effects of treatment will be discussed in another section.

Screening for and Management of Lasting Physical Effects of Cancer Treatments

It is not always easy to see the connection between cancer treatments and problems experienced long after treatment ends. PCPs are well versed in screening for chronic diseases and will find that screening for late effects in cancer survivors includes much of what they already do, but starts at younger ages.

Hematopoietic Stem Cell Transplantation Effects

Bone marrow suppression is a well-known acute effect of many chemotherapeutic agents. Cancer survivors may require treatment for relapses and may receive several different chemotherapy regimens over the course of several years. Repeated courses of chemotherapy may cause damage to the bone marrow, resulting in various cytopenias. Patients may develop secondary myelodysplastic syndromes as a result of prior chemotherapy or radiation therapy. Some of these may be resistant to treatment and may progress to acute leukemia.

Lymphedema

Lymphedema is often associated with mastectomy and axillary lymph node dissection; patients may not realize that it can occur in other areas of the body as well. Risk factors for the development of lymphedema include surgery and radiation to lymph node bearing areas or tumor involvement of lymphatic tissues. Treatment of lymphedema includes compression garments or wraps, mobilization of lymph fluid through massage, and treatment of pain associated with the condition. Patients may experience a neuropathic component to the pain; gabapentin, pregabalin, or tricyclic antidepressants may be helpful.

Cardiovascular System

Patients who have had breast or chest wall radiation are at risk for early development of atherosclerosis and cardiac conduction abnormalities. Certain chemotherapeutic agents, such as

doxorubicin and cyclophosphamide, and biologic agents, such as trastuzumab may lead to the development of heart failure. Decreases in left ventricular ejection fraction due to trastuzumab often reverse once the drug is stopped; however, impairment due to doxorubicin is usually permanent. Survivors of testicular cancer may develop hypercholesterolemia and hypertension at younger ages and should be screened for these once treatment has finished.

Respiratory System

Many chemotherapy and biotherapy agents affect the respiratory system. Some acute toxicities are reversible with prompt discontinuation of the offending agent, but some of the damage due to chemotherapy and biotherapy is irreversible and progressive. The most common late toxicities are interstitial fibrosis and pneumonitis; these may occur up to 10 years after treatment. Smoking, renal dysfunction, multidrug regimens, and concurrent radiation therapy all increase the risk of pulmonary injury. Signs and symptoms of pulmonary toxicities include dyspnea, tachypnea, fatigue, poor exercise tolerance, dry cough, crackles or rhonchi, and restlessness. Pulmonary function testing (including the diffusing capacity of the lung for carbon monoxide) is useful for detecting changes before symptoms develop. Treatment of these toxicities is focused on symptom management. There are conflicting reports of high-flow oxygen therapy worsening pulmonary toxicity due to bleomycin; those patients treated with this drug should discuss this with all providers, especially if procedures requiring inhalation anesthesia are contemplated.

Oral and Gastrointestinal Effects

Radiation therapy for head and neck cancers causes fibrosis of tissues, xerostomia, swallowing difficulties, and permanent taste changes. Decreased saliva leads to accelerated gingival disease and tooth loss; radiation therapy also leads to osteonecrosis which may be a factor in tooth loss. Use of sialagogues and artificial saliva can be helpful. The use of bisphosphonates is implicated in the development of osteonecrosis of the jaw; clinicians must be alert to complaints of jaw and tooth pain in these patients. Routine dental care, preferably by a dentist experienced in the treatment of radiation effects, is necessary. Taste changes, dysphagia, and limited mouth opening can all lead to weight loss; referral to a dietician can be helpful.

Patients who have undergone abdominal, pelvic, lower thoracic, or lumbar spine irradiation are at risk for developing radiation enteritis and are at risk for dehydration, malabsorption, and metabolic disturbances. Symptoms often occur shortly after eating and are unpredictable; which may lead to the patient becoming homebound. Dietary modifications, such as increased fiber intake and avoidance of problem foods; and use of antidiarrheal agents are helpful in controlling symptoms.

Surgical resection of bowel may lead to a malabsorptive diarrhea with a decrease in the absorption of electrolytes and bile salts. Short bowel syndrome occurs when 200 cm or more of bowel is resected (Coleman, 2010). Patients who have had partial gastrectomies may experience

dumping syndrome. Symptoms of dumping syndrome include facial flushing, lightheadedness, fatigue, and postprandial diarrhea following consumption of sugars and processed starches (Lee, Kelly, & Wassef, 2007). Dietary modifications and supplementation of fat-soluble vitamins are often necessary.

Treatment-related causes of constipation include adhesions due to surgical procedures, narrowed intestinal lumen due to surgery or radiation, and autonomic neuropathy due to chemotherapy. Taxanes, vinca alkaloids, platinum analogs, epothilones, proteasome inhibitors, and thalidomide are all associated with the development of peripheral neuropathy. Patients who have preexisting neuropathy due to diabetes or chronic alcohol use are at higher risk for chemotherapy induced peripheral neuropathy.

Musculoskeletal Effects

Many cancer survivors are at risk for osteoporosis related to hormonal manipulation of their cancers. It is well known that postmenopausal women are at risk for developing osteoporosis due to the loss of estrogen and its protective effects on bone density; women who have had oophorectomies are at risk for the development of osteoporosis at earlier ages than had they gone through natural menopause. Aromatase inhibitors often decrease bone density. This effect is most pronounced in the first two years of use, so bone density measurements should be done prior to starting these drugs and after six months to one year of use. Tamoxifen and other selective estrogen receptor modulators preserve bone density; tamoxifen may be the endocrine therapy of choice for postmenopausal women with preexisting osteopenia or osteoporosis. Men treated for prostate cancer with androgen deprivation therapy or orchiectomy and men treated for testicular cancers are also at risk for the development of osteoporosis and should be screened.

Steroids, such as prednisone and dexamethasone, are used in some chemotherapy regimens and may lead to the development of osteoporosis, avascular necrosis, and other long-term effects. All patients at risk for osteoporosis should be encouraged to get adequate amounts of calcium and Vitamin D, either through diet or supplementation. Those with osteopenia or osteoporosis usually require treatment with bisphosphonates or other bone-strengthening medications. Osteonecrosis of the jaw is a possible complication of bisphosphonate treatment. Patients on bisphosphonates should have thorough periodic dental examinations and inform providers immediately if experiencing jaw or tooth pain.

Endocrine and Neuroendocrine Effects

Patients and healthcare providers are aware that chemotherapy, surgery, radiation therapy, and hormonal therapies may result in infertility, but may not be familiar with the range of effects on the endocrine system as a whole. It is well known that postmenopausal women are at increased risk for hyperlipidemia, and coronary artery disease due to the loss of the protective effects of estrogen. Women who experience premature menopause as a result of cancer treatment may

experience these problems at earlier ages than their peers and should begin screening earlier than the general population. Testosterone deficiency in men resulting from orchiectomy and androgen deprivation therapy also predisposes them to the development or worsening of hyperlipidemia and should be screened and treated. Testicular cancer is often diagnosed in men in their 20s or early 30s; screening for cardiovascular disease and hyperlipidemia should start approximately five years after treatment is completed (Efstathiou and Logothetis, 2006)

Cranial irradiation and surgical resection of tumors often damages the pituitary gland, leading to hypopituitarism. Some chemotherapeutic agents, glucocorticoids, megestrol acetate, and interferon may also cause pituitary dysfunction. Growth hormone deficiency is often the earliest manifestation of pituitary dysfunction and causes reduced bone mineral density, decreased lean mass, increased adiposity, abnormal lipid profiles, and insulin resistance. Hyperprolactinemia is also implicated in the development of osteoporosis, as well as menstrual irregularities, erectile dysfunction, and insulin resistance. Damage to the hypothalamus-pituitary-thyroid axis from cranial irradiation also results in central hypothyroidism and gonadotropin deficiency. Adrenocorticotropic hormone deficiency is one of the least common, but most serious of the pituitary hormone disorders resulting from cranial irradiation or prolonged glucocorticoid therapy. Patients at risk for treatment-associated hypopituitarism should be screened periodically after completion of treatment and treated for any deficiencies.

Primary hypothyroidism may result from cranial and neck irradiation, or from various drugs used in cancer treatment. Drugs implicated in hypothyroidism include cytokines (e.g., interferon-alfa), tyrosine kinase inhibitors (e.g., sunitinib), retinoids, exemestane, and some combined antineoplastic regimens (e.g., cisplatin, etoposide, and bleomycin for testicular cancer). Thyroid stimulating hormone (TSH) (with FT_4 for abnormal TSH levels) should be checked every 6–12 months in survivors at risk for developing primary hypothyroidism.

Peripheral Neuropathy and Other Chronic Pain Syndromes

Chronic pain syndromes may be the result of surgery and radiation therapy; often a neuropathic component exists. Breast cancer survivors treated with breast-conserving surgery and radiation therapy may experience breast pain lasting long after treatment ends. Peripheral neuropathy (PN) may be caused by chemotherapy (taxanes, vinca alkaloids, platinum analogs, epothilones, proteasome inhibitors, thalidomide and lenalidomide) or direct injury to nerves from surgery, radiation therapy or adhesions. It is worse in those with preexisting neuropathies (e.g., diabetic, alcoholic, nerve injuries). Taxane-induced PN usually improves over time and may completely resolve about a year after completion of treatment. There may be incomplete resolution of PN in patients with diabetes mellitus or preexisting neuropathies. Treatments for PN include opioids (often at higher doses than for non-neuropathic pain), gabapentin or pregabalin, Lidoderm, tricyclic antidepressants, and duloxetine. Many providers are familiar with the sensory component of PN. However, some patients may present with PN that is predominantly an

autonomic neuropathy, as noted above. Treatment of autonomic neuropathy may include motility agents.

Healthcare Maintenance and Screening for Second Cancers

Health and wellness promotion is important for all survivors. Healthy diet, weight management, and exercise enhance well-being and reduce the risks of developing diabetes, cardiovascular disease, other chronic diseases, and second cancers. Smoking and alcohol use are implicated in the development of some cancers; smoking cessation and counseling regarding alcohol use can help reduce the risk. Many survivors have ongoing pulmonary effects of treatment and should have yearly influenza immunizations, as well as periodic immunization against pneumococcus. Those who have had stem cell transplants require immunization, usually beginning three to six months after transplantation.

Screening for Second Cancers

Second and higher order primary cancers often occur several years, even decades, after treatment for the primary cancer. There is little question that younger cancer survivors should undergo screening for second cancers, but there is not necessarily a consensus regarding screening for second primaries when the cancer survivor is an older adult. The concern is that older patients may not tolerate treatment as well as younger individuals. Age should not be the only criteria on which to make screening decisions; performance status can be more important than age in determining if a particular individual is a candidate for treatment if a second primary is found. Not all survivors embrace screening for second cancers. It is important for patient and provider to thoroughly discuss all concerns and to periodically revisit the issues. Patients who have recently completed difficult treatment regimens may initially decide that they will never undergo such treatment again, but may feel differently when faced with a new cancer.

The timing of screening for secondary cancers depends on a number of factors. It is often difficult to tease out which of these are caused by cancer treatments versus genetic, environmental, and other factors that may have led to the development of the initial malignancy. Family history may suggest the presence hereditary predisposition to certain cancers, as can age at diagnosis. Patients whose cancers occur at younger ages than usual or whose families contain cancer clusters should be referred for genetic counseling and testing. Genetic testing may reveal mutations (e.g., *BRCA* mutations, Lynch syndrome), which may alter treatment decisions. Women with certain *BRCA* mutations may be advised to consider prophylactic mastectomy or oophorectomy to reduce the risk of developing new primaries. The presence of a mutation is often important in guiding screening and risk reduction for siblings or children of cancer survivors. Guidelines for screening and risk reduction are available from NCCN, ASCO, and other organizations.

The risk of cancer recurrence is higher in the first few years after treatment, whereas second primaries may not manifest themselves for many years. Screening for recurrence is considered part of surveillance, whereas screening for new primaries is considered secondary screening. They both occur along a continuum as part of cancer survivorship. The same modalities are used to screen for both recurrence and secondary cancers.

TABLE 3. Sites and Types of Second Primary Cancers

Primary cancer	Second Primary Sites
Head and neck (squamous cell)	Aerodigestive tract (same site as primary; lung, esophagus, GI tract, liver, pancreas, bladder).
Breast	Breast; other cancers (ovarian, colon, bladder if Lynch syndrome or other familial cancer syndromes; ovarian or breast if *BRCA1* or *BRCA2*)
Hodgkin lymphoma	Lung, breast, bone, stomach, colon, thyroid, melanoma, acute leukemias, non-Hodgkin lymphomas
Testicular germ cell tumors	Lung, colon, pancreas, stomach
Note. Based on information from National Comprehensive Cancer Network, 2013a; National Comprehensive Cancer Network, 2013d; National Comprehensive Cancer Network, 2013e; National Comprehensive Cancer Network, 2013j.	

Certain treatment modalities increase the risk of secondary primary cancers in cancer survivors.

Anthracyclines/Herceptin

The anthracyclines can cause cardiac toxicity because of oxidative stress of the myocardial cells, which will induce apoptosis (Arozal et al., 2011). This can lead to congestive heart failure, arrhythmias, and left ventricular dysfunction. Because of the cardiotoxic effects of these agents, they have a maximum cumulative dose. If the cumulative dose exceeds above the maximum dose established for each agent the probability of developing cardiac dysfunction increases greatly. Preexisting cardiac disease can also increase a person's risk for progression of the already underlying disease. Therefore if at all possible, these agents should be avoided or careful monitoring of cardiac function must occur during administration. Other agents not in the anthracycline family can increase the risk of cardiac dysfunction so other agents with cardiotoxicities should be avoided. If cardiac toxicities do occur with anthracycline therapy,

leave are often not reversible. Finally, side effects may not present immediately during exposure to the agents but may occur years after therapy has completed. One study looked at the protective effect of carvedilol and lovastatin in vivo. This has not been replicated in humans at this time. Further studies are necessary (Arozal et al., 2011; Huelsenbeck et al., 2011).

The mechanism of trastuzumab cardiotoxicity is still unclear. HER2 signaling has been found to play a critical role in the embryonic development of the heart. If this pathway is blocked the heart is not able to repair. When other cardiotoxic chemotherapy agents are administered, HER2 expression increases, causing an anti-apoptotic effect. With the HER2 inhibition via trastuzumab, the response to cardiac damage is impaired and cardiac dysfunction occurs. Trastuzumab-related cardiac dysfunction is different from chemotherapy-induced cardiac dysfunction in that it does not generally cause death and is reversible once the drug is stopped. If cardiac dysfunction does occur with the administration of trastuzumab, once the agent is discontinued cardiac function will usually recover to normal, and the agent can often be restarted (Carver et al., 2007)

Cardiac function should be monitored with echocardiogram looking at ejection fraction for all patients receiving cardiotoxic chemotherapy. Currently, this is the only standardized testing (Carver et al., 2007). However, it has also been reported that cardiac magnetic resonance imaging (MRI) may be able to detect preclinical cardiac changes earlier than conventional echocardiogram. Studies are also looking at the use of biomarkers such as brain neutriarectic peptides, and troponins that may indicate myocyte damage earlier (Horacek et al., 2010; Ky & Carver, 2011).

Bleomycin

Bleomycin has been known to cause pulmonary toxicity and Raynaud phenomenon. Injury of the alveolar capillary barrier, neutrophil accumulation, and induction of pro-inflammatory cytokines in turn causes pulmonary fibrosis. Because of the risk of pulmonary fibrosis, the maximum lifetime dose is 400 units. If patients who have received bleomycin must undergo surgical procedures with administration of anesthesia, the use of high-dose oxygen therapy must be limited to reduce the risk of postoperative ventilation failure. High levels of oxygen are used during scuba diving, so this activity should also be limited or avoided (Zaniboni, Prabhu, & Audisio, 2005).

The risk for Reynaud phenomenon is not well understood. The cause is thought to be due to oxygen radical's release, which in turn causes ischemia in poorly oxygenated areas. It is thought to also be related to rate of infusion. There have been some case reports of gangrenous digits after the administration of bleomycin (Chaudhary & Haldas, 2003).

Platinum-Based Agents

Renal toxicities are associated with the platinum-based agents especially cisplatin. Cisplatin is turned into a much more potent toxin, which in turn causes cell apoptosis, inflammation, and necrosis. To ensure that long-standing renal insufficiency does not occur, careful monitoring of renal function and electrolytes and administration of diuretics and fluids are imperative during treatment. However, patients may still develop long-term renal insufficiency despite these measures. Close monitoring and consultation with a nephrologist is recommended. Optimization of renal function, avoidance of nephrotoxic agents, and strict management of comorbidities that can contribute to renal insufficiency, such as hypertension and diabetes, are necessary (Polovich, Whitford, & Olsen, 2014).

Immunomodulators

The uses of lenalidomide and thalidomide have been associated with an increased risk of developing secondary malignancies such as lymphomas and acute myeloid leukemia. Ongoing studies are continuing to look into this phenomenon (Ormerod, Fausel, Abonour, & Kiel, 2011).

Taxanes

The taxanes can cause peripheral neuropathies. This is often dose dependent. Other underlying comorbidities (e.g., diabetes, alcoholism, nutritional deficits) can also influence the development of peripheral neuropathies. Combining agents with overlapping peripheral neuropathy should also be avoided. In most cases if the drug is stopped or dose reduced, the neuropathies will resolve without any other intervention. Current studies are ongoing looking at the use of glutamine and glutathione in peripheral neuropathy treatment. Safety modifications to reduce falls due to decreased proprioception and deep tendon reflexes should be employed (Polovich, Whitford, & Olsen, 2014).

Vinca Alkaloids

Mixed sensory and motor neuropathies are often dose limiting and may continue to worsen even after agent discontinuation. Constipation, mega colon, and paralytic ileus have occurred due to the autonomic neuropathy (Polovich, Whitford, & Olsen, 2014).

Alkylating Agents

These agents are known to cause gonadal dysfunction, which can affect both hormones and fertility. Men may experience oligospermia/azoospermia. Women may experience oligomenorrhea, amenorrhea, or premature menopause. In both men and women, this may lead to infertility. Depending on the agent and a woman’s age at treatment, premature menopause may occur (Polovich, Whitford, & Olsen, 2014).

Cyclophosphamide has been associated with bladder cancer development. This may be due to the rapid proliferation of urothelial cells observed in hyperplastic urothelium caused by

cyclophosphamide expose. The lowest dose of the agent should be used, and those patients who have received more than 20 grams of cyclophosphamide should undergo routine urinalysis every three to six months to screen for microhematuria (Vlaovic & Jewett, 1999). It has also been associated with the development of acute leukemia in patients treated with cyclophosphamide for lymphomas (Ng, La Casce, & Travis, 2011).

Rituximab

One study showed an increase risk for myelodysplasia or acute leukemia with the addition of rituximab to high sequential therapy for lymphoma patients. There was also an increased risk of solid tumors (Tarella et al., 2010).

Bone Marrow Transplant

Patient who have received allogeneic bone marrow transplants are at risk for secondary malignancies along with graft versus host disease. The most common is nonmelanoma skin cancers and squamous cell cancer of the buccal cavity. The risk is highest in the older adult population (Hasegawa et al., 2005).

Management of Long-Term Side Effects

Thyroid Screening

Patients who have undergone radiation therapy to the neck for lymphoma, head and neck malignancies, or radioactive iodine will need to have lifelong monitoring for thyroid dysfunction. TSH should be monitored every six months. Treatment should be based on TSH level and patient symptomatology. All patients should be treated with hormone replacement for TSH greater than 4.5 with or without apparent side effects (Munyo-Estefan et al., 2009; Ng et al., 2011).

Cognitive Impairment

Cognitive impairment is commonly referred to by many patients, survivors, and providers as “chemobrain.” Very little is known about the prevalence, duration, or long-term issues of cognitive impairment. It can have a profound impact on the quality of life after treatment has been completed. Currently, little evidence supports effective cognitive impairment management. Some studies have tested the use of psychostimulants but have failed to show benefit (Raffa, 2011). Other studies have looked at the use of cognitive training, but these have been small samples and lacked a comparison group. More randomized controlled studies are needed to examine at effect evidence based interventions. If patient’s symptoms worsen or they are having a profound impact on everyday life, a referral to a neuropsychologist may be necessary so that a comprehensive cognitive assessment can be completed (Polovich, Whitford, & Olsen, 2014; Raffa, 2011).

Neurologic Impairment

Chronic peripheral neuropathies can have a profound impact on quality of life. Adequate pain management must be optimized. The use medications such as topical lidocaine, neuroleptics and opiate may be necessary for adequate pain control. These patients will most likely benefit from a pain management or neurology consult. Patients are also at risk for falls and injury due to proprioception and temperature changes. Referral to physical therapy may be beneficial (Polovich, Whitford, & Olsen, 2014).

Ocular and Auditory

For patients who have been treated with busulfan, long-term steroids, cranial radiation, or tamoxifen should undergo annual eye examinations to screen for cataracts. Cisplatin, high-dose carboplatin or ear irradiation, may also have a long-term effect on hearing. If hearing loss occurs after treatment with cisplatin, the patient should undergo and audiology evaluation (Polovich, Whitford, & Olsen, 2014).

Oral Cavity

Patients who experience dry mouth after radiation therapy have a risk of dental caries due to lack of saliva. Measures to help promote saliva production such as prescribing pilocarpine can be initiated. To reduce the development of dental caries, biannual dental examinations should be completed and fluoride treatments should be initiated (Polovich, Whitford, & Olsen, 2014).

Cardiovascular

All patients who have received cardiotoxic agents should undergo serial echocardiograms every year to assess function. If patients have received cardiotoxic agents and continue to experience cardiac issue, they should be referred to cardiology work up. They will most likely need to undergo echocardiogram, EKG, and possible cardiac catheterization (Polovich, Whitford, & Olsen, 2014). All patients who have received cardiotoxic agents should undergo routine laboratory studies to assess lipid profile. They also should be monitored for hypertension and signs of congestive heart failure. If patients have hypertension or dyslipidemia, they should be managed appropriate with health behavior modification such as diet and exercise. Medical management may also be necessary. If patients experience signs and symptoms of congestive heart failure, immediate referral to a cardiologist is warranted. Patient who have also undergone radiation to the neck are at risk of developing carotid stenosis. Currently, patients should undergo carotid artery ultrasounds every two to three years or if symptoms warrant evaluation.

Pulmonary

Patients who have received pulmonary toxic agents should have pulmonary function test routinely and for any new pulmonary symptoms. If there are changes in pulmonary status,

referral to a pulmonologist should be made so that pulmonary status can be optimized. For those patients who have undergone treatment with bleomycin, it is prudent that their oxygen exposure is limited so that ventilation failure does not occur (Zaniboni et al., 2005). Patients should also undergo vaccines to prevent pneumococcal infection as needed and an annual influenza vaccination.

Genitourinary

Patients who received cyclophosphamide will need to undergo annual urinalysis to screen for hematuria. If microscopic hematuria is detected ultrasound of kidneys, urine culture and spot urine calcium/creatinine should be ordered. If these come back negative, the patient many need to undergo further urologic evaluation with urine cytology or cystoscopy (Vlaovic & Jewett, 1999).

Reproductive and Gonadal Function

All sexually active patients are advised to use some form of birth control during treatment. After treatment, patients may experience long-term reproductive issues. Women may not only become infertile from treatment but may also experience premature menopause. Because of estrogen deficiency, early menopause can place women at risk for osteoporosis, atherosclerosis, hot flashes, and mood swings (Polovich, Whitford, & Olsen, 2014). These women should undergo bone densitometry evaluation and be treated based on these results. They should also be on a calcium and vitamin D supplement. Focus should also be on reducing the risk of cardiovascular disease, including screening for hypertension, diabetes, and dyslipidemia along with treatment of abnormalities. The use of hormone replacement and use of herbal therapies for treatment of postmenopausal symptoms should be avoided (Polovich, Whitford, & Olsen, 2014).

If a woman must undergo treatment, is of childbearing years, and still would like to have children, several fertility-preserving methods are being investigated. Consultation with a fertility specialist should be offered. Methods of cryopreservation of ovarian tissue and oocytes are currently being studied. The only cryopreservation method currently in use is freezing of embryos. Unfortunately, this is not feasible because the procedure requires at least two to five weeks of ovarian stimulation and oocyte collection, which would delay treatment. Also it requires a steady partner. Ovarian stimulation is also not recommended in women who have hormone dependent tumors (Ribeiro-Campos & Japur de Sa Rosa-e-Silva, 2011).

Men who are undergoing chemotherapy and are still hoping to have children have the option to sperm bank. This option should be offered to all males receiving chemotherapy or undergoing a surgical procedure that could affect fertility or sexual function (Ng et al., 2011; Polovich, Whitford, & Olsen, 2014).

RED FLAGS

When should a patient be referred back to the oncologist?

If a patient has signs that the cancer has recurred, the PCP should refer the patient back to the oncologist so that further testing can be completed. Signs of recurrence will be depend upon the original cancer diagnosis. The patient may have presenting symptoms, new findings on radiologic examinations, or abnormal laboratory values. Before referring the patient back to the oncologist, the PCP should conduct a complete physical examination. The referral back to the oncologist should be done in a timely fashion, and the patient should also be notified of the reason for the referral.

Additional Work-Up Before the Referral

Additional evaluation will also depend on the presentation of the potential recurrence. If the patient presents with specific symptoms, radiology examinations and laboratory studies may be warranted. However, once again the specific testing will be based upon the original cancer diagnosis. The radiology examination would most likely be looking for a cause of the symptom. For example, for a patient with a previous history of lung cancer who is now experiencing increasing shortness of breath, weight loss, and fatigue, a chest CT scan may be conducted before the referral back to the oncologist. This would help identify a recurrence, possible side effect of treatment, or new underlying condition.

Symptoms Suspicious for Recurrence

Back Pain

Back pain could be a sign of cord compression or a tumor on the spine. This should be evaluated immediately. Usually an MRI of the spine should be completed. The patient should also be assessed for bowel and bladder incontinence or retention as this may also indicate a cord compression. Cord compression is considered an oncologic emergency.

Pain

Unfortunately, pain can be due to many benign and malignant issues. However, the cancer survivor evaluated to identify if recurrence has occurred or if this is a side effect or previous treatment. The work up will be based upon location, type, frequency, duration, onset, character, aggravating factors, and relieving factors.

Headaches

New onset of headaches, especially if the patient is vomiting, or other neurologic changes associated with headache should be a trigger for an MRI of the brain to look for possible brain metastasis or brain lesion.

New Masses

New masses should be assessed and possibly biopsied. These could be benign, a recurrence, or a metastasis. Radiology examinations may also be necessary, depending on the location and suspicion for a malignancy.

Abdominal Pain or Fullness

This symptom would be more suspicious in patients that have either had gastrointestinal, genitourinary, or gynecologic malignancies. They could indicate a recurrence. Either abdominal ultrasound or abdominal CT scan should be completed. If there are tumor markers available for the specific type of cancer such as CEA, CA19-9, or CA-125, they should be completed also.

Weight Loss and Anorexia

Unintentional weight loss is a red flag that a patient's disease may be back. This is often a symptom that patients present with when first diagnosed. A patient may be eating the same caloric intake but still losing weight or may have early satiety or reduced appetite. With these symptoms workup for recurrence is necessary.

Shortness of Breath

Dyspnea could be an indication recurrence, metastasis, or side effect of previous treatment. Testing such as chest x-ray or chest CT scan would be helpful in the workup. A pulmonary function test may also be helpful in patients who have received bleomycin to rule out pulmonary toxicity from chemotherapy.

Bleeding

A complete blood count should be done to assess hemoglobin, hematocrit, and platelet count. Bleeding could be an indication of a tumor eroding through tissue. The location of the bleed will help determine the type of radiologic testing that should be completed. For those patients who have a history of a leukemia or lymphoma this could be an indication of thrombocytopenia due to marrow involvement. It also could be due to a high prothrombin time, partial thromboplastin time, or international normalized ratio due to liver dysfunction or liver metastasis.

Skin Changes

Skin changes may be indicative of late side effects of treatment such as radiation or chemotherapy. They also may indicate a recurrence. For example, peu d'orange skin of the breast is high suspicious of a breast tumor. Patients who have had skin cancer and present with a new lesion that is irregular in shape, changed, is larger than 6 mm, or has irregular borders, or lesions that will not heal, bleed, or evolve over time should be referred to an oncologist or dermatologist.

Psychosocial Issues

With the continued advancement in cancer treatments, the number of cancer survivors continues to grow (American Cancer Society, 2013). Cancer survivorship is a journey that flexes between different phases and transitions. After active cancer treatment ends cancer survivors return to their Primary Care Physician or Nurse Practitioner for routine care and follow-up.

New Normal

The uncertainty and anxiety of a cancer diagnosis and treatment can cause extreme changes in an individual's life (Gorman, 2006). As a result of the unpredictable nature of cancer, the majority of cancer survivors battle with the fear of cancer recurrence (Gorman, 2006). Several factors affect a cancer survivor's ability to adjust to the new situation. These include disease-related issues, such as site, stage, treatment, and rehabilitation. Holland (2003) also stated that personality, coping skills, belief system, culture, and support from others play a key role in the ability to adjust to their situation.

Even with continued education and support from the healthcare team, cancer survivors and their families expect to immediately transition from active treatment to surveillance and follow-up. Although their treatments have ended, their mental and spiritual outlook may still be focused on dealing with the aftermath of their cancer diagnosis. Oftentimes, cancer survivors will experience similar emotions and stress related to the completion of treatment as they did when they were first diagnosed. Cancer survivors may battle the fear of cancer recurrence or finally be able to deal with emotions they buried so they could be mentally strong enough to complete treatment. As their active treatment ends, survivors may experience a form of separation anxiety resulting from decreased interactions with their medical team (Boyle, 2006). Survivors may have concerns that they will have questions about their condition and no one will assist them; oftentimes, this can increase their fear of recurrence (Boyle, 2006). Often the most intense fear of cancer recurrence occurs immediately after active treatment, and on events such as birthdays, medical tests, and medical appointments (Boyle, 2006). As the time from active treatment to surveillance increases, the fear of recurrence diminishes and tends to resurface based on medical appointments and with the development of physical symptoms (Boyle, 2006). Oftentimes, the threat of death or pain followed by successful recovery provokes cancer survivors to look at their life and examine the meaning of spirituality, coping skills, and events in their daily life (Boyle, 2006).

Transitions back into a "precancer lifestyle" may occur at the completion of treatment (Boyle, 2006). Often, coworkers are flexible when an individual is receiving cancer treatments, expecting them to need assistance with daily activities (Boyle, 2006). Once treatment has been completed, survivors and their coworkers may not expect the lingering side effects. Fatigue, pain, and decreased range of motion are a few examples that may cause an individual to modify their working environment (Boyle, 2006). The fear of significant changes to their working ability can cause a survivor intense worry over feeling shunned, loss of benefits, and professional

discrimination, to name a few (Boyle, 2006). The Americans with Disabilities Act can help protect survivors from professional discrimination (Boyle, 2006).

Although cancer survivors are responsible for finding a new normal in their life, healthcare providers may play a pivotal role in assisting them in this process. It is important that healthcare providers are aware of the individual's cancer and its treatment. Many different tools are available that can provide this information. One such tool is the cancer care plan, which is a record of diagnosis, treatments, and acute and chronic treatment effects. A cancer care plan's purpose is to provide a brief summary of the patient's care, how it affects future health, and suggests ways to plan for and maintain a healthy lifestyle after cancer. ONS is one of five partners offering a survivorship care plan builder through Journey Forward (www.journeyforward.org).

Many individuals consider the end of medical treatment for a condition to also be the end of impending side effects. This is not the case for cancer survivors. Often, the latent side effects have the most impact on a cancer survivor's quality of life. The treatments for cancer and the chronic side effects for these treatments have psychosocial impact on patients and their families. Chronic fatigue, pain, neuropathy, infertility, incontinence, and impotence are just a few of the chronic side effects cancer treatment causes that can have lasting psychological effects (Holland, 2003). There are several key psychosocial issues that can affect a cancer survivor's quality of life.

Social Stigma

A sense of social detachment may occur with the cancer diagnosis and continue through survivorship as a result of fear of sudden changes, or feeling vulnerable (Boyle, 2006). This social detachment may occur as a result of the individual pulling away from the family and friends due to embarrassment or maybe an interpreted sense of social disappointment. This has been an issue for cancer survivors since the early 1800s and continues to some degree today (Holland, 2003). According to Holland (2003), physicians and families in the 1800s did not acknowledge an individual as having cancer because they felt the individuals would lose all hope and die sooner. This theory continued into the 20th century, evolving into a family secret. Many individuals were under the false impression that cancer was contagious and therefore even the families of individuals with cancer would be socially isolated for fear that they could spread the cancer to others (Holland, 2003). This fear of social isolation continues to some extent today. Oftentimes, individuals with specific diagnosis, such as lung cancer for example, feel socially isolated or rejected because in some way they have caused their disease (Holland, 2003). Side effects of cancer treatment can unknowingly affect an individual's sense of isolation through increasing fatigue, daily worry, and body image concerns (Boyle, 2006). Holland (2003) suggests that because a social stigma continues regarding mental health issues and is

compounded with the stigma of a cancer diagnosis, many individuals may not want to discuss their mental turmoil.

The United States population is a blend of individuals and families with different socioeconomic, ethnic, and religious backgrounds. The following questions may be helpful when assessing health and illness beliefs.

Health and Illness Belief Interview

- What do you call your problem?
- What would you say brought the problem on?
- When did you first notice the problem?
- How long have you had the problem?
- How long do you think the problem will last?
- Do you believe this to be a serious problem?
- How do you feel now compared to how you felt before the problem?
- What have you done to help the problem go away or help you feel better?
- How do you think the problem should be handled and by whom?

Note. Based on information from Kleinman et al., 1978.

From "Cultural Influences on the Psychosocial Experience" (p. 103), by D.P. Weekes in R.M. Carroll-Johnson, L.M. Gorman, and N.J. Bush (Eds.), *Psychosocial Nursing Care Along the Cancer Continuum* (2nd ed.), 2006, Pittsburgh, PA: Oncology Nursing Society. Copyright 2006 by Oncology Nursing Society. Reprinted with permission.

According to the NCCN Guidelines, every cancer survivor must be screened for distress (National Comprehensive Cancer Network, 2013c). Distress is defined as "unpleasant emotional experience … that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatments" (National Comprehensive Cancer Network, 2013c). Distress can include feeling vulnerable, depression, anxiety, social isolation, and emotional and spiritual crisis. Patients at an increased risk for distress include individuals with a history of substance abuse, social isolation, history of mental health issues, and or spiritual issues (National Comprehensive Cancer Network, 2013c).

Depression

Depression is a common response to a cancer diagnosis. Brown et al. (2009) report that approximately 20%–25% of individuals undergoing cancer treatment report depression symptoms. It has also been discovered that adults diagnosed with cancer are three times more likely to develop depression during treatment (Brown et al., 2009). Until recently, the symptoms of depression have been overlooked because they often mirror those of cancer treatment (Brown et al., 2009). However, if the emotional and spiritual effects of depression continue to linger, the physical recovery from cancer treatment will be delayed (Brown et al., 2009). Sharma (2008) states that increased distress can lead to inability to maintain treatment, dissatisfaction with medical care, and decreased quality of life. Symptoms of depression may include but are not limited to feelings of sadness, irritability, loss of interest or pleasure in normal activities, and fatigue (Mayo Clinic, 2012). The main goal for treatment of depression is to create and maintain a positive relationship between the healthcare provider and the individual seeking treatment. This can facilitate treatments to alleviate mental strain, allowing cancer treatment to begin or continue. In 2010, van Laarhoven et al. (2011) discovered through their quality-of-life research that active coping strategies, such as planning, reappraisal, and acceptance indicated a better quality of life and lower incidences of depression and the feeling of hopelessness. It is important for healthcare professionals to evaluate and reevaluate cancer survivors for mental health issues. One research study has shown that breast cancer survivors may maintain the risk of depression and suicide more than 24 years after diagnosis (Schairer et al., 2006).

Suicide

MedlinePlus (2012) defines *suicide* as the voluntary act of taking one's own life intentionally by a person of sound mind. Often, medical professional are leery to address concerns of suicide because of social taboos and the highly emotional nature of the topic (Albright & Valente, 2006). Screening tools similar to that of the NCCN's distress monitor are available for medical professionals to use when assessing and screening for risk of suicide. Examples of these screening tools are available in the appendix. According to Sharma (2008), the majority of suicides are related to unresolved psychiatric disorders such as depression, anxiety, and addiction. For some individuals with a history of depression, the initial shock, anger, and fear that occur with a cancer diagnosis may persist and cause symptoms such as anhedonia, insomnia, and weight loss to occur / recur (Aiello-Laws, 2010). Physical symptoms such as pain or fatigue can cause mental turmoil resulting in thoughts of suicide as a means for relief of their symptoms (Albright & Valente, 2006). Clues that an individual many be experiencing suicidal thoughts maybe written, spoken statements, or remarks that indicate they are losing hope or feeling worthless (Albright & Valente, 2006). Often, these statements are cries for help and compel the medical professional to respond. Answering specific questions regarding their intentions or plans are often what individuals need to voice their despair. Specific questions regarding their plan,

method, or how their plan evolved will help the medical professional develop an action plan and evaluate the level of their threat (Albright & Valente, 2006).

Post-traumatic stress disorder (PTSD) may occur as a result of experiencing or witnessing stressful or painful cancer treatments (Bush, 2006). This can affect a wide variety of cancer survivors from the individual receiving the treatment to the caregivers (Bush, 2006). Symptoms of PTSD include unrelenting reminders of the trauma, avoidance of factors related to the trauma, dulling of overall awareness, and increased stimulation (Mosher et al., 2005). When evaluating for depression or PTSD "flashback," a survivor specific emotional reaction must be considered (Boyle, 2006). Cancer survivors need screened for mental health issues through open-ended questioning.

Side Effects of Treatment

Side effects of cancer treatment can leave an individual battling with body image issues. Upon completing treatment, those lingering effects can lead to survivors thinking and feeling different about themselves (Bradley et al., 2005). These thoughts and feelings can, and often, persist long after treatment is over. Altered body image is a mental and physical side effect that can affect both men and women. Alopecia, weight gain or loss, amputation, and disfiguring surgery are just a few examples. An individual's previous mental health, type of cancer and specific treatment can affect their body image (Shell & Campbell-Norris, 2006). For example, breast cancer patients may endure feelings of loss of femininity, attractiveness, or sexual desire (Shell & Campbell Norris, 2006). A major factor affecting body image is the individuals' sense of control. Control can be defined as exerting control over their daily life or simply being able to control their bodily functions. Katz (2012) suggests that cancer survivors should allow their family and other loved ones to help them through a struggle with body image. She also notes the importance of improvement in treatments and the fact that one family members' experience may not be the same as another's (Katz, 2012). Both mental and physical control has a profound effect of an individual's body image (Shell & Campbell-Norris, 2006). In 1990, Stern described stages of adaptation that an individual must complete in order to adapt to the physical or mental change in body image.

Due to the psychological distress that can be caused by body image disturbance, interventions must be put into place to assist the individual cope with their distress (Shell & Campbell-Norris, 2006).

Sexuality

Treatment side effects, mental stress, or simply the cancer diagnosis negatively impact an individual's sexuality. Katz defines sexuality as the way we express ourselves as sexual beings and sexual functioning as an individual's sexual activity (2012). The following table offers examples as to how cancer treatments can impact sexual feelings and actions.

TABLE 4: Type of Treatment and Its Effects on Sexuality

Type of Treatment and Its Effects on Sexuality		
Malignancy	**Medical Intervention**	**Adverse Effects**
Head and neck	Surgical resection Laryngectomy Tracheostomy Radiotherapy Chemotherapy	Altered body image Facial disfigurement Difficult kissing Mucositis, xerostomia Fatigue Nausea Pain Alopecia Weight loss Skin color/texture change
Breast	Mastectomy Lumpectomy Radiotherapy Chemotherapy Hormone therapy Biotherapy	Altered body image Pain Fatigue Feelings of loss of femininity Breast edema Skin irritation Loss of nipple sensation Nausea Alopecia Neuropathy Decreased Libido

		Fluid retention Hot Flashes Post-menopausal bleeding
Lung	Pneumonectomy Lobectomy Radiotherapy Chemotherapy Biotherapy	Dyspnea Altered body image Fatigue Pain Neuropathy Skin irritation Nausea Alopecia
Colorectal	Colectomy Colostomy Radiotherapy Chemotherapy Biotherapy	Altered body image Feelings of embarrassment Pain Fatigue Diarrhea Nausea Mucositis
Bladder	Radical cystectomy Ileal conduit Radiotherapy Chemotherapy	Altered body image Erectile dysfunction Vaginal atrophy/shortening Fatigue Pain Urinary frequency

		Diarrhea Nausea Alopecia
Gynecologic	Hysterectomy Oophorectomy Aginectomy Vulvectomy Colostomy Ileal conduit Radiotherapy Chemotherapy Hormone therapy	Decreased libido Hot flashes Alopecia Nausea/vomiting Neuropathy Fatigue Pain Altered body image Vaginal atrophy Vaginal stenosis
Prostate	Prostatectomy Hormonal therapy Radiotherapy Chemotherapy	Erectile dysfunction Pain Urinary Incontinence Fatigue Hot flashes Altered body image
Note. From "Altered Sexuality" (pp. 328–329), by P.J. Anastasia in R.M. Carroll-Johnson, L.M. Gorman, & N.J. Bush (Eds.), *Psychosocial Nursing Care Along the Cancer Continuum* (2nd ed.), 2006, Pittsburgh, PA: Oncology Nursing Society. Copyright 2006 by Oncology Nursing Society. Reprinted with permission.		

Cancer treatments may affect sexuality in many ways, such as through altered hormone levels or decreased blood supply to sexual organs (Katz, 2010). Changes to sexuality or sexual functions

may be permanent or a temporary condition after treatment (Katz, 2010). Many cancer survivors and their sexual partners can experience a loss of libido during and after cancer treatments (Katz, 2010). Each cancer survivor needs to be assessed for sexual dysfunction during and after cancer treatment. Patients may be timid to discuss their sexuality with their healthcare team. Education provided to the patient on sexuality must be presented in a relaxed nonjudgmental environment (Anastasia, 2006).

Impact of Surgery

Changes in sexuality and sexual function related to surgery can be temporary or develop into chronic conditions. Surgical procedures used in cancer treatment are a main factor in causing altered body image facing cancer survivors. Surgical procedures can result in disfigurement, loss of feeling of femininity or masculinity, impotence, and urinary incontinence (Anastasia, 2006). Some individuals may have to deal with an ostomy bag as a result of their treatment. There are a variety of different ways to help individuals control their anxiety related to body image and sexuality. Concerns such as appearance, odors, and sounds may make the cancer survivor and their partner uncomfortable with sexual activity (Anastasia, 2006). There are many different devices that can be used or it may be as simple as emptying the bag prior to activity. Katz (2010) suggests finding an ostomy therapist in your area for further support.

Impact of Radiation

Changes in sexual functioning due to radiation may be temporary or chronic. Fatigue affects sexuality temporarily by decreasing stamina and sexual desire. Other treatment effects, such as scarring or hormonal imbalances, often cause permanent alterations in sexual functioning (Anastasia, 2006). With radiation, the impact on their sexual function is related to the local field of treatment. Men may experience impotence after prostate cancer radiation and women may develop vaginal narrowing or dryness related to pelvic radiation (Anastasia, 2006).

Impact of Chemotherapy

Chemotherapy can impact an individual's sexuality in many different ways. Side effects such as nausea, fatigue, and depression can greatly decrease an individual's sexual desire (Anastasia, 2006). More permanent side effects such as peripheral neuropathy can have a long term effect on the individual's sense of touch resulting in painful or decreased physical contact (Anastasia, 2006).

Hormonal Agents: Antiestrogen and androgen deprivation therapies

The final phase for certain cancers such as breast cancer and melanoma are antiestrogen hormonal therapies. Immediate side effects of this therapy may include decreased sexual desire or function, hot flashes, mood changes, insomnia, memory loss, nausea and fatigue (Anastasia, 2006). Men who receive androgen deprivation therapy experience rapid decrease in testosterone levels. This rapid decrease can result in loss of libido, impotence, or hot flashes (Katz, 2010).

Various pharmacologic interventions to reduce the side effects of antiestrogen and androgen deprivation therapy have been tried, but are not always effective. Interventions to manage the side effects of androgen therapy must equal the severity of symptoms reported (Kaplan, 2011). Through analayzing pertinent research studies, treatment recommendations can be made based upon the level of evidence of their efficacy. The ONS Putting Evidence into Practice Project performs such analysis and assigns interventions into one of various classifications: recommended for practice, likely to be effective, benefits balanced with harm, effectiveness nt established, effectiveness unlikely, or not recommended for practice (Oncology Nursing Society, 2013a). For survivors with moderate to severe hot flashes the following are likely to be effective (Kaplan, 2011):

- Clonidine
- Cytoproterone Acetate
- Gabapentin
- Venlafaxine

Premature Menopause

Premature menopause can be the result of cancer treatments, such as chemotherapy, surgery, or radiation. Women who undergo medical menopause through chemotherapy or surgical interventions experience rapid hormone changes causing sudden and severe symptoms of menopause as compared to healthy women whose estrogen levels gradually decline (Baber, Hickey, & Kwik, 2005). Menopause can cause symptoms such as hot flashes, vaginal dryness, and vaginal atrophy (Edgington & Morgan, 2011). Signs and symptoms of menopause may or may not include the following; irregular periods, decreased fertility, vaginal dryness, hot flashes, sleep disturbances, mood swings, increased abdominal fat, thinning hair, and loss of breast fullness (Mayo Clinic, 2013). Prior to medical treatment, women may find it beneficial to take strategies to ease their symptoms such as dressing in layers; avoiding foods that can trigger a hot flash such as caffeine, alcohol, and spicy foods; lowering the room temperature; and using over-the-counter vaginal moisturizers (Edgington & Morgan, 2011).

Sleep Disturbances

Sleep-wake disturbances can be defined as “actual or perceived changes in night sleep with resulting daytime impairment” (Oncology Nursing Society, 2013b). There are a variety of

factors that contribute to its development and worsen its intensity. These include disease, environment, and treatment related factors that impact the cancer survivor including such symptoms as hot flashes, anxiety, nausea, and pain. As stated previously, through the analysis of the literature, certain interventions have been found to be helpful at treating or reducing its impact. Cognitive behavioral intervention is one such intervention found likely to be effective, whereas the effectiveness of medications such as mirtazapine has not been established (Oncology Nursing Society, 2013b).

Communication

A family is often defined as the social support for an individual; in some cases they may not be related. Change to the dynamics of this family social structure, such as a cancer diagnosis, can cause the structure of the family unit to change. The cancer diagnosis in a family member will impact each family member differently depending on the intensity of their relationship, knowledge of the situation, personal strengths, and ability to cope

There are many barriers to family communication along the cancer journey. Some of these barriers may still be present when treatment ends and cancer surveillance begins. Examples of possible communication barriers are fear, anger, and guilt. Fear can develop into a major barrier to communication at the time of diagnosis and once again after active treatment. If this fear is not managed, it can develop into isolation of the individual and decreased positive family communication. Anger and guilt are a common response both in the cancer survivor and their caregivers. Guilty feelings can occur both in the survivor and their caregivers related to thoughts that should have done more to encourage the individuals to seek medical care or caused the situation (e.g., exposing a loved one to secondhand smoke) (Cooper, 2006). Guilt is a negative emotion and can increase the already stressful nature of cancer survivorship. Feelings of guilt can begin with the development of cancer and extend into long-term survivorship. Often, the sources of the guilt are misconceptions regarding the individual's health, and the patient or family needs clarification on the source of their guilt. Other times, the source of the guilt is factual, and the patient or family may need assistance in developing positive coping skills and managing their guilt (Cooper, 2006).

Caregiver Stress

The strains placed on a caregiver are well documented throughout the literature; these demands maybe emotional, physical, or spiritual in nature. Examples of caregiver strain may include financial loss, depression, physical strain, patient care, symptom management, transportation barriers, hopelessness, emotional stress, anxiety, anger, and guilt (Klemm & Wheeler, 2005) Caregivers often can have overwhelming guilt, questioning what they could have done to prevent or detect the cancer earlier (Boyle, 2006). Often the family caregivers are receiving the medical

information second hand and feel helpless because they cannot do more for their loved one (Boyle, 2006).

Because of the possible change in the responsibilities or the realization of the possible consequences of a cancer diagnosis, the individual's family caregivers need to be evaluated for distress and depression. There are many aspects to evaluate when looking at the changing role of a caregiver. The caregiver may be overwhelmed with financial stressors, lack of social support, and feeling helpless because of role change (Northfield & Nebauer, 2010). The new stress in their life may not provide them with the opportunity to process their changing role, leaving them open to emotional distress. Adler and Page (2008) report that caregivers can experience equal or greater amounts of distress compared to the cancer survivors. Healthcare professionals must be aware of the increased stress on the caregivers and ensure that they are seeking support. Moules, Simpson, Prins, Angus, and Bel (2004) state that for caregivers to be most effective, they must be self-aware and use personal strategies to support their needs in order to manage the stress and grief in their life.

Conclusion

The numbers of cancer survivors across the United States and globe is increasing due to many factors, including advances in diagnosis and with treatment. They are living longer and with this longevity, come unique health concerns related to long-term effects of cancer therapy. Cancer survivors face a variety of barriers that must be identified with steps taken to minimize or avoid their impact on survivor's quality of life. Nurses across all disciplines need to have a solid understanding of the needs and issues affecting cancer survivors today. They need to know what resources are available and how to best assist their patients in accessing those resources. Nurses need to assess for physical and psychological changes in their patients that may be related to their original cancer diagnosis, and maintain open communication between the oncologist and primary care physicians.

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Tools and Resources

ASSOCIATION OF CANCER ONLINE RESOURCES, ONLINE COMMUNITIES, AND E-MAIL LISTS

Air Charity Network
Toll Free: 800-549-9980
http://www.aircharitynetwork.org

AMC Cancer Fund
Phone: 303-233-6501
Toll Free: 800-321-1557
http://www.amc.org/

AMC Cancer Fund Cancer Information and Counseling Line
Toll Free: 1-800-525-3777
http://www.amc.org/programs.html

American Association for Cancer Research
Phone: 215-440-9300
Toll Free: 866-423-3965
http://www.aacr.org

American Cancer Society
Phone: 404-320-3333
Toll Free: 800-ACS-2345
TTY: 866-288-4327
http://www.cancer.org

American Cancer Society Cancer Action Network
Phone: 800-ACS-2345
http://www.acscan.org

American College of Surgeons: Commission on Cancer
Phone: 312-202-5085
Toll Free: 800-621-4111
http://www.facs.org/cancer/index.html

American Hospice Foundation
Phone: 202-223-0204
Toll Free: 800-347-1413
http://www.americanhospice.org

American Institute for Cancer Research (AICR)
Phone: 202-328-7744
Toll Free: 800-843-8114
http://www.aicr.org

American Pain Foundation
Phone: 888-615-PAIN (7246)
http://www.painfoundation.org

American Psychosocial Oncology Society
Phone: 434-293-5350
http://www.apos-society.org

American Society for Radiation Oncology
Phone: 703-502-1550
Toll Free: 1-800-962-7876
https://www.astro.org

American Society of Breast Surgeons
Phone: 410-992-5470
Toll Free: 1-877-992-5470
http://www.breastsurgeons.org

Arab Community Center for Economic and Social Services (ACCESS)
Phone: 313-842-7010
http://www.accesscommunity.org

Association of Cancer Online Resources
http://www.acor.org

Association of Community Cancer Centers
Phone: 301-984-9496
http://www.accc-cancer.org

Association of Oncology Social Work
Phone: 215-599-6093
http://www.aosw.org

Association of Pediatric Hematology/Oncology Nurses (APHON)
Phone: 847-375-4724
http://www.apon.org

Cancer & Careers
Phone: 212-685-5955 ext.32
http://www.cancerandcareers.org

Cancer Financial Assistance Coalition
http://www.cancerfac.org

Cancer Hope Network
Phone: 908-879-4039
Toll Free: 800-552-4366
http://www.cancerhopenetwork.org

Cancer News on the Net
http://www.cancernews.com

Cancer Pain Management in Children
http://www.childcancerpain.org

Cancer Research Foundation
Phone: 312-630-0055
http://www.cancerresearchfdn.org

Cancer Research Institute
Phone: 800-99CANCER (800-992-2627)
http://www.cancerresearch.org

Cancer Support Community
Phone: 202-659-9709
Toll Free: 888-793-WELL (9355)
http://cancersupportcommunity.org

Cancer Survivors Gathering Place
http://www.cancersurvivorsplace.org

Cancer*Care*
Phone: 212-712-8400
Toll Free: 800-813-HOPE (4673)
http://www.cancercare.org

CANCER101: Basics for the Diagnosed
Phone: 646-638-2202
http://www.cancer101.org

CancerGuide
http://www.cancerguide.org

CancerQuest
Phone: 404-727-0308
http://cancerquest.org

CaringBridge
Phone: 651-789-2300
http://www.caringbridge.org

Center for Mind-Body Medicine
Phone: 202-966-7338
http://www.cmbm.org

Center to Advance Palliative Care
Phone: 212-201-2670
http://www.capc.org

Centers for Disease Control and Prevention
Phone: 404-639-3311
Toll Free: 800-311-3435
http://www.cdc.gov

Children's Cause for Cancer Advocacy
Phone: 202-336-8375
http://www.childrenscause.org

Closure
http://www.closure.org

Coalition of Cancer Cooperative Groups
Phone: 877-227-8451
http://www.cancertrialshelp.org

College of American Pathologists
Toll Free: 800-323-4040 x7439
http://www.MyBiopsy.org

Corporate Angel Network, Inc.
Phone: 914-328-1313
Toll Free: 866-328-1313
http://www.corpangelnetwork.org

Dia de La Mujer Latina
Phone: 281-489-1111
http://www.diadelamujerlatina.org

Disability Rights Legal Center:
Cancer Legal Resource Center
Toll Free: 866-843-2572
http://www.cancerlegalresourcecenter.org

ENACCT: Education Network to Advance Cancer Clinical Trials
Phone: 240-482-4730
http://www.enacct.org

ECaP: Exceptional Cancer Patients
Phone: 814-337-8192
http://www.ecap-online.org

Federation of American Societies for Experimental Biology
Phone: 301-634-7000
http://www.faseb.org

Hope for Two: The Pregnant with Cancer Network
Toll Free: 800-743-4471
http://www.pregnantwithcancer.org

Hospice Education Institute
Phone: 207-255-8800
Toll Free: 800-331-1620
http://www.hospiceworld.org

Hospice Foundation of America
Phone: 202-457-8511
http://www.hospicefoundation.org

ICare: International Cancer Alliance for Cancer Research Education
Phone: 301-656-3461
http://www.icare.org

Imerman Angels
Toll Free: 877-274-5529
http://www.imermanangels.org

Inspire
Phone: 703-243-0303
Toll Free: 800-945-0381
http://www.inspire.com/

Intercultural Cancer Council
Phone: 713-798-4617
http://iccnetwork.org

International Association for Hospice and Palliative Care
Phone: 936-321-9846
Toll Free: 866-374-2472
http://www.hospicecare.com

International Psycho-Oncology Society
Phone: 434-293-5350
http://www.ipos-society.org

Jack and Jill Late Stage Cancer Foundation
Phone: 404-537-5253
http://jajf.org/home/

Lesbian Community Cancer Project
Phone: 773-561-4662
http://www.lccp.org

LIVESTRONG
Phone: 512-236-8820
Toll Free: 866-236-8820
http://www.livestrong.org

Look Good...Feel Better (LGFB)
Phone: 202-331-1770
Toll Free: 800-395-5665
http://www.lookgoodfeelbetter.org

Mautner Project
Phone: 202-332-5536
Toll Free: 866-MAUTNER (866-628-8637)
http://www.mautnerproject.org

Men's Health Network
Phone: 202-543-6461
http://www.menshealthnetwork.org

Minnie Pearl Cancer Foundation
Phone: 615-467-1936
Toll Free: 1-877-467-1936
http://www.minniepearl.org

MyOncofertility.org
Toll Free: 1-866-708-3378
http://www.myoncofertility.org

National Association for Home Care & Hospice
Phone: 202-547-7424
http://www.nahc.org

National Cancer Coalition
Phone: 919-821-2182
http://www.nationalcancercoalition.org

National Cancer Institute
Phone: 301-435-3848
Toll Free: 800-4-CANCER
TTY: 800-332-8615
http://www.cancer.gov

National Cancer Institute Cancer Trials Support Unit
Phone: 888-691-8039
http://www.ctsu.org

National Cancer Survivors Day Foundation
Phone: 615-794-3006
http://www.ncsdf.org

National Center for Complementary and Alternative Medicine
Phone: 301-519-3153
Toll Free: 888-644-6226
http://www.nccam.nih.gov

National Coalition for Cancer Survivorship
Phone: 301-650-9127
Toll Free: 877-NCCS-YES

(877-622-7937)
http://www.canceradvocacy.org

National Comprehensive Cancer Network
Phone: 215-690-0300
http://www.nccn.com

National Family Caregivers Association
Phone: 301-942-6430
Toll Free: 800-896-3650
http://www.nfcacares.org

National Hospice and Palliative Care Organization
Phone: 703-837-1500
Multilingual: 877-658-8896
Toll Free: 877-658-8898
http://www.nhpco.org

National LGBT Cancer Network
Phone: 212-675-2633
http://www.cancer-network.org

National Library of Medicine
Phone: 301-594-5983
Toll Free: 888-FIND-NLM (888-346-3656)
http://www.nlm.nih.gov

National Lymphedema Network
Toll Free: 800-541-3259
http://www.lymphnet.org

National Organization for Rare Disorders (NORD)
Phone: 203-744-0100
Toll Free: 800-999-6673
http://www.rarediseases.org

Native American Cancer Research
Phone: 303-975-2449
Toll Free: 800-537-8295
http://natamcancer.org

NOAH: New York Online Access to Health
http://www.noah-health.org

Nueva Vida, Inc.
Phone: 202-223-9100
Toll Free: 1-866-986-8432
http://www.nueva-vida.org

Office of Cancer Survivorship
Phone: 301-402-2964
http://dccps.nci.nih.gov/ocs

Oley Foundation
Phone: 518-262-5079
Toll Free: 800-776-OLEY (6539)
http://www.oley.org

OncoLink
http://www.oncolink.org

Oncology Nursing Society (ONS)
Phone: 412-859-6100
Toll Free: 866-257-4ONS (4667)
http://www.ons.org

Partnership for Prescription Assistance
Phone: 888-4PPA-NOW (477-2669)
http://www.pparx.org

Patient Advocate Foundation
Phone: 757-873-6668
Toll Free: 800-532-5274
http://www.patientadvocate.org

Patient Resource Publishing
Phone: 816- 584-8227
http://www.patientresource.net

Prepare to Live
http://www.preparetolive.org

Prevent Cancer Foundation
Phone: 703-836-4412
Toll Free: 800-227-2732
http://www.preventcancer.org

R.A. Bloch Cancer Foundation, Inc.
Phone: 816-854-5050
Toll Free: 1-800-433-0464
http://www.blochcancer.org

Research Advocacy Network
Phone: 877-276-2187
http://www.researchadvocacy.org

Sam Fund
Toll Free: 866-439-9365
http://www.thesamfund.org

Scott Hamilton CARES Initiative
www.Chemocare.com

Self chec
http://www.selfchec.org/main.html

Siteman Cancer Center: Your Disease Risk
Phone: 314-362-5196
Toll Free: 800-551-3492
http://www.yourdiseaserisk.wustl.edu

Stand Up 2 Cancer
http://www.standup2cancer.org

SuperSibs
Phone: 847-705-SIBS (7427)
Toll Free: 866-444-SIBS (7427)
http://www.supersibs.org

Teens Living With Cancer
http://www.teenslivingwithcancer.org

Ulman Cancer Fund for Young Adults
Phone: 410-964-0202
Toll Free: 888-393-FUND (3863)
http://www.ulmanfund.org

United Ostomy Associations of America (UOAA)
Phone: 800-826-0826
http://www.ostomy.org

University of Texas MD Anderson Cancer Center
Anderson Network, A Program of Volunteer Services
Toll Free: 800-345-6324
http://www.mdanderson.org/andersonnetwork

U.S. Department of Health and Human Services
Office of Minority Health
Phone: 800-444-6472
http://minorityhealth.hhs.gov

V Foundation for Cancer Research
Phone: 919-380-9505
Toll Free: 1-800-454-6698
http://www.jimmyv.org

Vital Options and *The Group Room* Cancer Radio Show
Phone: 818-508-5657
Toll Free: 800-GRP-ROOM (800-477-7666)
http://www.vitaloptions.org

COMPLEMENTARY AND ALTERNATIVE MEDICINE RESOURCES

American Cancer Society (ACS)

Toll-free: 800-ACS-2345 (800-227-2345)

Web site: http://www.cancer.org

American Botanical Council (ABC)

Telephone: 512-926-4900

Web site: http://abc.herbalgram.org

Emergency Use Investigational New Drug Program for Oncology Drugs

Toll-free: 888-463-6332

FDA Center for Food Safety and Applied Nutrition (CFSAN)

Toll-free: 800-FDA-1088

Web site: http://vm.cfsan.fda.gov

Web site (dietary supplement information): http://www.cfsan.fda.gov/dms/supplmnt.html

Memorial Sloan-Kettering Cancer Center

Telephone: 212-639-2000

Web site: http://www.mckcc.org/mskcc/html/11570.cfm

National Agricultural Library Food and Nutrition Information Center (FNIC)

Telephone: 301-504-5414

Web site: http://fnic.nal.usda.gov

National Cancer Institute (NCI)

Toll-free: 800-4-CANCER (800-422-6237)

Web site: http://www.cancer.gov

Web site (Spanish version): http://www.cancer.gov/espanol

NCI Cancer Topics

Web site: http://cancer.gov/cancerinformation

NCI Clinical Trials

Web site: http://www.cancer.gov/clinicaltrials

NCI Physicians' Data Query (PDQ®) Database

Web site: http://www.cancer.gov/cancertopics/pdq

National Institutes of Health (NIH): National Center for Complementary and Alternative Medicine (NCCAM)

Toll-free: 888-644-6226

Web site: http://nccam.nih.gov

NIH Office of Dietary Supplements (ODS)

Telephone: 301-435-2920

Web site: http://ods.od.nih.gov/

National Library of Medicine (includes Medline)

Toll-free: 888-FIND-NLM (888-346-3656)

Web site: http://www.nlm.nih.gov

PubMed

Web site: http://www.ncbi.nlm.nih.gov/PubMed

Quackwatch

Web site: http://www.quackwatch.com

Society for Integrative Oncology

Web site: http://www.integrativeonc.org/

The University of Texas M.D. Anderson Cancer Center Complementary and Integrative Medicine Education Resources

Toll-free: 800-392-1611

Web site: http://www.mdanderson.org/departments/cimer/index.cfm

SURVIVORSHIP RESOURCES

American Society of Clinical Oncologists (ASCO) Cancer Treatment Summaries
http://www.cancer.net/survivorship/asco-cancer-treatment-summaries

Journey Forward
http://journeyforward.org

LIVESTRONG Care Plan
www.livestrongcareplan.org

TREATMENT SIDE EFFECT RESOURCES

Diabetes
American Association of Clinical Endocrinologist
www.aace.com/pub/pdf/guidelines/DMGuidelines2007.pdf

American Diabetes Association
www.diabetes.org/diabetes-basics/type-2

Dyslipidemia
National Heart, Lung, and Blood Institute
www.nhlbi.nih.gov/guidelines/cholesterol/atp3_rpt.htm

Hypertension

National Heart, Lung, and Blood Institute
www.nhlbi.nih.gov/guidelines/cholesterol/atp3_rpt.htm

Hypothyroidism
American Association of Clinical Endocrinologist
www.aace.com/pub/pdf/guidelines/hypo_hyper.pdf

Obesity
National Heart, Lung, and Blood Institute
www.nhlbi.nih.gov/guidelines/obesity/prctgd_c.pdf

Osteoporosis
National Osteoporosis Foundation
www.nof.org/professionals/clinical-guidelines