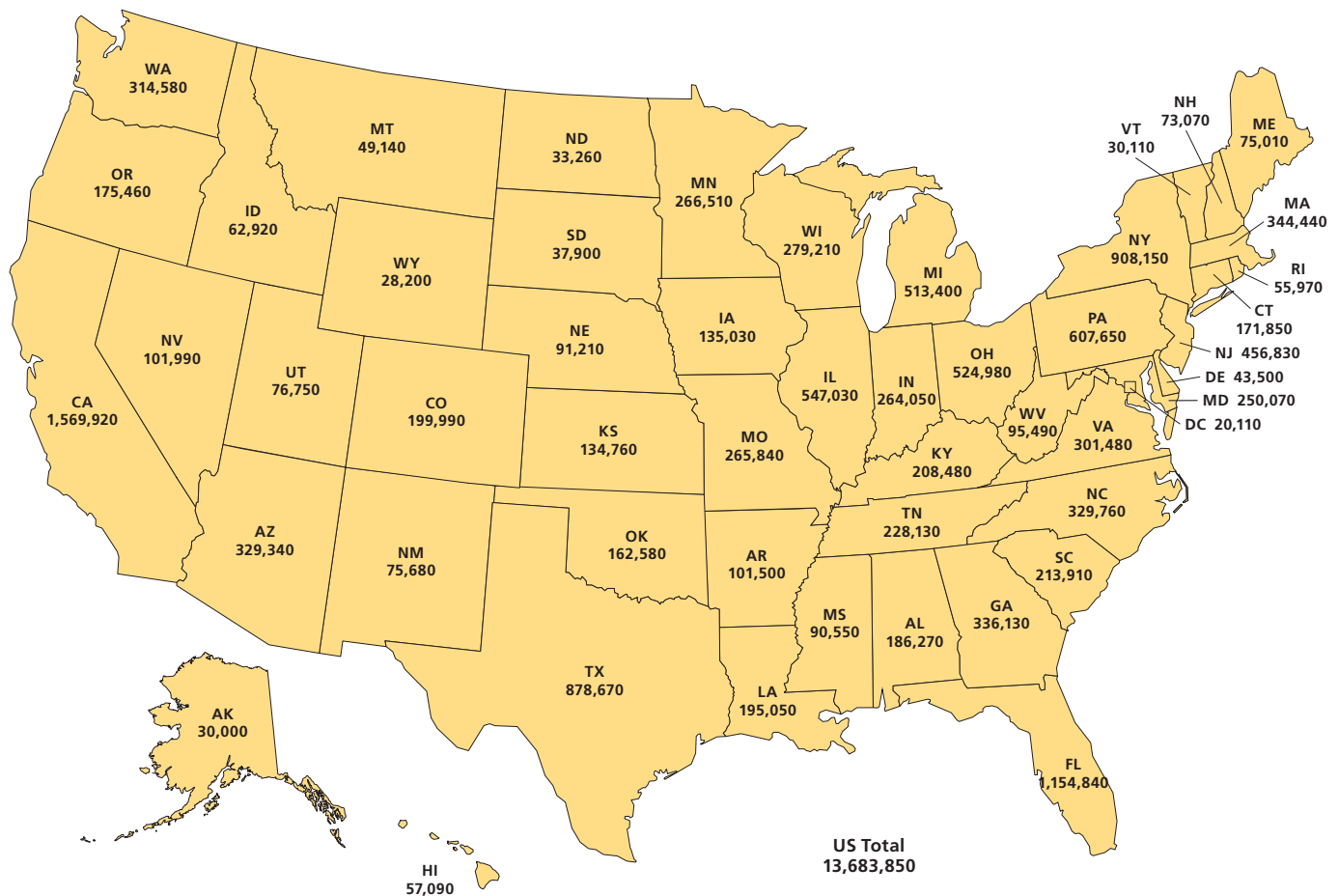


# Cancer Treatment & Survivorship Facts & Figures

## 2012-2013

Estimated Numbers of Cancer Survivors as of January 1, 2012



Note: State estimates may not sum to US total due to rounding

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## For more information, contact:

Carol DeSantis, MPH  
Rebecca Siegel, MPH  
Ahmedin Jemal, DVM, PhD

National Home Office: American Cancer Society Inc.  
250 Williams Street, NW, Atlanta, GA 30303-1002  
(404) 320-3333

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# Introduction

## Who Are Cancer Survivors?

A cancer survivor is any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life. There are at least three distinct phases associated with cancer survival, including the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival.<sup>1</sup> In practice, however, the concept of survivorship is often associated with the period after active treatment ends. It encompasses a range of cancer experiences and trajectories, including:

- Living cancer-free for the remainder of life
- Living cancer-free for many years but experiencing one or more serious, late complications of treatment
- Living cancer-free for many years, but dying after a late recurrence
- Living cancer-free after the first cancer is treated, but developing a second cancer
- Living with intermittent periods of active disease requiring treatment
- Living with cancer continuously without a disease-free period

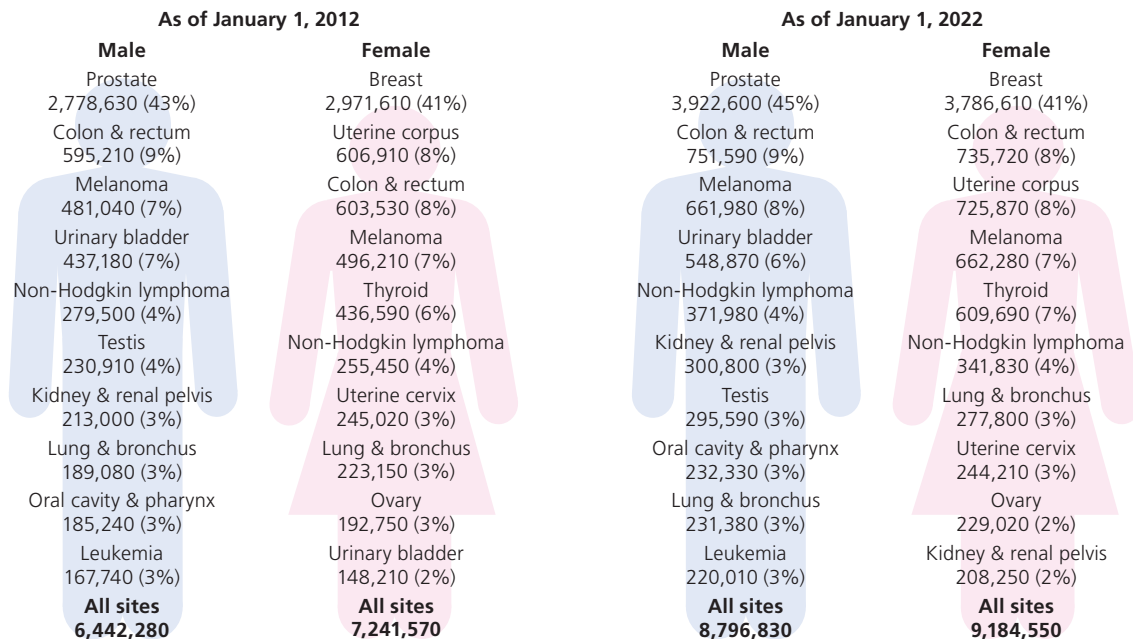
The goals of treatment are to “cure” the cancer if possible and/or prolong survival and provide the highest possible quality of life during and after treatment. For many patients diagnosed with cancer, the initial course of therapy is successful and the cancer never returns. However, many of these cancer-free survivors must cope with the long-term effects of treatment, as well as psychological concerns such as fear of recurrence. Cancer patients, caregivers, and survivors must have the information and support they need to play an active role in decisions that affect treatment and quality of life.

Throughout this document, the terms cancer patient and survivor are used interchangeably. It is also recognized that not all people with a cancer diagnosis identify with the term “cancer survivor.”

## How Many Cancer Survivors Are Alive in the US?

An estimated 13.7 million Americans with a history of cancer were alive on January 1, 2012. This estimate does not include carcinoma in situ (non-invasive cancer) of any site except urinary bladder, and does not include basal cell and squamous cell skin cancers. The 10 most common cancer sites represented among survivors are shown in Figure 1. The three most common cancers among male survivors are prostate (43%), colon and rectum (9%), and melanoma (7%). Among female survivors, the most common cancers are breast (41%), uterine corpus (8%), and colon and rectum (8%).

**Figure 1. Estimated Numbers of US Cancer Survivors by Site**



Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society, Intramural Research, 2012

The majority of cancer survivors (64%) were diagnosed 5 or more years ago, and 15% were diagnosed 20 or more years ago (Table 1). Almost half (45%) of cancer survivors are 70 years of age or older, while only 5% are younger than 40 years (Table 2).

## How Many Cancer Survivors Are Expected to Be Alive in the US in 2022?

As of January 1, 2022, it is estimated that the population of cancer survivors will increase to almost 18 million: 8.8 million males and 9.2 million females.

**Table 1. Estimated Numbers of US Cancer Survivors by Sex and Time Since Diagnosis as of January 1, 2012**

Time since diagnosis	Male			Female		
	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
0 to <5 years	2,608,320	40%	40%	2,339,950	32%	32%
5 to <10 years	1,628,010	25%	65%	1,595,410	22%	54%
10 to <15 years	997,060	15%	80%	1,135,160	16%	70%
15 to <20 years	570,290	9%	89%	791,880	11%	81%
20 to <25 years	305,140	5%	94%	536,670	7%	88%
25 to <30 years	154,470	2%	96%	343,300	5%	92%
30+ years	179,010	3%	100%	499,210	7%	100%

Note: Percentages may not sum to 100% due to rounding.

Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

**Table 2. Estimated Number of US Cancer Survivors by Sex and Age as of January 1, 2012**

	Male			Female		
	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
All ages	6,442,280			7,241,570		
0-14	36,770	1%	1%	21,740	<1%	<1%
15-19	24,860	<1%	2%	23,810	<1%	1%
20-29	74,790	1%	3%	105,110	1%	2%
30-39	134,630	2%	5%	250,920	3%	5%
40-49	350,350	5%	10%	647,840	9%	14%
50-59	930,140	14%	24%	1,365,040	19%	33%
60-69	1,705,730	26%	50%	1,801,430	25%	58%
70-79	1,858,260	29%	79%	1,607,630	22%	80%
80+	1,326,740	21%	100%	1,418,050	20%	100%

Note: Percentages may not sum to 100% due to rounding.

Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

## Selected Cancers

This section contains information about treatment, survival, and other related concerns for the most common cancer types. More information on the side effects of cancer treatment can be found beginning on page 20.

### Breast (Female)

In 2012, it is estimated that there were more than 2.9 million women living in the US with a history of invasive breast cancer as of January 1, and an additional 226,870 women will be diagnosed. The median age at the time of breast cancer diagnosis is 61 (Figure 2, page 4). About 20% of breast cancers occur among women younger than age 50 and about 40% occur in those older than 65 years. The treatment and prognosis (forecast of disease outcome) for breast cancer depend on the stage at diagnosis, the biological characteristics of the tumor, and the age and health of the patient. Overall, 60% of breast cancers are diagnosed at the localized stage (Figure 3, page 5). Screening for breast cancer with mammography detects many cancers before a lump can be felt and when they are more likely to be localized stage.

**Treatment and survival:** Surgical treatment for breast cancer usually involves breast-conserving surgery (BCS) (i.e., lumpectomy or partial mastectomy) or mastectomy (surgical removal of the breast). The decision about surgery is complex and often difficult for women. Research shows that when BCS is appropriately used for localized or regional cancers, long-term survival is

the same as with mastectomy.<sup>2</sup> However, some patients require mastectomy because of large or multiple tumors.

Women who undergo mastectomy may elect to have breast reconstruction with either an implant or with a skin or muscle flap of tissue moved from elsewhere in the body. Most women treated with BCS do not choose to have plastic surgery. Fifty-seven percent of women diagnosed with early stage (I or II) breast cancer have BCS, 36% have mastectomy, 6% have no surgical treatment, and about 1% do not receive any treatment (Figure 4, page 6). In contrast, among women with late-stage (III or IV) breast cancer, 13% undergo BCS, 60% have mastectomy, 18% have no surgical treatment, and 7% do not receive any treatment (Figure 4, page 6).

Treatment may also involve radiation therapy, chemotherapy, hormone therapy (e.g., tamoxifen, aromatase inhibitors, ovarian ablation, and luteinizing hormone-releasing hormone [LHRH] analogs), or targeted therapy. Radiation is recommended for nearly all women undergoing BCS, and approximately 83% receive it.<sup>3</sup> Radiation therapy is also indicated after a mastectomy in certain situations.

The benefit of chemotherapy is dependent on multiple factors, including the size of the tumor, the number of lymph nodes involved, the presence of estrogen or progesterone receptors, and the amount of human epidermal growth factor receptor 2 (HER2) protein made by the cancer cells. Women with breast cancer that tests positive for hormone receptors are candidates for treatment with hormonal therapy to reduce the likelihood that the cancer returns.

### How Is Cancer Staged?

Staging describes the extent or spread of disease at the time of diagnosis. Proper staging is essential in determining treatment options and in assessing prognosis.

A number of different staging systems are used to classify cancers. The TNM staging system assesses cancers in three ways: the size of the tumor and/or whether it has grown to involve nearby areas (T), absence or presence of regional lymph node involvement (N), and absence or presence of distant metastases (M). Once the T, N, and M are determined, a stage of I, II, III, or IV is assigned, with stage I being early stage invasive cancer and stage IV being the most advanced. The TNM staging system is commonly used in clinical settings.

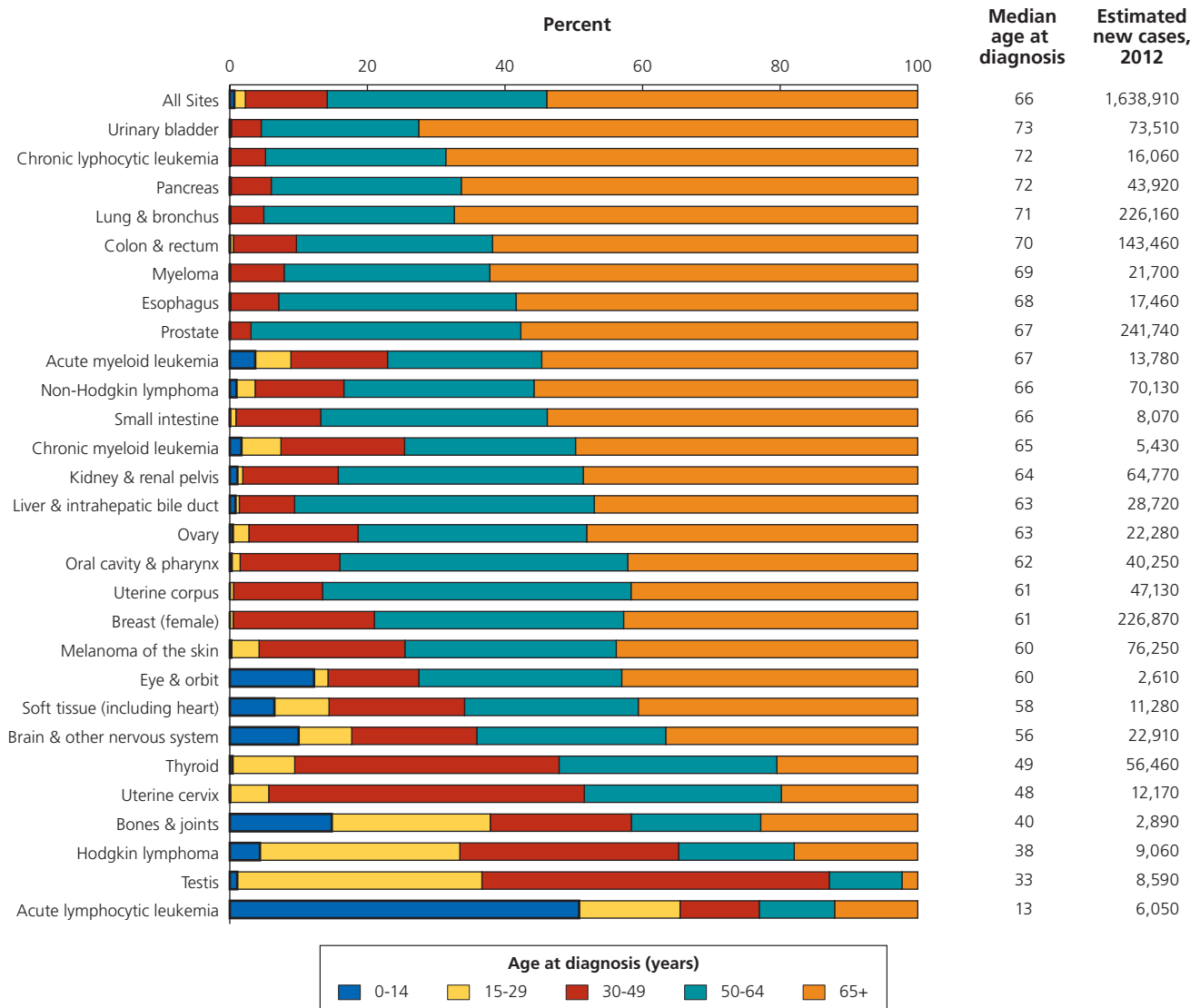
A second and less complex staging system, called Summary Stage, has historically been used by central cancer registries. Cancers are classified as in situ, local, regional, and distant. Cancer that is present only in the original layer of cells where it developed is classified as in situ. If cancer cells have penetrated the original layer of tissue, the cancer is invasive and is categorized as local (confined to the organ of origin), regional (spread

to lymph nodes in the area of the organ of origin), or distant (spread to other organs or parts of the body). As the molecular properties of cancer have become better understood, prognostic models and treatment plans for some cancer sites (e.g., breast) have incorporated the tumor's biological markers and genetic factors in addition to stage.

Both the TNM and Summary Stage staging systems are used in this publication depending on the source of the data (tumor registry versus hospital data). Although there are some exceptions, the TNM staging system generally corresponds to the Summary Stage system as follows:

- Stage 0 corresponds to in situ
- Stage I corresponds to local stage
- Stage II corresponds to either local or regional stage depending on lymph node involvement
- Stage III corresponds to regional stage
- Stage IV cancers correspond to distant stage

**Figure 2. Age Distribution (%), Median Age at Diagnosis, and Estimated Number of New Cases by Site**



Note: Sites are ranked in order of median age at diagnosis from oldest to youngest.

Sources: Age distribution based on 2008 data from NAACCR and excludes the District of Columbia, Maryland, Nevada, and Wisconsin. Median age at diagnosis is based on cases diagnosed between 2004-2008 in the 17 SEER registries. 2012 estimated cases from *Cancer Facts & Figures 2012*.

American Cancer Society, Intramural Research, 2012

For premenopausal women, the standard hormonal treatment is tamoxifen for 5 years. For those who are postmenopausal, hormonal treatments may include tamoxifen and/or an aromatase inhibitor (e.g., letrozole [Femara], anastrozole [Arimidex], or exemestane [Aromasin]); these drugs are also typically administered for 5 years after surgery or chemotherapy and can be prescribed using multiple treatment strategies.<sup>4</sup> Other hormone therapy drugs (e.g., Faslodex) are available for treatment of advanced disease.

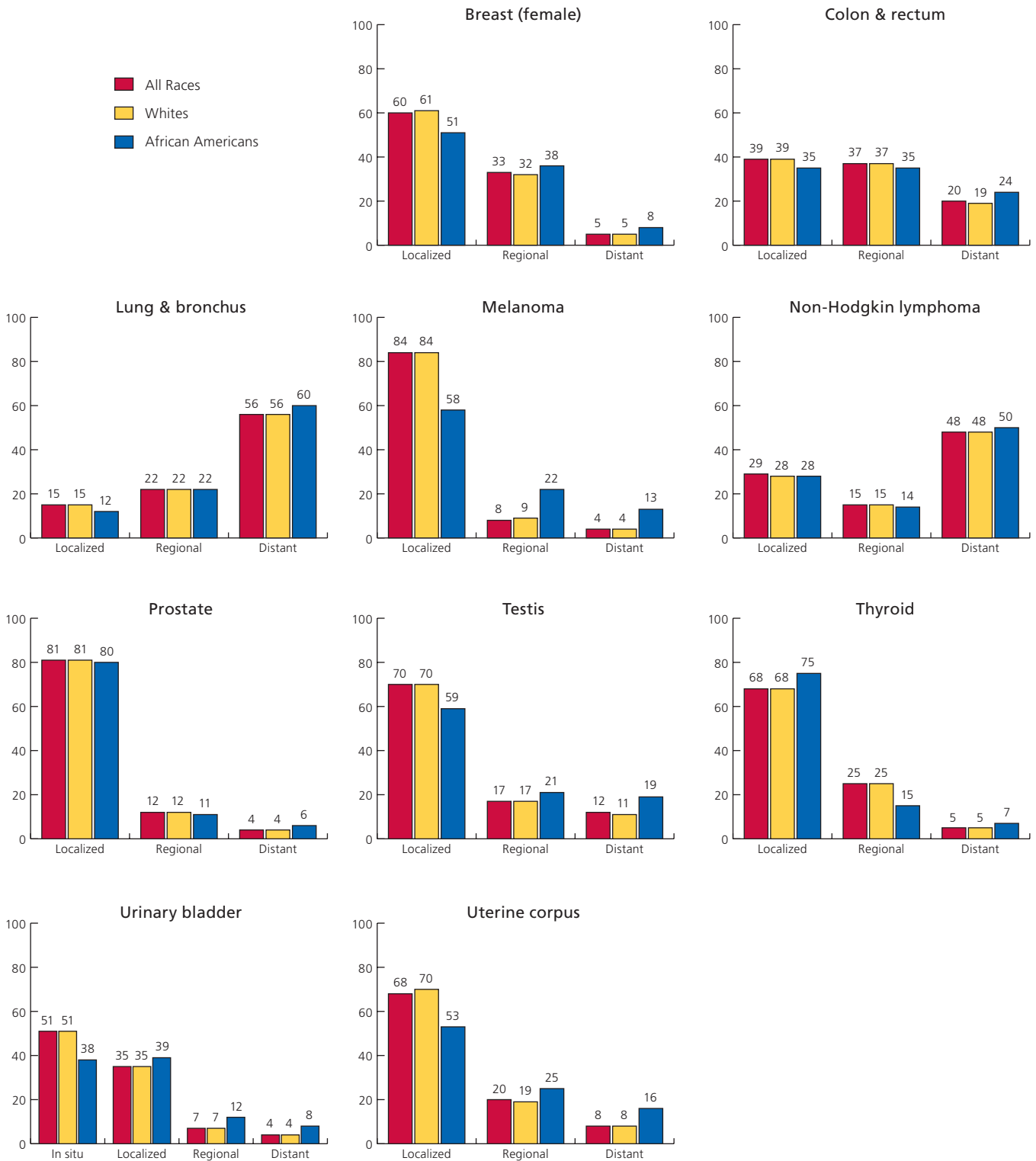
For women whose cancer tests positive for HER2, approved targeted therapies include trastuzumab (Herceptin) and, for advanced disease, lapatinib (Tykerb). By attacking the HER2

receptor, targeted therapies block the spread and growth of cancer. Targeted therapies are often administered in combination with chemotherapy.

The overall 5-year relative survival rate for female breast cancer patients has improved from 63% in the early 1960s to 90% today. This increase is due largely to improvements in treatment (i.e., chemotherapy and hormone therapy) and to widespread use of mammography screening.<sup>5</sup>

The 5-year relative survival for women diagnosed with localized breast cancer is 99%; if the cancer has spread to nearby lymph nodes (regional stage) or distant lymph nodes or organs (distant

**Figure 3. Distribution (%) of Selected Cancers by Race and Stage at Diagnosis, 2001-2007.**

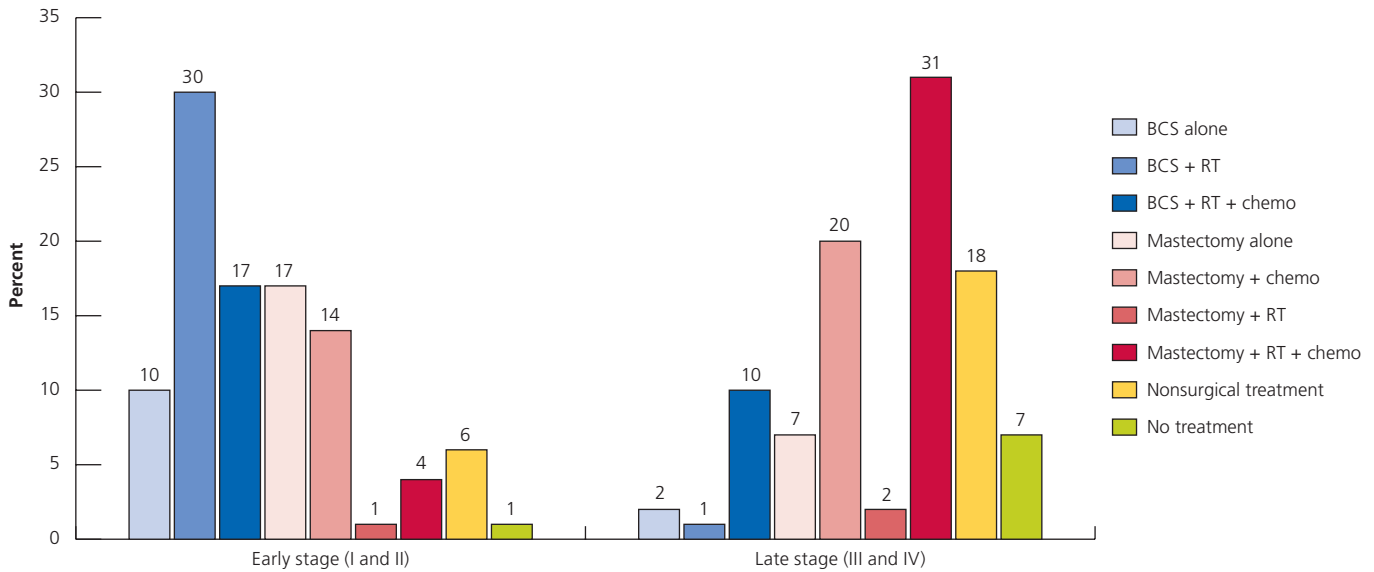


Stage categories may not sum to 100% because sufficient information is not available to stage all cancers.

Source: Howlader, et al, 2011.<sup>7</sup>

American Cancer Society, Intramural Research, 2012

**Figure 4. Female Breast Cancer Treatment Patterns by Stage, 2008**



BCS = breast-conserving surgery; RT = radiation therapy; Chemo = chemotherapy and may include common targeted therapies. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

stage), the survival rate falls to 84% or 23%, respectively (Figure 5). In addition to stage, factors that influence survival include tumor grade, hormone receptor status, and HER2 status.

African American women are less likely than white women to be diagnosed with local-stage breast cancer (Figure 3, page 5) and generally have lower survival than white women within each stage (Figure 5). The reasons for these differences are complex but may be explained in large part by socioeconomic factors, less access to care among African American women, and biological differences in cancers.

**Special concerns of breast cancer survivors:** Lymphedema of the arm is a common side effect of breast cancer surgery and radiation therapy that can develop soon after treatment or years later. It is the buildup of lymph fluid in the tissue just under the skin caused by removal or damage of the axillary (underarm) lymph nodes. Risk of lymphedema is reduced when sentinel-node biopsy (only the first lymph nodes to which cancer is likely to spread are removed) is performed rather than axillary dissection (many nodes are removed) to determine if the tumor has spread. There are a number of effective therapies used for lymphedema, and some evidence exists that upper-body exercise and physical therapy may reduce the severity and risk of developing of this condition.<sup>6</sup>

Other long-term local effects of surgical and radiation treatment include numbness or tightness and pulling or stretching in the chest wall, arms, or shoulders. In addition, women diagnosed and treated for breast cancer at younger ages may experience

impaired fertility and premature menopause and are at an increased risk of osteoporosis. Treatment with aromatase inhibitors can cause muscle pain, joint stiffness and/or pain, and sometimes osteoporosis.

For more information about breast cancer, see *Breast Cancer Facts & Figures*, available online at [cancer.org/statistics](http://cancer.org/statistics).

## Childhood Cancer

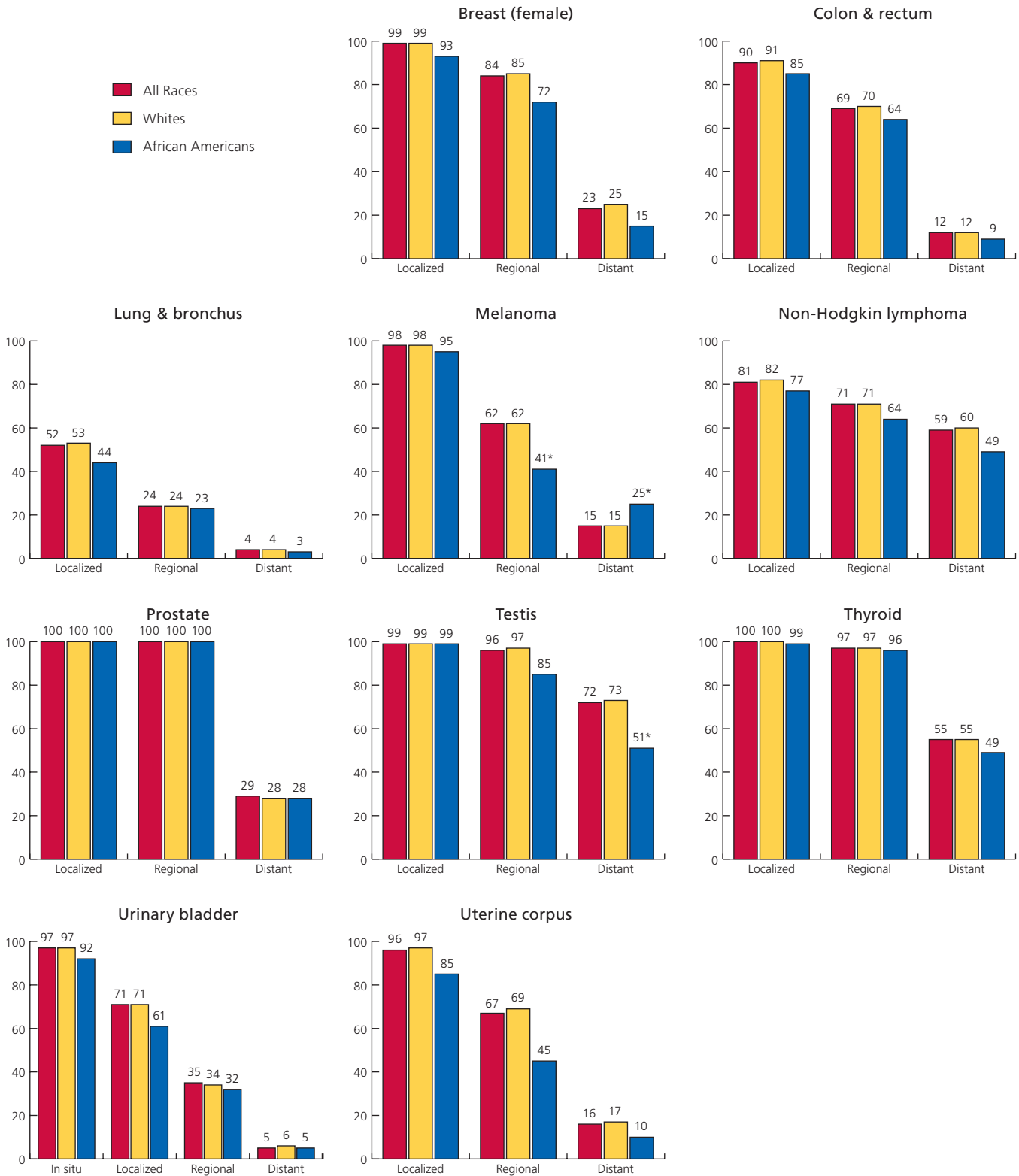
Childhood cancers (ages 0 to 14 years) are rare, representing less than 1% of all new cancer diagnoses, but they are the second leading cause of death in children, exceeded only by accidents. It is estimated that there were 58,510 cancer survivors ages 0-14 years living in the US as of January 1, 2012, and an additional 12,060 children will be diagnosed in 2012.

The types of cancer most commonly diagnosed in children differ from those in adults. Approximately 34% of cancers in children are leukemias, and 27% are brain and other nervous system cancers; other cancers in children include:

- Neuroblastoma (7%), a cancer of the nervous system that is most common in children younger than 5 years of age and usually appears as a swelling in the abdomen
- Wilms tumor (5%), a kidney cancer that may be recognized as a swelling in the abdomen
- Non-Hodgkin lymphoma (4%) and Hodgkin lymphoma (4%), which affect lymph nodes and may spread to other organs



**Figure 5. Five-Year Relative Survival Rates (%) among Patients Diagnosed with Select Cancers by Race and Stage at Diagnosis, 2001-2007.**

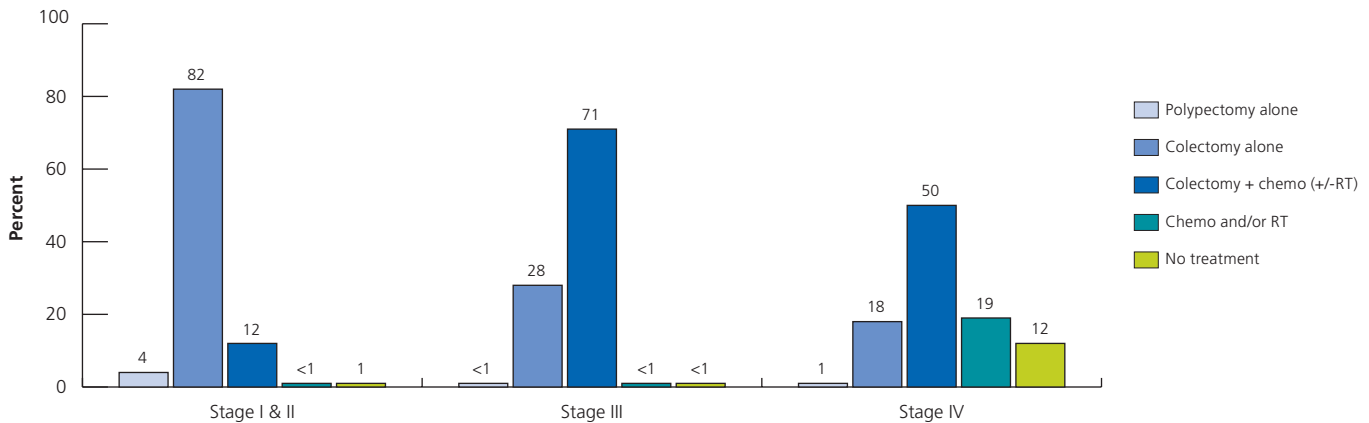


\*The standard error of the survival rate is between 5 and 10 percentage points.

Source: Howlader, et al, 2011.<sup>7</sup>

American Cancer Society, Intramural Research, 2012

**Figure 6. Colon Cancer Treatment Patterns by Stage, 2008**



Chemo = chemotherapy and may include common targeted therapies; RT = radiation therapy. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

- Rhabdomyosarcoma (3%), a soft-tissue sarcoma that can occur in the head and neck, genitourinary area, trunk, and extremities
- Retinoblastoma (3%), an eye cancer that is typically recognized because of discoloration of the eye pupil and usually occurs in children younger than 5 years of age
- Osteosarcoma (3%), a bone cancer that most often occurs in adolescents and commonly appears as sporadic pain in the affected bone
- Ewing sarcoma (1%), another type of cancer that usually arises in the bone, is most common in adolescents, and typically appears as pain at the tumor site.

**Treatment and survival:** Childhood cancers can be treated with a combination of therapies (surgery, radiation, and chemotherapy) chosen based on the type and stage of the cancer. Treatment most commonly occurs in specialized centers and is coordinated by a team of experts, including pediatric oncologists and surgeons, pediatric nurses, social workers, psychologists, and others. Research has led to dramatically improved survival rates for many childhood cancers over the past several decades.

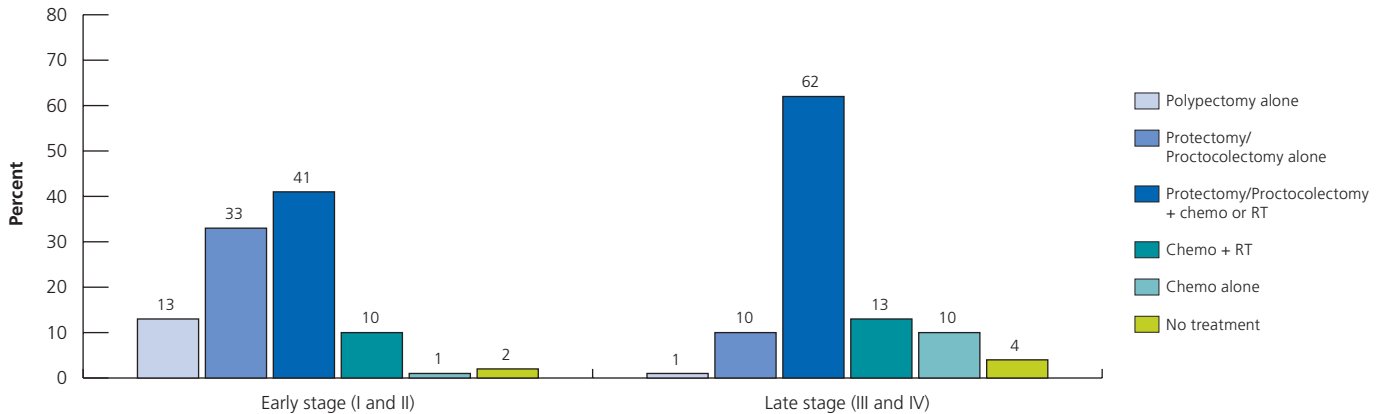
For all childhood cancers combined, the 5-year relative survival rate has improved markedly over the past 30 years, from less than 50% before the 1970s to 80% today, due to new and improved treatments.<sup>7</sup> However, rates vary considerably depending on cancer type, patient age, and other characteristics. For the most recent time period (2001-2007), the 5-year relative survival rate among children ages 0 to 14 years for retinoblastoma is 98%; Hodgkin lymphoma, 95%; Wilms tumor, 88%; non-Hodgkin lymphoma, 86%; leukemia, 83%; neuroblastoma, 74%; brain and other nervous system tumors, 71%; osteosarcoma, 70%; and rhabdomyosarcoma, 68%.<sup>7</sup>

**Special concerns of childhood cancer survivors:** Children diagnosed with cancer may experience treatment-related side effects not only during treatment, but many years after diagnosis as well. Aggressive treatments used for childhood cancers, especially in the 1970s and 1980s, resulted in a number of late effects, including increased risk of second cancers. Growing evidence suggests that even some of the newer, less toxic, therapies may increase the risk of serious health conditions in long-term childhood cancer survivors.<sup>8</sup> Late treatment effects can include impairment in the function of specific organs, cognitive impairments, and secondary cancers. For more information on late effects, see page 24.

The most common types of second cancers occurring among childhood cancer survivors are female breast, brain/central nervous system, bone, thyroid, soft tissue, melanoma, and acute myeloid leukemia.<sup>9</sup> The Children's Oncology Group (COG) has developed long-term follow-up guidelines for screening and management of late effects in survivors of childhood cancer. For more information on childhood cancer management, see the COG Web site at [survivorshipguidelines.org](http://survivorshipguidelines.org). The Childhood Cancer Survivor Study, which continues to follow more than 14,000 long-term childhood cancer survivors, has also provided valuable information about the late effects of cancer treatment. For more information, visit [ccss.stjude.org](http://ccss.stjude.org).

**Special concerns when cancer arises in adolescents and young adults (AYA):** Cancers occurring in adolescents (ages 15 to 19 years) and young adults (ages 20 to 39 years) are associated with a unique set of issues. Many childhood cancer types are rarely diagnosed after the age of 15, while others, such as Ewing sarcoma and osteosarcoma, are most common during adolescence. Young adults diagnosed with cancer usually receive care from health care providers with adult-focused practices even if

**Figure 7. Rectal Cancer Treatment Patterns by Stage, 2008**



Chemo = chemotherapy and may include common targeted therapies; RT = radiation therapy. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

these young adults have cancers that are more common in children. However, outcomes are often more successful when treatment is managed by a children’s cancer center.

Studies find that improvements in survival among adolescents and young adults have dramatically lagged behind those in children and even behind those for older adult patients, yet the current 5-year overall relative survival rate is the same as that for children.<sup>10</sup> There is relatively little specific information on survivorship concerns in this age group; however, adolescents and their families have unique stresses and concerns related to cancer, and they could benefit from the coordinated care and psychosocial support provided in specialized pediatric cancer centers.

At the age of 18 and beyond, childhood cancer survivors and newly diagnosed AYA cancer patients often face additional challenges related to insurance coverage. Medicaid covers cancer treatment for pediatric cancer patients who meet income criteria, but the more generous coverage by Medicaid for children lapses at age 18 or 21, depending on the state. Young adults diagnosed with cancer also face unique challenges of coping with cancer while beginning careers and families of their own.

## Colon and Rectum

It is estimated that as of January 1, 2012, there were almost 1.2 million men and women living in the US with a previous colorectal cancer diagnosis, and an additional 143,460 will be diagnosed in 2012. The median age at diagnosis for colorectal cancer is 68 for males and 72 for females.<sup>7</sup>

Use of recommended colorectal cancer screening tests can both detect cancer earlier and prevent colorectal cancer by promoting removal of precancerous polyps. However, only 59% of men and women 50 years of age and older receive colorectal cancer

screening according to guidelines.<sup>11</sup> Consequently, less than 40% of cases are diagnosed at a local stage, when treatment is most successful (Figure 3, page 5).

**Treatment and survival:** Treatment for cancers of the colon and rectum varies by stage at diagnosis (Figures 6 and 7). Surgery to remove the cancer and nearby lymph nodes is the most common treatment for early stage (I and II) colon (94%) and rectal (74%) cancer. Surgical procedures for colorectal cancer include polypectomy (removal of polyps), colectomy (removal of all or part of the colon), proctectomy (removal of the rectum), and proctocolectomy (removal of the rectum and all or part of the colon).<sup>3</sup> A colostomy (creation of an abdominal opening for elimination of body waste) may also be needed; this is more common for rectal cancer than for colon cancer. For some patients, the colostomy is temporary. In a procedure called colostomy reversal surgery, the opening is closed and the ends of the intestine are reconnected after the patient has healed from the original surgery.

Chemotherapy alone, or in combination with radiation, is often given to patients with late-stage disease.<sup>3</sup> In contrast to colon cancer, chemotherapy for rectal cancer is often given before surgery (neoadjuvant); almost 80% of chemotherapy for early stage rectal cancer is neoadjuvant. Three targeted monoclonal antibody therapies are approved by the FDA to treat metastatic colorectal cancer: bevacizumab (Avastin), which blocks the growth of blood vessels to the tumor, and cetuximab (Erbix) and panitumumab (Vectibix), which block the effects of hormone-like factors that promote cancer growth.

The 1- and 5-year relative survival rates for persons with colorectal cancer are 83% and 64%, respectively. Survival continues to decline to 58% at 10 years after diagnosis. When colorectal cancer is detected at an early stage, the 5-year relative survival rate is 90% (Figure 5, page 7); however, only 39% of cases are diagnosed at this

stage (Figure 3, page 5), in part due to the underuse of screening. After the cancer has spread regionally to involve adjacent organs or lymph nodes, the 5-year survival drops to 69%. When the disease has spread to distant organs, 5-year survival is 12%.

**Special concerns for colorectal cancer survivors:** Most long-term survivors of colorectal cancer report a very good quality of life, but some are troubled by bowel dysfunction and other health-related issues. In particular, those with a permanent colostomy may experience problems around intimacy and sexuality, embarrassment and social inhibition, and body-image disturbance. As many as 40% of patients treated for local and locally advanced (tumor has invaded nearby organs) colorectal cancer will have a recurrence; colorectal cancer survivors are also at increased risk of second primary cancers of the colon and rectum.<sup>12</sup>

For more information about colorectal cancer, see *Colorectal Cancer Facts & Figures*, available online at [cancer.org/statistics](http://cancer.org/statistics).

## Leukemias and Lymphomas

Leukemia is a cancer of the bone marrow and blood. Almost 90% of cases can be classified into one of four main groups according to cell type and rate of growth: acute lymphocytic leukemia (ALL), chronic lymphocytic leukemia (CLL), acute myeloid leukemia (AML), and chronic myeloid leukemia (CML). It is estimated that as of January 1, 2012, there were 298,170 leukemia survivors living in the US, and an additional 47,150 people will be diagnosed with leukemia in 2012.

Almost 90% of leukemia patients are diagnosed at age 20 and older; AML and CLL are the most common types of leukemia in adults. Among children and teens, ALL is most common, accounting for three-fourths of leukemia cases. The median age at diagnosis for ALL is 13 years; the median ages at diagnosis for CLL, AML, and CML are 72, 67, and 65, respectively (Figure 2, page 4).

Lymphomas are cancers that begin in cells of the immune system. There are two basic categories of lymphomas: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL), which includes a large, diverse group of cancers. It is estimated that as of January 1, 2012, there were 188,590 HL survivors and 534,950 NHL survivors, and that 9,060 and 70,130 new cases, respectively, will be diagnosed in 2012.

Both HL and NHL can occur at any age; however, the majority (65%) of HL occurs before age 50, whereas 83% of NHL occurs in those ages 50 and older (Figure 2, page 4).

### Treatment and survival:

**AML.** Acute myeloid leukemia (also called acute non-lymphocytic or acute myelogenous leukemia) is a type of leukemia in which the bone marrow makes abnormal white blood cells of a type other than lymphocytes. It is called acute because it is rapidly fatal in the absence of treatment.

Chemotherapy is the standard treatment for AML (Figure 8). Some patients may also receive radiation therapy or a bone-marrow transplant using their own or a closely related sibling's cells. Treatment in adults has two phases. The first, called induction, is designed to clear the blood of leukemia cells and put the disease into remission. Induction usually kills most cancer cells. The goal of the second phase, called consolidation, is to kill any remaining leukemia cells. Approximately 60%-70% of adults with AML can expect to attain complete remission status following the first phase of treatment, and more than 25% of adults survive 3 or more years and may be cured.<sup>13</sup> About 4% of AML cases occur in children ages 14 and younger, for whom the prognosis is substantially better than among adults.

**CML.** Chronic myeloid leukemia (also called chronic granulocytic leukemia or chronic myelogenous leukemia) is a type of cancer that starts in the blood-forming cells of the bone marrow and invades the blood. Once suspected, CML is usually easily diagnosed because the involved cells have a distinctive chromosomal abnormality called the Philadelphia chromosome. There are three phases of CML: chronic, accelerated, and blastic. The chronic phase is least aggressive, and characterized by no or mild symptoms; the accelerated phase has noticeable symptoms, such as fever, poor appetite, and fatigue; the blastic phase is most aggressive with more severe symptoms that may also include an enlarged spleen. CML is most common in adults, but can also occur in children.

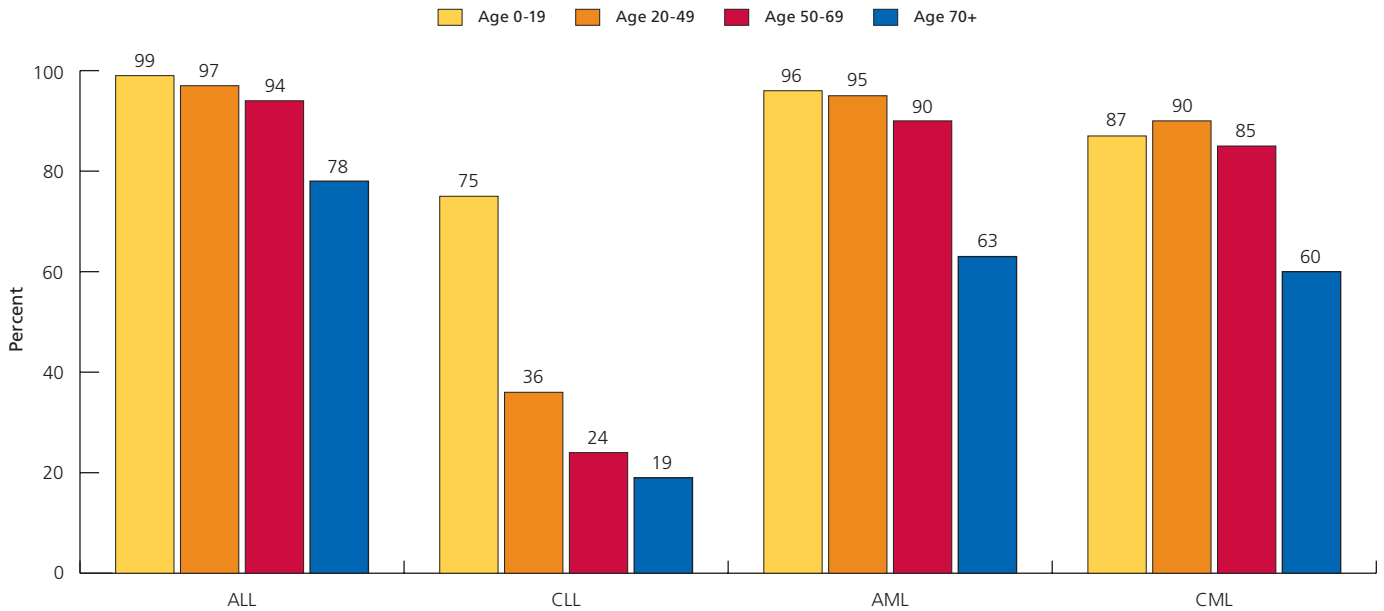
In the past 10 years, the standard of care for CML is to treat with a type of targeted drug called a tyrosine kinase inhibitor (such as imatinib [Gleevec]). These drugs are very effective at inducing remission and decreasing progression to the accelerated phase, but must be taken continuously to keep the disease in check. In part due to the discovery of these targeted therapies, the 5-year survival rate for CML increased from 31% for cases diagnosed during 1990-1992 to 55% for those diagnosed during 2001-2007.<sup>7</sup>

**ALL.** Acute lymphocytic leukemia is a rapidly progressing disease in which too many immature lymphocytes (type of white blood cell) are produced in the bone marrow. It is the most common cancer diagnosed in children, with approximately 2,900 children and teens diagnosed each year in the US.<sup>14</sup>

Incidence of ALL is highest among children ages 2 to 3 years, among whom rates are about 4 times higher than for children ages 8 to 10 years.<sup>14</sup> Treatment typically involves chemotherapy given for 2 to 3 years; other treatments such as surgery and radiation therapy may be used in special circumstances.

One of the most serious potential long-term side effects of ALL therapy is the development of AML. This occurs in about 5% of patients after they have received chemotherapy drugs called epipodophyllotoxins (e.g., etoposide or teniposide) or alkylating agents (e.g., cyclophosphamide or chlorambucil).<sup>15</sup> Less often, children cured of leukemia may later develop non-Hodgkin lymphomas or other cancers. Among children with ALL, more than

**Figure 8. Chemotherapy Use among Leukemia Patients by Age, 2008**



Note: Chemotherapy may include common targeted therapies.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

95% attain remission and 75%-85% are free of recurrence for at least 5 years after diagnosis.<sup>16</sup>

**CLL.** Chronic lymphocytic leukemia is characterized by the overabundance of abnormal white blood cells. It usually progresses slowly and is the most common type of leukemia in adults, with 95% of cases occurring in those age 50 and older (Figure 2, page 4). Treatment is not likely to cure the disease and is often unnecessary in uncomplicated early disease; active surveillance (carefully monitoring disease progression over time) is a common initial treatment approach. For later-stage disease, available treatments include chemotherapy, immunotherapy, radiation therapy, and surgery (removal of the spleen). The overall 5-year relative survival for CLL is 78%; however, there is a large variation in survival among individual patients, ranging from several months to normal life expectancy.<sup>7</sup>

**HL.** Hodgkin lymphoma is a cancer of the lymph nodes that often starts in the chest, neck, or abdomen. It occurs in all age groups, but is most common in early adulthood (61% of cases are diagnosed between ages 15 and 49, Figure 2, page 4). There are two major types of HL: classic, which is the most common and is distinguishable by the presence of Reed Sternberg cells, and nodular lymphocyte predominant, which is rare and tends to be more slow growing than classic HL.

Treatment varies slightly by type. Classical Hodgkin disease is generally treated with multi-agent chemotherapy often along

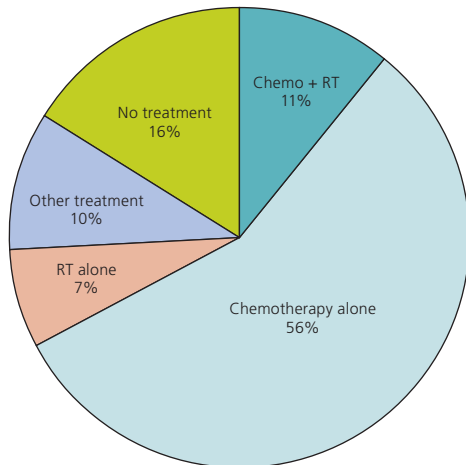
with radiation therapy. Stem cell transplant may also be recommended for some patients. Brentuximab vedotin (Adcetris) was recently approved to treat HL in certain patients who failed to respond to previous therapies.

For those diagnosed with nodular lymphocyte predominant HL, radiation alone may be appropriate for patients with early stage disease. For those with later-stage disease, chemotherapy plus radiation, as well as the monoclonal antibody rituximab (Rituxan), may be recommended.

Survival rates have improved substantially since the early 1970s. During the most recent time period, the 1-year relative survival rate for all patients diagnosed with Hodgkin disease was 92%; the 5- and 10-year rates were 84% and 79%, respectively.

**NHL.** The most common types of NHL are diffuse large B-cell lymphoma, representing about one-third of NHL cases, and follicular lymphoma, which represents about one-fifth of NHL cases. Diffuse large B-cell lymphomas grow quickly, yet about half of all patients are cured with treatment. It can affect any age group, but occurs most often in adults ages 50 and older. In contrast, follicular lymphomas tend to grow slowly and often do not require treatment until the lymphoma causes symptoms. Although standard treatment will not usually cure this cancer, patients may still live a long time. The overall 5-year relative survival rate is 67%.<sup>7</sup> Over time, some follicular lymphomas change into the fast-growing diffuse B-cell type.

**Figure 9. Non-Hodgkin Lymphoma Treatment Patterns, 2008**



Note: Chemotherapy may include common targeted therapies.  
RT= radiation therapy

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

NHL is usually treated with chemotherapy either in combination with radiation (11%) or without radiation (56%); radiation without chemotherapy (7%) is used less often (Figure 9). Targeted therapies such as rituximab (Rituxan), alemtuzumab (Campath), and ofatumumab (Arzerra) are also used for some types of NHL.

#### Special concerns of leukemia and lymphoma survivors:

Treatments for leukemia and lymphoma can result in a number of significant late effects. Some children with ALL may receive cranial radiation therapy to treat any spread of leukemia to the central nervous system (CNS), which can cause long-term cognitive deficits. Young women treated in childhood with radiation to the chest for Hodgkin lymphoma are at increased risk for developing breast cancer. This type of radiation is also associated with increased risk of various heart complications (e.g., valvular heart disease and coronary artery disease), which can occur decades after treatment is received.

Several forms of leukemia and lymphoma in adults involve long periods of slow progression or remission with the likelihood of eventual accelerated disease or recurrence. While most welcome this period of relatively healthy survivorship, it may pose unique challenges to patients and their loved ones due to anxiety about eventual outcomes.

### Lung and Bronchus

It is estimated that there were 412,230 men and women living in the US with a history of lung cancer as of January 1, 2012, and 226,160 will be newly diagnosed in 2012. The median age at diagnosis for lung cancer is 70 years for males and 71 years for females.<sup>7</sup>

The majority of lung cancers (56%) are diagnosed after the cancer has spread to distant regions because symptoms usually do not appear until the disease is already in an advanced stage (Figure 3, page 5).

Much research has focused on identifying effective methods of early detection. Recent results from a large clinical trial showed that annual screening with chest x-ray does not reduce lung cancer mortality.<sup>17</sup> However, newer tests, such as low-dose spiral computed tomography (CT) scans, have produced promising results in detecting lung cancers at earlier, more operable stages in those at high risk (i.e., current or former heavy smokers).

Results from the National Lung Screening Trial, a clinical trial designed to determine the effectiveness of lung cancer screening in high-risk individuals, showed 20% fewer lung cancer deaths among a group of current or former heavy smokers who were screened with spiral CT compared to standard chest x-ray.<sup>18</sup> However, it is not known how relevant these results are to individuals with a lesser smoking history compared with the study participants, who had a history of heavy smoking – the equivalent of at least a pack of cigarettes per day for 30 years.

**Treatment and survival:** Lung cancer is classified as small cell (14% of cases) or non-small cell (85%) for the purposes of treatment. Based on type and stage of cancer, treatments include surgery, radiation therapy, chemotherapy, and targeted therapies.

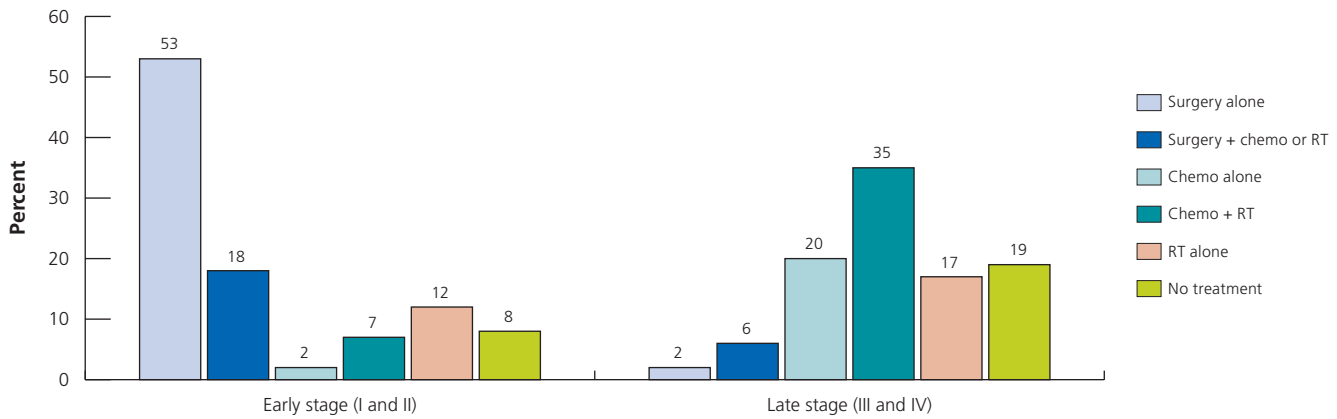
Radiation alone (for limited disease) or combined with chemotherapy (for extensive disease) is the usual treatment of choice for small cell lung cancer. On this regimen, 70-90% of patients with limited disease and 60-70% of those with extensive disease experience remission, though the cancer almost always returns.<sup>19</sup>

For early stage non-small cell lung cancers, the majority of patients (71%) undergo surgery and approximately 18% also receive chemotherapy or radiation therapy (Figure 10). Advanced-stage non-small cell lung cancer patients are treated with chemotherapy alone (20%), radiation therapy alone (17%), or a combination of the two (35%). Targeted therapies, such as bevacizumab (Avastin), erlotinib (Tarceva), cetuximab (Erbix), and crizotinib (Xalkori), may also be used in treating advanced-stage disease.

The 1-year relative survival for all lung cancers combined increased from 37% in 1975-1979 to 43% in 2004-2007, largely due to improvements in surgical techniques and combined therapies. The 5-year survival rate is 52% for cases detected when the disease is still localized (Figure 5, page 7), but only 15% of lung cancers are diagnosed at this early stage (Figure 3, page 5). The overall 5-year survival for small cell lung cancer (6%) is lower than that for non-small cell (17%).<sup>7</sup>

**Special concerns for lung cancer survivors:** Many lung cancer survivors have impaired lung function, especially if they have had surgery. In some cases respiratory therapy and medi-

**Figure 10. Non-Small Cell Lung Cancer Treatment Patterns by Stage, 2008**



Chemo = chemotherapy and may include common targeted therapies; RT = radiation therapy. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

cations can improve fitness and ability to resume normal daily activities. Those lung cancer survivors who smoke should be encouraged to quit, as survivors of smoking-related cancers are at increased risk of additional smoking-related cancers, especially in the head and neck and urinary tract. Survivors may feel stigmatized because of the connection between smoking and lung cancer, which can be particularly difficult for lung cancer survivors who never smoked.

## Melanoma

It is estimated there were nearly 1 million melanoma survivors living in the US as of January 1, 2012, and an additional 76,250 people will be diagnosed in 2012. Melanoma incidence rates have been increasing for at least 30 years.

About 84% of melanomas are diagnosed at a localized stage, when they are highly curable (Figure 3, page 5). The median age at diagnosis for melanoma is 63 for males and 56 for females.<sup>7</sup> Though melanoma is rare before age 30, it is the third most commonly diagnosed cancer, after thyroid and testicular cancer, in those ages 20 to 29 years.

**Treatment and survival:** Surgery is the primary treatment for malignant melanoma; the tumor and up to 4 centimeters of surrounding normal tissue are removed. Sometimes a sentinel (nearest to the tumor site) lymph node is biopsied to determine stage. More extensive lymph node surgery, known as a complete lymph node dissection, may be needed if the nodes are enlarged or the sentinel nodes contain cancer.

Melanomas with deep invasion or that have spread to lymph nodes may be treated with surgery, followed by immunotherapy with interferon alfa. Radiation therapy may be given to areas of lymph node spread after the nodes are removed. For advanced

disease, chemotherapy, immunotherapy, and/or radiation therapy may be used. Two newer drugs, ipilimumab (Yervoy) and vemurafenib (Zelboraf), have recently been approved by the FDA and may extend survival in people with advanced melanoma.

The 5- and 10-year relative survival rates for persons with melanoma are 91% and 89%, respectively. For localized melanoma, the 5-year survival rate is 98%; 5-year survival rates for regional and distant stage diseases are 62% and 15%, respectively (Figure 5, page 7).

**Special concerns for melanoma survivors:** Melanoma survivors are nearly 9 times more likely than the general population to develop additional melanomas due to genetic risk factors and/or overexposure to ultraviolet radiation.<sup>20</sup>

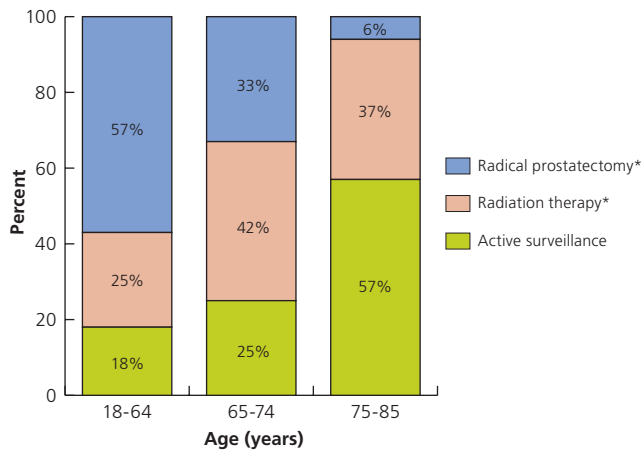
## Prostate

It is estimated that there were nearly 2.8 million men living with prostate cancer in the US as of January 1, 2012, and 241,740 men will be diagnosed with prostate cancer in 2012. The median age at diagnosis is 67 (Figure 2, page 4). Most prostate cancers in the US are diagnosed by prostate-specific antigen (PSA) testing, although many expert groups, including the American Cancer Society, have concluded that data are insufficient to recommend routine use of this screening test.

**Treatment and survival:** Treatment options vary depending on stage and grade of the cancer, as well as age and other medical conditions of the patient. Surgery (conventional, laparoscopic, or robotic-assisted laparoscopic), external beam radiation, or radioactive seed implants (brachytherapy) are commonly used to treat men with early stage disease.

More than half (57%) of men younger than 65 are treated with radical prostatectomy (removal of the prostate along with

**Figure 11. Prostate Cancer Primary Treatment Patterns by Age, 2008**



\*Initial treatment received.

**Source:** Surveillance Epidemiology and End Results (SEER) Program, SEER 17 Registries, 2008, Division of Cancer Control and Population Science, National Cancer Institute, 2011.

American Cancer Society, Intramural Research, 2012

nearby tissues) (Figure 11). Those in the 65- to 74-year age range commonly undergo radiation therapy (42%), though radical prostatectomy (33%) is also often used. Data show similar survival rates for patients with early stage disease treated with either of these methods. For men with less aggressive tumors and particularly for older men, active surveillance (also referred to as watchful waiting) rather than immediate treatment is a reasonable and commonly recommended approach.

Hormonal therapy (also known as androgen deprivation therapy), chemotherapy, bone-directed therapy (such as zoledronic acid or denosumab), radiation, or a combination of these treatments is used to treat more advanced disease. The main type of hormone therapy used in the US works to reduce the production of male hormones that stimulate cancer growth. This approach, called medical castration, uses drugs such as goserelin acetate (Zoladex) and leuprolide (Lupron or Viadur) to block the androgen production of the testes. Another approach, called surgical castration or orchiectomy, involves an outpatient procedure to remove the testicles. Both approaches may control advanced prostate cancer for long periods by shrinking the size or limiting the growth of the cancer, thus helping to relieve pain and other symptoms. Other drugs, such as anti-androgens and the new drug abiraterone (Zytiga), are also forms of hormone therapy that can be helpful in treating advanced prostate cancer.

More than 90% of all prostate cancers are discovered in the local or regional stages, for which the 5-year relative survival rate approaches 100%. Over the past 25 years, the 5-year relative sur-

vival rate for all stages combined has increased from 68% to almost 100%. According to the most recent data, 10- and 15-year relative survival rates are 98% and 92%, respectively.

**Special concerns for prostate cancer survivors:** Many prostate cancer survivors who have been treated with surgery or radiation therapy experience symptoms and side effects of treatment, including incontinence, erectile dysfunction, and bowel complications. Patients receiving hormonal treatment may experience menopausal-like symptoms, including loss of libido, hot flashes, night sweats, irritability, and osteoporosis (which can lead to fractures). Bone-directed therapies such as zoledronic acid (Zometa) and denosumab (Prolia and Xgeva) have been successful in reducing bone loss and decreasing the risk of fractures.<sup>21</sup> In the long term, hormone therapy also increases the risk of diabetes, cardiovascular disease, and obesity.<sup>22</sup>

## Testis

It is estimated that there are 230,910 testicular cancer survivors in the US, and an additional 8,590 men will be diagnosed in 2012. Testicular germ cell tumors (TGCTs) account for the majority of testicular cancers. These tumors arise from testicular cells that normally develop into sperm cells.

There are 2 main types of TGCTs: seminomas and nonseminomas. Seminomas are slow-growing and generally occur among men in their late 30s to early 50s. Nonseminomas are more common, tend to grow more quickly, and generally occur among men in their late teens to early 40s.

Most testicular cancers can be found early; a lump on the testicle is usually the first sign. Overall, 70% of cases are diagnosed at the localized stage (Figure 3, page 5).

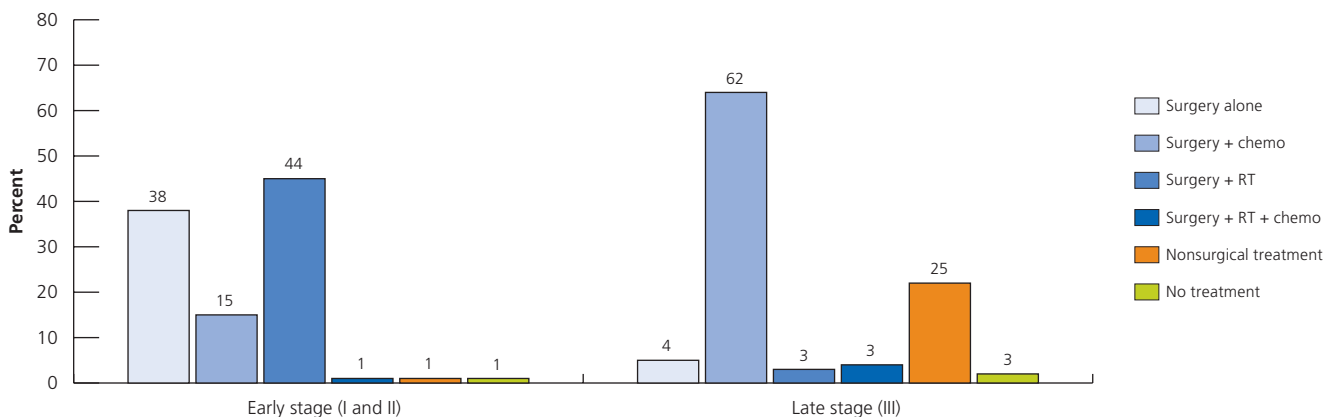
**Treatment and survival:** Treatment of almost all TGCTs begins with orchiectomy, a type of surgery involving the removal of the testicle in which the tumor arose. Subsequent treatment depends on stage and cancer type. After orchiectomy, early stage seminomas are often treated with radiation (46%), whereas late-stage seminomas are generally treated with chemotherapy (68%) (Figure 12).

Men with nonseminomas are often treated with chemotherapy in addition to orchiectomy, especially at later stages (Figure 13). For men with early stage disease, removal of the retroperitoneal lymph nodes (RPLND), which are located at the back of the abdomen and through which testicular cancer is most likely to spread, is recommended as a way to control recurrence and improve survival.

The 5-year relative survival rate for men diagnosed with early stage testicular cancer is 99%. Survival declines to 96% for regional stage disease and 72% for distant stage (Figure 5, page 7).



**Figure 12. Treatment Patterns for Seminomatous Testicular Germ Cell Tumors, 2008**



Chemo = chemotherapy and may include common targeted therapies; RT = radiation therapy. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

**Special concerns of testicular cancer survivors:** Testicular cancer survivors are often concerned about sexual and reproductive impairments after treatment. Although most men who have one healthy testicle produce sufficient male hormones and sperm to continue sexual relations and father children, sperm banking is recommended prior to treatment.

## Thyroid

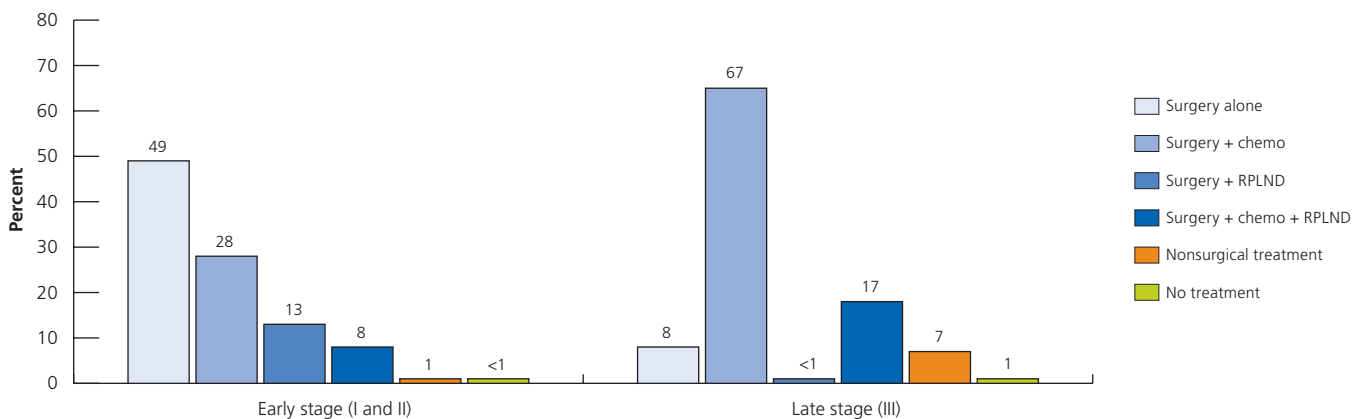
It is estimated that there are 558,260 people living with thyroid cancer in the US, and an additional 56,460 will be diagnosed in 2012. The incidence rate of thyroid cancer has been increasing sharply since the mid-1990s, and it is the fastest-increasing cancer in both men and women. Reasons for these increases are not

known. Some studies suggest the increasing rates are due to detection of small tumors (through ultrasound and confirmation via fine needle aspiration),<sup>23, 24</sup> while others argue that the increase is in part real, and involves both small and large tumors.<sup>25-27</sup>

Thyroid cancer commonly occurs at a younger age than most other adult cancers; the median age at diagnosis for thyroid cancer is 54 for males and 48 for females.<sup>7</sup> Overall, 68% of thyroid cancers are diagnosed at the localized stage (Figure 3, page 5).

**Treatment and survival:** Most thyroid cancers are either papillary or follicular carcinomas, both of which are slow-growing and highly curable. About 5% of thyroid cancers are medullary

**Figure 13. Treatment Patterns for Nonseminomatous Testicular Germ Cell Tumors, 2008**

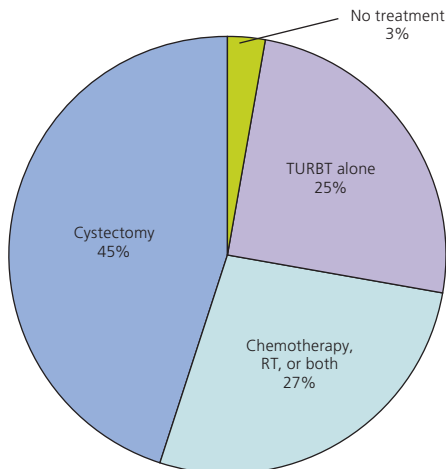


Chemo = chemotherapy and may include common targeted therapies; RPLND = retroperitoneal lymph node dissection. Totals may not sum to 100% due to rounding.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

**Figure 14. Muscle Invasive Bladder Cancer Treatment Patterns, 2008**



RT = radiation therapy; cystectomy = surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes; TURBT = transurethral resection of the bladder tumor; chemotherapy may include common targeted therapies.

Source: National Cancer Data Base, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

carcinoma or anaplastic carcinoma, and are more difficult to treat because they grow more quickly and have often already spread to other organs by the time they are diagnosed.

The first choice of treatment in nearly all cases is surgery, with patients receiving either total (84%) or partial (15%) thyroidectomy (removal of the thyroid gland).<sup>3</sup> Treatment with radioactive iodine (I-131) after surgery may be recommended to destroy any remaining thyroid tissue. Thyroid hormone therapy is given to replace hormones normally produced by the thyroid gland and to prevent the body from making thyroid-stimulating hormone, decreasing the likelihood of recurrence.

The 5-year relative survival rate for all thyroid cancer patients is 97%.<sup>7</sup> However, survival varies markedly by stage, age at diagnosis, and disease subtype. The 5-year survival rate approaches 100% for localized disease, is 97% for regional stage disease, and 56% for distant stage disease. For all stages combined, survival varies by age, and is highest for patients under 45 years (almost 100%), and progressively decreases to 82% for those 75 or older.

**Special concerns of thyroid cancer survivors:** Patients who had all or part of their thyroid gland removed will need to take thyroid hormone replacement pills (levothyroxine) and have follow-up visits to ensure that these pills are the proper dose. Thyroid cancer survivors are often monitored for recurrence by measuring levels of thyroglobulin, a substance produced in the thyroid gland at high levels in people with papillary and follicular cell cancer. These levels are not helpful in patients with high

levels of anti-thyroglobulin antibodies, who are monitored through other means, such as periodic whole-body I-131 scans. Although data are limited on thyroid cancer recurrence rates, it appears that late recurrences (5 or more years after initial treatment) are not uncommon.

## Urinary Bladder

It is estimated that as of January 1, 2012, there were 585,390 urinary bladder cancer survivors living in the US; 73,510 people will be diagnosed with bladder cancer in 2012. Half of all bladder cancer patients are diagnosed while the tumor is in situ (noninvasive, present only in the layer of cells in which the cancer developed). Cancer of the urinary bladder is most common among older adults. The median age at diagnosis is 73 for males and 74 for females.<sup>7</sup>

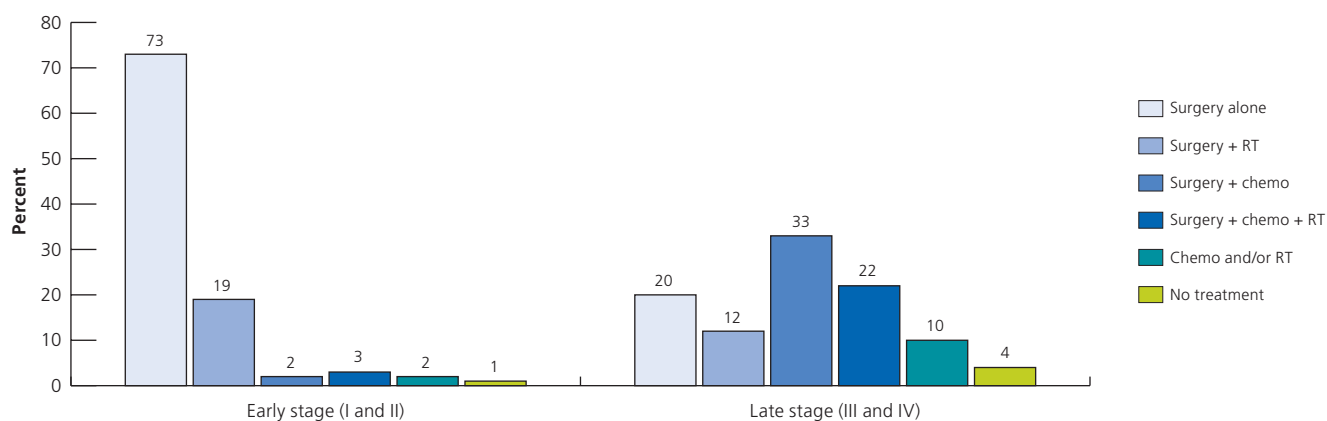
**Treatment and survival:** Treatment for urinary bladder cancer varies by stage and age. For cancers that do not involve the muscle layer of the bladder wall, most patients are diagnosed and treated with a minimally invasive procedure called transurethral resection of the bladder tumor or TURBT. This endoscopic surgery may be followed by chemotherapy (17%) or intravesical biological therapy with *bacillus Calmette-Guerin* (BCG) solution (29%).<sup>3</sup> BCG is a type of immunotherapy, which means it stimulates the body's own immune system to kill bladder cancer cells.

Among patients with tumors that involve the muscle layer of the bladder, almost half (45%) receive cystectomy, a surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes (Figure 14). Twenty-seven percent of patients receive chemotherapy, high-dose radiation therapy, or both, without surgery (Figure 14). In appropriately selected cases, this bladder-sparing approach is as effective as cystectomy at preventing the cancer from returning.<sup>28</sup> For advanced cancers that have not spread to other organs, chemotherapy either alone or with radiation therapy may be effective at shrinking the size of the tumor, thus permitting cystectomy.

For all stages combined, the 5-year relative survival rate is 78%.<sup>7</sup> Survival declines to 72% at 10 years and 66% at 15 years after diagnosis. When in situ urinary bladder cancer is diagnosed, 5-year survival is 97%.<sup>7</sup> Patients with invasive tumors diagnosed at a localized stage have a 5-year survival rate of 71%; 35% of cancers are detected at this early stage. For regional and distant-stage disease, 5-year survival is 35% and 5%, respectively (Figure 5, page 7).

**Special concerns of urinary bladder cancer survivors:** Given the high rate of recurrence among bladder cancer patients (ranging from 50%-90%), attentive bladder cancer surveillance is very important.<sup>29-31</sup> Surveillance includes cystoscopy (examination of the bladder with a small scope) and urine cytology, as well as newer tests for markers such as NMP22 in the urine.

**Figure 15. Uterine Cancer Treatment Patterns by Stage, 2008**



Chemo = chemotherapy and may include common targeted therapies; RT = radiation therapy. Totals may not sum to 100% due to rounding.

Source: National Cancer Database, 2008.<sup>3</sup>

American Cancer Society, Intramural Research, 2012

Other tests may also be recommended for patients with muscle-invasive disease, such as chest x-rays and bladder washings. Patients who had their bladder removed (cystectomy) will also have to undergo a procedure to divert their urine, which can affect quality of life. A neo-bladder (creation of “new” bladder using the intestine) is the most common procedure, but some patients may have a urostomy (a conduit emptying into a bag worn inside the abdomen).

## Uterine Corpus

It is estimated there were 606,910 women living in the US with a previous diagnosis of uterine corpus cancer as of January 1, 2012, and 47,130 women will be diagnosed in 2012. Uterine corpus cancer is the second most common cancer among female cancer survivors, following breast cancer. More than 90% of these cancers occur in the endometrium (lining of the uterus). Most uterine corpus cancers (68%) are diagnosed at an early stage because of postmenopausal bleeding, a frequent early sign. The median age at diagnosis for uterine corpus cancer is 61 (Figure 2, page 4).

**Treatment and survival:** Uterine corpus cancers are usually treated with surgery, radiation, hormone therapy, and/or chemotherapy, depending on the stage of disease (Figure 15). Surgery alone, consisting of hysterectomy (removal of the uterus and cervix) often along with bilateral salpingo-oophorectomy (removal of both ovaries and Fallopian tubes), is the treatment regimen for 73% of patients with early stage endometrial cancers (Figure 15). In addition to surgery, about 22% of all patients have higher-risk early stage disease and therefore will also receive radiation therapy, either alone or in combination with chemotherapy.<sup>3</sup>

Among women with advanced-stage endometrial cancer, the majority (67%) receive surgery followed by radiation and/or chemotherapy (Figure 15). Clinical trials are currently assessing the most appropriate regimen of radiation and chemotherapy, in addition to targeted therapies, such as bevacizumab (Avastin), for women with metastatic or recurrent endometrial cancers.

The 1- and 5-year relative survival rates for uterine corpus cancer are 92% and 83%, respectively. The 5-year survival rates are 96%, 67%, or 16%, respectively, if the cancer is diagnosed at a local, regional, or distant stage (Figure 5, page 7). Relative survival in whites exceeds that for African Americans by at least 7 percent-age points for every stage of diagnosis.

**Special concerns of uterine corpus cancer survivors:** Any hysterectomy causes infertility. For those who were premenopausal before surgery, removing the ovaries will also cause menopause. This can lead to symptoms such as hot flashes, night sweats, and vaginal dryness. Sexual problems are commonly reported among endometrial cancer survivors. Removing lymph nodes in the pelvis can lead to a buildup of fluid in the legs, a condition called lymphedema. This occurs more often if radiation is given after surgery.

# Navigating the Cancer Experience: Diagnosis and Treatment

Newly diagnosed cancer patients face numerous challenges. There are many difficult decisions to be made, from selecting a doctor and treatment facility to choosing between recommended treatment options. These demands are even more overwhelming for patients who experience barriers to quality cancer care.

## Choosing a Doctor

Choosing an oncologist (a doctor who specializes in treating cancer) is one of the most important decisions for people who are newly diagnosed with cancer. Assistance is often needed because most patients have no experience in this area. The doctor who made the preliminary diagnosis, usually the patient's primary care physician, will often recommend appropriate cancer specialists.

There are three primary types of oncologists: medical, surgical, and radiation. Medical oncologists treat cancer using chemotherapy and other drugs. Surgical oncologists treat cancer by surgically removing the cancer and surrounding tissue. Radiation oncologists treat cancer with radiation therapy.

Some types of oncologists focus on specific populations. For example, pediatric oncologists specialize in the care of children, gynecologic oncologists only treat patients with female reproductive cancers (e.g., cervical, uterine, and ovarian), and hematologists specialize in patients with blood disorders. Some cancers, such as skin and prostate cancer, may be treated by doctors who specialize in specific body systems (i.e., dermatologists and urologists, respectively). Plastic surgeons may also be involved in cancer-directed treatments and perform reconstructive surgeries that occur as part of cancer care, particularly for patients with breast cancer.

Depending on the type of cancer and treatments recommended, the doctor overseeing the first course of treatment will likely be a surgeon, medical oncologist, or radiation oncologist. Regardless of which specialist sees the person first, doctors of the other specialties will likely be involved in planning and providing treatment. The extent and timing of their involvement depend on the type and stage of cancer, the organization of cancer care in each community, and other patient and tumor-related characteristics. However, most oncology specialists participate in a team that consults regularly about cancer management in individual cases, and on a regular basis in conferences where cases and treatment advances are discussed.

The American Society of Clinical Oncology, the world's leading professional organization representing physicians of all oncology subspecialties, has a searchable database of member oncologists on their Web site, [cancer.net](http://cancer.net). Many other physician organizations, such as the American Society of Hematology, Society of Surgical Oncology, American Medical Association, American College of Surgeons, and American Osteopathic Association, also have searchable Web sites.

Once a list of potential specialists is identified, the patient should consider selecting a cancer specialist who:

- Is board-certified
- Has experience with their cancer type
- Accepts the patient's health insurance (most insurance plans have Web sites that can be searched for doctors by specialty)
- Has privileges at a hospital that is acceptable and approved by the patient's insurance

Finding this type of information may not be easy. Cancer patients should not hesitate to ask prospective doctors direct questions about their level of experience, including the number of cases they have treated or surgical procedures they have performed. They may also want to ask about how the doctor organizes cancer care with other members of the cancer treatment team (doctors and others), whether cases are presented at a cancer conference, and whether the doctor makes participation in clinical research trials an option to patients.

## Choosing a Treatment Facility

There are many excellent cancer care centers throughout the United States, and a number of resources are available to learn about them.

**Commission on Cancer.** The Commission on Cancer (CoC), a program of the American College of Surgeons, has designated more than 1,500 hospitals or facilities throughout the United States as approved for the delivery of cancer care. Hospitals with this special designation are required to meet certain standards regarding quality cancer care and offer a range of cancer care services.

CoC-approved cancer programs include major treatment centers as well as community hospitals. Approved programs generally provide high-quality diagnostic, staging, and treatment services and are staffed by a variety of specialists. However, some community hospitals may provide diagnostic and treatment services by referral, and may not have board-certified specialists in all major oncology-related disciplines on staff.

Most CoC hospitals provide information on the annual number of patients treated by cancer site on the American College of Surgeons Web site, [facts.org/cancer/nedb/publicaccess](http://facts.org/cancer/nedb/publicaccess). A link to a searchable list of CoC-approved facilities is also available.

## Clinical trials

Clinical trials are used to learn whether new treatments for diseases, such as cancer, are both safe and effective. Generally, participants receive either the state-of-the-art standard treatment or a new therapy that may offer improved survival and/or fewer side effects. It is a common misperception that patients may receive a placebo or no treatment at all. There is no right or wrong answer to the question of whether clinical trial participation is a good choice because each patient's situation is different. The decision is personal and depends on factors such as the benefits and risks of the study and what will be achieved by taking part. It also depends on individual values, preferences, and priorities. Information about clinical trials that are available for a specific cancer type and stage of disease progression is helpful in leading to the most appropriate decision. Patients are encouraged to inquire about what clinical trials are available at their treating facility.

For more information about clinical trials, including how to enroll, call the American Cancer Society at 1-800-303-5691 or visit [cancer.org/clinicaltrials](http://cancer.org/clinicaltrials). Information can also be obtained by visiting the National Cancer Institute's Web site at [cancer.gov/clinicaltrials](http://cancer.gov/clinicaltrials) or by calling 1-800-4-CANCER.

**National Cancer Institute.** The National Cancer Institute (NCI) recognizes and funds two types of cancer centers that excel in research – basic and comprehensive cancer centers. Basic or NCI-designated cancer centers are required to conduct research in at least one of the following areas: laboratory, clinical, or population science. Comprehensive cancer centers must demonstrate expertise in all 3 research areas. In addition, they must initiate and conduct early phase innovative clinical trials and provide outreach and education for both health care professionals and the general public. These centers are often university hospitals affiliated with medical schools, but may also be freestanding. Not all patients treated at these centers are research subjects. A searchable list of the NCI-designated Cancer Centers is available on their Web site, [cancercenters.cancer.gov](http://cancercenters.cancer.gov).

**Association of Community Cancer Centers.** Founded in 1974, the Association of Community Cancer Centers (ACCC) has more than 700 member community cancer centers in the US. First published in 1988, ACCC's standards expand upon those of the American College of Surgeons' Commission on Cancer and outline the major components of a cancer program, regardless of setting, and dictate how the components should relate to one another.

A searchable directory of the member community centers by state describing each facility, available support services, areas of expertise, and ongoing research is available on their Web site, [acc-cancer.org/membership\\_directory](http://acc-cancer.org/membership_directory).

**Children's Oncology Group.** The Children's Oncology Group's mission is to cure and prevent childhood and adolescent cancer through scientific research and comprehensive care. More than 90% of children with cancer in the United States are treated at centers that are Children's Oncology Group (COG) members. COG has more than 200 affiliated centers that are linked to a university or children's hospital.

A listing of COG institutions by state can be found on their Web site, [curesearch.org/resources/cog.aspx](http://curesearch.org/resources/cog.aspx).

## Choosing among Recommended Treatments

Many factors are important in choosing among treatment options. The goal is to select the treatment that will most effectively eliminate the cancer while ensuring the highest possible level of physical functioning after treatment. Cancer treatment strives to both improve survival and maintain quality of life.

Treatment for cancer can involve surgery, chemotherapy, radiation, hormone therapy, immunotherapy, targeted therapy, and bone marrow transplantation. In some cases, the best approach is not to initiate any treatment. Called active surveillance (formerly known as "watchful waiting"), this may be a good choice when it is anticipated that a cancer will grow or progress so slowly that it is unlikely to cause symptoms or affect the patient's health. The most common example is in the treatment of early prostate cancer in some older men. The American Cancer Society provides a list of questions cancer survivors should ask when choosing among recommended treatments. A link to this list is available at [cancer.org/Treatment](http://cancer.org/Treatment).

It is important to recognize that in some cases, effective treatment may not be available. In those circumstances, conversations between the patient and physician about the benefits of palliative (relief of symptoms without curing) and hospice care are appropriate, preferably before the patient is extremely ill (see page 22 for more information on palliative care).

## Barriers to Treatment and Cancer Disparities

Quality of cancer care determines the likelihood of survival and the quality of life after cancer treatment. State-of-the-art cancer treatments available in the US are not delivered equally across all segments of the population. As a result, disparities in cancer treatment and outcomes have been documented for racial and ethnic minorities, persons who are uninsured and underinsured, and the elderly population, as well as other medically underserved populations.<sup>32</sup>

The availability and quality of cancer care may be influenced by structural barriers, as well as provider and patient factors.<sup>33</sup> Structural barriers include inadequate health insurance, distance to the treatment facility and its hours of operation, and

access to transportation. Physician factors may include attitudes, preferences, and biases that influence treatment recommendations. Patient decision making is influenced by attitudes and beliefs about specific treatments, ability to navigate the medical system, resilience in the face of structural and other barriers, and personal perspectives and biases.

The relative importance of structural, provider, and patient factors is not well understood; however, there is substantial evidence that inadequate health insurance is an important barrier to receiving timely and appropriate care.<sup>34</sup> Even when patients have private or government health insurance, out-of-pocket costs of cancer care often pose a significant financial burden for them and their families.

Average annual health care expenses for newly diagnosed cancer patients younger than 65 years were \$16,910 in 2007, with \$2,159 (13%) paid directly out of survivors' pockets.<sup>35</sup> In comparison, annual health care expenses and out-of-pocket expenses for individuals without a cancer diagnosis were \$3,303 and \$679 on average, respectively. Out-of-pocket costs were estimated to be slightly less for the 65-and-older population than for the younger population.<sup>36</sup>

Costs for cancer patients who have no health insurance at the time of diagnosis vary by state and type of treatment facility, and may be based in part on income. Facilities that accept a substantial responsibility of serving the uninsured, such as "safety net" hospitals or those run by religious orders, typically only require patients to pay an amount they can realistically afford. The remainder of the cost is covered by donations, government funding, or other sources. Many states currently allow newly diagnosed cancer patients to enroll in Medicaid if they meet income guidelines after taking into account treatment costs and other state-specific eligibility requirements, such as requiring the patient to be disabled.



## Common Effects of Cancer and Its Treatment

Management of symptoms related to cancer and its treatment is an important part of cancer care, affecting patient quality of life, functional status, and completion of treatment. The vast majority of cancer patients experience one or more symptoms or side effects during treatment.<sup>37</sup> The most common side effects are pain, fatigue, and emotional distress.<sup>38</sup> These and other side effects of chemotherapy and radiation are described in the sidebars on pages 21 and 22. Many of these side effects are also associated with surgery, as well as targeted and hormonal therapies.

**Pain.** Cancer patients may experience pain at the time of diagnosis, during the course of active treatment, or after treatment has ended, even if their cancer does not return. Pain is one of the most important factors affecting the quality of life of people with cancer; it can interfere with normal daily activities, diminish enjoyment of everyday pleasures, prevent relaxation and sleep, and increase anxiety, stress, and fatigue. It can also cause people to withdraw from others, decrease social activities, and reduce contact with friends or family. Pain is common and often more severe among people with advanced disease. Regardless of the stage of disease or recovery, pain associated with cancer can almost always be relieved by proper treatment.

Pain control is an important component of quality cancer care. Treatment guidelines recommend that doctors and other health care providers ask about pain and other symptoms throughout the course of cancer treatment and continuing care. Cancer patients and their caregivers are responsible for describing the severity and nature of pain so that the right treatment can be given. The Society offers an online resource, *Cancer-Related Pain: A Guide for Patients and Caregivers*, which is available at [cancer.org](http://cancer.org).

The degree of pain experienced by a cancer patient depends largely on medical factors, such as the type, location, and stage of the cancer and the type of treatment received. There is also a great deal of variability in the experience of pain from person to person or even in the same person at different times. For more information on cancer-related pain, see *Cancer Facts & Figures 2007*, Special Section available online at [cancer.org/statistics](http://cancer.org/statistics).

**Fatigue.** Cancer-related fatigue is a distressing, persistent feeling of tiredness related to cancer or its treatment that interferes with usual activities.<sup>39</sup> Compared with the fatigue experienced by healthy individuals, cancer-related fatigue is more severe, more distressing, and less likely to be relieved by rest. Almost all patients receiving chemotherapy, radiation therapy, or bone marrow transplantation experience fatigue.<sup>39</sup> As for cancer side effects in general, fatigue in cancer patients has been underdiagnosed, underreported, and undertreated.<sup>40</sup> Studies have found that fatigue in cancer patients seldom occurs by itself but is commonly associated with sleep disturbance, emotional distress (e.g., depression, anxiety), or pain.<sup>41</sup> A variety of interventions are recommended for cancer patients experiencing fatigue, including exercise, medications, and counseling.<sup>41</sup>

## Side Effects Associated with Chemotherapy and Radiation Treatment

**Appetite changes, eating problems, and weight loss** – Chemotherapy can cause nausea, taste changes, or mouth and throat problems that may make it difficult to eat. Radiation to the head and neck or parts of the digestive system may lead to difficulty eating and digesting. Loss of appetite, as well as weight loss, may result directly from effects of the cancer on the body's metabolism. Appetite loss may also be related to other side effects, such as depression or fatigue.

**Constipation** – Some chemotherapy drugs and pain medications can cause constipation. Constipation may also result from changes in diet and/or activity level.

**Diarrhea** – Chemotherapy can cause diarrhea by affecting the cells lining the intestine. Radiation to the stomach, abdomen, or pelvis can also cause diarrhea. Diarrhea is usually defined as 2 or more loose stools in 4 hours.

**Fatigue** – Ranging from mild lethargy to feeling completely exhausted, fatigue is one of the most common side effects of cancer treatment. It is different from feeling tired after a long day and does not get better with rest or sleep. Fatigue tends to be the worst at the end of a treatment cycle.

**Hair changes** – Chemotherapy can cause hair loss (alopecia) on all parts of the body, not just the scalp, whereas hair loss resulting from radiation is limited to the specific area of treatment. Not all chemotherapy drugs cause hair loss. For most patients hair grows back after treatment, but it may be thinner or a different texture than it was before treatment. Some targeted therapies may cause facial hair to grow faster than usual, including longer, thicker eyelashes.

**Immune suppression** – Chemotherapy and radiation therapy can suppress or weaken the immune system by lowering the number of white blood cells (especially neutrophils) and other immune system cells or cause them not to work the way they should. A weakened immune system results in an increased risk of infection.

**Infertility** – For men, chemotherapy can reduce the number and quality of sperm, which may result in short- or long-term infertility. Chemotherapy can also cause infertility in women. Whether this happens and how long it lasts depends on many factors, including the type of drug, the doses given, and the age of the patient. Radiation to the pelvis can also affect fertility.

**Memory and thinking problems** – Chemotherapy and radiation to the brain can impact the cognitive (thinking) functions of the brain, including concentration, memory, comprehension, and reasoning. The changes that are found in patients are often very subtle.

**Mouth, gum, and throat problems** – Chemotherapy and radiation to the head and neck can cause sores in the mouth and throat. It can make these areas dry and irritated or cause them to bleed. This can interfere with the intake of food and even liquids, leading to malnutrition and dehydration. Mouth sores are not only painful, but there is also concern of infection that may spread to other parts of the body.

**Nausea and vomiting** – These symptoms may start during chemotherapy treatment and last a few hours. Less often, severe nausea and vomiting can last for a few days. Some people getting chemotherapy feel queasy even before treatment begins; this is called anticipatory nausea. Radiation to certain regions of the body can also cause nausea or vomiting.

**Sexual problems** – Chemotherapy and radiation to the pelvis can result in loss of libido, erectile dysfunction, and vaginal dryness and infections. Some sexual side effects of chemotherapy can remain after treatment.

**Shortness of breath (dyspnea)** – Radiation to the chest can cause shortness of breath. It may also occur as a result of chemotherapy-induced anemia.

**Skin changes** – Chemotherapy may cause minor skin problems, including color changes, redness, itching, peeling, dryness, rashes, and acne. When these symptoms occur on the palms of the hand and soles of the feet it is known as hand-foot syndrome. Some drugs may make skin more sensitive to the sun. Most chemotherapy-related skin problems go away, but a few require immediate attention. Certain drugs can cause long-term tissue damage if they leak out of an IV. Symptoms of an allergic reaction, including sudden or severe itching, rash, or hives, should be reported right away. Radiation may make skin look red, irritated, swollen, blistered, sunburned, or tanned in treatment areas. After a few weeks, skin may become dry, flaky, itchy, or peel. Most skin reactions to radiation slowly go away after treatment; however, skin in the treatment area may remain darker than it was before.

**Urine changes, bladder, and kidney problems** – Some chemotherapy drugs can irritate the bladder or cause kidney damage. They may also cause the urine to change color (orange, red, green, or yellow) or have a strong or medicine-like odor. Radiation to the pelvis can also irritate the bladder and lead to painful or frequent urination.

## Side Effects Associated Primarily with Chemotherapy Treatment

**Anemia** – A common side effect of chemotherapy, anemia is a condition where the body has too little hemoglobin contained in red blood cells to carry oxygen to the rest of the body. It can cause the following symptoms: fatigue, dizziness, paleness, a tendency to feel cold, shortness of breath, weakness, and racing heart.

**Bleeding or clotting problems** – Chemotherapy can affect the bone marrow's ability to make platelets that help stop bleeding. Patients without enough platelets may bleed or bruise more easily than usual, even from a minor injury. Some chemotherapy drugs also increase the risk of the formation of serious blood clots that form in the veins of the legs (deep vein thrombosis).

**Nerve and muscle problems** – Certain chemotherapy drugs can cause peripheral neuropathy, a potentially serious nerve problem that causes tingling, pins and needles, burning sensations, weakness, and/or numbness in the hands and feet. Some chemotherapy drugs can also cause short-term problems with the nerves in the throat, which can lead to pain with swallowing, especially food or liquids of extreme temperature.

**Weight gain** – Chemotherapy can cause some people to gain weight, which may be due to inactivity, electrolyte imbalances, fluid retention, or steroids contained in the drug regimen.

**Distress.** Cancer-related distress is a complex response to the effects of pain, fatigue, and/or the myriad of other stressors associated with cancer diagnosis and treatment. Almost half of all cancer patients report measurable levels of distress, though this is thought to be an underestimate.<sup>42</sup> Distress in cancer patients may be difficult to identify because the signs often overlap with the symptoms of disease and treatment (e.g., fatigue, changes in appetite, sleep disruptions).

The National Comprehensive Cancer Network recommends routine screening for distress and has developed a measurement tool called the Distress Thermometer.<sup>43</sup> Patients are asked to indicate their distress level on the thermometer's scale, which ranges from 0 (no distress) to 10 (extreme distress), to establish a numeric score. Patients who are mildly distressed may benefit from discussing their concerns with their cancer treatment team while those with moderate to severe distress are often referred to appropriate supportive services (mental health, social work, and counseling).

### Palliative Care

Palliative care is medical care that specializes in the relief of pain and other symptoms related to cancer and its treatment. It plays an important role in quality cancer care throughout active treatment and survivorship. The goal of palliative care is to improve the quality of life for all patients and their caregivers (family and friends). This care is often provided by a team of doctors, nurses, and specialists who work with the patient, the family as needed or desired, and the patient's other doctors. Palliative care can be administered along with curative treatment.

Palliative care offers patients and families more control and choice about treatment options and decision making. Giving patients and families a shared role in decisions helps ensure that their treatments and symptom control align with their goals and preferences. Engaging all members of the health care team also reduces communication barriers to optimal symptom management. Palliative care has been consistently shown to improve patient quality of life, and can also reduce the family caregiver burden.<sup>44</sup>

In response to the increasing numbers and needs of Americans living with serious, complex, and chronic illnesses like cancer, the number of palliative care teams in hospitals has more than doubled in the past 5 years.<sup>45</sup> Although there are currently about 1,500 hospitals providing palliative care services nationwide, millions of Americans still do not have access to these services, with considerable variation in availability from state to state.<sup>45,46</sup> The Society is working with American Society for Clinical Oncology, the Center to Advance Palliative Care, and other partners to help enhance understanding about palliative care as an essential part of cancer treatment.<sup>47</sup>

To learn more about palliative care or find palliative care professionals, visit [getpalliativecare.org](http://getpalliativecare.org).



## Transitioning from Active Treatment to Recovery

After primary, curative treatment ends, most cancer patients transition to the recovery phase of survivorship. Challenges during this time may include difficulty returning to former roles such as parent or employee, anxiety about paying medical bills for cancer treatment, or decisions about which provider to see for the various health care needs that arise. Family and friends who went out of their way to provide support during treatment typically return to more normal levels of engagement and support, and the frequency of meetings with the cancer care team generally declines. These issues can make it difficult to smoothly negotiate the transition from treatment to recovery.

Regular medical care following primary treatment is particularly important for cancer survivors because of the potential lingering effects of treatment, as well as the risk of recurrence and additional cancer diagnoses. In 2006, the Institute of Medicine's (IOM) Committee on Cancer Survivorship published a report highlighting the need for a strategy to improve the coordination of ongoing care for survivors.<sup>12</sup> A follow-up report recommended that patients and their primary care providers be given a summary of their treatment and a comprehensive survivorship care plan developed by one or more members of the oncology team. The comprehensive treatment summary, which provides a foundation for the plan, contains the following personalized, detailed information:

- Type of cancer, stage, and date of diagnosis
- Specific treatment and dates (e.g., names of surgical procedures, chemotherapy drug names and dosages, radiation dosages, etc.)
- Complications (side effects of treatment, hospitalizations, etc.)
- Supplemental therapy (e.g., physical therapy, adjuvant therapy, such as tamoxifen, etc.)

The survivorship care plan should be tailored to address each individual's specific needs. In addition to the treatment summary, the plan may include:

- A schedule of follow-up medical visits, tests, and cancer screenings, including who will perform them and where
- Symptoms that may be a sign of cancer recurrence
- Potential long-term treatment effects and their symptoms
- Behavior recommendations to promote a healthy recovery
- Community resources



Studies are currently under way to determine how survivorship care plans can most effectively improve the cancer experience. These plans are a relatively new concept and have not been widely adopted, so patients should request one from their oncologist if it is not offered. All of the information should be reviewed and approved by the entire oncology team as well as the patient to ensure that it is comprehensive and accurate. Several organizations have developed standardized formats for survivorship care plans, including the Minnesota Cancer Alliance, LIVESTRONG, and the American Society of Clinical Oncology. For more information on these and other plans, please visit [cancer.org/survivors](http://cancer.org/survivors).

There are numerous obstacles to the implementation of survivorship care plans in the current health care system, such as lack of compensation and lack of clarity about who is responsible for their production. The IOM recommends that the document “be written by the principal provider(s) that coordinated oncology treatment” and “this service should be reimbursed by third-party payers of health care.”<sup>12</sup> Some suggest that oncologists should develop survivorship care plans and discuss them with their patients during a transition visit. Another approach includes the development of consensus guidelines in order to produce an electronic decision support system to facilitate the process of developing survivorship care plans. An electronic system could reduce the time it takes to tailor these documents to individual survivors.<sup>48</sup>

# Long-term Survivorship

Long-term survivorship can be both stressful and hopeful. Survivors are relieved to have completed treatment, but may have to make physical, emotional, social, and spiritual adjustments to their lifestyle – in other words, to find a “new normal.” The following section includes common issues related to quality of life, long-term and late effects, risk of recurrence and subsequent cancers, and health behaviors of cancer survivors.

## Quality of Life

Quality of life is a broad multidimensional concept that considers a person’s physical, emotional, social, and spiritual well-being (Figure 16).<sup>49</sup> Physical well-being is the degree to which symptoms and side effects, such as pain, fatigue, and poor sleep quality, affect the ability to perform normal daily activities. Emotional, or psychological, well-being refers to the ability to maintain control over anxiety, depression, fear of cancer recurrence, and problems with memory and concentration. Social well-being primarily addresses relationships with family members and friends, including intimacy and sexuality. Employment, insurance, and financial concerns also affect social well-being. Finally, spiritual well-being is derived from drawing meaning from the cancer experience, either in the context of religion or through maintaining hope and resilience in the face of uncertainty about one’s future health.

Although quality of life may suffer considerably during and shortly after active cancer treatment, the majority of disease-free cancer survivors (5 years or more) report a quality of life comparable to those with no history of cancer.<sup>50</sup> Still, many survivors continue to suffer. Individuals who have a history of more invasive and aggressive treatments tend to report poorer functioning and quality of life in the long term. Certain groups, such as non-whites, those who were diagnosed at younger ages, and those with lower socioeconomic status, also report greater difficulty regaining quality of life.<sup>51-53</sup> For example, one study of breast cancer survivors, found that African Americans and women with lower socioeconomic status had poorer physical functioning than survivors of other race/ethnicities and with higher socioeconomic status.<sup>54</sup> Age is also an important predictor of quality of life; survivors diagnosed at a younger age tend to have poorer emotional functioning, whereas older age at diagnosis is often associated with poorer physical functioning.<sup>55, 56</sup> Some survivors of childhood cancer have cognitive or functional deficits that impact their ability to successfully complete their education and find employment, which in turn can impact psychological well-being and lower quality of life.<sup>57</sup>

## Long-term and Late Effects

After treatment is completed, cancer survivors are at risk for a wide range of ongoing symptoms that are often referred to as long-term and late effects. Specifically, long-term effects are those symptoms that arise during treatment and remain problematic, while late effects tend to have a later onset, typically surfacing months or even years after cancer treatment has ended. Long-term and late effects may be emotional (e.g., anxiety, depression) and/or physical (e.g., heart, lung and kidney damage, mental impairment, and infertility). Cancer survivors are also at risk for recurrence of the original cancer or the development of a new, biologically distinct, second primary cancer, with risk dependent on the original type of cancer, stage of disease, and treatments received.<sup>58-60</sup> Below is a description of some of the major long-term and late effects cancer survivors may experience.

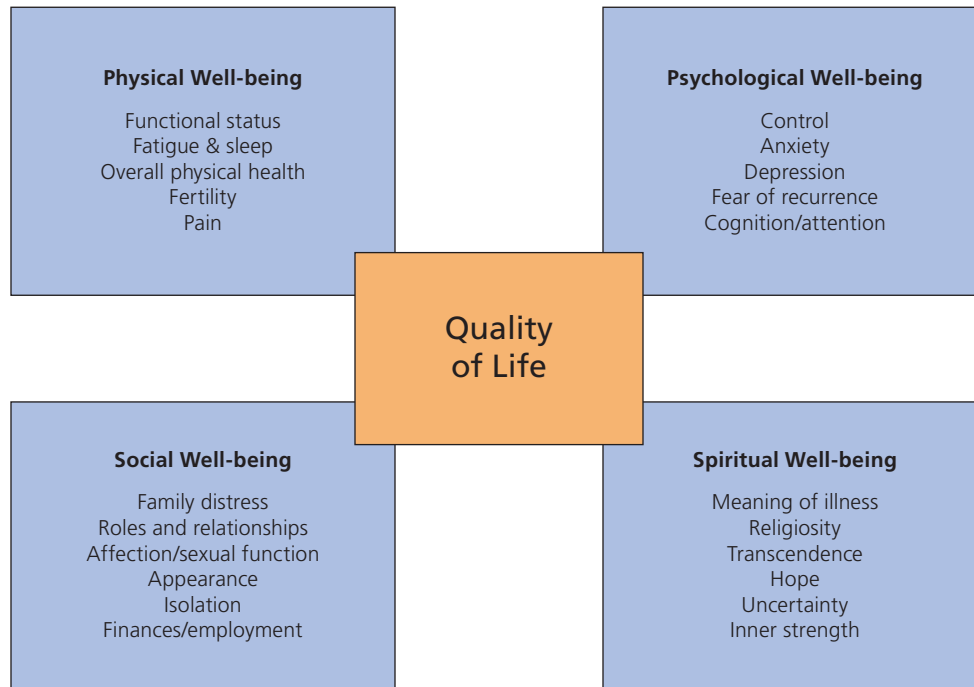
**Chronic pain.** Some cancer survivors continue to experience pain, even when they are cancer-free. The degree of pain depends largely on the type, location, and stage of the cancer and the type of treatment received. Both surgery and radiotherapy can damage nerve cells, resulting in chronic pain. Chemotherapy drugs, especially vincristine and the taxanes, can damage sensory nerve cells, causing painful sensations in the hands and feet (peripheral neuropathy). Patients often complain of skin sensitivity when they attempt to bear weight on their feet. The extent of the damage is directly related to the dose of the drug and can take months or years to resolve. Chronic pain can interfere with returning to normal life activity and may lead to depression and fatigue.

**Cognitive problems.** Cancer survivors may experience problems with attention, concentration, memory, and delayed thought process. Although these issues usually resolve with time, they can be disabling. The risk of mental impairments from chemotherapy is greater among those who are older, had lower pre-treatment IQ, and those with a genetic mutation that is associated with Alzheimer’s disease.<sup>61</sup>

**Damage to the heart.** Some chemotherapy drugs may cause cardiotoxicity, a condition in which there is damage to the heart muscle that reduces heart functioning. If severe, this could lead to permanent heart damage (cardiomyopathy). Anthracycline chemotherapies such as doxorubicin can be particularly harmful to the heart.

**Decreased bone density.** Various cancer treatments can result in decreased bone density (osteoporosis) and the less severe osteopenia (thinning of bone mass). These conditions may cause pain and increase the risk of bone fractures. Certain prostate cancer treatments, including androgen deprivation therapy or bilateral orchiectomy, increase the risk for developing osteoporosis.<sup>62</sup> Women treated for breast and gynecologic cancers are also prone to decreased bone density and fractures that can result in premature menopause and bone loss.

**Figure 16. Domains of Quality of Life**



**Source:** City of Hope Beckman Research Institute, 2004. Adapted and reproduced with permission from Betty Ferrell, PhD and Marcia Grant, DNSc.

**Decreased lung function.** Surgery for lung cancer is usually associated with dyspnea (labored breathing) and reduced lung functioning. In addition, damage to the respiratory system from chemotherapy and radiation for many types of cancer may progress without symptoms for some time after treatment until the survivor develops shortness of breath and other breathing problems.

**Fatigue.** Fatigue is a common side effect of active cancer treatment (see page 20). Although fatigue resolves for most survivors, for some it persists long after treatment has been completed and the survivor is considered disease-free. Published reports of the prevalence rates for cancer-related fatigue in survivors vary widely; however, studies suggest that 17-26% of cancer survivors deal with persistent fatigue.<sup>41</sup> As with chronic pain, the debilitating effects of fatigue can make it more difficult to return to normal activities, leading to employment and social limitations that can result in isolation and loneliness.<sup>63</sup>

**Fear of cancer recurrence.** Fear of cancer recurrence is the fear or worry that cancer will return. A number of studies provide evidence that these fears are among the chief concerns of post-treatment cancer survivors and may persist long after treatment ends.<sup>64,65</sup> For example, data from the American Cancer Society Studies of Cancer Survivors indicate that nearly 60% of 1-year survivors reported moderate to severe concerns about their disease recurring.<sup>66</sup>

**Infertility.** Infertility can result from surgery, radiation, or chemotherapy. For younger survivors, the loss of fertility can be a life-changing, long-term effect of cancer, with irreversible consequences that can affect quality of life. Uterine radiation is associated with infertility, miscarriage, preterm labor, and low birth-weight infants.<sup>67</sup> Younger women (<35 years of age) are at risk for infertility and premature menopause, even though menses usually return. Toxic effect of chemotherapy on the ovaries increases with older age, higher doses, and longer duration of treatment. Male infertility from cancer surgery or radiation can result from anatomic changes, hormonal imbalances, or lower production and quality of sperm.

**Lymphedema.** Lymphedema is a swelling of the arms or legs that can cause problems in functioning, pain, and body image. It occurs most often among women treated for breast cancer (see page 6).<sup>68</sup> However, surgical treatment in the pelvic area can cause lymphedema of the legs for men and women diagnosed with other types of cancer.

**Sexual problems.** Although difficulties with sexual function typically resolve after treatment is completed, some survivors continue to report a reduced interest in sex.<sup>69</sup> Furthermore, problems such as erectile dysfunction and vaginal dryness may become permanent and interfere with sexual activity and satisfaction.

**Positive outcomes of cancer.** The negative effects of treatment-related symptoms and side effects on cancer survivors' functioning have been well-documented. However, there has also been growing recognition that the cancer experience may result in a wide range of positive outcomes as well. Indeed, many survivors report that they have gained a greater appreciation for life, have improved relationships with family and friends, feel an enhanced sense of meaning and purpose in their life, and have become more effective in coping with stress and other life challenges as a result of their cancer experience.<sup>70</sup>

## Risk of Recurrence and Subsequent Cancers

Cancer survivors are at risk for recurrence of the original cancer or the development of a second primary cancer. Even after treatment of the original cancer appears to have been effective, cancer cells may persist in the body and eventually grow to the point where they are detected either near the site of the original cancer or elsewhere in the body. When this occurs, it is called a recurrence or metastasis. A second (or multiple) primary cancer is the occurrence of a new cancer that is biologically distinct from the original cancer. Whether a new cancer is a new primary or a recurrence of the original cancer is important because it determines staging procedures, prognosis, and treatment.

Although national estimates of recurrence are not available because data on recurrence are not collected by cancer registries, a large breast cancer study found that recurrence rates varied depending on tumor characteristics, stage of disease, and treatments received.<sup>71</sup> Scientists are studying genetic tests that may predict the likelihood that cancers such as breast, colon, and melanoma will recur. For some types of cancer, there are formulas that can help estimate the chance of recurrence. Prostate cancer is one type of cancer for which recurrence projections can be made, based on stage and grade of the cancer at the time of diagnosis.

The risk of developing a subsequent cancer varies by the type of first cancer diagnosed (referred to as the first primary site), treatment received, age at diagnosis, environmental exposures, and genetic and other factors. Similar to cancer in general, the risk of a second cancer increases with age. As a whole, cancer survivors have a small (14%) increased lifetime risk of developing a second primary cancer, though some have a much higher risk. Ratios of the observed to the expected number of cancer cases (O/E) are used to describe the risk for a subsequent cancer diagnosis among cancer survivors. Figures 17 and 18 (page 27 and 28) provide O/E ratios by primary site for adult and childhood cancer survivors. Adult survivors of Hodgkin lymphoma and cancers related to tobacco use (cancer of the oral cavity and pharynx, lung and bronchus, kidney and renal pelvis, esophagus, and urinary bladder) have the highest risk of subsequent cancers (Figure 17). The risk of developing a subsequent cancer is

higher for survivors of childhood cancer. Among those diagnosed before age 20, survivors of retinoblastoma, Ewing sarcoma, and Hodgkin lymphoma have the highest risk of developing a second cancer (Figure 18, page 28).

Factors associated with developing more than one cancer include familial cancer syndromes and other genetic susceptibility factors, common exposures (e.g., tobacco), and the carcinogenic effects of cancer treatment.<sup>72</sup> For example, survivors of Hodgkin lymphoma have increased risk of additional cancers (e.g., breast cancer) largely as a result of radiation treatment; risk increases with higher radiation doses. Individuals with a tobacco-related cancer are at increased risk of developing an additional tobacco-related cancer. Avoiding tobacco use is the main strategy to reduce the burden of primary and secondary cancers related to tobacco. More information on health strategies to reduce the risk of recurrence and additional cancers is provided in the next section. For more information on multiple primary cancers, see *Cancer Facts & Figures 2009*, Special Section, available online at [cancer.org/statistics](http://cancer.org/statistics).

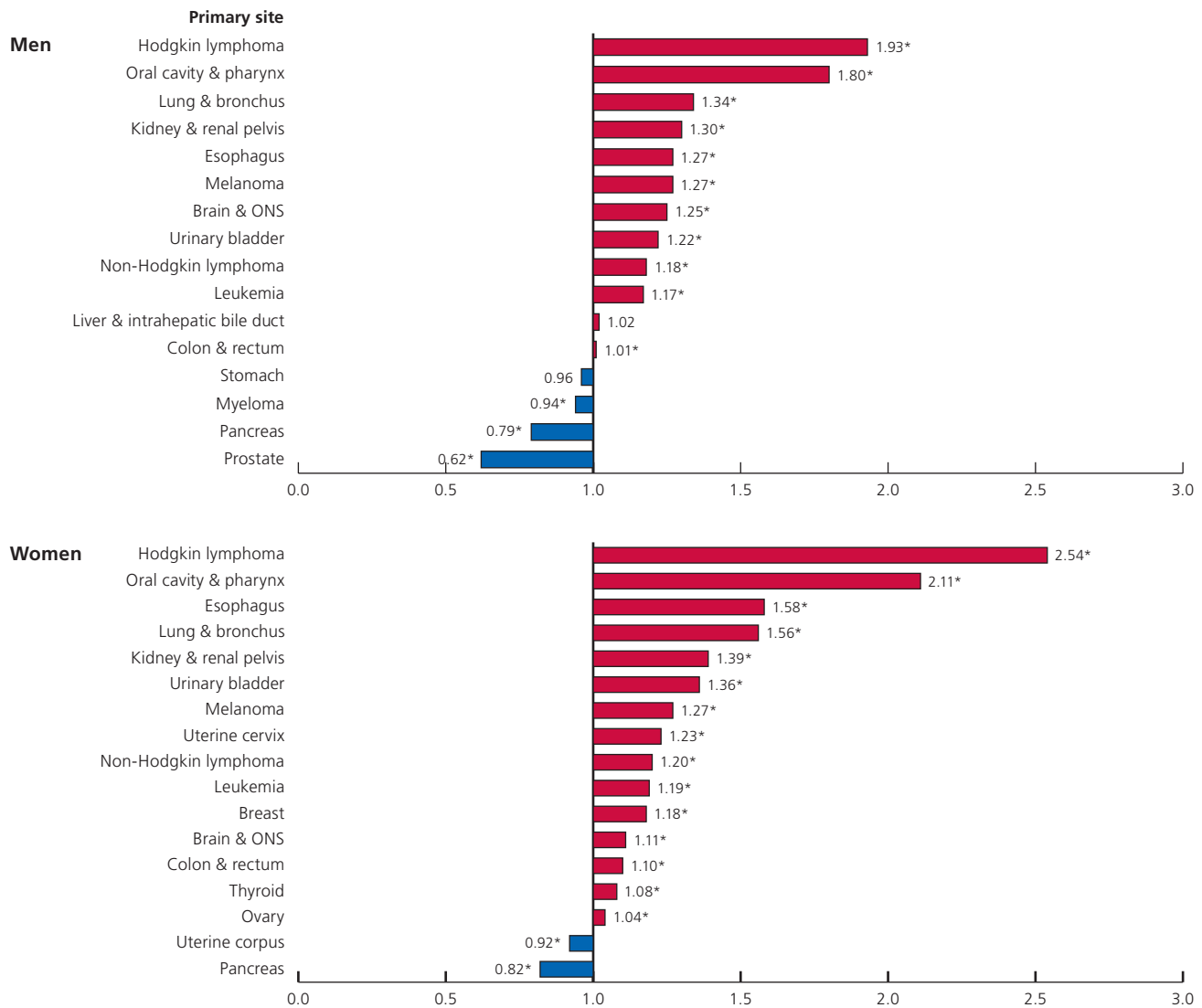
## Regaining and Improving Health through Healthy Behaviors

Health behaviors – exercise, diet, not smoking – may be especially important for survivors due to their increased risk for recurrence and developing a new cancer. For example, post-treatment physical activity has been associated with increased recurrence-free and overall survival, whereas overweight and obesity have been consistently associated with increased risk of recurrence and poorer survival for many cancers.<sup>73-76</sup> Continued smoking after treatment increases the risk of recurrence and second cancers.<sup>77,78</sup>

In addition to improving disease outcomes, healthy behaviors may also improve survivor functioning and quality of life.<sup>79</sup> Clinical trials demonstrate that exercise can improve heart and lung function and reduce cancer-related fatigue among survivors.<sup>80,81</sup> The growing evidence that primary preventive health behaviors are beneficial to survivors led the American Cancer Society to develop a guide for physical activity and nutrition during and after cancer treatment, the most recent version of which was published in April 2012.<sup>82</sup>

**Physical activity.** Physical activity can hasten recovery from the immediate side effects of treatment, prevent long-term effects, and may reduce the risk of recurrence and increase survival.<sup>83</sup> In observational studies among breast cancer survivors, moderate physical activity has been associated with reduced risk of death from all causes (24-67%) and breast cancer (50-53%).<sup>84</sup> Similar benefits have been observed among colon cancer survivors.<sup>85</sup> Intervention studies have shown that exercise can improve fatigue, anxiety, depression, self-esteem, happiness, and quality of life in cancer survivors.<sup>80</sup>

**Figure 17. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site and Sex, Ages 20 and Older, 1973-2008**



\*p<0.05

Note: Observed-to-expected ratio is the number of cancers observed in a population of cancer survivors divided by the number of cancers expected. An O/E greater than 1 (red bar) indicates that the risk is greater than expected while an O/E less than 1 (blue bar) indicates reduced risk.

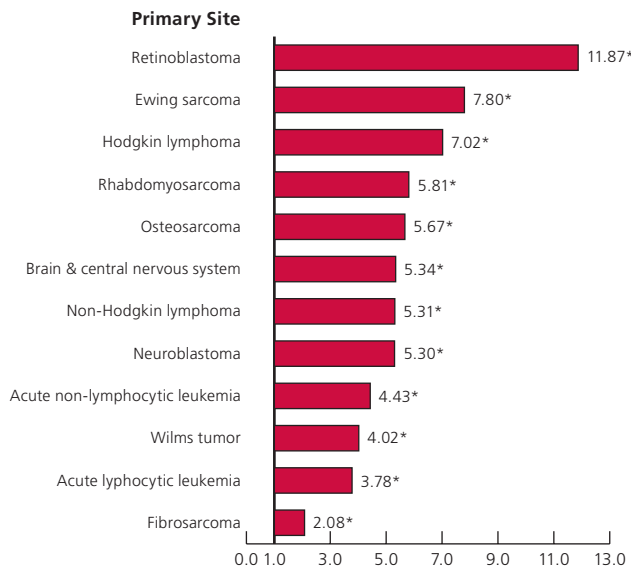
Source: Surveillance, Epidemiology, and End Results (SEER) Program, 17 SEER registries, 1973-2008, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society, Intramural Research, 2012

Exercise for cancer survivors should be individualized and tailored according to the disease site and stage and the survivor's capabilities. Barriers to engaging in physical activity may be symptomatic (e.g., fatigue, pain, and nausea), physical (e.g., amputees, lymphedema, neuropathy), psychosocial (e.g., feelings of fear, lack of motivation, or hopelessness), or financial.<sup>85</sup> Other barriers include lack of awareness of exercise programs, unfavorable community environments, and work and family obligations.

**Nutrition and maintaining a healthy body weight.** Weight management is an important issue for many survivors. Some patients begin the treatment process in a state of overweight or obesity, some may gain weight while in treatment, while others may become underweight due to treatment-related side effects (e.g., nausea, vomiting, difficulty swallowing).<sup>86</sup> Numerous studies have shown that obesity and weight gain in breast cancer survivors lead to a greater risk of recurrence and decreased survival; the evidence is less clear for colorectal and other cancers.<sup>87</sup>

**Figure 18. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site, Ages 0-19, 1973-2008**



\*p<0.05

Note: Observed-to-expected ratio is the number of cancers observed in a population of cancer survivors divided by the number of cancers expected.

Source: Surveillance Epidemiology, and End Results (SEER) Program, SEER 17 Registries, 1973-2008, Division of Cancer Control and Population Science, National Cancer Institute.

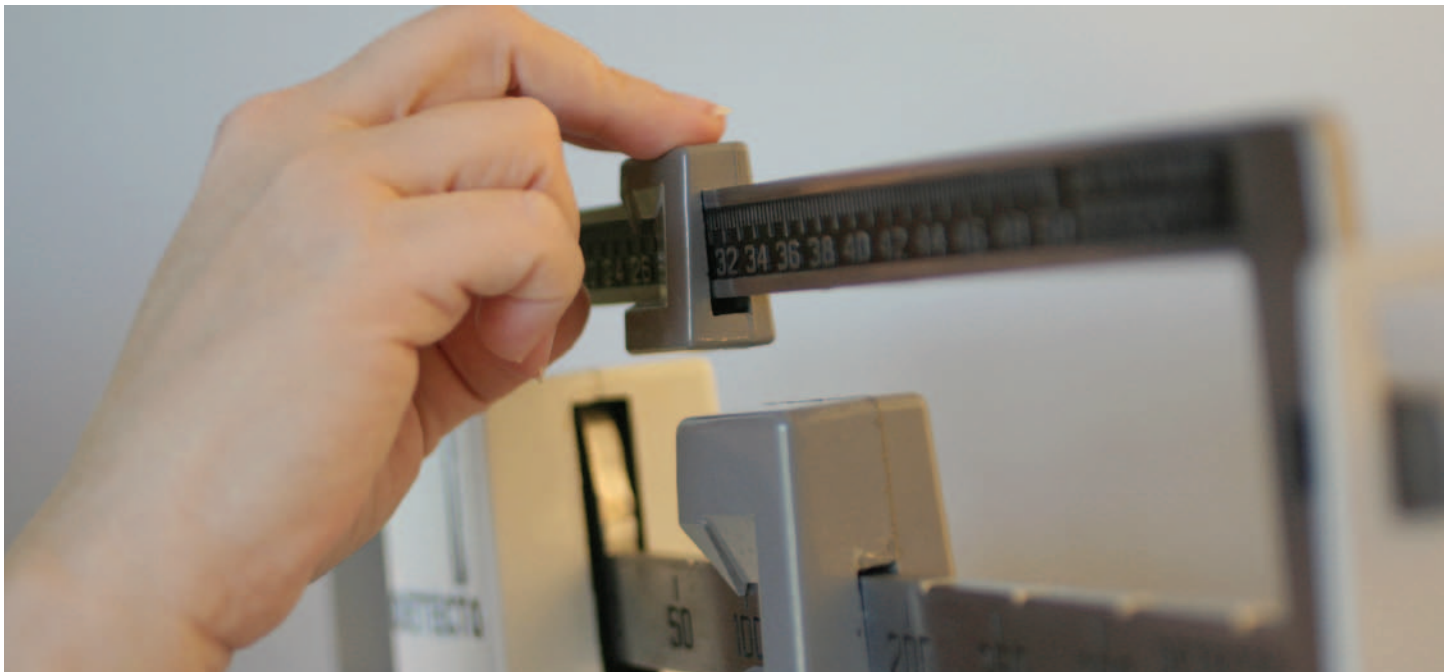
American Cancer Society, Intramural Research, 2012

cancers and the risk of chronic diseases.<sup>88</sup> In addition, alcohol consumption is an established cause of cancers of the mouth, pharynx, larynx, esophagus, liver, colorectum, and breast; therefore, the Society recommends that those who consume alcoholic beverages limit their consumption (2 drinks per day for men and 1 drink per day for women).<sup>87</sup>

**Smoking cessation.** Despite their increased risk for chronic health conditions and premature death, a significant number of cancer survivors continue to smoke after their diagnosis. The majority of survivors who smoke were smokers before diagnosis.<sup>89</sup> According to data from the National Health Interview Survey (2000-2008), 40% of cancer survivors ages 18 to 44 years are current smokers, compared to 24% of the general population.<sup>89</sup> This information is troubling because of the known association between smoking and cancer development, the fact that survivors have a higher risk of developing second cancers, and because smoking interferes with some common treatments for cancer.<sup>90</sup> Studies have shown that smoking cessation efforts are most successful when they are initiated soon after diagnosis.<sup>91</sup> Cessation interventions tailored to cancer survivors are needed. For more information on Society resources for smoking cessation, see page 33.

**Sun exposure.** Along with other susceptibilities, survivors increase their risk of developing skin cancer through overexposure to UV light from the sun. In addition, survivors who have undergone radiation therapy are at an increased risk of skin cancer.<sup>92</sup> Cancer survivors should adopt skin care behaviors to decrease the risk of developing skin cancer, including: wearing sunscreen and protective clothing and avoiding sunbathing and artificial tanning.

A diet that is plentiful in fruit, vegetables, and whole grains, but contains limited amounts of fat, red and processed meat, and simple sugars may reduce both the risk of developing second



## Concerns of Caregivers and Families

Cancer not only affects survivors but also their family members and close friends. As hospital space becomes limited to acute care and cancer treatments are delivered more frequently in outpatient care settings, the tremendous responsibility of picking up where the health care team leaves off increasingly rests with the survivor's loved ones. Caregivers may feel unprepared and overwhelmed in their new role, which can result in deterioration of their mental and physical health and a decline in quality of life.<sup>93</sup> Caregiver responsibilities can include gathering information to advise treatment decisions, attending to treatment side effects, coordinating medical care, managing financial issues, and providing emotional support to the survivor. One study found that even 2 years after the cancer diagnosis, caregivers were still spending an average of 8 hours a day providing care.<sup>94</sup>

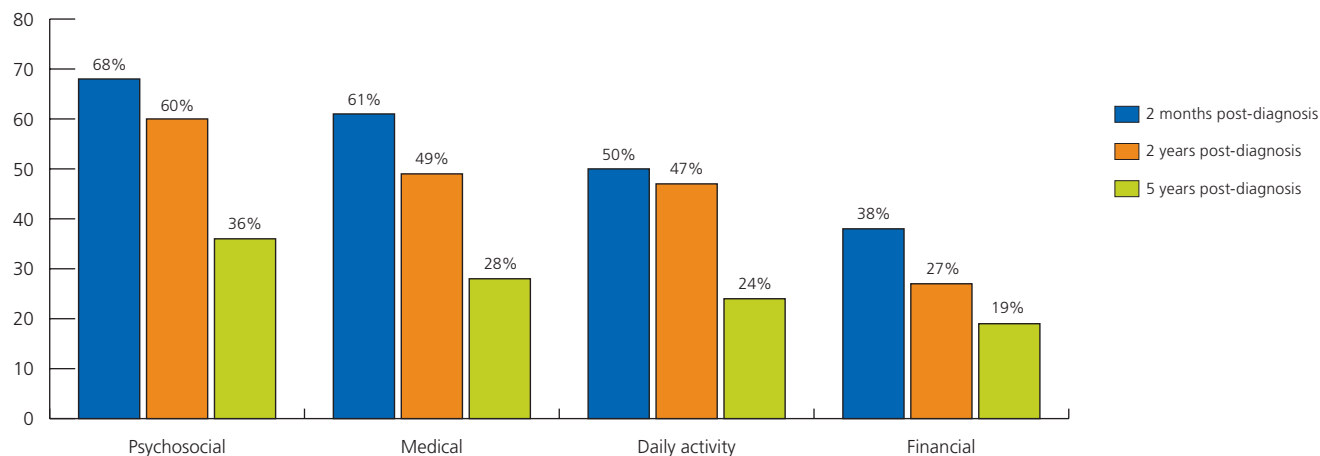
Over time caregivers become increasingly vulnerable to psychological distress, depression, and anxiety, which can be exacerbated by feelings of social isolation. How the caregiver copes with these feelings can play a crucial role in their well-being.<sup>95</sup> Social support can help buffer the negative consequences of caregiver stress, and can serve to maintain, protect, or improve health. Caregivers fare better when they participate in social support programs aimed at teaching effective coping skills. Consultation with palliative care teams have also been shown to help ease family caregiver burdens (see page 22 for more information on palliative care).

During the post-treatment period of cancer survivorship, the focus shifts to adjusting to a new “normal,” adopting a healthy lifestyle, and coping with fear of recurrence. For both survivors and caregivers, a cancer diagnosis is often seen as a “teachable moment,” wherein the illness experience becomes a catalyst for behavior change and sustainable lifestyle benefits.<sup>96</sup> Increasing evidence has shown that caregivers may also be motivated to make positive changes to improve their health after a loved one's cancer diagnosis.<sup>97</sup> It is within the “teachable moment” that health behavior interventions can become ingrained habits and have the greatest potential for long-term success throughout the cancer continuum for both survivors and caregivers.

Learning how to deal with the uncertainty about the future and worrying about whether the cancer will return are lingering issues for caregivers.<sup>98</sup> Not surprisingly, a higher level of fear of recurrence is usually experienced by caregivers of survivors diagnosed at a more advanced stage or with a more severe type of cancer.<sup>99</sup> With fewer oncology visits and a lack of consistent contact with health care providers, caregivers can be apprehensive as they reintegrate into life after treatment.<sup>100</sup> To ease this transition, caregivers may benefit from coping strategies, such as stress management or relaxation techniques, to reduce anxiety associated with thoughts of cancer recurrence.

Across the cancer trajectory, caregivers often experience persistent levels of psychological distress that are equal to or greater than those of the survivor.<sup>101</sup> There are also differences between men and women in caregiver adjustment. For example, numerous studies have shown that female caregivers experience more care-related distress than their male counterparts and have a higher risk of poor physical and emotional health.<sup>102-104</sup>

**Figure 19. Unmet Caregiver Needs by Time Since Diagnosis**



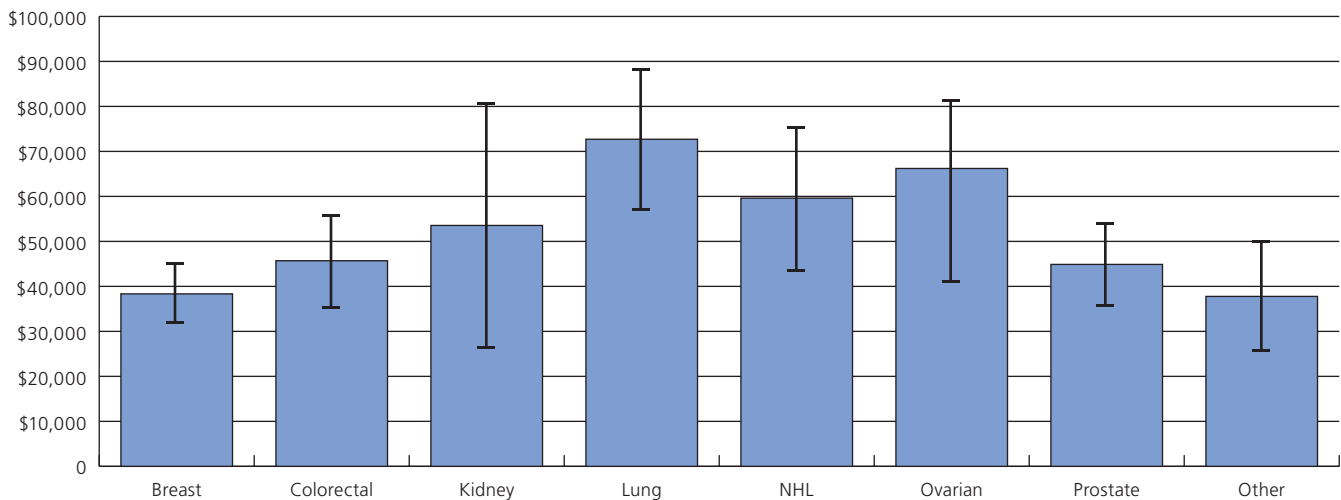
**Source:** Kim, et al.<sup>105</sup> Reprinted from *Psychooncology* 2010; 19(6):573-582. This material is reproduced with the permission of John Wiley & Sons, Inc.



Caregivers report a variety of persistent unmet needs (Figure 19, page 29).<sup>105</sup> Caregivers' psychosocial needs are primarily centered on their ability to help the cancer survivor deal with their emotional distress and find meaning in the cancer experience. Ongoing medical needs include obtaining information about the cancer, its treatment, and side effects, and obtaining the best possible care for the survivor. Issues relating to caregivers' daily life, including their ability to balance their own personal care with the demands of caregiving, seem to be the most affected within two years of diagnosis.

Although cancer caregiving can be physically and emotionally demanding, it can also be a meaningful and satisfying experience. The phenomenon of finding good from difficult life experiences is known as benefit-finding or post-traumatic growth. Encountering a serious disease like cancer can prompt individuals to reprioritize life to better align with values, restore personal relationships, adopt a more positive self-view, and become more empathetic toward others. Recent studies have shown that both survivors and their caregivers often find benefit in the challenges associated with cancer.<sup>106,107</sup> Better adjustment and overall quality of life have been attributed to such positive growth. The cancer survivor's family members and friends become co-survivors in the cancer journey. Ensuring that caregivers are healthy, both emotionally and physically, is imperative for optimal survivorship care.

**Figure 20. Monetary Value of Caregiver Time in the Two Years Following Diagnosis by Cancer Type**



NHL: Non-Hodgkin lymphoma. Other: melanoma of the skin and cancers of the bladder and uterus. Bars represent cost estimates and lines represent 95% confidence intervals.

Source: Yabroff and Kim.<sup>94</sup> Reprinted from *Cancer* 2009; 115(18 suppl):4362-4373. This material is reproduced with the permission of John Wiley & Sons, Inc.



# The American Cancer Society

## How the American Cancer Society Saves Lives

The American Cancer Society is working relentlessly to save lives from cancer by helping people stay well and get well, by finding cures, and by fighting back against the disease.

## Helping People Stay Well and Get Well

The American Cancer Society provides information that empowers people to take steps that help them prevent cancer or find it early, when it is most treatable. In addition, the Society helps eliminate barriers to cancer care through a number of high-profile programs. Among the most notable are the Road To Recovery® program (provides transportation to and from cancer treatments), the Hope Lodge® program (provides temporary housing for patients and families receiving treatment away from home), and the Patient Navigator Program (aids patients, families, and caregivers in navigating the cancer treatment process).

The Society also funds intramural and extramural research to help save more lives, prevent suffering, and address disparities in cancer care. Understanding that conquering cancer is as much a matter of public policy as scientific discovery, the Society's nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network<sup>SM</sup> (ACS CAN), strives to eliminate cancer disparities and enhance quality cancer care through policy and public health programs at the federal and state levels.

## Cancer Information

**Information, 24 hours a day, 7 days a week.** The American Cancer Society is available 24 hours a day, seven days a week online at cancer.org and by calling 1-800-227-2345. Callers are connected with a Cancer Information Specialist who can help them locate a hospital, understand cancer and treatment options, learn what to expect and how to plan, help address insurance concerns, find financial resources, find a local support group, and more. The Society can also help people who speak languages other than English or Spanish find the assistance they need, offering services in 170 languages in total.

Information on every aspect of the cancer experience, from prevention through survivorship, is also available through the Society's Web site, cancer.org. The site includes an interactive cancer resource center containing in-depth information on every major cancer type.

The Society also publishes a wide variety of pamphlets and books that cover a multitude of topics, from patient education, quality of life, and caregiving issues to healthy living. A complete list of Society books is available for order at cancer.org/bookstore.

In addition, the Society publishes a variety of information sources for health care providers, including three clinical journals: *Cancer*, *Cancer Cytopathology*, and *CA: A Cancer Journal for Clinicians*. More information about free subscriptions and online access to *CA* and *Cancer Cytopathology* articles is available at cancer.org/journals. The Society also collaborates with numerous community groups, nationwide health organizations, and large employers to deliver health information and encourage Americans to adopt healthy lifestyle habits through the Society's science-based worksite programs.

## Programs and Services

**Day-to-day help and emotional support.** The American Cancer Society can help cancer patients and their families find the resources they need to make decisions about the day-to-day challenges that can come from a cancer diagnosis, such as transportation to and from treatment, financial and insurance needs, and lodging when having to travel away from home for treatment. The Society also connects people with others who have been through similar experiences to offer emotional support.

**Help with the health care system.** Learning how to navigate the cancer journey and the health care system can be overwhelming for anyone, but it is particularly difficult for those who are medically underserved, those who experience language or health literacy barriers, or those with limited resources. The American Cancer Society Patient Navigator Program was designed to reach those most in need. As the largest oncology-focused patient navigator program in the country, the Society has specially trained patient navigators at 134 cancer treatment facilities across the nation. Patient navigators work in cooperation with patients, family members, caregivers, and staff of these facilities to connect patients with information, resources, and support to decrease barriers and ultimately to improve health outcomes. In 2011, 90,000 people relied on the Patient Navigator Program to help them through their diagnosis and treatment. The Society collaborates with a variety of organizations, including the National Cancer Institute's Center to Reduce Cancer Health Disparities, the Center for Medicare and Medicaid Services, numerous cancer treatment centers, and others to implement and evaluate this program.

**Transportation to treatment.** Cancer patients cite transportation to and from treatment as a critical need, second only to direct financial assistance. The American Cancer Society Road To Recovery program matches these patients with specially trained volunteer drivers. This program offers patients an additional key benefit of companionship and moral support during the drive to medical appointments. The Society's transportation grants program allows hospitals and community organizations to apply for resources to administer their own transportation programs. In some areas, primarily where transportation assistance programs are difficult to sustain, the Society helps patients or their drivers via prepaid gas cards to help defray

## National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society and the George Washington Cancer Institute, funded by the Centers for Disease Control and Prevention. Its goal is to shape the future of post-treatment cancer survivorship care and to improve the quality of life of cancer survivors. The Survivorship Center staff and more than 100 volunteer survivorship experts nationwide developed the tools listed below for cancer survivors, caregivers, health care professionals, and policy and advocacy efforts.

### Tools for cancer survivors and caregivers

**Life After Treatment Guide** – a quick, easy-to-read information guide to help cancer survivors and their caregivers understand the various aspects of the survivorship journey. The guide also includes trusted resources for survivorship information and encourages communication with health care professionals. The guide is available online at [cancer.org/survivorshipguide](http://cancer.org/survivorshipguide).

**Survivorship Information Resource Inventory** – an inventory of information resources to assist post-treatment survivors, available online at [cancer.org/survivorshipresourceinventory](http://cancer.org/survivorshipresourceinventory)

### Tools for health care professionals

**Prescription for Cancer Information** – a tool to help health care professionals talk to survivors about resources available in their office or clinic, in the community, online, and over the telephone. This tool is available online at [cancer.org/survivorshipprescription](http://cancer.org/survivorshipprescription).

**Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide** – a brief guide detailing indicators and outcome measures that can be used to monitor the success of survivorship programs, available online at [cancer.org/survivorshipprogramevaluation](http://cancer.org/survivorshipprogramevaluation)

### Tools for advocates and policy makers

The Survivorship Center recognizes the importance of policies that support quality survivorship care. To educate policy makers on these issues, a white paper was created describing the priority areas for improving survivorship care. This paper is available online at [cancer.org/survivorshippolicypaper](http://cancer.org/survivorshippolicypaper).

To find out more about The Survivorship Center's activities, visit [cancer.org/survivorshipcenter](http://cancer.org/survivorshipcenter).

costs associated with transportation to treatment. In 2010, the American Cancer Society provided more than 1.3 million transportation services to more than 63,000 cancer patients. Requests for transportation assistance increased by 11% in 2010 over the previous year, and the number of rides provided in 2010 increased by 35%.

**Lodging during treatment.** When someone diagnosed with cancer must travel away from home for the best treatment, where to stay and how to afford accommodations are immediate concerns that sometimes affect treatment decisions. American Cancer Society Hope Lodge facilities provide free, homelike, temporary lodging for patients and their caregivers close to treatment centers, thereby easing the emotional and financial burden of finding affordable lodging. In 2011, the 31 Hope Lodge locations provided 250,000 nights of free lodging to nearly 40,000 patients and caregivers – saving them more than \$23 million in lodging expenses.

**After treatment.** The transition from active treatment to recovery can often create new questions for cancer survivors and their families. The American Cancer Society can help by providing information on many common concerns, such as post-treatment side effects, risk of recurrence, screening and early detection, and nutrition and physical activity, as well as helping provide emotional support through its support pro-

grams. The Society has established a collaborative effort with National Cancer Survivorship Resource Center to address the needs of post-treatment cancer survivors.

**Breast cancer support.** Breast cancer survivors provide one-on-one support, information, and inspiration to help people facing the disease cope with breast cancer through the American Cancer Society Reach To Recovery® program. Volunteer survivors are trained to respond in person or by telephone to people facing breast cancer diagnosis, treatment, recurrence, or recovery.

**Prostate cancer support.** Men facing prostate cancer can find one-on-one or group support through the American Cancer Society Man To Man® program. The program also offers men the opportunity to educate their communities about prostate cancer and to advocate with lawmakers for stronger research and treatment policies.

**Cancer education classes.** People with cancer and their caregivers need help coping with the challenges of living with the disease. Doctors, nurses, social workers, and other health care professionals provide them with that help by conducting the American Cancer Society I Can Cope® educational classes to guide patients and their families through their cancer journey.

**Hair-loss and mastectomy products.** Some women wear wigs, hats, breast forms, and bras to help cope with the effects of mastectomy and hair loss. The American Cancer Society “tlc” *Tender Loving Care*®, which is a magazine and catalog in one, offers helpful articles and a line of products to help women battling cancer restore their appearance and dignity at a difficult time. All proceeds from product sales go back into the Society’s programs and services for patients and survivors.

**Help with appearance-related side effects of treatment.** When women are in active cancer treatment, they want to look their best, and Look Good...Feel Better® helps them do just that. The free program, which is a collaboration of the American Cancer Society, the Personal Care Products Council Foundation, and the Professional Beauty Association | National Cosmetology Association, helps women learn beauty techniques to restore their self-image and cope with appearance-related side effects of cancer treatment. Certified beauty professionals, trained as Look Good...Feel Better volunteers, provide tips on makeup, skin care, nail care, and head coverings. Additional information and materials are available for men and teens.

**Finding hope and inspiration.** People with cancer and their loved ones do not have to face their cancer experience alone. They can connect with others who have “been there” through the American Cancer Society Cancer Survivors Network® (csn.cancer.org). The online community is a welcoming and safe place that was created by and for cancer survivors and their families. The American Cancer Society Circle Of Sharing™ program (circleofsharing.cancer.org) allows users to share reliable medical information and resources with their trusted circle of caregivers, family, and friends for a more holistic approach to managing their disease.

Another online support resource is a community called WhatNext, a network of people committed to providing those facing cancer with timely access to peers, perspectives, and relevant American Cancer Society resources. The WhatNext program provides an organized way for individuals to share their cancer journey and insights, so others can get a better idea of what they might expect as they move through their own cancer journey. For more information, visit [acs.whatnext.com](http://acs.whatnext.com).

**Smoking cessation.** The Society helps people quit tobacco through the American Cancer Society Quit For Life® Program, managed and operated by Alere Wellbeing. The two organizations have 35 years of combined experience in tobacco cessation coaching and have helped more than 1 million tobacco users. Information about this program is available at [quitnow.net](http://quitnow.net). A link to additional information on smoking cessation is available on the Society Web site, [cancer.org/healthy](http://cancer.org/healthy).

## Other Sources of Survivor Information and Support

### CancerCare

800-813-HOPE or 800-813-4673  
[cancercares.org](http://cancercares.org)

Professionally facilitated support services to anyone affected by cancer, including a toll-free counseling line, various support groups (online, telephone, or face-to-face), and Connect Education Workshops

### Cancer Support Community

888-793-9355  
[cancersupportcommunity.org](http://cancersupportcommunity.org)

Support services available through a network of professionally led, community-based centers, hospitals, community oncology practices, and online. Focused on providing essential, but often overlooked, services including support groups, counseling, education, and healthy lifestyle programs. In collaboration with LIVESTRONG, the Cancer Support Community developed the Cancer Transitions program for post-treatment cancer survivors, which covers the benefits of exercise, nutrition, emotional support, and medical management.

### Family Caregiver Alliance

800-445-8106  
[caregiver.org](http://caregiver.org)

The Family Caregiver Alliance (FCA) is a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy. FCA established the National Center on Caregiving (NCC) to advance the development of high-quality, cost-effective programs and policies for caregivers in every state in the country. The NCC sponsors the Family Care Navigator to help caregivers locate support services in their communities.

### LIVESTRONG

855-220-7777  
[livestrong.org](http://livestrong.org)

LIVESTRONG SurvivorCare is a one-on-one support program to help cancer survivors learn about cancer and their fertility risks, address financial, insurance, and employment issues, and connect to new treatments in development. The LIVESTRONG Guidebook offers guidance through the cancer experience from the moment of diagnosis, during cancer treatment, and after treatment. The LIVESTRONG Guidebook Planner and Journal provides worksheets and calendars to help plan and keep track of the cancer journey. The LIVESTRONG Care Plan is a tool to help patients work with their oncologist and primary health

care provider to address the medical and psychosocial challenges that may arise post-treatment. Visit [LIVESTRONG.org/CancerSupport](http://LIVESTRONG.org/CancerSupport) for these cancer resources and support services and more.

### **National Coalition for Cancer Survivorship**

888-650-9127  
[canceradvocacy.org](http://canceradvocacy.org)

National Coalition for Cancer Survivorship (NCCS) offers free publications and resources that empower people to become strong advocates for their own care or the care of others. The coalition's flagship program is the award-winning Cancer Survival Toolbox, a self-learning audio series developed by leading cancer organizations to help people develop crucial skills to understand and meet the challenges of their illness.

### **Patient Advocate Foundation**

800-532-5274 (English), 800-516-9256 (Spanish)  
[patientadvocate.org](http://patientadvocate.org)

The Patient Advocate Foundation (PAF) is a national nonprofit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of financial stability. PAF serves as an active liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through professional case managers, doctors and health care attorneys.

### **Finding Cures**

Research is at the heart of the American Cancer Society's mission. For more than 60 years, the Society has been finding answers that save lives – from changes in lifestyle to new approaches in therapies to improving cancer patients' quality of life. No single non-governmental, not-for-profit organization in the US has invested more to find the causes and cures of cancer than the American Cancer Society. We relentlessly pursue the answers that help us understand how to prevent, detect, and treat all cancer types. We combine the world's best and brightest researchers with the world's largest, oldest, and most effective community-based anti-cancer organization to put answers into action.

As of January 6, 2012, the Society is funding approximately \$66 million in cancer treatment research and more than \$77 million in cancer control, survivorship, and outcomes research. Through a funding partnership with the National Palliative Care Research Center, the Society has awarded 64 grants in symptom management and palliative care focused on patient, survivor, and quality of life research over the past five years, with 14 new grantees added in 2011.

Specific examples of ongoing and recent intramural and extramural research include:

- Exploring physical and psychosocial adjustment to cancer and identifying factors affecting quality of life through the Society's ongoing, nationwide studies of cancer survivors
- Identifying and prioritizing gaps in information and resources for cancer survivors as they transition from active treatment back to the community care setting
- Investigating the impact of the family's involvement in cancer care on the quality of life of the cancer survivor and the caregiver
- Developing and implementing a process to measure the effective control of pain, other symptoms, and side effects for those who have been affected by cancer
- Identifying patients at significantly greater risk for delays in breast cancer treatment, which may be a contributing factor in persistent racial disparities in breast cancer outcomes
- Examining symptoms related to the use of aromatase inhibitors, including effective methods of symptom management
- Identifying genes that may determine susceptibility to lymphedema
- Comparing the effectiveness of follow-up cancer survivorship care in childhood cancer patients randomized to either 1) a specialty survivor clinic or 2) a patient's primary care doctor empowered with care recommendations provided by a cancer survivor specialist

### **Fighting Back**

Conquering cancer is as much a matter of public policy as scientific discovery. Whether it's advocating for quality, affordable health care for all Americans, increasing funding for cancer research and programs, or enacting laws and policies that help decrease tobacco use, government action is constantly required. The American Cancer Society and its nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), use applied policy analysis, direct lobbying, grassroots action, and media outreach to ensure elected officials nationwide pass laws furthering the organizations' shared mission to create a world with less cancer.

Created in 2001, ACS CAN is the force behind a new movement uniting and empowering cancer patients, survivors, caregivers, and their families. ACS CAN is a community-based grassroots movement that unites cancer patients, cancer survivors and caregivers, volunteers and staff, health care professionals, researchers, public health organizations, and other partners. ACS CAN gives ordinary people extraordinary power to fight back against cancer. In recent years, the Society and ACS CAN have successfully partnered to pass a number of laws at the federal, state, and local levels focused on preventing cancer and detecting it early, increasing research on ways to prevent and treat cancer, improving access to lifesaving screenings and treatment, and improving quality of life for cancer patients.

Some of our recent advocacy accomplishments impacting cancer patients include:

- Passage and implementation of the Affordable Care Act (ACA) of 2010, comprehensive legislation that:
  - Prohibits insurance companies from denying insurance coverage based on a preexisting conditions (children starting in 2010, adults in 2014)
  - Prohibits insurance coverage from being rescinded when a patient gets sick
  - Removes lifetime limits from all insurance plans
  - Allows children and young adults to be covered under their parents' insurance plans until they turn 26
  - Makes coverage for routine care costs available to patients who take part in clinical trials
  - Establishes a National Institutes of Health Interagency Pain Research Advisory Committee to coordinate pain management research initiatives and an Institute of Medicine Pain Conference series that will be important to relieving cancer-related pain and other chronic pain conditions
  - Establishes a National Prevention and Health Promotion Strategy; a National Prevention, Health Promotion and Public Health Council; and a Prevention and Public Health Fund with mandatory funding to prioritize, coordinate, oversee, and fund prevention-related activities nationwide
  - Requires all new health insurance plans and Medicare to cover preventive services rated “A” or “B” by the US Preventive Services Task Force (USPTF) at no cost to patients (including breast, cervical, and colorectal cancer screening and smoking cessation treatment)
  - Requires state Medicaid programs to provide pregnant women with tobacco cessation treatment at no cost
  - Protects children and families against states rules that limit program eligibility or increase premiums or enrollment fees in Medicaid
  - Provides new funding to states to make expansions or improvements to Medicaid
  - Saves states money in uncompensated care by replacing local dollars with new federal subsidies
  - Expands coverage to all low-income adults below 133% of the federal poverty level eligible for Medicaid beginning in 2014
  - Prioritizes health disparities at the National Institutes of Health, establishes a network of federal-specific offices of minority health, and creates an Office of Women's Health
  - Enhances data collection and reporting to ensure racial and ethnic minorities are receiving appropriate, timely, and quality health care
  - Authorizes grants to help states and local jurisdictions address health workforce needs
  - Secures coverage for a new annual wellness visit with a personalized prevention plan and gradually reduces out-of-pocket costs for prescription drugs for Medicare beneficiaries

- Creates incentives for health care providers to deliver more coordinated and integrated care to beneficiaries enrolled in Medicare and Medicaid
- Requires chain restaurants to provide calorie information on menus and have other nutrition information available to consumers upon request and requires chain vending machine owners or operators to display calorie information for all products available for sale
- Improving quality of life and reducing suffering by ensuring that patients and survivors receive high-quality cancer care that matches treatments to patient and family goals. The Society and ACS CAN have:
  - Advocated for balanced pain policies in multiple states and at the federal level to ensure patients and survivors have continued access to the treatments that promote better pain management and improved quality of life
  - Passed federal legislation to promote patient- and family-centered quality cancer care, survivorship care planning, pain and symptom management, and care coordination to improve quality of life for patients, survivors, and their families
  - Advanced a new quality-of-life legislative platform to include and implement palliative care as a patient-centered and quality-of-life improvement for people facing serious illnesses such as cancer
  - Increased public awareness of the increasingly urgent cancer drug shortage problem and advocated for solutions to the complex, multiple causes of cancer drug shortages

Together, ACS CAN and the American Cancer Society are taking action to move toward integrating palliative care in our nation's health care delivery system. The public policy goal is to provide patients greater access to palliative care at the point of diagnosis as an essential element of providing quality patient-centered care. The Society's targeted research programs and ACS CAN's associated advocacy initiatives include a specific focus on:

- Managing physical and psychosocial symptoms
- Reducing barriers to receiving care
- Increasing cancer knowledge and empowering patient and caregiver decision making and communications with treatment teams

Some efforts in the fight against cancer are more visible than others, but each successful battle is an important contribution to what will ultimately be victory over the disease. The Society, working together with ACS CAN and its grassroots movement, is making sure the voice of the cancer community is heard in the halls of government and is empowering communities everywhere to fight back. The Society is also rallying people to fight back against the disease through our Relay For Life®, Making Strides Against Breast Cancer®, and DetermiNation® events.

## Sources of Statistics

**Prevalence.** Cancer prevalence (i.e., the number of cancer survivors) was projected using the Prevalence Incidence Approach Model (PIAMOD), a method that calculates prevalence from cancer incidence, cancer survival, and all-cause mortality.<sup>108</sup> Incidence and survival were modeled by cancer type, sex, and age group using malignant cancer cases diagnosed during 1975-2007 from the nine oldest registries in the Surveillance, Epidemiology, and End Results (SEER) program. (The most recent year of available incidence data – 2008 – was excluded due to anticipated undercounts as a result of delays in reporting.) Survival was assumed to be constant from 2001 through 2022. Mortality data for 1969-2008 were obtained from the National Center for Health Statistics and projected mortality for 2009 to 2022 were obtained from the Berkeley Mortality cohort life tables. Population projections for 2008 to 2022 were obtained from the US Bureau of Census. For more information on this method, please see Mariotto et al, 2006<sup>109</sup> and Mariotto et al, 2011.<sup>110</sup>

**New cancer cases.** The numbers of new US cancer cases in 2012 are projected using a two-step process. First, the total number of cases in each state is estimated using a spatiotemporal model based on incidence data from 47 states and the District of Columbia for the years 1995-2008 that met the North American Association of Central Cancer Registries' (NAACCR) high-quality data standard for incidence, which covers about 95% of the US population. This method considers geographic variations in sociodemographic and lifestyle factors, medical settings, and cancer screening behaviors as predictors of incidence, as well as accounting for expected delays in case reporting. Then, the number of new cases nationally and in each state is projected four years ahead using a temporal projection method.

**Survival.** This report presents relative survival rates to describe cancer survival. Relative survival adjusts for normal life expectancy (and events such as death from heart disease, accidents, and diseases of old age) by comparing survival among cancer patients to that of people not diagnosed with cancer who are of the same age, race, and sex. Five-year survival statistics presented in this publication were originally published in the National Cancer Institute's *Cancer Statistics Review 1975-2008* and are for diagnosis years 2001 to 2007, with all patients in the 17 SEER registries followed through 2008. In addition to 5-year relative survival rates, 1-year, 10-year, and 15-year survival rates are presented for selected cancer sites. These survival statistics are generated using the National Cancer Institute's SEER 17 database and SEER\*Stat software version 7.0.5. One-year survival rates are based on cancer patients diagnosed from 2004 to 2007, 10-year survival rates are based on diagnoses from 1995 to 2007, and 15-year survival rates are based on diagnoses from 1990 to 2007; all patients were followed through 2008.

**National Cancer Data Base.** The National Cancer Data Base (NCDB) is a hospital-based cancer registry jointly sponsored by the American Cancer Society and the American College of Surgeons, and includes approximately 70% of all malignant cancers in the United States from more than 1,400 facilities accredited by the American College of Surgeons' Commission on Cancer (CoC). Begun in 1989, the NCDB now contains approximately 26 million records from hospital cancer registries across the United States and has been used in more than 300 peer-reviewed publications. The NCDB contains standardized data regarding patient demographics and cancer type and histology and staging, as well as first course of treatment. One of the primary purposes of the NCDB is to provide information back to CoC-accredited cancer treatment facilities about their quality of care. The NCDB, which is housed at the American College of Surgeons, is not publicly available, but has been made available to health service researchers at the American Cancer Society as a sponsoring organization. The NCDB collects information using the same coding rules as population-based cancer registries. However, unlike the population-based registries, users of NCDB data are able to access data on chemotherapy treatments. It is recognized that chemotherapy data collected by the NCDB may be less complete than data on surgery or radiation therapy; however, we believe that the chemotherapy data collected in the NCDB is sufficiently complete to be used to describe cancer treatment patterns by cancer site and stage. Some common targeted therapies may be included in data on chemotherapy use. For further information regarding the classification of anti-cancer drugs into the categories of chemotherapy, immunotherapy, hormonal therapy, and targeted therapy, see the SEER-Rx Web site, [seer.cancer.gov/tools/seerrx](http://seer.cancer.gov/tools/seerrx)

Although the NCDB is a powerful tool in describing cancer treatment, data are only collected for patients diagnosed or treated at CoC-accredited facilities, which are more likely to be located in urban areas and tend to be larger centers compared to non-CoC accredited facilities.<sup>111</sup> Additionally, cancers that are treated and diagnosed in non-hospital settings (e.g., melanoma, prostate cancer and non-muscle invasive bladder cancer) are less likely to be captured by the NCDB because it is a hospital-based registry. Though the NCDB is not population-based, trends in disease severity and treatment for common cancer sites are similar to those found in SEER and SEER-Medicare linked studies. A recent study compared prostate cancer cases in the NCDB and SEER and reported similar distributions of stage, Gleason Score, and prostate specific antigen levels.<sup>112</sup> Also, rates of chemotherapy receipt among NCDB breast patients age 65 and older are similar to those in the SEER-Medicare data.<sup>113, 114</sup> More information on the NCDB can be found at their Web site, [facs.org/cancer/ncdb](http://facs.org/cancer/ncdb).

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### **For more information, contact:**

Carol DeSantis, MPH; Rebecca Siegel, MPH; Ahmedin Jemal, DVM, PhD



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