

## *Executive Summary*

- ❖ Cancer is a chronic disease that people can and do survive. It is not inevitable that it is a disabling or fatal disease, but can have long-term effects on an individual's life.
- ❖ Approximately 29,000 Vermont adults are living with a current or previous diagnosis of cancer.
- ❖ The term "cancer survivor" refers to someone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life.
- ❖ The Vermont Department of Health (VDH) is working to reduce the impact of cancer on individuals, families, and communities in Vermont. VDH conducts activities and monitors progress in support of the *Vermont State Cancer Plan* as well as partners with many organizations and individuals throughout the state who are involved in this common effort.
- ❖ The percentage of people ever diagnosed with cancer reporting that their general health is good or excellent increased from 78 percent in 2004 to 80 percent in 2007.
- ❖ Vermont's grade on the Pain Policy Report Card improved from a C+ in 2004 to a B+ in 2007.
- ❖ Cancer treatment accounted for an estimated \$72.1 billion nationally in 2004, just under 5 percent of U.S. spending for all medical treatment.
- ❖ Nationally, survival trends are generally improving. For all cancer sites combined, survival has increased since 1975. Prostate, female breast, colon, and lung cancer survival have all improved. Among these four cancers, five-year survival rates are highest for prostate and female breast cancers and lowest for lung cancer.
- ❖ Many resources exist for cancer survivors. See page 19 for more information.

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## *Background*

Throughout our lives, our body's cells continually grow, divide, and die in a regular and orderly process. During our early years, normal cells divide rapidly, but when one reaches adulthood, cells generally only divide when needed to replace depleted or dying cells and to repair injuries. In some cases, certain cells continue to grow and divide uncontrollably. Any disease in which abnormal cells develop, divide, grow, and have the potential to spread throughout the body can be called cancer.

Nationally cancer incidence rose steadily in the latter part of the 20th century until the mid-1990s, when it began falling. Declining incidence may be related to a number of factors. The drop in female breast cancer incidence may be related to declining use of hormone replacement therapy, as well as the recently reported decline in use of screening mammography. Effective tobacco control efforts, may explain a decline in lung cancer incidence. Decreased colon cancer incidence is likely due to prevention through the removal of precancerous polyps during colonoscopy. Still, roughly one out of every two men and one out of every three women will develop cancer in their lifetime.

For the past 40 years, the three leading causes of death in Vermont have been heart disease, cancer, and stroke, with approximately 1,200 Vermonters dying from cancer each year. In contrast to the dramatic declines in the death rates for heart disease and stroke, the cancer death rate rose steadily over the past few decades (a result of the aging population and the continued rise in death rates from lung cancer) before decreasing in recent years. The Centers for Disease Control and Prevention (CDC) attributes the decline in cancer death rates nationally to "important progress in the fight against cancer that has been achieved through effective tobacco control, screening, early detection, and appropriate treatment."

With our aging population and decreasing mortality from cancer, there are more people than ever living with cancer. The prevalence of cancer in Vermont - the number of living people who have ever been diagnosed with cancer divided by the total population - is estimated to be between 4 and 6%. This equals roughly 29,000 persons [2007 BRFSS and Surveillance, Epidemiology, and End Results]. It is not unusual to know several people who have cancer. As a population ages, the occurrence of new cancer cases is expected to increase. With treatment advances, people are living longer with a cancer diagnosis; the number of cancer survivors has doubled in the past 20 years.

The term "cancer survivor" is often used to describe someone living with a prior diagnosis of cancer, although not everyone who has experienced cancer categorizes themselves as a "survivor." Because of the broad reaching effects of cancer, the term "cancer survivor" is sometimes broadened to include family members, friends, and caregivers. However, for the purposes of this report, "cancer survivors" include Vermonters who have been diagnosed with cancer, from the time of diagnosis through the rest of their lives.

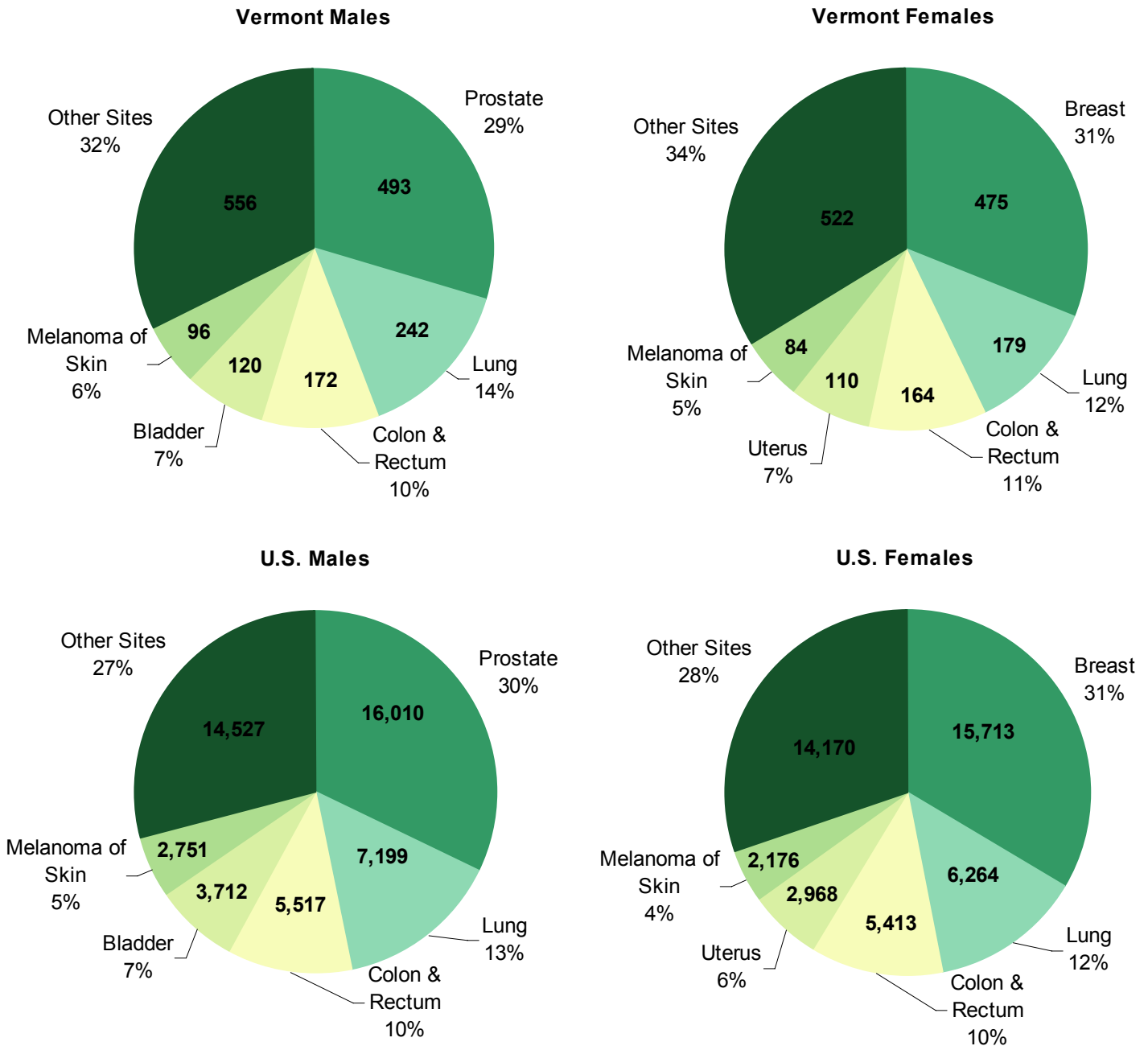
*"People suggested it would be hard, but no one said how hard." — Vermont Cancer Survivor*

# New Cancers Diagnosed

Defined as the number of *new* cases occurring in a population during a defined time interval, incidence rates are a useful measure of the risk of disease.

**Figure 1. The most commonly diagnosed cancers in males and females – Vermont and United States, percentage and number of new cases per year, 2000-2004.**

## New Cancers Diagnosed by Site



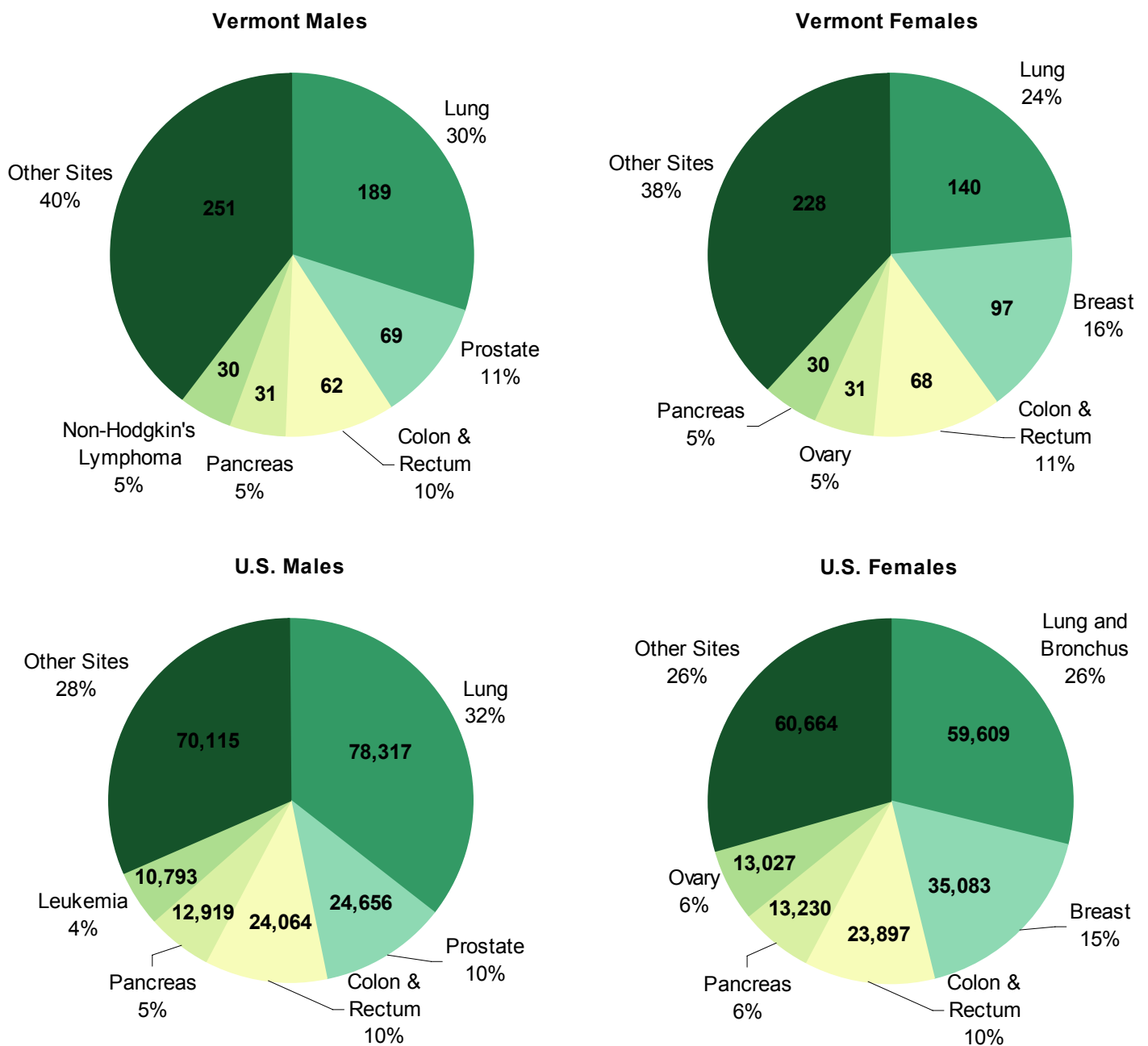
❖ Over 50 percent of new cancers diagnosed among men are lung, prostate, and colon cancers. Over 50 percent of new cancers diagnosed among women are lung, breast and colon cancers.

## Cancer Related Deaths

The mortality rate is a measure of the number of deaths (due to cancer) in a population during a specific period of time. These mortality statistics are based on the underlying cause of death as recorded on a death certificate.

**Figure 2. The most common causes of cancer deaths in males and females – Vermont and United States, percentage and number of deaths per year, 2000-2004.**

### Cancer Deaths by Site

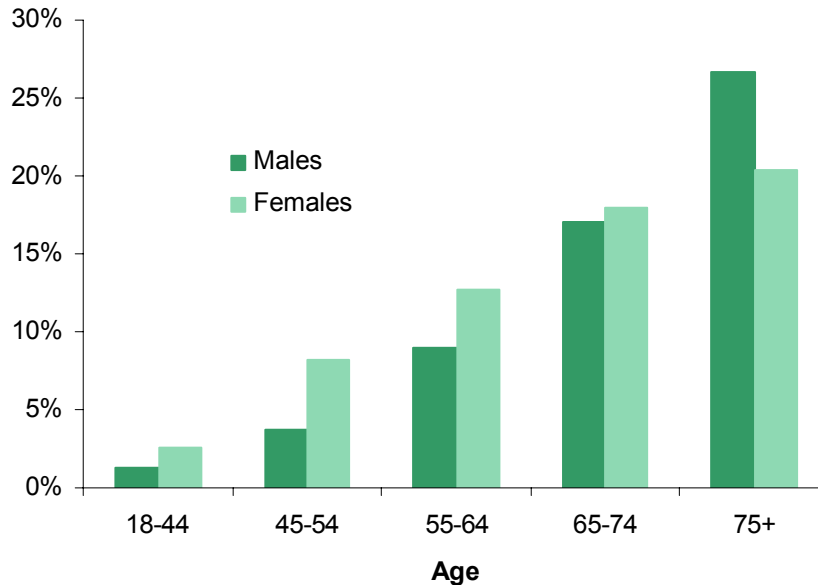


- ❖ Over 50 percent of cancer deaths among men are lung, prostate, and colon cancers. Over 50 percent of cancer deaths among women are lung, breast and colon cancers.

## Cancer Prevalence

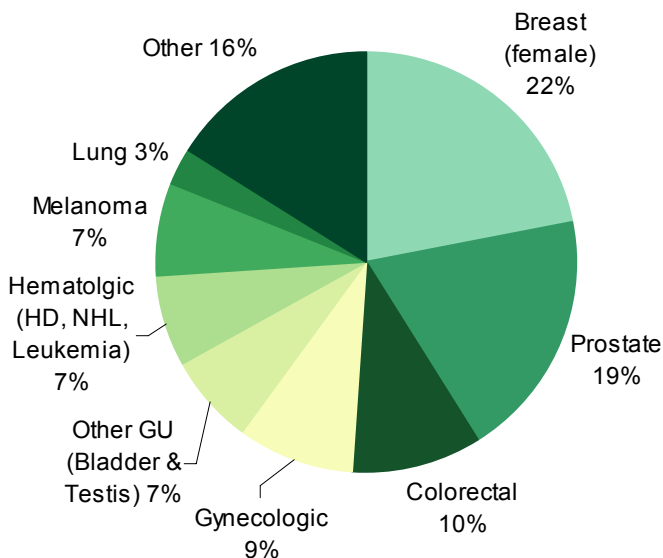
Cancer prevalence is defined as the number of people living with a current or previous diagnosis of cancer, divided by the number of individuals in the population. Among Vermont adults age 18 and older, it is estimated that there are 29,000 cancer survivors [2007 BRFSS and Surveillance, Epidemiology, and End Results]. Nationally, cancer is fairly uncommon among children, accounting for one percent of both newly diagnosed cases each year and of survivors.

**Figure 3. Cancer prevalence by age and gender among adults – Vermont, 2007.**



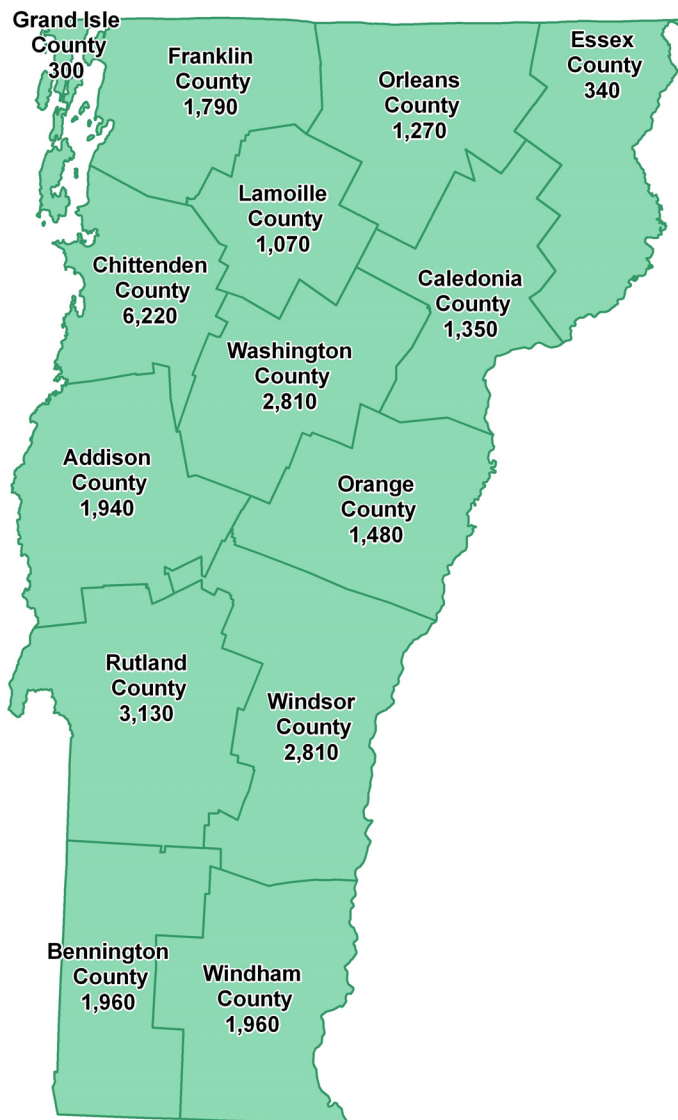
- ❖ Cancer prevalence increases with age. Roughly one in five Vermonters age 75 and older has ever had cancer.
- ❖ Cancer is more prevalent among Vermont females age 18 and older (8.5 percent) than males (6.1 percent).

**Figure 4. Estimated number of persons alive in the U.S. diagnosed with cancer by site as of January 1, 2004 (total number = 10.8 million persons).**



- ❖ The number of people alive who have ever been diagnosed with a particular type of cancer varies by the incidence (number of new cases), opportunities for early diagnosis (screening), and treatment options.
- ❖ In the U.S., over 50 percent of cancer survivors have had breast, prostate, or colorectal cancers.

Figure 5. Estimated cancer prevalence – Vermont counties, 2007.



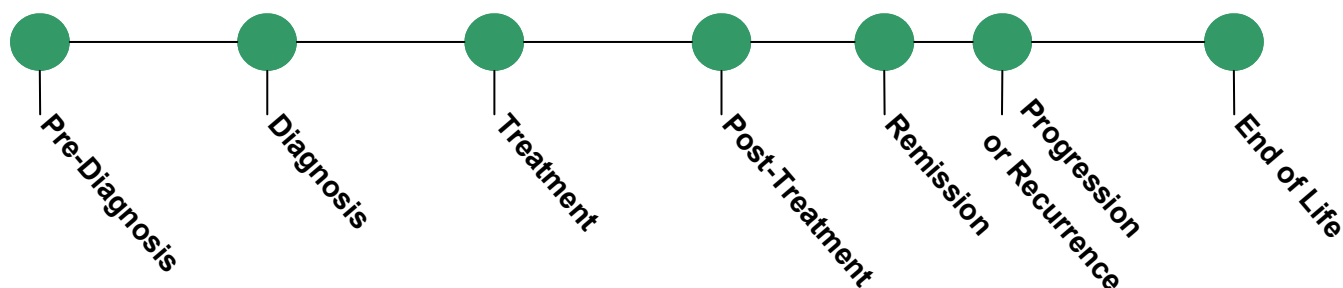
- ❖ Prevalence refers to the number of people alive today who have ever been diagnosed with cancer.
- ❖ Relative to the number of people living in each county, the number of cancer survivors is consistent throughout the state.
- ❖ Approximately 29,000 Vermont adults are living with a current or previous diagnosis of cancer.
- ❖ Public health professionals use these numbers to estimate the need for cancer survivor services.

# Cancer Survivor Continuum

*“I’m really very healthy, except for a touch of cancer every few years.”*  
— Vermont Cancer Survivor

Approximately 65 percent of cancer survivors are expected to live at least five years after diagnosis. With innovations in early detection and medical treatment, cancer is increasingly survivable. However, a diagnosis of cancer can be a tremendous burden. Treatments that prolong life, even curing certain cancers, can also cause serious and sometimes long-term problems. More than half of adult cancer patients and survivors report substantial disabilities at some point in their treatment, recovery, or survivorship. Aside from the physical aspects of the disease survivors will often need to contend with emotional and financial issues as they live with, through, and beyond their cancer diagnosis.

**Figure 6. Continuum for Cancer Survivors: living with, through, and beyond a cancer diagnosis.**



Cancer survivors can find themselves at different points along this continuum at different times. Each phase of survivorship brings with it a special mix of needs for medical, emotional, and financial support. Every individual’s experience is unique. This document attempts to address each phase of cancer survivorship and some of the resources available to meet those needs.

## Pre-Diagnosis

### Risk Factors

Cancer develops gradually as a result of a complex mix of factors related to lifestyle choices, environment and genetics. Each type of cancer is caused by a different set of factors, some well established, some uncertain, and some unknown. The exact causes of most cancers are unknown, and research continues to examine how and why normal cellular growth becomes uncontrolled. A risk factor is a condition, an activity, or an exposure that increases a person’s chance of developing cancer. Different kinds of cancers have different risk factors. However, people with known risk factors may never develop cancer, and many people who develop cancer have none of the known risk factors. While the exact cause of most cancers is unknown, researchers have identified several risk factors including:

- ❖ **Age:** Anyone can develop cancer; however, the risk of being diagnosed with cancer increases with age and most cancers occur in adults who are middle age or older.
  - Approximately 76 percent of all new cancers diagnosed each year occur among Vermonters age 55 and older.
- ❖ **Gender:** While many cancers have similar prevalence in men and women, some are exclusively male (prostate) or female (ovarian) and some favor a particular gender.
  - Women are more likely to develop thyroid or breast cancer than men.
  - Men are more likely to develop kidney or bladder cancer than women.

- ❖ **Race and Ethnicity:** Race and ethnicity plays a complex role in an individual's risk for developing cancer. Nationwide, whites have a higher risk compared to people of other races for female breast, melanoma, and bladder cancer. Whites have a lower risk compared to other races for prostate, colorectal, and cervical cancer. African Americans are more likely to develop and die from cancer than any other racial group. Recent immigrants may also have unique risk factors related to their country of origin as well as language and cultural barriers related to accessing cancer screening and treatment.
- ❖ **Socioeconomic Status (SES):** The causes of cancer health disparities are complex and interrelated, but elements related to income, occupation, wealth, educational attainment, housing, and overall standard of living influence access to preventive health care, screening, and treatment. People with a lower SES have both higher overall cancer incidence and mortality.
- ❖ **Diet and Physical Activity:** A poor diet, not having enough physical activity, or obesity may be related to an increased risk of several types of cancer. Individuals whose diet is high in fat have an increased risk of cancers of the colon, uterus, and prostate. Lack of physical activity and being overweight are risk factors for cancers of the breast, colon, esophagus, kidney, and uterus.
  - The percentage of Vermont adults age 18 and older who engage in regular, moderate physical activity (30+ minutes per day, 5 days per week) is 58 percent. (Goal: 63%).
- ❖ **Sunlight:** Skin cancer is directly linked to unprotected exposure to strong Ultraviolet (UV) radiation. UV radiation comes from not only the sun but also sunlamps and tanning booths, and causes early aging of the skin and skin damage that can lead to skin cancers such as melanoma. Melanoma affects people of all age groups and is one of the most common cancers among individuals age 20-49 in Vermont.
- ❖ **Tobacco:** Use of tobacco, including cigarettes, cigars, chewing tobacco, and snuff, are established risk factors for cancers of the lung, mouth, larynx, bladder, kidney, cervix, esophagus, and pancreas. Nationally, smoking causes 180,000 cancer deaths and about 368 cancer deaths in Vermont each year.
- ❖ **Alcohol:** Having more than two drinks each day for many years may increase the chance of developing cancers of the mouth, throat, esophagus, larynx, liver, and breast. The risk increases with the amount of alcohol that a person drinks. For most of these cancers, the risk is higher for individuals who also use tobacco.
- ❖ **Family History:** Most cancers develop because of changes that take place to cells (gene mutations). Some gene changes that increase the risk of cancer are passed from parent to child and are present at birth in all cells of the body. It is uncommon for cancer to run in a family, and when it does, it is most often coincidental. Certain types of cancer, such as melanoma and cancers of the breast, ovary, prostate, and colon, sometimes run in families.
- ❖ **Ionizing Radiation:** Ionizing radiation can cause cell damage that leads to cancer. Radiation comes from radioactive fallout, radon gas, x-rays, rays that enter the Earth's atmosphere from outer space, and other sources.
- ❖ **Certain Chemicals and Other Substances:** Individuals in certain fields of employment (such as painters, construction workers, and those in the chemical industry) have an increased risk of cancer. Many studies have shown that exposure to asbestos, benzene, benzidine, cadmium, nickel, or vinyl chloride in the workplace can cause cancer.
- ❖ **Some Viruses and Bacteria:** Infection with certain viruses or bacteria may increase the risk of developing cancer.
  - Each year, an estimated 225 cancers diagnosed among Vermonters are thought to be caused by infectious agents.
  - *Human papillomavirus (HPV)* is the main cause of cervical cancer. It also may be a risk factor for other types of cancer.
  - Liver cancer can develop after many years of infection with *hepatitis B* or *hepatitis C*.

- *Human T-cell leukemia/lymphoma virus (HTLV-1)* infection increases a person's risk of lymphoma and leukemia.
  - *Human immunodeficiency virus (HIV)* is the virus that causes AIDS. People who have HIV infection are at greater risk of cancer, such as lymphoma and a rare cancer called Kaposi's sarcoma.
  - Infection with *Epstein-Barr virus (EBV)* has been linked to an increased risk of lymphoma.
  - *Human herpesvirus 8 (HHV8)* is a risk factor for Kaposi's sarcoma.
  - *Helicobacter pylori*, a bacterium which can cause stomach ulcers, can cause stomach cancer and lymphoma in the stomach lining.
- ❖ **Certain Hormones:** A physician may recommend hormones, including estrogen or estrogen along with progestin, to help control menopausal conditions such as hot flashes, vaginal dryness, and osteoporosis. However, studies show that menopausal hormones may also increase the risk of breast cancer, heart attack, stroke, or blood clots.

## Prevention

Lifestyle - factors that may be within a person's control - play a bigger role in cancer risk than the environment (water, air, or soil). Tobacco use, diet, infectious diseases, as well as chemicals and radiation, cause an estimated 75% of all cancer cases in the United States. Among these factors, tobacco use, unhealthy diet, and physical activity are most likely to affect cancer risk and are behaviors that can be changed to reduce a person's risk of developing cancer.

The following actions can be taken to reduce a person's risk of developing cancer: avoid tobacco smoke; consume alcohol in moderation; maintain a healthful weight; balance caloric intake with physical activity; eat five or more servings of a variety of vegetables and fruits each day; choose whole grains in preference to processed grains and sugars; and limit consumption of red meats, especially high-fat and processed meats. Additionally, many of the more than one million annual skin cancers can be prevented by protection against harmful UV exposure.

## Screening and Early Detection

Many cancers can be treated quickly and effectively if they are detected early. Screening is a way of checking for disease when there are no symptoms. Some screening tests are used to find cancers early and decrease the chance of dying from these cancers. People of certain ages and genders are recommended to undergo screening tests, such as mammograms for breast cancer, Pap tests for cervical cancer, and colonoscopies for colorectal cancer.

The American Cancer Society provides cancer screening guidelines for people at average risk for cancer and without any specific symptoms. For more information, visit: <http://www.cancer.org>.

According to the 2006 Behavioral Risk Factor Surveillance System (BRFSS):

- Approximately 68 percent of Vermonters aged 50 and older report receiving the recommended colorectal cancer screening tests. (Goal: 75 percent)
- Approximately 79 percent of Vermont females age 40 and over report receiving a mammogram within the past two years. (Goal: 85 percent)
- Approximately 83 percent of Vermont females age 18 and over report having had a Pap test in the past three years. (Goal: 90 percent)

Other screening tests can detect cancers that have not been proven in clinical trials to decrease the risk of dying from cancer. The mouth, skin, and prostate are just a few examples of cancers that can be screened for in this way.

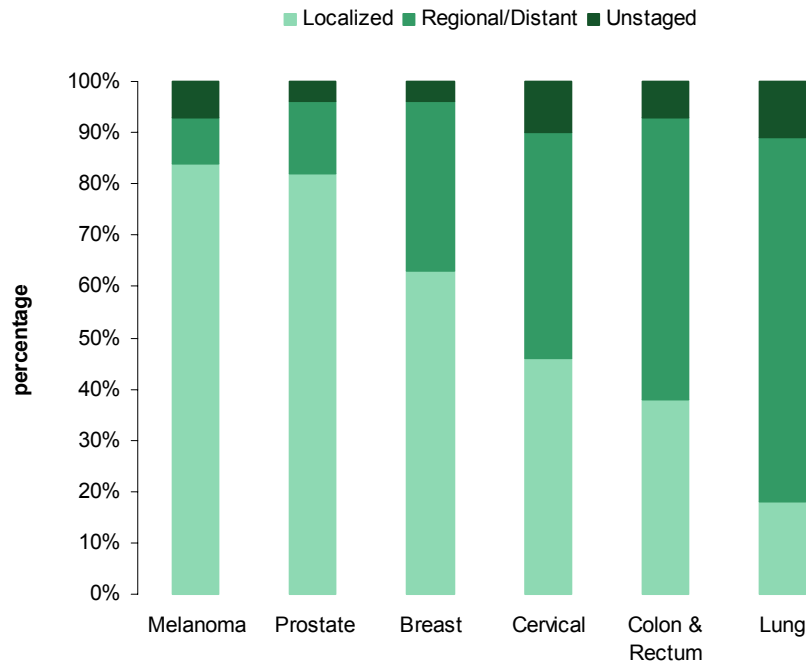
Many types of cancer have no recommended screening tests and are often diagnosed when symptoms are already present. There are many signs and symptoms that may indicate the presence of cancer or some other non-cancer medical condition. For example, weight loss and abdominal pain can be indicative of stomach cancer or an ulcer; pink or reddish urine can be caused by kidney cancer or by a kidney infection; abdominal pain and yellow discoloration of your skin and whites of your eyes can be caused by liver cancer or a liver infection. Healthcare professionals use diagnostic tests, such as laboratory tests, imaging techniques, and scopes, to identify (or rule out) a cancer diagnosis.

## Diagnosis

A diagnosis of cancer involves attempting to accurately identify the site of the malignancy and the type of cells involved. The site refers to the location of the cancer within the body. The body part in which cancer first develops is known as the **primary site**. A cancer's primary site may determine how the tumor will behave, if and where it might spread (metastasize), and the symptoms it may cause. The most common sites in which cancer occurs include: skin, lungs, breasts, prostate, colon and rectum, and the uterus. A **secondary site** re-

fers to the body part where metastasized cancer cells grow and form secondary tumors. A cancer is always described in terms of the primary site, even if it has spread to another part of the body. For example, cancer that started as colon cancer and spread to the liver is still colon cancer.

**Figure 7. Cancer stage at diagnosis – male and female, Vermont, 2000-2004.**



A biopsy (removal of tissue for microscopic evaluation) is the preferred method to confirm or rule out a diagnosis of cancer. The biopsy potentially provides information about histological type, grade, potential aggressiveness and other information that may help determine the best treatment. The **histological type** (the composition of cells and tissues) is determined by microscopic examination of a tissue sample from a tumor. If the histological type is different from what is usually found in the tissue being examined, it can mean the cancer has spread to that area from some primary site. Various histological types have different growth rates and prognoses. Once cancer has been confirmed, the pathologist tries to determine how closely the cancer cells resemble healthy, mature cells (differentiated) or immature appearing cells that do not look like their healthy counterparts (undifferentiated). The pathologist assigns a pathological **grade** (the measure of the progress of a tumor) according to how aggressive the tissue looks under the microscope. For example a low grade tumor more closely resembles the original tissue than a high grade tumor.

More clinical information is used to further classify cancers according to **stage**, which describes how far a cancer has progressed based on the size of the primary tumor and whether and where it has spread. Cancer stage can be classified as:

- **In Situ:** cancer cells are present, but the tumor has not invaded the supporting structure of the organ on which it arose.
- **Localized:** cancer cells are limited to the organ of origin.
- **Regional:** the tumor has extended beyond the limits of the organ of origin and there is potential for spread.
- **Distant:** tumor cells have broken away from the primary tumor and have traveled to other parts of the body.

“There is no profit in curing the body if in the process we destroy the soul.”  
— *City of Hope Hospital Mission Statement*

## Treatment

Cancers can be treated with a number of therapies or combination of therapies based on the staging of the cancer and other medical factors. For more information about treatment guidelines, visit the National Comprehensive Cancer Network (NCCN) at: [http://www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp).

**Surgery** to remove a tumor can be a primary treatment of cancer. Cancers can be cured if entirely removed by surgery, but this is not always possible. When the cancer has metastasized to other sites in the body prior to surgery, complete surgical removal is usually impossible. Surgical procedures for cancer include mastectomy for breast cancer and prostatectomy for prostate cancer. The objective of a surgery can be the removal of only the tumor, the entire organ, or the entire organ plus surrounding tissues.

Following surgery a pathologist will examine the surgical specimen to determine if a margin of healthy tissue is present, lessening the possibility that microscopic cancer cells are left behind. A single cancer cell that remains after treatment is invisible to the naked eye but can re-grow into a new tumor. As well as removing the primary tumor, surgery is often needed for staging (determining the extent of the disease) and whether it has metastasized (spread) to other sites. Staging can determine prognosis and the need for adjuvant therapy (additional treatments after surgery). Occasionally, surgery is necessary to control symptoms such as spinal cord compression or a bowel obstruction but is not intended to be a cure. Although the control of the symptoms of cancer (**palliative treatment**) is not typically thought of as a treatment directed at the cancer, it is an important determinant of the quality of life of cancer patients, and plays an important role in the decision whether the patient is able to undergo additional treatments.

**Chemotherapy** is a treatment method that uses drugs to destroy cancer cells. Chemotherapy can be used as the only cancer treatment, but more often, it will be used along with other forms of treatment. Neoadjuvant chemotherapy may be offered before surgery, to shrink a primary tumor, making other therapies such as surgery or radiotherapy less damaging or more effective. Chemotherapy given in combination with surgery, to increase the chances of a cure, is called adjuvant therapy. Chemotherapy may be offered to some patients following surgery, even if the doctor removes the entire visible tumor, to kill any remaining cancer cells. Finally, chemotherapy may be used to ease cancer symptoms, such as shrinking a tumor that is causing pain or pressure, as part of palliative care. The way the chemotherapy is given depends on the type and stage of the cancer being treated. Chemotherapy drugs interfere with cell division in various ways, either with the duplication of DNA or the separation of newly formed chromosomes. Most forms of chemotherapy target all rapidly dividing cells and are not specific for cancer cells, although some degree of specificity may come from the inability of many cancer cells to repair DNA damage, while normal cells generally can. Chemotherapy has the potential to harm healthy tissue, especially those tissues that have a high replacement rate; however, these cells typically repair themselves after chemotherapy.

**Radiation** therapy (ionizing radiation to control cancer cells) is a treatment that uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing. Radiation therapy may be used to treat almost every type of solid tumor, including cancers of the brain, breast, cervix, larynx, lung, pancreas, prostate, skin, stomach, uterus, or soft tissue sarcomas. Radiation is also used to treat leukemia and lymphoma. The way the radiation therapy is given depends on the type and stage of the cancer being treated. Radiation dose to each site depends on a number of factors, including the radiosensitivity (the relative susceptibility of cells, tissues, or organs to the harmful effect of ionizing radiation) of each cancer type and whether there are tissues and organs nearby that may be damaged by radiation.

**Biologic therapy** is a treatment that uses the patient's immune system to fight cancer. Substances made by the body or made in a laboratory are used to boost, direct, or restore the body's natural defenses against cancer. This type of cancer treatment is also called "biotherapy" or "immunotherapy." Treatment for some cancers may also include **bone marrow transplantation** where healthy stem cells from very immature cells,

found in the marrow, that produce blood cells, are used to replace white blood cells that are damaged or destroyed by treatment. Bladder, non-Hodgkin Lymphoma, and breast cancer are among the tumors that may be treated with this therapy.

**Hormonal therapies** may be used when the growth of some cancers can be inhibited by providing or blocking certain hormones. Common examples of hormone-sensitive tumors include certain types of breast and prostate cancers.

**Complementary and alternative medicine (CAM) treatments** include healing practices and products that are not part of conventional medicine. Oncology has a long history of incorporating unconventional or botanical treatments into mainstream cancer therapy. "Complementary medicine" refers to methods and substances used along with conventional medicine, while "alternative medicine" refers to compounds used instead of conventional medicine.

- In 2007, 41 percent of Vermont cancer survivors reported using some type of CAM in the past year.

**Clinical trials** are generally designed to compare potentially better therapy with therapy that is currently accepted as standard and can be an important option for many individuals when considering treatment of this disease. Most of the progress made in identifying curative therapies for cancers has been achieved through clinical trials.

- In 2005, over 100 Vermonters participated in clinical trials through the Vermont Cancer Center.

Information about ongoing clinical trials, including how to find a clinical trial in your area, is available from the National Cancer Institute at: <http://www.cancer.gov/clinicaltrials/search>.

**Palliative care** is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than halting or delaying progression of the disease itself or providing a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious, complex illness.

Pain from cancer, cancer treatment, or co-morbidity (disorders or illness in addition to cancer) impacts all dimensions of quality of life and can be one of the most difficult symptoms to treat. Although doctors generally have the ability to reduce pain, nausea, vomiting, diarrhea, hemorrhage and other common problems in cancer patients, the multidisciplinary specialty of *palliative care* has arisen specifically in response to the needs of cancer patients. Pain medication and other drugs to suppress nausea and vomiting are very commonly used in patients with cancer-related symptoms and have made aggressive treatments much more feasible for cancer patients. However drowsiness, lethargy, constipation, and nausea that can often accompany pain medications may be difficult to accept for someone whose primary goal following treatment is to return to and maintain normal day-to-day activities.

Chronic pain due to cancer is almost always associated with continuing tissue damage from the disease process or the treatment (i.e. surgery, radiation, chemotherapy). Cancer pain management is directed towards getting the patient as comfortable as possible using opioids and other medications, surgery, and physical measures. Doctors have been reluctant to prescribe narcotics for pain in terminal cancer patients, for fear of contributing to addiction or suppressing respiratory functions. However, the move towards palliative care, an offshoot of the hospice movement, has created more widespread support for preemptive pain treatment for cancer patients.

## Post Treatment

Cancer survivors are at risk for recurrence or for developing second cancers. The effects of treatment, lifestyle behaviors, underlying genetics, or risk factors that contributed to the first cancer are all factors for continued risk of disease. At the end of treatment, survivors should discuss with their health care providers an appropriate plan for screening, the types of screening needed, and which members of their care team will be in charge of supervising their long-term care.

Cancer survivors may have different health care needs following their treatment and diagnosis, and many survivors may be at risk for developing late or long-term side effects as a result of their primary treatments. Survivors need access to a variety of resources to manage the physical and psychological issues that may develop or persist following treatment:

- Screening for cancer recurrence.
- Monitoring for other possible health concerns (testing for heart problems among survivors of childhood cancers).
- Participation in psychological or support group services.
- Planning for possible infertility.
- Management of pain and resulting comorbidity that cause pain.
- Specific immunizations such as influenza.

Two common concerns for cancer survivors are related to the management of pain and fatigue.

**Fatigue** occurs in a majority of people with cancer, particularly those undergoing treatment. Fatigue is difficult to describe and people with cancer may express it in different ways, such as saying they feel tired, weak, exhausted, weary, worn-out, heavy, or slow. Unlike normal fatigue, cancer-related fatigue is not relieved by rest and often interferes with everyday activities. Underlying factors that contribute to fatigue should be evaluated and treated when possible. Contributing factors include anemia, depression, anxiety, pain, dehydration, nutritional deficiencies, sedating medications, and therapies that may have poorly tolerated side effects.

Most of the treatments for fatigue in cancer patients are for treating symptoms and providing emotional support because the causes of fatigue that are specifically related to cancer have not been determined. Patients should tell their doctors when they are experiencing fatigue and ask for information about fatigue related to underlying causes and treatment side effects.

**Pain** occurs in approximately 30 to 50 percent of people with cancer who are undergoing treatment, and 70 to 90 of people with advanced cancer experience pain. Nearly half of survivors with cancer pain are undertreated. Cancer pain can be managed effectively in most patients with cancer or with a history of cancer. Although cancer pain cannot always be relieved completely, therapy can lessen pain in most patients. Pain management improves the patient's quality of life throughout all stages of the disease.

Flexibility is important in managing cancer pain. As patients vary in diagnosis, stage of disease, responses to pain and treatments, and personal likes and dislikes, management of cancer pain must be individualized. Patients, their families, and their health care providers must work together closely to manage a patient's pain effectively.

For information about palliative care please see page 13 and page 15. For additional information about fatigue, pain, other complications and side effects, nutritional concerns, emotional concerns, and other treatment related issues please visit <http://www.cancer.gov/cancertopics/coping>.

## Remission, Relapse & Recurrence

**Remission** is a period of time when the cancer is responding to treatment or is under control. In a complete remission, all the signs and symptoms of disease disappear. It is also possible for an individual to have a par-

tial remission in which some, but not all, signs and symptoms of cancer have disappeared. Remission can last from several weeks to many years, and complete remissions may continue for years and be considered cures. If the cancer returns, another remission often can occur following additional treatment. A **relapse** is a return of signs and symptoms of cancer after a period of improvement. **Recurrent cancer** or **recurrence** is disease that has come back, usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body.

The risk of recurrence is different for each cancer survivor. It depends on many factors, including the type of cancer, the treatment received, and the length of time since last treatment. Many cancer survivors are concerned about the likelihood of recurrence. It is recommended that cancer survivors talk with their physicians about the possibility of recurrence in their specific situations. Each person's situation is unique, no matter what statistics may be provided during a time of consultation.

## End of Life Care

When it is determined that a cancer can no longer be controlled, medical testing and cancer treatment often stop. The patient's care continues but the focus shifts to making the patient comfortable. Medications and treatments to control pain and other symptoms, such as constipation, nausea, and shortness of breath are used. Some patients remain at home during this time, while others enter a hospital or other facility. Either way, services are available to help patients and their families with the medical, psychological, and spiritual issues surrounding dying.

The goal of hospice care<sup>1</sup> is achievement of the best quality of life for patients and their families, which:

- Affirms life and regards dying as a normal process.
- Neither hastens nor postpones death.
- Provides relief from pain and other distressing symptoms.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Can be provided from the point of diagnosis of a life-threatening, chronic or terminal illness—not just in the last days or weeks of a person's life.
- Is an approach to care that is foremost patient-centered and addresses patient needs within the context of family and community.
- Assists patients in establishing goals of care, clarifying priorities, promoting informed choices and providing an opportunity for negotiating a care plan with providers.
- Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patient and family.
- Uses a team approach to caring for a patient and his or her family with attention to the physical, spiritual, psychosocial and emotional aspects of living with a life threatening condition.
- Allows active treatment, such as chemotherapy, to continue.

Hospice care means taking care of the whole person—body, mind and spirit. By providing hope, comfort and support, a skilled palliative care team can help guide patients and families as they make the transition through the changing goals of care while ensuring the best quality of life possible<sup>2</sup>.

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<sup>1</sup> VNA in collaboration with the Vermont Ethics Network and Fletcher Allen Health Care offers several publications including a *Guide to Palliative Care Resources* available at : <http://www.vna-vermont.org/assets/files/mdii/Resource%20Guide.pdf>.

<sup>2</sup> The Vermont VNA End-of-Life Care services, through their educational program the Madison-Deane Initiative (MDI), advocates for the strengthening and coordination of quality end-of-life care and provides information about end-of-life care to Vermonters. For more information visit: <http://www.vna-vermont.org/services/end-of-life-care/madison-deane-initiative>.

# Survivorship Issues

*“It’s a journey.” — Vermont Cancer Survivor*

Survivors face many physical, psychological, social, and financial issues from the time of their diagnosis, throughout the course of their treatment, and oftentimes for the rest of their lives.

As difficult as a diagnosis of cancer is, many cancer survivors suggest that the experience was an important life changing experience. Appreciation and awareness of each new day, learning how to take better care of themselves, and appreciation for how others care for them are often mentioned by survivors as a result of their experiences. Citing a need to give back, many go on to become advocates for improved cancer research, treatment, and care.

Improving the quality of life of survivors is a priority in the **Vermont State Cancer Plan**<sup>3</sup>. Meeting the needs of cancer survivors is within the Vermont Department of Health’s (VDH) mission to continuously assess, vigorously pursue, and document measurable improvements to the health and safety of Vermont’s population. In collaboration with **Vermonters Taking Action Against Cancer (VTAAC)**<sup>4</sup>, VDH is committed to using sound epidemiology and cancer surveillance practices to guide planning, research, collaborative activities, and resource use. We continue to promote improvements in health among all Vermonters, specifically addressing disparities among sub-populations.

In 2006, VDH organized a focus group study<sup>5</sup> to identify the greatest needs of Vermonters living with cancer. Six focus groups were conducted throughout the state in order to identify variations in survivors’ experiences and needs by geographic region, urban/rural character, and availability of medical and support services. From these focus groups, several primary themes were identified:

**Support** for individuals with cancer as well as their caregivers plays a critical role, but the need is not well met in many parts of the state. Peer contact with other cancer survivors is highly valued and there is a need for peer support due to a lack of support groups in some parts of the state, or groups that are limited to the most common cancers.

**Information.** There is a profound and ongoing desire for information among survivors. Information needs change as individuals transition through different stages of survivorship. Information should be offered repeatedly and on an ongoing basis. Information and resources for less common cancers and for younger survivors is hard to find.

**Financial** costs incurred by survivors and their families were another important concern. Many survivors and spouses work through their illness and often beyond retirement age to retain health insurance. While most have health insurance of some kind, premium costs and out-of-pocket costs are a large burden. Many reported large amounts of debt and have to make treatment decisions based on financial and work-related issues.

*“I do feel the medical profession handles the physical parts of the disease very well. But there’s always all those other things.” — Vermont Cancer Survivor*

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<sup>3</sup> Vermont State Cancer Plan, 2006-2010: [http://healthvermont.gov/pubs/cancerpubs/state\\_cancer\\_plan.aspx](http://healthvermont.gov/pubs/cancerpubs/state_cancer_plan.aspx).

<sup>4</sup> A network of groups and individuals that speaks with one voice about reducing cancer risk, detecting cancers earlier, creating better access to quality cancer treatment, and improving the quality of life for cancer survivors. Visit <http://vtaac.org/> or call (802) 872-6303.

<sup>5</sup> *Cancer Survivor Focus Group Study*, August 2006: <http://healthvermont.gov/prevent/ccc/documents/CancerSurvivorFocusGroups.pdf>.

**Transition** from active treatment to follow-up care often presents emotional challenges as the end of treatment is often difficult and frightening. There is a pervasive lack of discharge planning for smooth transitions. Many survivors are unprepared for depression and anxiety at transition times.

**Psychosocial** issues include the emotional challenges that can accompany a serious illness as well as the life challenges that can prevent good healthcare and the patients' ability to take care of themselves. Survivors are generally satisfied with the quality of cancer-related care. Often there is a lack of clarity about who to consult regarding side effects, residual treatment effects, and potentially non-cancer related ailments, resulting in fragmented care and stressful transitions.

**Complementary and Alternative Medicine (CAM)** use is prevalent throughout the state. However, traditional medical practitioners have a variety of reactions to CAM including resigned tolerance, neutrality, and encouragement. There are many barriers to using CAM including cost and lack of reliable information on safety and efficacy.

**Decision Making.** Most survivors follow the advice and recommendations of their care providers for treatment decisions after initial diagnosis, and over time become more assertive with decision-making. Assistance with navigating service delivery systems is needed but rarely received.

Focus group participants identified demographic differences among Vermonters living with cancer. Survivors diagnosed as young adults have few resources available to them. Participants with less common cancers noted that the relative abundance of programs, support, and information for breast and prostate cancer is in sharp contrast with what was available to them. For example, female participants with other cancers were frustrated that they were not welcome in a breast cancer support group. Most pronounced differences were seen in parts of the state that are relatively isolated from urban centers and major medical centers. Barriers include lack of transportation to treatment and distance to treatment. Participants generally seemed satisfied with the quality of the care they received. To a great extent, those who had access to treatment "locally" (which could include facilities as much as an hour away), may have gone outside the area for second opinions or consults. However, they often chose to get their care close to home rather than traveling to a comprehensive cancer center. The most frequently cited reason for receiving care outside the local area was the unavailability of radiation therapy locally, which required traveling many hours on a daily basis.

## *Vermont State Cancer Plan*

**The Vermont State Cancer Plan** provides a strategic roadmap to reduce the impact of cancer on individuals, families, and communities in Vermont. The Plan identifies strategic priorities in the following areas:

- **Prevent future cancers** by reducing exposure to known risk factors.
- **Detect new cancers** as early as possible through appropriate screening.
- **Increase access** to high quality cancer treatment and follow-up care.
- **Improve the quality of life** of Vermonters who are living with, through and beyond any diagnosis of cancer.
- **Improve end-of-life care** for cancer patients through effective pain management and palliative care.

**Vermonters Taking Action Against Cancer (VTAAC)** is a statewide collaborative partnership of nearly 200 organizations, healthcare providers and individuals working together to reduce the burden of cancer among **all** Vermonters. VTAAC workgroups and affiliate organizations develop and implement specific strategies and activities to achieve the objectives of the Vermont State Cancer Plan. Activities and progress towards these objectives are routinely assessed and reported annually<sup>6</sup>.

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<sup>6</sup> Vermont Cancer Plan Status Report, 2007: <http://healthvermont.gov/prevent/cancer/documents/CancerProgressSheet100207.pdf>.

For more information about VTAAC, the State Cancer Plan or current activities and progress, visit: <http://healthvermont.gov/cancer>.

In 2007 activities associated with the *Vermont State Cancer Plan* focused on:

- **Clinical Trials Preparation:** The Centers for Disease Control and Prevention, along with national partners, have offered technical assistance in this area. VTAAC identified co-chairs for a workgroup, which was convened in March, and a statewide needs assessment based on a model used in New Hampshire is currently under review.
- **Insurance Coverage:** The American Cancer Society and several VTAAC partners worked on the development of the Catamount Health Plan, ensuring that cancer screening would be covered in the plan.
  - **Health Insurance:** 96.7 percent of Vermont cancer survivors have health insurance compared to 85.7 percent of the rest of the Vermont population (BRFSS 2007).
  - **Personal Doctor:** 95.8 percent of Vermont cancer survivors have a personal doctor compared to 88.3 percent of the rest of the Vermont population (BRFSS 2007).
- **Survivorship:** In addition to the American Cancer Society and other partners that promote and provide support services across Vermont, a new affiliate, the Vermont Cancer Survivor Network (VCSN), was incorporated as a tax-exempt organization. VCSN started a pilot of a peer-to-peer support program, “Kindred Connections,” which connects cancer patients with others who have had the same experiences. VCSN organized three National Cancer Survivor’s Day celebrations.
  - **Emotional Support:** 77.6 percent of Vermont cancer survivors report that they always or usually received the social and emotional support needed compared to 82.7 percent of the rest of the Vermont population (BRFSS 2007).
  - **Health Status:** 80.1 percent of Vermont cancer survivors report that their health is good to excellent, compared to 89.6 percent of the rest of the Vermont population (BRFSS 2007).
- **Pain Management, Hospice and Palliative Care Availability:** The American Cancer Society and several VTAAC partners continued working to implement policies in Vermont’s “Pain Report Card” grade of B+<sup>7</sup>. Vermont improved its grade to a B+ by advocating for changes in legislation, such as the drug abuse control policy, pharmacy and medical board guidelines, and the patients’ bill of rights. Vermont is working with local and national partners in a coordinated effort to educate patients and health care providers on the concept of palliative care (pain management) starting at the time of diagnosis and throughout one’s life with cancer.
- **Advanced Directives:** In 2006, the Vermont Department of Health launched a statewide electronic Advance Directives Registry. VTAAC and the Vermont Ethics Network are promoting use of this on-line service. As of December 2008, over 3,500 Vermonters have registered for this free service.

Many national, state and local organizations are working to implement the survivorship portion of the plan and there are numerous partnership listings in the resource section.

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<sup>7</sup> [http://www.cancer.org/docroot/COM/content/div\\_NE/COM\\_1\\_1x\\_Vermont\\_Pain\\_Initiative.asp](http://www.cancer.org/docroot/COM/content/div_NE/COM_1_1x_Vermont_Pain_Initiative.asp)

## Resources

This alphabetical listing is provided as a convenience and is not intended to be exhaustive. The Vermont Department of Health does not endorse any one resource over another. Many of the organizations listed may be able to offer guidance or suggestions for additional or more specific resources.

**Agency of Human Services, Department of Aging and & Disabilities:** Provides a listing of all Nursing Home, Assisted Living, and Residential Care Facilities. Visit <http://www.dail.vermont.gov/> or call (802) 241-2400.

**American Cancer Society:** is the nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. ACS offers many free support resources for cancer patients including: products for women, transportation to treatment, lodging during treatment, and support groups. To learn more visit: [www.cancer.org](http://www.cancer.org) or contact 1-800-ACS-2345 for assistance 24 hours a day, 365 days of the year.

**American Cancer Society Hope Lodge:** is located next to Fletcher Allen Health Care in Burlington and provides comfortable, homelike lodging for cancer patients and their families who must travel for cancer treatment. For more information visit [www.cancer.org/hopelodgeburlington](http://www.cancer.org/hopelodgeburlington) or call (802) 658-0649.

**Cancer Patient Support Services:** was created by a group of cancer survivors and others who have been touched by cancer. Based at Fletcher Allen Health Care, the program offers supportive and rehabilitative services to cancer patients and their families. For more information visit: <http://www.cpspvt.org/> or call 1-800-358-1144 x 4848.

**Catamount Health Plan and Green Mountain Care:** is a family of low-cost and free health coverage programs for Vermonters and is offered by the state of Vermont and its partners. Green Mountain Care provides uninsured Vermonters with access to quality, comprehensive health care coverage at a reasonable cost. For more information visit: <http://www.greenmountaincare.org/> or call 1-800-250-8427.

**Centers for Disease Control and Prevention (CDC)** is working with national, state, and local partners to create and implement successful strategies to help the millions of people in the United States who live with, through, and beyond cancer. For more information about CDC's cancer related activities visit <http://www.cdc.gov/cancer/> or for more information about what CDC is doing about cancer survivorship, visit: [http://www.cdc.gov/cancer/survivorship/what\\_cdc\\_is\\_doing](http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing).

**Champlain Valley Agency on Aging:** Provides information, referral, and advocacy services for people 60 and older and younger adults with disabilities in Northwestern Vermont. The agency provides assistance and support with a variety of health and social service needs and can assist with advance care planning. To learn more visit: <http://www.cvaa.org> or call (802) 865-0360.

**Frymoyer Community Health Resource Center:** is available for help in finding health information and local resources. Located at Fletcher Allen Health Care, individuals can stop by to visit or contact them by phone or e-mail. Computers are available to search the internet as well as a large collection of books and magazines. Visit: [www.fahc.org/Health\\_Improvement/Resource\\_Center/resource\\_center.asp](http://www.fahc.org/Health_Improvement/Resource_Center/resource_center.asp) or call 802-847-8821.

**Forest Moon:** works to improve the quality of life for cancer survivors and their families and friends in New England. Interactive programs in home-like settings introduce therapeutic activities and foster group learning and revelation. For more information visit: <http://www.forestmoon.org/> or call (802) 380-4238.

**Hospice and Palliative Care Council of Vermont:** is committed to assuring access to high quality palliative and end-of-life care including caregiver support and bereavement services for all Vermonters. For more information visit: <http://www.hpccv.org> or call (802) 229-0579.

**Lance Armstrong Foundation:** in partnership with the CDC, and along with other experts in cancer survivorship and public health has developed A National Action Plan for Cancer Survivorship. Through the LIVESTRONG program, the Foundation offers support, information and advocacy for all cancer survivors. For more information visit: [www.livestrong.org](http://www.livestrong.org) or call 866-235-7205.

**The Leukemia and Lymphoma Society (LLS):** is a national organization that provides services through a regional office to Vermonters living with blood cancers. The Society provides toll-free and on-line information, area support groups, educational programs and financial assistance. For more information visit [www.lls.org](http://www.lls.org) or call 1-800-955-4572.

**National Center for Complementary and Alternative Resources (NCCAM):** is the Federal Government's lead agency for scientific research on complementary and alternative medicine (CAM). NCCAM sponsors and conducts research using scientific methods and advanced technologies to study medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. For more information visit: <http://nccam.nih.gov> or <http://www.nih.gov> or call 1-888-664-6226.

**National Cancer Institute (NCI):** provides toll-free and on-line support for cancer survivors. Their “Thinking Forward” series of booklets addresses issues faced by survivors and caregivers. For more information visit: [www.cancer.gov](http://www.cancer.gov) or call 1-800-4CANCER.

**The National Family Caregivers Association:** educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. For more information visit <http://www.thefamilycaregiver.org>.

**Vermont Advanced Directives Registry (VADR):** is free to Vermonters and is an electronic database that stores advance directive documents and makes them accessible to hospitals or other medical service providers. An advance directive is what many people think of as a “living will,” or a “durable power of attorney for healthcare.” To learn more visit: <http://healthvermont.gov/vadr/index.aspx> or call (802) 951-1222.

**Vermont Blueprint for Health, Healthier Living Workshops:** provides tools to Vermonters for: dealing with frustration, fatigue, pain; improving strength, flexibility and endurance; managing medications; improving communication with family, friends, and health providers; and healthier eating. For more information visit: <http://healthvermont.gov/prevent/blueprint/selfmanage.aspx> or call (802) 652-2096.

**Vermont Cancer Center:** offers information on cancer patient services as well as clinical trials. For more information visit: <http://www.vermontcancer.org/> or call 1-877-540-HOPE.

**Vermont Cancer Registry:** is Vermont's statewide population-based cancer surveillance system. The registry collects information about all cancers (except non-melanoma skin cancers and carcinoma in situ of the cervix) and all benign brain tumors diagnosed in Vermont. VCR is part of a statewide effort to reduce the impact of cancer on individuals, families and communities in Vermont. For more information call (802) 865-7749 or e-mail [VTCancerRegistry@vdh.state.vt.us](mailto:VTCancerRegistry@vdh.state.vt.us).

**Vermont Cancer Survivor Network:** was created by and for cancer survivors. The Network hosts celebratory events, provides educational activities for cancer survivors, their families and caregivers, and is creating a peer-to-peer support network called *Kindred Connections*. For more information visit: [www.vcsn.net/](http://www.vcsn.net/) or call 1-800-652-5064.

**Vermont Department of Health Comprehensive Cancer Control Program:** The VDH Comprehensive Cancer Control program works with Vermonters Taking Action Against Cancer (VTAAC) to reduce the incidence, suffering and death related to the leading cancers among Vermonters. The program coordinator can be reached at: (802) 865-7706.

**Vermonters Taking Action Against Cancer (VTAAC):** is a statewide partnership of cancer survivors, advocates, public health and health care professionals working together to reduce the impact of cancer on all Vermonters. To find out more visit: <http://vtaac.org/> or call (802) 872-6303.

**Visiting Nurses Association (VNA) of Chittenden and Grand Isle Counties:** provides home care for cancer patients in Northwestern Vermont, as well as palliative and respite care along with educational resources at <http://www.vna-vermont.org/> or (802) 860-4410.

**VNA Health Systems of Vermont:** is a network of Vermont's 11 not-for-profit home health agencies and Visiting Nurse Associations. The primary functions of the VNAHS are to develop, implement, and monitor statewide standards of care, measure and monitor quality improvement efforts, and serve as a contracting entity for the member agencies. For more information visit <http://vnavt.com> or call (802) 229-0579. To contact the agency that serves your town, dial 1-800-HOMECARE (1-800-466-3227).

# Cancer Type Descriptions

This list of common cancer types includes cancers that are diagnosed with the greatest frequency in Vermont and the United States.

**Table 1. Common cancer types.**

Cancer Type	Description
Bladder	Cancer that forms in tissues of the bladder (the organ that stores urine).
Brain/Nervous System	The growth of abnormal cells in the tissues of the brain. Brain tumors can be benign (non-cancerous) or malignant (cancerous).
Breast	Cancer that forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). It occurs in both men and women, although male breast cancer is rare.
Cervix	Cancer that forms in tissues of the cervix (the organ connecting the uterus and vagina). It is usually a slow-growing cancer that may not have symptoms but can be found with regular Pap tests.
Colon and Rectum	Cancer that forms in the tissues of the colon (the longest part of the large intestine) or the rectum (the last several inches of the large intestine closest to the anus).
Esophagus	Cancer that forms in tissues lining the esophagus (the muscular tube through which food passes from the throat to the stomach).
Kidney (Renal Cell)	Cancer that forms in the lining of very small tubes in the kidney that filter the blood and remove waste products.
Larynx	Cancer that forms in cells in the lining of the throat. The larynx is an organ at the front of your neck. It is also called the voice box.
Leukemia	Cancer that starts in blood-forming tissue such as the bone marrow and causes large numbers of blood cells to be produced and enter the bloodstream.
Liver	Cancer that forms in the tissues of the liver.
Lung	Cancer that forms in tissues of the lung, usually in the cells lining air passages.
Lymphoma (Hodgkin and Non-Hodgkin)	Any of a large group of cancers of the immune system. Lymphomas are generally categorized as either Hodgkin or non-Hodgkin lymphoma; the primary difference between the two is in the specific lymphocyte involved. Hodgkin and non-Hodgkin lymphomas are differentiated by examining the cancer cells under a microscope. If a specific type of abnormal cell is detected (called a Reed-Sternberg cell), the lymphoma is classified as Hodgkin lymphoma.
Melanoma of the Skin	A form of cancer that begins in melanocytes (cells that make the pigment melanin).
Myeloma	A type of cancer that begins in plasma cells (white blood cells that produce antibodies).
Oral Cavity/Throat	Cancer that forms in tissues of the lip or mouth. This includes the front two thirds of the tongue, the upper and lower gums, the lining inside the cheeks and lips, the bottom of the mouth under the tongue, the bony top of the mouth, and the small area behind the wisdom teeth.
Pancreas	A disease in which malignant (cancer) cells are found in the tissues of the pancreas.
Prostate	Cancer that forms in tissues of the prostate (a gland in the male reproductive system found below the bladder and in front of the rectum).
Stomach	Cancer that forms in tissues lining the stomach. Also called gastric cancer.
Testis	Cancer that forms in tissues of the testis (one of two egg-shaped glands inside the scrotum that make sperm and male hormones).
Thyroid	Cancer that forms in the thyroid gland (an organ at the base of the throat that makes hormones that help control heart rate, blood pressure, body temperature, and weight).
Uterus (Endometrial)	Cancer that forms in the tissue lining the uterus (the small, hollow, pear-shaped organ in a woman's pelvis in which a baby grows).

# Incidence

**Table 2. Incidence rates per 100,000 and average number of cases per year of most commonly diagnosed cancers in males and females, all ages – Vermont and United States, 2000-2004.**

Male		Female		VT Cases (per year)		VT Cases (per year)	
Cancer Site	U.S. Rate	VT Rate	Cancer Site	U.S. Rate	VT Rate	VT Rate	VT Cases (per year)
All Sites Combined	569.5	582.7	All Sites Combined	433.4	432.6	432.6	1,535
<b>Prostate</b>	170.3	167.9	<b>Breast (female)</b>	136.5	134.2	134.2	475
<b>Lung and Bronchus</b>	78.2	86.1	<b>Lung and Bronchus</b>	53.3	50.7	50.7	179
<b>Colon and Rectum</b>	59.6	61.5	<b>Colon and Rectum</b>	44.0	44.7	44.7	164
<b>Bladder</b>	40.9	43.3	<b>Uterus</b>	25.7	31.0	31.0	110
<b>Melanoma of the Skin</b>	28.1	32.5	<b>Melanoma of the Skin</b>	19.5	25.2	25.2	84
Non-Hodgkin Lymphoma	25.3	22.7	Non-Hodgkin Lymphoma	17.4	16.0	16.0	58
Leukemia	17.4	18.6	Bladder	10.3	12.5	12.5	47
Kidney	17.9	17.5	Ovary	14.3	11.7	11.7	42
Oral Cavity/Throat	15.7	15.5	Thyroid	13.8	11.5	11.5	38
Pancreas	12.9	12.2	Kidney	9.1	10.0	10.0	35
Stomach	9.6	8.9	Leukemia	10.3	9.7	9.7	34
Brain/Nervous System	8.6	8.8	Pancreas	9.8	8.5	8.5	31
Esophagus	8.3	8.6	Cervix	7.0	8.1	8.1	27
Larynx	6.2	7.5	Oral Cavity/Throat	6.4	5.2	5.2	19
Testis	6.7	7.4	Brain/Nervous System	6.1	4.8	4.8	16
Liver	7.1	6.2	Myeloma	4.2	3.5	3.5	13
Myeloma	6.9	6.1	Stomach	4.3	3.4	3.4	13
Thyroid	4.9	4.1	Hodgkin Lymphoma	2.7	3.1	3.1	10
Hodgkin Lymphoma	3.3	3.9	Esophagus	2.0	2.5	2.5	9
			Larynx	1.3	2.3	2.3	8
			Liver	2.6	1.7	1.7	6

✗ Higher than the U.S. SEER white rate.

★ Lower than the U.S. SEER white rate.

New cases per year exclude basal cell and squamous cell skin cancers and in situ (malignant but non-invasive) carcinomas except urinary bladder.

## Childhood Cancer Incidence

**Table 3. Incidence rates per 100,000 and average number of cases per year of most commonly diagnosed cancers, ages 0 to 19 – Vermont and United States, 2000-2004.**

<b>Male and Female Cancer Site</b>	<b>U.S. Rate</b>	<b>VT Rate</b>	<b>VT Cases (per year)</b>
All Sites Combined	18.0	19.3	32
Leukemia	4.5	6.5 <i>X</i>	10
Brain and Other Nervous System	3.3	2.1	3
Hodgkin Lymphoma	1.2	1.5	3
Non-Hodgkin Lymphoma	1.2	1.6	3
Melanoma of the Skin	0.8	0.9	2

*X* Higher than the U.S. SEER white rate.

★ Lower than the U.S. SEER white rate.

*New cases per year exclude basal cell and squamous cell skin cancers and in situ (malignant but non-invasive) carcinomas except urinary bladder.*

# Mortality

Table 4. Mortality rates per 100,000 and average number of deaths per year of most commonly diagnosed cancers in males and females, all ages – Vermont and United States, 2000-2004.

Male		Female		VT Deaths (per year)	
Cancer Site	U.S. Rate	VT Rate	Cancer Site	U.S. Rate	VT Rate
All Sites Combined	234.7	235.7	All Sites Combined	161.4	161.4
Lung and Bronchus	72.6	68.3	Lung and Bronchus	42.1	39.3
Prostate	25.6	29.4 $\chi$	Breast (female)	25.0	26.1
Colon and Rectum	22.9	23.5	Colon and Rectum	15.9	17.7
Non-Hodgkin Lymphoma	9.9	11.3	Ovary	9.2	8.5
Pancreas	12.0	11.2	Pancreas	9.0	8.1
Leukemia	10.3	10.1	Non-Hodgkin Lymphoma	6.4	6.3
Bladder	7.9	8.7	Leukemia	5.8	6.1
Esophagus	7.7	8.0	Uterus	3.9	5.8 $\chi$
Liver	6.5	6.1	Bladder	2.3	3.0
Kidney	6.2	6.1	Brain/Nervous System	3.9	3.0
Brain/Nervous System	5.8	5.9	Cervix	2.3	2.6
Melanoma of the Skin	4.3	4.9	Kidney	2.8	2.6
Stomach	5.2	4.5	Myeloma	2.8	2.4
Myeloma	4.4	4.1	Stomach	2.6	2.4
Oral Cavity and Pharynx	3.8	3.6	Esophagus	1.7	2.3
Larynx	2.2	1.9	Liver	2.8	1.8 $\star$
Thyroid	0.5	n/a	Melanoma of the Skin	2.0	1.6
Hodgkin Lymphoma	0.6	n/a	Oral Cavity and Pharynx	1.5	n/a
Testis	0.3	n/a	Larynx	0.5	n/a
			Hodgkin Lymphoma	0.4	n/a
			Thyroid	0.5	n/a
					<1

$\chi$  Higher than the U.S. SEER white rate.

$\star$  Lower than the U.S. SEER white rate.

## Data Sources

**Vermont Cancer Registry:** The Vermont Cancer Registry is a central bank of information on all cancer cases diagnosed or treated in Vermont since January 1, 1994. The registry enables the state to collect information on new cases (incidence) of cancer. Previously, the state only kept records on deaths from cancer. The information maintained by the registry allows the Health Department to study cancer trends and improve cancer education and prevention efforts. Vermont Department of Health Cancer Registry, 1995-2004. The Vermont Cancer Registry can be contacted at 802-865-7749 ([http://healthvermont.gov/research/cancer\\_registry/registry.aspx](http://healthvermont.gov/research/cancer_registry/registry.aspx)).

**Vermont Vital Statistics:** In Vermont, towns are required to file certified copies of death certificates with the Department of Health for all deaths occurring in their jurisdictions. The Health Department is responsible for maintaining the vital statistics system. Vermont Department of Health Vital Statistics System, 1995-2004 ([http://healthvermont.gov/research/stats/vital\\_stats.aspx](http://healthvermont.gov/research/stats/vital_stats.aspx)).

**Behavioral Risk Factor Surveillance System:** Since 1990, Vermont and 49 other states and three territories track risk behaviors using a telephone survey of adults called the Behavioral Risk Factor Survey. Suggested Citation: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2007.

**Surveillance, Epidemiology, and End Results:** The National Cancer Institute funds a network of Surveillance, Epidemiology and End Results (SEER) registries. The SEER Program currently collects and publishes cancer incidence and survival data from 14 population-based cancer registries and three supplemental registries covering approximately 26 percent of the U.S. population. These rates are used to estimate the U.S. cancer incidence rates. U.S. incidence is based on the SEER 9 Registries white rates. Suggested Citation: Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Mariotto A, Feuer EJ, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, 2007 ([http://www.seer.cancer.gov/csr/1975\\_2004](http://www.seer.cancer.gov/csr/1975_2004)).

**U.S. Vital Statistics:** The U.S. Public Use Database Vital Statistical System maintains the U.S. mortality

rates. Rates represented in this report are for the U.S. white population. Suggested Citation: Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)) SEER\*Stat Database: Mortality - All COD, Public-Use With State, Total U.S. (1969-2004), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2007. Underlying mortality data provided by NCHS ([www.cdc.gov/nchs](http://www.cdc.gov/nchs)).

## Data Sources for Figures and Tables:

- Figure 1.** Vermont Cancer Registry
- Figure 2.** Vermont Vital Statistics
- Figure 3.** Vermont Behavioral Risk Factor Surveillance System
- Figure 4.** National Cancer Institute
- Figure 5.** Vermont Behavioral Risk Factor Surveillance System  
Surveillance, Epidemiology, and End Results
- Figure 6.** Vermont Cancer Registry
- Figure 7.** Vermont Cancer Registry
- Table 1.** National Cancer Institute
- Table 2.** Vermont Cancer Registry  
Surveillance, Epidemiology, and End Results
- Table 3.** Vermont Cancer Registry  
Surveillance, Epidemiology, and End Results
- Table 4.** Vermont Vital Statistics  
U.S. Vital Statistics

## Technical Notes and Definitions

**Age Adjustment:** All rates in this document are age-adjusted to the 2000 U.S. standard population. This allows the comparison of rates among populations having different age distributions by standardizing the age-specific rates in each population to one standard population.

**Incidence:** Incidence refers to the number or rate of newly diagnosed cases of cancer. The incidence rate is calculated as the number of new cancer cases diagnosed in the state during one year divided by the number of residents in the state during the same year. The incidence data presented in this report were coded using the International Classification of Disease for Oncology (ICD-O) coding system. Incidence site groupings are based on ICD-O-3 (<http://seer.cancer.gov/siterecode/>).

**Mortality:** Mortality refers to the number or rate of deaths from cancer. The mortality data presented here were coded using the International Classification of Diseases (ICD). Cause of death was coded according to ICD-10. Cause of death before 1999 was coded according to ICD-9. Comparability ratios were applied to pre-1999 mortality rates to allow for continuity in trends across the ICD revisions.

**Race:** U.S. incidence and mortality rates for whites, rather than those for all races, are used for comparison because racial minority groups were estimated to make up 3.1 percent of the total Vermont population, compared with the total U.S. non-white population of 19.6 percent in 2004. Nationwide, whites have a higher risk compared to people of other races for female breast, melanoma, and bladder cancer incidence. Whites have a lower risk compared to other races for prostate, colorectal, and cervical cancer. The much smaller populations of Vermont residents of other races may have very different risks of these

cancers. Combining data over many years will be required to determine cancer rates.

**Federal Poverty Level (FPL):** The set minimum amount of income that a family needs for food, clothing, transportation, shelter and other necessities. In the United States, this level is determined by the Department of Health and Human Services. FPL varies according to family size. The number is adjusted for inflation and reported annually in the form of poverty guidelines. Public assistance programs, such as Medicaid in the U.S., define eligibility income limits as some percentage of FPL.

**Statistical Significance:** The use of the terms “higher” and “lower” in this document refer to a “statistically significant” difference. A statistically significant difference indicates that there is statistical evidence that there is a difference that is unlikely to have occurred by chance alone.

**Small Numbers:** Rates are not presented in this report if they are based on fewer than 6 cases.

### Suggested Citation

Vermont Department of Health, *Living with Cancer in Vermont*, 2009.

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