



WHAT IS A SURVIVOR?

Due to advances in treatment and earlier screenings, more and more people are living after a cancer diagnosis. The American Cancer Society (ACS) defines a cancer survivor as any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life. Survivorship, like cancer itself, is complex and can be difficult to navigate.

There are three phases of cancer survival — the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long term survival.¹ More often than not, the terms “survivor” and “survivorship” are associated with the transitional period after treatment ends. However, survivorship includes a wide range of cancer experiences and paths², 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; and
- Living with cancer continuously without a disease-free period.

The preferred path for most cancer patients is to receive treatment and be “cured”. This is the primary goal of all cancer treatment when possible. For many cancer patients, the initial course of treatment is successful and the cancer does not return.

Many of survivors must still cope with the mid- and long-term effects of treatment, as well as any psychological effects — such as fear of returning disease.² It is important that cancer patients, caregivers, and survivors have the information and support needed to help minimize these effects and improve quality of life and treatment.

Survivorship by the Numbers

An estimated 13.7 million Americans with a history of cancer were alive on January 1, 2012, according to the ACS. This estimate does not include carcinoma in situ (non-invasive cancer) of any site, except urinary bladder, and does not include basal and squamous cell carcinomas. If current estimates continue, by January 1, 2022, the population of cancer survivors will increase to almost 18 million nationwide.

According to the Indiana State Cancer Registry, as of December 31, 2012, there were an estimated 286,973 cancer survivors for all cancers combined [Table 17]. The four highest-burden cancers for the state (lung, breast, colorectal and prostate) account for approximately 56 percent of these survivors [Table 18].

Table 17. Indiana Cancer Survivor Counts*

Cancer Type	Counts
Female Breast	63,051
Cervical	4,190
Colorectal	30,491
Lung	16,812
Melanoma	14,950
Prostate	47,482
All Types	286,973

* Survivors (anyone treated for an invasive cancer, and still living) as of December 31, 2012

Source: Indiana State Cancer Registry

Table 18. Percent of Survivors from Four Highest-Burden Cancers*

Cancer Type	Survivorship (Counts)	Survivorship (Percentage)
Female Breast	63,051	22%
Colorectal	30,491	11%
Lung	16,812	6%
Prostate	47,482	17%

* Survivors (anyone treated for an invasive cancer, and still living) as of December 31, 2012.

Source: Indiana State Cancer Registry

Female Breast

Breast cancer is the second leading cause of cancer death, and, excluding skin cancers, the most frequently diagnosed cancer among Indiana females, with about 4,400 cases diagnosed each year. Sex and age are the two greatest risk factors for developing breast cancer. Females have a much greater risk of developing breast cancer than do males, and that risk increases with age. [See the breast cancer section of this report for more information.]

The overall five-year relative survival rate for female breast cancer patients has improved from 75 percent between 1975 and 1977 to 91 percent during 2004 through 2010.² For the most part, this is attributed to improvements in treatment and increased use of mammography screening.³

According to the ACS, the five-year relative survival rate varies depending on the cancer stage. When breast cancer is detected early, in the local stage, the five-year survival rate is 99 percent. If the cancer has spread regionally (e.g., to a nearby lymph node), that rate decreases to 84 percent. In instances where the breast cancer has spread to distant lymph nodes or organs (the distant stage), the five-year survival rate decreases to 23 percent. Other factors, such as tumor grade, hormone

receptor status, and increased human epidermal growth factor receptor 2 (HER2) protein made by the cancer cells, can influence survival rates.

A common side effect of breast cancer surgery and radiation therapy is lymphedema of the arm. Lymphedema is a buildup of lymph fluid in the tissue under the skin caused by the removal or damage of the lymph nodes under the arm (called the axillary lymph nodes). It can develop soon after treatment, or even several years later. Lymphedema risk can be reduced when only the first lymph nodes to which cancer is likely spread are removed, rather than removing many lymph nodes to determine whether or not the cancer has spread. For patients with lymphedema, there are a number of effective therapies that can be used. Some evidence also suggests that upper-body exercise and physical therapy may reduce the severity and risk of developing this condition.⁴

Other long-term local effects of surgery or 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 a younger age may experience impaired fertility and premature menopause, and are at increased risk of osteoporosis. Aromatase inhibitor treatment can cause muscle pain, joint stiffness and/or pain, and sometimes osteoporosis.

Colorectal Cancer

Colorectal cancer is the third most commonly diagnosed cancer and cause of cancer-related death among both males and females in Indiana. In 2014, the ACS estimated that 3,020 Indiana adults would be diagnosed with colorectal cancer, and 1,090 would die because of the disease. The lifetime risk of developing colorectal cancer is about five percent for both males and females in the United States. Sex and age are the two greatest risk factors. In addition, the *The Health Consequences of Smoking — 50 Years of Progress: A Report of the Surgeon General* indicates that smoking causes colorectal cancer and increases the failure rate of treatment for all cancers. In Indiana, African Americans have higher colorectal cancer incidence and mortality rates than whites, and males have higher rates than females. [See the colorectal cancer section of this report for more information.]

The ACS reports that the one- and five-year survival rates for colorectal cancer are 83 percent and 65 percent, respectively. The ten-year survival rate decreases to 58 percent. When colorectal cancer is detected early (in the local stage), the five-year survival rate is 90 percent.² When the cancer has spread regionally, the five-year survival rate decreases to 70 percent. The five-year survival rate decreases to only 13 percent when colorectal cancer spreads distantly.

While most long-term survivors report a high quality of life, some are troubled by bowel dysfunction and other

health-related issues. For those with a permanent colostomy (a surgical procedure that brings one end of the large intestine out through the abdominal wall), some issues such as problems around intimacy and sexuality, embarrassment, social inhibition, and body-image disturbances may occur.

According to the ACS, as many as 40 percent of patients treated for localized colorectal cancer, and colorectal cancer that has spread to nearby organs, are also at increased risk of second primary cancers of the colon and rectum.

Lung Cancer

Lung cancer is not a single disease; rather, it is a group of cancers that originate in the lung and associated tissues. Lung cancer is the leading cause of preventable and premature cancer deaths in Indiana, killing an estimated 4,000 Indiana residents every year. Smoking accounts for 87 percent of lung cancer deaths and at least 30 percent of all cancer deaths. However, in Indiana, about 22 percent of adults continue to smoke tobacco, placing them at great risk for developing lung and other types of cancer.⁵ [See the lung cancer section of this report for more information.]

The ACS reports that the one-year relative survival rate for all lung cancers combined increased from 37 percent during 1975-1979 to 45 percent during 2006-2009, largely due to improvements in surgical techniques and combined therapies. The five-year survival rate is highest (54 percent) if the lung cancer is diagnosed when it is confined entirely within the lung (localized). The overall five-year survival rate for small cell lung cancer is six percent, which is lower than that for non-small cell lung cancer (18 percent).

Lung cancer survivors often have impaired lung function, especially if surgery is part of treatment. Respiratory therapy and medications can improve the ability to resume to normal daily activities and improve fitness. Lung cancer survivors who continue to smoke should be encouraged to quit. Survivors of smoking-related cancers are at an increased risk for additional smoking-related cancers, especially in the head, neck and urinary tract. Some survivors may feel stigmatized because of the connection between smoking and lung cancer. This is especially difficult for lung cancer survivors who never smoked.

Prostate Cancer

Prostate cancer is an uncontrolled growth and spread of cells in the prostate, an exocrine gland in the male reproductive system. Excluding all types of skin cancer, prostate cancer is the most commonly diagnosed cancer and the second leading cause of cancer death among Indiana males. There were approximately 2,844 new cases of prostate cancer diagnosed in Indiana during 2012, and there were 606 deaths due to prostate cancer during that same year. The ACS estimates that there were nearly three million males with a history of prostate

cancer living in the US as of January 1, 2014. Older males, African American males, and males with a family history of prostate cancer have a higher risk of being diagnosed. [See the prostate cancer section of this report for more information.]

The five-year survival rate of prostate cancer is almost 100 percent when discovered in the local or regional stages. The ACS reports that the five-year survival rate for all stages combined has increased over the past 25 years from 68 percent to almost 100 percent. According to the most recent data, the 10- and 15-year survival rates are 99 percent and 94 percent, respectively.

Many prostate cancer survivors who have been treated with surgery or radiation therapy experience side effects from treatment. These include incontinence, erectile dysfunction and bowel complications. Patients who received hormonal treatment may experience symptoms similar to menopause in women such as loss of libido, hot flashes, night sweats, irritability, and osteoporosis. In the long term, hormone therapy also increases risk of diabetes, cardiovascular disease, and obesity.⁶

Resources

The National Cancer Survivorship Resource Center is a collaboration between the ACS and the George Washington Cancer Institute, funded by the CDC. Its goal is to shape the future of post-treatment cancer survivorship care, and to improve the quality of life for cancer survivors. Staff and more than 100 volunteer survivorship experts nationwide developed tools for cancer survivors, caregivers, health care professionals, and policy and advocacy efforts. For more information, visit www.cancer.org/survivorshipcenter.

The National Coalition for Cancer Survivorship offers free publications and resources that empower people to become strong advocates for their own care or the care of others. The coalition's Cancer Survival Toolbox is 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. For more information, visit www.canceradvocacy.org.

The Patient Advocate Foundation 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. The foundation serves as an active liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and debt crisis matters relative to their diagnosis through professional cancer managers, doctors and health care attorneys. For more information, visit www.patientadvocate.org.

Visit the Indiana Cancer Consortium website at IndianaCancer.org to learn more about local resources in your area.

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