

Division of Chronic Disease, Primary Care,
and Rural Health



Cancer Survivorship



Indiana
Department
of
Health



Bottom Line

Due to advances in treatment, changes in screening recommendations, and the growing aging population, 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 remainder of their life.¹ 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.² 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 paths, including:¹

- 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 preferred path for most cancer patients is to receive treatment and be “cured”. This is the primary goal of all cancer treatment when possible. Additionally, the goals of treatment include prolonging survival and providing the highest possible quality of life during and after treatment. Many survivors must still cope with the mid-and long-term effects of treatment, as well as any psychological effects – such as fear of disease recurrence.¹ 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 18.1 million Americans with a history of cancer were alive as of January 2022, 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 Jan. 1, 2030, the population of cancer survivors will increase to almost 22.1 million nationwide according to the Indiana State Cancer Registry, which began collecting cancer cases on Jan. 1, 1987. As of Dec. 31, 2020, there were an estimated 394,096 cancer survivors for all cancers combined [Table 18]. The four highest-burden cancers for the state (lung, breast, colorectal and prostate) account for 49 percent of these survivors. Improvement in survival is a result of the combination of earlier diagnosis and advances in treatments.¹



TABLE 18 . INDIANA CANCER SURVIVOR COUNTS-2020

Table 18. Indiana Cancer Survivor Counts*	
Cancer Type	Counts
Female Breast	92,873
Cervical	16,645
Colorectal	31,441
Lung	14,589
Melanoma	33,715
Prostate	53,085
All Types	394,096

Female Breast

Breast cancer is the second leading cause of cancer death, and, excluding skin cancers, the most frequently diagnosed cancer among female Hoosiers, with about 4,915 cases diagnosed each year, according to the Indiana State Cancer Registry.³ Sex and age are the two greatest risk factors for developing breast cancer. Women have a much greater risk of developing breast cancer than males, and that risk increases with age. [See the breast cancer section of this report for more information.]

Nationally, the overall five-year relative survival rate for female breast cancer patients is 90 percent.¹ For the most part, this is attributed to improvements in treatment and increased use of mammography screening.⁴

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 approaches 100 percent. For women diagnosed with stage IV breast cancer survival declines to 28 percent.¹ 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. Black women remain less likely to be diagnosed at earlier stages and have lower survival within each stage, with the largest disparity for stage III disease (77 percent in whites versus 65 percent in Blacks).¹

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. Twenty percent of women who undergo axillary lymph node dissection and about 6 percent of women who undergo sentinel lymph node biopsy will develop arm lymphedema.⁵ 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.⁶

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.¹

Colorectal Cancer

Colorectal cancer is the third-most commonly diagnosed cancer among both males and females in Indiana, as well as the United States overall. It is the second leading cause of cancer-related death among males, and the third leading cause of cancer-related death among females in Indiana.

In 2024, the ACS estimates that 3,390 Hoosiers would be diagnosed with colorectal cancer, and 1,190 would die as a result of the disease.⁷ The lifetime risk of developing colorectal cancer is about five percent for both men and women in the United States.⁸

Sex and age are the two greatest risk factors. In addition, 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, Blacks have higher colorectal cancer incidence and mortality rates than Whites, and men have higher rates than women. [See the colorectal cancer section of this report for more information.]

The ACS reports that the five-year survival rate is 91 percent for colorectal cancer and 85 percent for stage II cancer. However, only 20 percent and 22 percent of patients are diagnosed at these stages. Survival declines to 68 percent for stage III and 12 percent for stage IV disease.¹

While most long-term survivors report a high quality of life, but higher rates of depression.⁹ Some survivors 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.¹

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 and the U.S., killing an estimated 3,846 Indiana residents every year.³ Smoking accounts for 80 to 90 percent of all lung cancer deaths.¹ However, in Indiana, 19.4 percent of adults reported the use of cigarettes, placing them at greater risk for developing lung and other types of cancer.¹⁰ The five-year relative survival rate for lung cancer is 25 percent.¹ Because symptoms usually do not appear until the disease has spread to other parts of the body, only about 1 in 5 lung cancer patients are diagnosed with stage I disease, for which 5-year survival is 57 percent.¹ [See the lung cancer section of this report for more information.]

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 normal daily activities and improve fitness. Lung cancer survivors who continue to smoke should be encouraged to quit. The utilization of low-dose computed tomography (CT) scans in screening high-risk patient populations has been shown to be effective in decreasing mortality from lung cancer. Individuals at high risk are defined as those aged 50 to 80 who have a 20-pack-per-year tobacco smoking history, those who currently smoke or have quit smoking in the last 15 years, and those who currently smoke.¹¹ 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 can be especially difficult for lung cancer survivors who never smoked.¹

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 third leading cause of cancer deaths among Hoosier men. There were 394,096 survivors in Indiana as of 2020 [table 18].³ The ACS estimates there will be about 299,010 new cases of prostate cancer diagnosed in the United States in 2024.¹ Older men, Black men, and men 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. According to the most recent data, the 10- and 15-year survival rates are 98 percent and 95 percent, respectively.¹



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. One of the long-term side effects of hormone therapy is the increased risk of developing diabetes, cardiovascular disease, and/or obesity.^{12,13}

Life After Treatment

As the population of cancer survivors in the U.S. grows, it will become increasingly essential to optimize healthcare delivery and long-term outcomes among survivors and their caregivers.¹ Transitioning into post-treatment or the survivorship phase of care can be one of the hardest times for cancer patients. Patients often have anxiety related to cancer recurrences after their treatment is over. There are often physical and psychosocial challenges patients experience as they transition into the survivorship phase of care. Up to one-half of cancer patients show a significant level of distress.¹⁴ At the same time, patients are managing ongoing cancer symptoms and side effects from treatment that can last months to years after the completion of treatment.¹⁵ According to the 2020 Indiana Behavioral Risk Factor Surveillance System (IN-BRFSS), 45.4 percent of cancer survivors had ever received a written summary of all the cancer treatments from any doctor, nurse, or other health professional.¹⁰

Quality of life is a broad multidimensional concept that considers a person's physical, emotional, social, and spiritual well-being.¹ Approximately 1 in 4 cancer survivors report a decreased quality of life due to physical problems and 1 in 10 due to emotional problems. Quality of life not only includes physical well-being, but social and spiritual well-being as well.¹⁶ According to the IN-BRFSS, 78.7 percent of cancer survivors reported having the same or fewer poor mental health days over the past 30 days as people without cancer in 2022. Additionally, 64.5 percent of survivors reported having the same or fewer poor physical health days over the past 30 days as people without cancer.¹⁰

Survivorship care plans have been implemented by numerous organizations such as the American Cancer Society, the CDC, the American Society of Clinical Oncology, and other national and local healthcare and cancer organizations. These plans can be utilized to assist patients with what to expect over the next five years after they complete primary treatment. The plans are patient-specific and include information such as:

- Personal information
- The medical care team
- Information on the patient's specific cancer diagnosis
- Surgical history
- Radiation therapy history



- Chemotherapy/biotherapy/hormone therapy history
- Information on clinical trials
- Family history of cancer
- After-treatment care
- Potential late and long-term side effects of their treatment
- Follow-up tests and appointments
- Recommendations for healthy living

How Can Cancer Survivors Stay Healthy After Treatment?

Approximately a third of cancer survivors feel inadequately informed about the adverse effects from their treatment.¹⁷ Pretreatment counseling with your provider helps to improve informed decision-making and treatment experiences.

Additionally, many local community and national support organizations exist to help survivors on their path to living without cancer. Routine yearly visits to primary care providers play a significant role in leading a healthy lifestyle and ensuring the appropriate age-related screenings are being discussed and completed. In some cases, many cancers can be identified at early stages via preventive screenings.

According to the 2022 IN-BRFSS, 67.0 percent of adult survivors reported they had received instructions from a doctor nurse, or other health professional about where they should return or whom they should see for routine cancer check-ups after completing their cancer treatment and the instructions received were written down or printed on paper for them.¹⁰ Primary care providers can ensure patients are up-to-date on vaccinations, complete recommended screenings, remain physically active, utilize sunscreen, and eat a healthy diet.

As of 2022, 16.0 percent of Indiana survivors still smoke cigarettes.¹⁰ For people who do not use tobacco, the most important modifiable determinants of cancer, and health risk, are weight control, dietary choices, and levels of physical activity. In Indiana in 2022, only 24.7 percent of survivors are at a healthy weight and 37.2% are considered obese.¹⁰

Resources

The National Cancer Survivorship Resource Center is a collaboration between the ACS 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 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.

Cancer Support Community offers support services 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. For more information, visit cancersupportindy.org.

The Little Red Door Cancer Agency provides support to cancer patients and their families throughout their cancer journey. They offer services for cancer patients and survivors, including transportation to treatment, nutritional supplements, meal delivery, lymphedema garments, medical supplies, wig and breast form fittings, massage, physical activity classes, cooking classes, psychosocial support programming, and resource referrals. For more information, visit www.littlereddoor.org.

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 healthcare attorneys. For more information, visit www.patientadvocate.org.

Due to continual changes in recommendations as scientific updates are developed, visit www.uspreventiveservicestaskforce.org for the most up-to-date screening guidelines and recommendations.

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



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