

The Costs of Cancer in Working-age People



Cancer takes a huge physical toll on people facing the disease and comes with many costs. This fact sheet explores the costs of cancer in working-age people, which we define as people ages 18-64 years (unless otherwise specified). While we recognize that some individuals continue working past 64 years of age, the availability of Medicare for most people ages 65+ makes this a useful dividing point in the data.

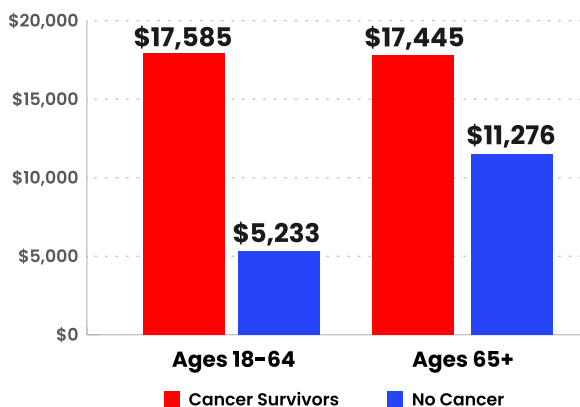
The financial costs of cancer do not impact all people with cancer equally. Evidence consistently shows that certain factors impact cancer diagnosis, treatment, survival and financial hardship experienced by people with a cancer history and their families:

- Age
- Race/ethnicity
- Sexual orientation
- Health insurance status
- Family income
- Where you live
- Cancer type

Working-age people with a cancer history incur significantly higher costs than those of similar ages without a history of cancer, and are significantly more likely to experience financial hardship than people with a history of cancer aged 65+.

Overall, working-age people with cancer have more than triple the health care expenses as those working-age people who have not been diagnosed with cancer.¹ These differences are also seen in individuals ages 65 and over but to a lesser extent.

Annual Average Health Care Expenditures for Working-age Individuals, 2018–2020



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018–2020. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp. July 2023.

All analyses incorporated complex survey design.

The Costs of Cancer in My Own Words

Colter Quinn

South Dakota



Colter Quinn never grew up thinking he would be impacted by cancer. As the only child of a single parent, Colter had a happy childhood in Hartford, South Dakota, helping his mom, Rosey,

at the animal shelter she founded in their hometown. Even after leaving the animal shelter, Rosey continued her passion for helping others by working at a nonprofit organization assisting low-income people in the Sioux Falls area, and by advising animal shelters around the country.

Rosey worked full time, but, after her grant-funded position ended in 2020, she was unable to afford health insurance. After she began losing weight rapidly, Rosey was referred to a specialist for additional testing and was diagnosed with pancreatic cancer.

Rosey continued working as much as she could after her diagnosis, but required additional flexibility given the new physical limitations from her illness. Colter put his life on hold to care for his mother. He dropped out of college and picked up extra hours at work to help her financially. Rosey was paying for everything out of pocket and couldn't afford chemotherapy treatment. She passed away in October 2021.

Since losing his mom, Colter has been trying to get his life in order again, even while still receiving his mom's medical bills in the mail. He estimates there's about \$25,000 in medical debt piled up in letters on his desk.

Cancer's Impact on Working-age People

- ▶ As of 2022, there were an estimated 5.9 million working-age people with a history of cancer in the U.S. who were ages 20-64 years. This represents 33% of the cancer survivors in the U.S.²
- ▶ Certain cancer types are more likely than others to be diagnosed in people under the age of 64. The top five most likely are:³

Testicular cancer



Thyroid cancer



Leukemia



Uterine cervix cancer



Ovarian cancer



■ <Age 50 ■ Ages 50-64

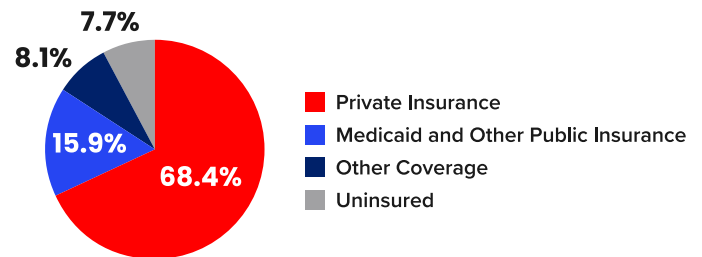
- ▶ Cancer survivors are more likely to experience work-related challenges, like being unable to work or being limited in the amount or type of work they can do because of health problems. Data show that these problems persist many years after diagnosis.⁴

Health Insurance Coverage in Working-age People

The details of an individual's health insurance coverage – or lack thereof – have a huge impact on what costs that person pays for their treatment.

- ▶ Working-age people with a history of cancer are more likely to be insured than those without a history of cancer.⁵
- ▶ For working-age people with cancer who are insured, the type and details of their insurance coverage are an important determinant of their out-of-pocket costs. More than half of working-age people with a history of cancer, ages 18-64 years, have private insurance.

Insurance Type, Working-age Individuals with a History of Cancer, Ages 18-64



Source: National Center for Health Statistics: National Health Interview Survey, 2019-2022. Public-use data file and documentation. Retrieved from: <https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>. July 2023.

All analyses incorporated complex survey design.

- ▶ More and more people are enrolled in lower premium high deductible health plans (HDHPs), despite high up-front costs and mounting evidence that these plans cause them to delay important cancer care and have worse cancer outcomes.^{6,7,8} The majority (57%) of privately insured working-age people with a history of cancer have an HDHP.⁹

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I understand why people die from cancer – they can't afford it.

COLTER QUINN, SOUTH DAKOTA

The Costs of Cancer in My Own Words

Michelle Lawrence

New Hampshire



Fourteen years ago, around her 31st birthday, Michelle Lawrence was diagnosed with a rare, chronic cancer. At that time, she worked as a case manager at a

nonprofit organization, and she paid for private health insurance through her employer. While Michelle's peers were celebrating purchasing homes or having children, she felt singularly focused on having her newly diagnosed chronic illness treated and working to afford her treatment without the potential of leaving medical debt to her surviving family when she passed away.

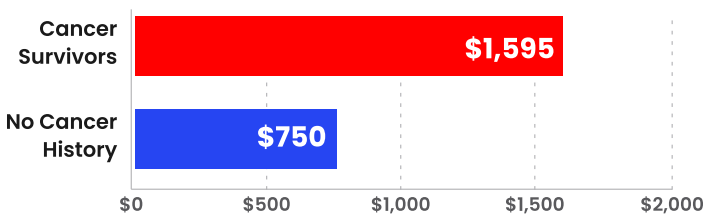
As a single person supporting herself, most of Michelle's income went to copays and deductibles. In 2022, her employer let her go, and she knew she could not keep up with health care costs while also meeting her basic needs. Unable to afford COBRA insurance, Michelle found that applying for Medicaid was her best option. Thankfully, she qualified, and Medicaid has enabled her to access her palliative care doctor, a therapist and medications ever since. Access to Medicaid has relieved the financial burden of Michelle's chronic cancer immensely.

What Working-age People With a Cancer History Pay Out of Pocket for Care

Cancer treatment is often complex, involves many services and is expensive. Research consistently shows that people who have been diagnosed with cancer have higher out-of-pocket costs than those without a cancer history.¹⁰ These increased costs often continue even years after the patient has finished active cancer treatment.

- ▶ The median annual household income for individuals under 65 years of age in the U.S. in 2021 was \$80,734.¹¹
- ▶ Working-age people with a cancer history spend an average of \$1,595 every year on out-of-pocket medical expenses, which is more than double that of those without a cancer history. And that doesn't even take into account monthly insurance premiums.¹²

Average Annual Out-of-Pocket Expenses, Working-age Individuals, 2018-2020



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2020. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp. July 2023.

All analyses incorporated complex survey design.

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Medicaid has made things so much easier. I don't have to choose between: Am I getting fresh fruits and vegetables this week, or am I going to go see my doctor? It's the first time I can take a deep breath.

MICHELLE LAWRENCE, NEW HAMPSHIRE

The Costs of Cancer in My Own Words

Kat Klawes

Milwaukee, Wisconsin



Kat Klawes is a 29-year-old small business owner living in Milwaukee, Wisconsin. In 2020, Kat heard the words, “you have cancer” for the first time.

She is insured through the Affordable Care Act, and although she has coverage, Kat has struggled with extremely high costs of care.

Kat has been burdened by \$40,000 in medical debt, and as a young woman beginning her adult life, it's had major impacts. In 2021, she was ready to move in with her partner, and they began looking for an apartment together. Due to medical debt, Kat's credit score was low, and she kept getting denied for apartments – putting her in the precarious situation of becoming housing insecure.

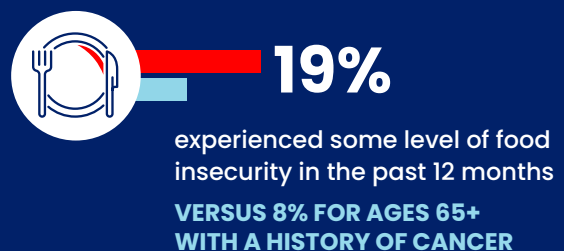
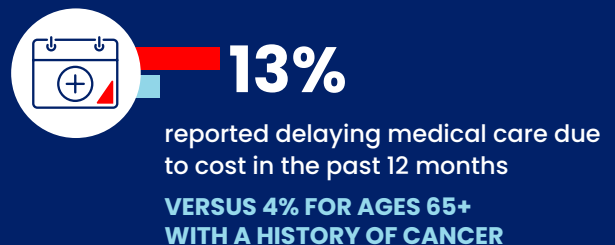
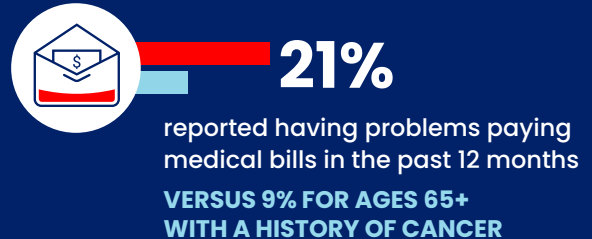
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I have paid off most of my medical debt, but I still struggle with a low credit score. I have had to go to court and show past records of disputed payments I've made to the hospital. No cancer patient should have to face this burden. It has been four years, and I'm still dealing with disputed bills.

KAT KLAWES, WISCONSIN

The Impacts of the Costs of Cancer on Working-age People

The high costs of cancer have many adverse impacts. Research shows that among people ages 18-64 years with a history of cancer:¹³



ACS CAN Supports Policies That Will Reduce the Costs of Cancer for Working-age People

The American Cancer Society Cancer Action NetworkSM (ACS CAN) supports policies that will reduce the costs of cancer for working-age people with a history of the disease. We want to make sure that everyone has a fair and just opportunity to prevent, detect, treat and survive cancer. To reduce the costs of cancer for working-age people with a history of the disease, ACS CAN supports:

- ▶ **Expanding Medicaid in the remaining states that have not done so.** Medicaid helps to improve cancer outcomes by offering access to prevention services and timely cancer screening and early detection services, as well as affordable treatment services and care. There are millions of people who fall into the “Medicaid coverage gap.” That gap refers to individuals who remain ineligible for Medicaid but earn too little to qualify for premium tax credits for qualified health plans in the marketplace. Many people in this gap are adults with no

children, and these working-age individuals don’t have other avenues for affordable health insurance coverage. Medicaid is a lifeline for thousands of families that – without health insurance – would not have access to the screening, early detection, treatment and follow-up care they need. ACS CAN advocates for all states to expand Medicaid and for Congress to close the coverage gap for lower-income Americans who live in states that have failed to expand to reduce cancer disparities.

- ▶ **Making expanded marketplace subsidies permanent.** Most of the millions of adults who are uninsured are under the age of 65 and in working families, including families with low incomes.¹⁵ The Inflation Reduction Act extended increased subsidies through December 31, 2025, making premiums and cost sharing more affordable for millions of people. However, this extension is not permanent. People who need health insurance coverage through the marketplace need these subsidies to be permanent so their costs will stay affordable, and so they aren’t in danger of losing coverage.

In Their Own Words: Experience with Costs and Debt

The American Cancer Society Cancer Action Network (ACS CAN) gives voice to people with cancer on critical public policy issues that affect their lives. In 2021, we conducted a survey about cost and debt issues. Working-age people with cancer told us they had problems affording treatment, dealing with worry and anxiety and medical debt.¹⁴

Problems affording treatment

It was difficult to afford my health care expenses.

66%

The cost of a treatment influences whether I get a treatment that my health care provider recommends.

47%

I delayed or did not pay other household expenses (like utility bills) to use the money for health care costs instead.

24%

Medical debt

I have current or past medical debt associated with my cancer care.

61%

- ▶ I have been contacted by a collections agency about debt related to my cancer care.

58%

(of those reporting current or past debt)

I declared bankruptcy due to health care costs or debts.

5%

Worry and anxiety

I am concerned about my ability to pay for current or future health care costs related to my cancer.

79%

I am concerned about incurring new debt for my cancer care.

73%



▶ **Ensuring working people with cancer, survivors and caregivers have paid leave.**

Cancer treatment is time consuming – often requiring time off from work for doctor’s visits, surgery and recovery; chemotherapy; and radiation. The flexibility to balance cancer treatment and employment is essential. Studies show that people with cancer who have paid leave have higher rates of job retention and lower rates of financial burden.^{16,17} Yet not all people with cancer and caregivers who work have access to paid leave. Without paid leave, they risk losing employment or not getting the care they need. ACS CAN supports policies at the national, state and local levels that increase access to job-protected paid family and medical leave that can be used for cancer treatments, survivorship care and caregiving, as well as other illnesses.

▶ **Limiting the sale of noncomprehensive insurance plans.**

Short-term limited duration (STLD) health care plans often exclude important benefits, require high out-of-pocket costs and, in general, provide severely inadequate coverage. However, their cheaper premiums often attract enrollees who are unaware they are enrolling in a noncomprehensive plan. STLD plans can negatively impact the availability and affordability of Affordable Care Act (ACA)-compliant plans by siphoning off younger, healthier consumers who will be more likely to purchase cheaper, bare bones plans.¹⁸ ACS CAN supports policies that help consumers distinguish between an STLD plan and comprehensive health coverage and strengthen patient protections and continues to urge policymakers to consider prohibiting or limiting the availability of STLD and other non-ACA compliant plans or requiring these plans to follow ACA rules.

▶ **Protecting coverage of fertility preservation for people with a history of cancer.**

More than 80,000 young adults between the ages of 20 and 30 are diagnosed with cancer each year.¹⁹ Some cancer treatments can cause infertility, and, as a result, individuals with cancer may choose to preserve their fertility prior to treatment.²⁰ ACS CAN supports legislation that provides insurance coverage for fertility preservation services for people with cancer and opposes legislation that prevents a person’s ability to preserve fertility prior to initiating cancer treatment.

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The struggles I’ve had with private insurance are insurmountable and have taken years off of my life.

MICHELLE LAWRENCE, NEW HAMPSHIRE

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Support for this project was provided by Bristol Myers Squibb.



About ACS CAN

The American Cancer Society Cancer Action Network (ACS CAN) advocates for evidence-based public policies to reduce the cancer burden for everyone. We engage our volunteers across the country to make their voices heard by policymakers at every level of government. We believe everyone should have a fair and just opportunity to prevent, detect, treat and survive cancer. Since 2001, as the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN has successfully advocated for billions of dollars in cancer research funding, expanded access to quality affordable health care and advanced proven tobacco control measures. We stand with our volunteers, working to make cancer a top priority for policymakers in cities, states and our nation's capital.

Visit [fightcancer.org](https://www.fightcancer.org) to join the fight.