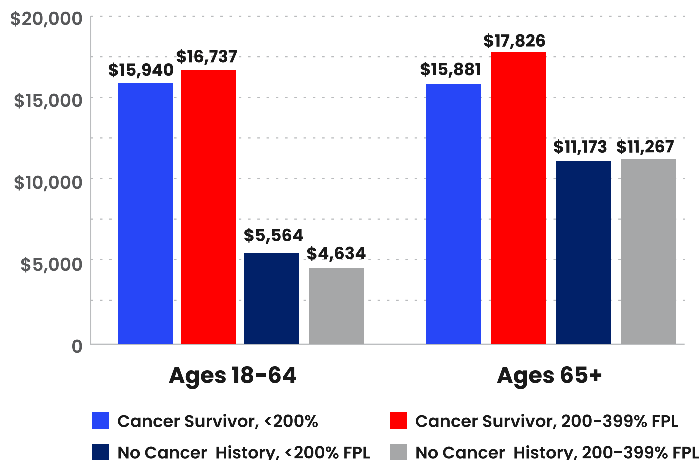
The Costs of Cancer for People with Limited Incomes

As a leading cause of death and disease in the U.S., cancer takes a huge toll on the health of patients and survivors, and it also has a great impact on their finances. The costs of cancer do not impact all patients equally. Evidence consistently shows that certain factors – like race/ethnicity, health insurance status, income and where a person lives – impact cancer diagnosis, treatment, survival and financial hardship experienced by people with cancer and their families. This fact sheet explores the costs of cancer on people with limited incomes, which unless otherwise indicated include individuals whose annual income is equal to or less than 400% of the Federal Poverty Level (FPL).[1]

People facing cancer and survivors with limited incomes experience higher health care costs and significantly more financial hardship compared to individuals who have not been diagnosed with cancer.

Overall, cancer survivors with limited incomes have significantly more health care expenditures, or costs, than people with limited incomes who have not been diagnosed with cancer (almost triple the amount in younger ages).[2]

Annual Average Health Care Expenditures for Individuals with Limited Incomes



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2019. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216. July 2022.

The Costs of Cancer in My Own Words

Melissa Taylor

DeLeon Springs, Florida

Melissa Taylor was diagnosed with breast cancer in 2015 after a baseline mammogram that her family doctor had asked her to get when she was 35. The mammogram indicated the next step would be a biopsy that confirmed what she was afraid of, cancer. A lumpectomy was scheduled. It was during that procedure that turned Melissa's world upside down, both medically and financially. The surgeon instead discovered that the cancer had spread and appeared like "an explosion" in Melissa's breast. The cancer had spread to her lymph nodes on her left side, which had to be removed. The chemotherapy and treatments resulted in long-term health issues that Melissa continues to battle every day.

As Melissa's health and quality of life began to plumet, her medical debt began to skyrocket. As a mother of two, she lost her job as a soil manager, leading to the family losing their dream home and moving into an RV. Melissa had insurance when her cancer journey began, but the copays, out-of-pocket and unexpected expenses combined with losing her job created an avalanche of medical debt. Despite all of this, Melissa continues to be denied Social Security Disability Insurance program benefits and the health insurance that would allow her to receive the kind of care a cancer survivor needs.

Melissa lives in Florida, one of 12 states that has not expanded Medicaid. If Medicaid were expanded, she would qualify and no longer continue to incur unnecessary medical debt. The care Melissa could receive would be coordinated and patient centered, which is exactly what she needs to continue fighting cancer. Despite efforts to coordinate her own care through a patchwork system, Melissa is desperate for relief and keeps slipping through the cracks.

> “
>
> I had a family with kids. We lost everything due to my medical debt. The hospital turned me away when I showed up for my surgery. They said I had an old outstanding bill for $800. There I was, in the lobby, ready to have my cancer removed with no way to pay the money. I knew I needed the surgery to save my life, but the hospital was drawing a line in the sand. Luckily, my mother was there with me and allowed me to borrow the money from her so that I could have surgery. Otherwise, I’m not sure I’d be here.
>
> **MELISSA TAYLOR, FLORIDA**

Cancer’s Impact on People with Limited Incomes

Residents of limited-income areas share an unequal burden of cancer deaths. Persistent poverty is linked with increased rates of cancer deaths.[3] The reasons for higher rates of cancer incidence and mortality in limited-income areas are multidimensional and influenced by adverse differences in social determinants of health.

- U.S. counties that experience persistent poverty have higher mortality rates for all cancer types (12.3% higher), as well as for cancers of lung (16.5% higher), colorectal (17.7% higher), stomach (43.2% higher) and liver and intrahepatic bile duct (27.6% higher).[4]
- Cancer death rates vary significantly in counties of different income levels, with a mean cancer death rate per 100,000 person-years of 185.9 in high-income counties, 204.9 in medium-income counties, and 229.7 in low-income counties.[5]

Cancer Death Rates, 2016-2017

185.9 HIGH-INCOME COUNTIES

204.9 MEDIUM-INCOME COUNTIES

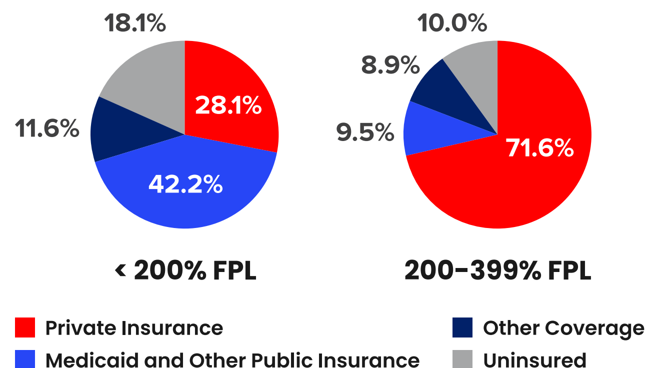
229.7 LOW-INCOME COUNTIES

Health Insurance Coverage Among People with Limited Incomes

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

- Patients who are uninsured are responsible for all of their treatment costs, which can be very large sums of money. In 2012-2014, 6.1% of individuals with incomes lower than 200% FPL and 3% of individuals with incomes 201-400% FPL newly diagnosed with cancer were uninsured – compared to only 1.4% of those with higher incomes.[6]
- For those individuals with limited incomes who are insured, the type and details of their insurance coverage can determine a great deal of their costs. Those with the most limited incomes are more likely to be eligible for, and therefore enrolled in, Medicaid or other public insurance, where their out-of-pocket costs are also limited.

Insurance Type, Individuals with Limited Incomes and a History of Cancer, Ages 18-64



Source: National Center for Health Statistics: National Health Interview Survey, 2019-2020. Public-use data file and documentation. Retrieved from: https://www.cdc.gov/nchs/nhis/2020nhis.htm. July 2022.

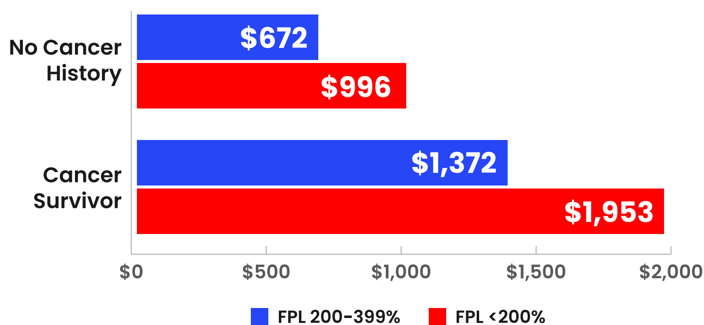
- More and more individuals are enrolled in high-deductible health plans (HDHPs), despite their high upfront costs and mounting evidence that these plans cause patients to delay important cancer care and have worse cancer outcomes.[7,8,9] Nearly 45% of privately insured cancer survivors with incomes 200-399% FPL have an HDHP.[10]

What Patients & Survivors with Limited Incomes 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.[11] These increased costs often continue even years after the patient has finished active cancer treatment.

- Younger people with a cancer history and limited incomes spend significantly more out-of-pocket than individuals without a cancer history (this does not include monthly health insurance premiums).[12] People over the age of 65 with incomes less than 200% FPL pay the highest amount of annual average out-of-pocket expenses: $2,017. This amount is higher than the average amount paid by their higher-income counterparts.[13]

Average Annual Out-of-Pocket Expenses, Individuals Ages 18-64 with Limited Incomes



Federal Poverty Levels (FPL), 2022	For a family of 1:	For a family of 4:
	200% FPL = $27,180	200% FPL = $55,500
	400% FPL = $54,360	400% FPL = $111,000

Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2019. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216. July 2022.

The Costs of Cancer in My Own Words

Kris Walker

Kansas City, Missouri

I'm Kris Walker, a 49 years 'young' cancer patient from Kansas City, Missouri. I was diagnosed with non-small cell lung cancer. On April 4, 2022, I found out that my cancer is terminal. I've done chemotherapy and radiation, but neither worked.

I found out that part of my insurance doesn't work well in Missouri. It's a platinum plan, which is supposed to be one of the best, but I have a $250 deductible to see a specialist. As a cancer patient, nearly all of my visits are with specialists. Hospitals in my area aren't taking it now. The good thing is that when the office staff see that I've applied for Medicaid they still allow you to continue treatment. They're upfront and will tell you that you're going to get a bill in the mail and ask that you try to pay a little toward the bill. But even paying a little is too much for me right now.

Dealing with the financial aspects of a terminal cancer diagnosis has been a humbling experience. I'm not accustomed to not working, but I'm in a situation now where I have to ask others for financial help. Asking family for help is tough, but asking friends is even tougher. Tough and embarrassing. I've applied for food stamps and found a few food banks. I applied for rental and utility assistance through a local nonprofit, and I'm waiting to see if they will help me. I thought about starting a GoFundMe. I don't want to, but I need to. Money has to come from somewhere to cover my bills. Asking for help is hard because I've always worked and supported myself. I've always been the employee who would come in early, stay late and work extra hours if needed. I try not to worry too much about my medical debt. Hopefully my Medicaid will kick in and cover my outstanding bills. I'm lucky to be single in this case, because no matter how much debt there is, my family doesn't have to take care of it. When I pass, it's gone. My biggest concern right now is covering my monthly bills.

ACS CAN Supports Policies That Will Reduce the Costs of Cancer in Individuals with Limited Incomes

The American Cancer Society Cancer Action Network (ACS CAN) wants to make sure that everyone has a fair and just opportunity to prevent, detect, treat and survive cancer. To reduce the costs of cancer in individuals with limited incomes, ACS CAN supports:

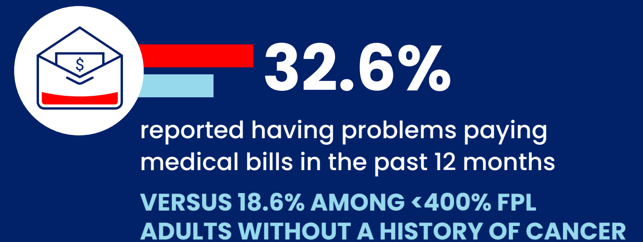
- **Expanding Medicaid in the 12 remaining states that have not done so.** The health coverage provided by Medicaid helps to improve outcomes and reduce the burden of cancer by offering access to prevention services and timely cancer screening and early detection services, as well as affordable treatment services and care. In 12 states, there are more than 2.2 million people who should be able to see a doctor but cannot. They don't qualify for Medicaid, but also don't fall into the income bracket that allows them to receive marketplace subsidies. This is the Medicaid coverage gap – 60% of these uninsured individuals are people of color, and the vast majority live in the American South, which includes a large Black/African American population. All states should expand Medicaid, and Congress must close the coverage gap for lower income Americans who live in states that have failed to expand.

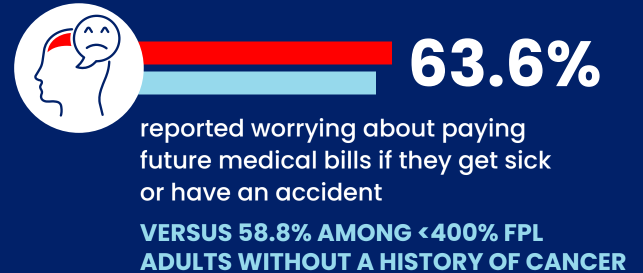
- **Making expanded marketplace subsidies permanent.** The recent Inflation Reduction Act has extended increased subsidies for three more years (through December 31, 2025), making premiums and cost sharing more affordable for millions of people. However, this extension is not permanent. People who need health insurance coverage through the marketplace need these subsidies to be permanent so their costs will stay affordable and they aren't in danger of losing coverage.

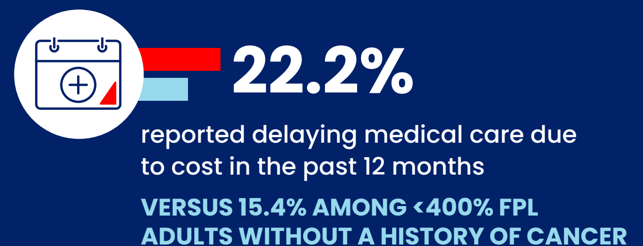
- **Ensuring working people with cancer, survivors and caregivers have paid leave.** Cancer treatment is time consuming – often requiring time off from work for doctor's visits, surgery and recovery, chemotherapy and radiation. The flexibility to balance cancer treatment and employment is essential. Studies show that people facing cancer who have paid leave have higher rates of job retention and lower rates of financial burden.[15,16] Yet not all people facing cancer, survivors and caregivers who work have access to paid leave, and

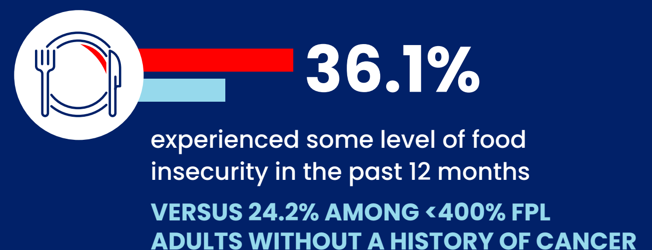
The Impacts of the Costs of Cancer on Individuals with Limited Incomes

The high costs of cancer have many adverse impacts. Research shows that individuals ages 18-64 with a history of cancer experience significantly more financial hardship than individuals without a cancer history:[14]









without it 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.

> A previous ACS CAN survey showed that respondents who were less likely to report having paid family and medical leave were those with lower levels of income, and respondents who reported having issues with cancer/caregiving and their job – including the quality of their work suffering, having to take two or more days off of work in a row, or having to leave work early – most often tended to be those in lower-income households.[17]

- **Addressing patient costs to diversify participation in clinical trials.** While patient willingness to enroll in clinical trials is high, some people with cancer decline due to costs. They are frequently responsible for non-medical costs such as transportation and lodging associated with trial enrollment. These costs can occur when no local trials are available and patients have to travel to distant trial sites, or when there is a need for more frequent clinic visits for additional trial-related treatment or monitoring. The additional costs can lead to unequal participation rates between high- and limited-income people facing cancer and the patients most impacted tend to be those traditionally underrepresented. To address this issue, the DIVERSE Trials Act would allow clinical trial sponsors to provide financial support to trial participants and the technology needed to participate in trials remotely. Offering to reimburse patients for non-medical costs associated with trials can increase overall enrollment and thereby help make it less costly for patients to access innovative therapies through clinical trials during their cancer treatment. The bill also further requires the FDA to issue guidance on the use of decentralized trial tools to address disparities in clinical trial participation. This guidance would help make participation in clinical trials easier for patients by reducing or removing the need to travel to specific trial sites.

In Their Own Words: Experience with Costs and Debt

The American Cancer Society Cancer Action Network (ACS CAN) gives voice to people with cancer and survivors on critical public policy issues that affect their lives. In February 2022 we conducted a survey of cancer survivors on cost and debt issues. Cancer survivors with limited incomes[18] told us they had problems affording treatment, dealing with worry and anxiety and medical debt.[19]

Problems affording treatment

It was difficult to afford my health care expenses.
44%

The cost of a treatment influences whether I get a treatment that my health care provider recommends.
46%

I delayed or did not pay other household expenses (like utility bills) to use the money for health care costs instead.
18%

Medical debt

I have current or past medical debt associated with my cancer care.
58%

- I have been contacted by a collections agency about debt related to my cancer care.
  54%*
- I declared bankruptcy due to health care costs or debts.
  5%*

**Note: This is the percentage of survey respondents who indicated they have current or past medical debt.*

Worry and anxiety

I am concerned about my ability to pay for current or future health care costs related to my cancer.
77%

I am concerned about incurring new debt for my cancer care.
74%

- **Improving access to and ensuring long-term sustainable payment of patient navigation services.** Patient navigation has become increasingly recognized for improving patient outcomes, reducing unnecessary treatment costs and increasing patient satisfaction. However, patient navigation is still absent or limited in many cancer programs and hospital settings due to cost concerns and a lack of long-term funding to pay for these services. Instead, patient navigation programs are often financed via short-term funding like private or governmental grants. ACS CAN supports and advocates to improve health equity by increasing access to quality cancer care among communities that have been under-resourced by extending the reach of navigation services. The expansion and sustainability of patient navigation services will only be achieved by ensuring that these services can be paid for the long term, thereby ensuring everyone everywhere will have access to the patient navigation services needed to ensure better patient experience and outcome due to a cancer diagnosis.

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1 In 2022, the FPL for a family of one is $13,590. For more information, please visit: https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines.

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13 Ibid.

14 Note that all differences between populations presented in this graphic are statistically significant. Source for all data in this section: National Center for Health Statistics: National Health Interview Survey, 2019-2020. Public-use data file and documentation. Retrieved from: https://www.cdc.gov/nchs/nhis/2020nhis.htm. July 2022.

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18 For the data in this section, "limited incomes" is defined as a reported income of under $35,000 per year.

19 Survivor Views web survey, May 16-26, 2022, 2,611 cancer patients and survivors nationwide including 1,370 oversampled by race, ethnicity, and income.

Support for this project was provided by Bristol Myers Squibb.

About ACS CAN

The American Cancer Society Cancer Action Network (ACS CAN) makes cancer a top priority for policymakers at every level of government. ACS CAN empowers volunteers across the country to make their voices heard to influence evidence-based public policy change that improves the lives of people with cancer and their families. We believe everyone should have a fair and just opportunity to prevent, find, 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're more determined than ever to stand together with our volunteers to end cancer as we know it, for everyone. **Join the fight by visiting www.fightcancer.org.**

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