Cancer, Hands Off My Bank Account!

10 Strategies to Keep Costs Under Control

September 16, 2019 By Mike Robbins

Lee Tomlinson knew his Stage III throat cancer could cost him his life. What he didn't know is that it would cost him his home, his savings and his career.

When Tomlinson received his diagnosis in 2013, he was an award-winning TV producer. Two years later, his cancer was in remission—but his finances were on life support. Not only were tens of thousands of dollars in medical bills not covered by his health insurance, but intensive treatments left him unable to work—he could barely speak. He eventually declared bankruptcy. "I was without income for almost a year and a half," says Tomlinson, who remains in remission. "I've worked my butt off all my life, but cancer just ruined me financially."

The Cost of Cancer

Great strides in cancer treatment in recent years have come at a steep financial cost. The average monthly price of oncology drugs more than doubled in the decade from 2006 through 2015. Some now cost more than $400,000 for a course of treatment—on top of the bills from doctors, hospitals and labs. Even if you're covered by insurance, a growing share of this burden may land in your lap—deductibles, co-pays and co-insurance continue to rise.

What's more, the typical person with cancer sees his or her earnings drop by almost 40% in the years following diagnosis. Between the massive costs and diminished income, 42% of patients burn through their entire life savings within two years. Studies find that costs lead some people to refuse or delay treatments—even if they are insured. Financial stress can be deadly: A 2016 study found that people diagnosed with cancer who declared bankruptcy are 80% more likely to die over the following years than those who remained solvent.

This financial toll is so devastating that the cancer community has given it a name of its own: financial toxicity. "A lot of people are blindsided by it," says Michelle Landwehr, MPH, who is COO of The Samfund, a nonprofit that provides support to young adult cancer survivors. "Understandably, they've been focused on their treatment. They're truly unprepared for the fallout in terms of finances."

Finding Solutions

America's health care system could protect people with cancer from financial toxicity in a number

of ways. Providers could make it easier to determine prices in advance. Drugmakers could charge less. Insurance companies could cover more—or at least make it easier to figure out what will and won't be covered. "This is a pervasive problem that reflects deficiencies in our health care system and the intense nature of cancer care," explains Veena Shankaran, MD, codirector of the Hutchinson Institute for Cancer Outcomes Research. "It is not your fault."

But while people with cancer are not responsible for this problem, they and their families can significantly reduce the odds that a cancer diagnosis will turn into a financial disaster by using the following strategies:

1. Discuss costs with health care providers as soon as possible. "Patients should express their financial concerns to their health care team just as they would their concerns about any other side effects," says Yousuf Zafar, MD, an oncologist and associate professor of medicine at Duke University in Durham, North Carolina. "If I know it's a concern, there might be alternatives." For example, oral chemotherapy drugs often have far higher out-of-pocket costs than their intravenous alternatives—even when they're not more effective.
2. Apply for grants. Merissa Pemberton was a recent college grad just months into her first job when she was diagnosed with Stage II Hodgkin lymphoma in 2017. She paid off around 75% of her $14,000 medical debt by securing grants from nonprofit organizations.

Track down grant programs that help cancer patients by searching the websites of organizations such as the Cancer Financial Assistance Coalition, CancerCare and Cancer.Net. The Patient Advocate Foundation's My Resource Search app can help locate additional assistance through community groups. (For the addresses of websites mentioned in this article, see "Online Help" below.) Pemberton also googled the name of her specific cancer along with other keywords related to her situation, such as "young adult." Even if the website didn't mention a grant program, she contacted the organization to ask what other organizations she should reach out to for financial help. She learned to include details about her hobbies and goals in grant applications so that she would stand out from the pack. She's now cancer-free and free of medical debt—though it wasn't easy. "It takes a lot of perseverance," Pemberton says.

3. Ask drug companies for deals. Most pharmaceutical companies have patient assistance programs that provide free or heavily discounted medications to patients who otherwise could not afford them. Complete the program applications as soon as you learn which drugs you'll need. (You can find these applications on drug company websites or through NeedyMeds.org.) When you report current income on these forms, remember to take into account that if cancer impairs your ability to work, your income may be lower this year.
4. Get help with transit and lodging. The American Cancer Society's Road to Recovery and Patient Lodging Programs provide free rides to medical facilities and housing near them. The Healthcare Hospitality Network can point to additional housing options. Angel Flight and Air Care Alliance provide free flights to patients in need.
5. Reach out to support groups and social workers. Nonprofit organizations associated with your specific type of cancer may be able to help you locate resources. Ask the hospital where you

receive care whether there is a social worker on staff who can help. Also, reach out to the Cancer Support Community, a nonprofit that provides information and community for cancer patients. “They’re lifesavers,” says Tomlinson, who now goes by “Patient Ted” and gives keynote addresses and TED talks on the role of compassion in medicine. “Any question you have about anything, they’re your resource.”

6. Include your health insurance company in the planning process. As soon as you work out a care plan with your doctors, contact your health insurance provider, ask to speak with a case manager, discuss the extent to which this treatment plan will be covered by your insurance and then ask the case manager for cost-cutting ideas. Perhaps you could save a bundle by getting an MRI at a freestanding MRI center rather than a hospital, for example. “People have a lot of issues with insurance companies,” says Vilmarie Rodriguez, director of patient assistance at the nonprofit CancerCare, which provides free support services. “But you have to use the tools you have, and they’re the ones who make the payments and the decisions.

7. Know your rights regarding your job—and your student loans. The Americans with Disabilities Act protects people with cancer from discrimination and requires employers to offer them “reasonable accommodations,” such as flexible working hours and rest breaks. The Family Medical Leave Act often allows cancer patients and their caregivers to take up to 12 weeks of unpaid leave per year. Speak with your employer’s human resources department—or, if necessary, an attorney specializing in labor law. If you have student loans, you may be able to defer payment for the duration of treatment plus six months; contact lenders to make this request.

8. Confirm—and reconfirm—that health care providers are in network. The odds that you will be responsible for a big share of a medical bill skyrocket if you are treated by a doctor or hospital that’s out of network. Caitlin Donovan, director of outreach for the National Patient Advocate Foundation, recommends these steps to avoid problems:

- Ask your insurer whether hospitals and doctors are in network; ask providers whether they are in network for your insurance. Use email, if possible, as proof of the responses.
- Use the search tools on your insurer’s website to find additional evidence that providers are in network. Take and save screenshots.
- Get the name of every doctor who will be involved in hospital procedures—including anesthesiologists and radiologists—and confirm that every one of them is in network.
- When you check into the hospital and are instructed to sign forms agreeing to pay, also write: “I do not agree to receive treatment from out-of-network providers without my consent.”

9. Reevaluate your health insurance coverage each year. Cancer treatment often extends over more than one calendar year, and you don’t have to stick with the same insurance throughout. “Every single year, patients should be looking at their health insurance options and making comparisons to lower their out-of-pocket expenses,” says Joanna Morales, a cancer rights attorney and CEO of Triage Cancer, a nonprofit focused on practical and legal cancer issues.

Explore the coverage options offered by your employer or through the Affordable Care Act during

open enrollment, or review the Medigap, Medicare Advantage and Medicare Part D plans available to you. Select the coverage that minimizes the out-of-pocket costs for your treatments and medications and includes your preferred oncologists and hospitals in its network.

10. Try to trim big bills. When you receive medical bills, look up the CPT (current procedural terminology) codes listed on a website such as Coder.AAPC.com. (If you don't see codes listed, ask the provider for an itemized bill—you have a right to see them.) If some codes do not seem to correspond to treatments you received, call the provider and question them—billing errors are common.

If your insurer does not cover as much of a bill as you believe it should, file an appeal. Details about filing these appeals can be found in the resources section of the Patient Advocate Foundation's website. If the insurer argues that a procedure was not medically necessary, ask your doctor to provide a letter explaining why it was necessary and include this with your appeal.

If you have hospital bills you cannot afford, ask a hospital's financial counselor whether the facility has a financial assistance program and, if so, how you can apply. If all else fails, tell the provider that you cannot possibly afford all your medical bills and try to use this as leverage to negotiate a lower price. Or hire a medical billing advocate to tackle these bill-trimming strategies for you.

Finding Your Way

In a better world, people who are using their mental and physical energies to get the best cancer care, manage side effects and maintain a good quality of life shouldn't also have to fight financial threats. But help is available—and it's growing. "We're finding more resources," says Landwehr. "A lot of it is knowing where to look."

Online Help

These resources can help people with cancer get financial support. They are all mentioned in this article:

Air Care Alliance: aircarealliance.org

American Cancer Society/Patient Lodging: cancer.org/treatment/support-programs-and-services/patient-lodging.html

American Cancer Society/Road to Recovery: cancer.org/treatment/support-programs-and-services/road-to-recovery.html

Angel Flight: angelflight.com

CancerCare: cancercare.org/financial_assistance

Cancer Financial Assistance Coalition: cancerfac.org

Cancer.Net: cancer.net/navigating-cancer-care/financial-considerations/financial-resources

Cancer Support Community: cancersupportcommunity.org

Healthcare Hospitality Network: hhnetwork.org

NeedyMeds.org: needymeds.org

Patient Advocate Foundation: patientadvocate.org

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