# FINANCIAL IMPACT OF CANCER POCKET GUIDE

**Patient Pocket Guides** 

#### **FAST FACTS**

- In one large survey, approximately 4 in 10 people with cancer said their out-of-pocket (self-paid) expenses were higher than they expected.<sup>1</sup>
- People with cancer spend more on massage, supplements, and other complementary and alternative medicine treatments than people who do not have cancer and tend to pay out of pocket for these treatments.<sup>2</sup>
- People with cancer or a history of cancer may be more likely to skip filling a prescription or skip doses to cut costs than people without cancer.<sup>3</sup>

# THE FINANCIAL IMPACT OF CANCER

If you or a loved one are diagnosed with cancer, financial worries may be the last thing on your mind. Learning more about the cancer, treatment options, and expected outlook are probably first. So, it might surprise you to learn that cancer and its treatment can have serious, sometimes lasting effects on your finances.

This pocket guide is designed to help you assess your situation, spot financial pitfalls, and avoid what many health-care providers call "financial toxicity."

# "Financial toxicity" - A lesser-known side effect

Financial toxicity happens when the cost of having cancer—including treatment, sick time, or in some cases being unable to work—causes problems for you and your family. Problems can include:

- Having difficulty paying regular bills (food, housing, utilities).
- Losing income if you are not able to work or need to take medical leave.
- Going into debt to pay regular bills, treatment costs, or both.
- Losing health insurance if you lose your job.
- Selling assets or spending your savings on treatment.
- Additional costs such as transportation, parking, cost of medications.

The financial effects of cancer can affect your family and future plans, whether you are paying for ongoing treatment or receiving care for post-treatment side effects, called late effects.<sup>4</sup>

Raymond Wadlow, MD, is a medical oncologist at the Inova Schar Cancer Care Institute in Fairfax, Virginia. "I see a lot of variation in how cancer affects people's finances," he says. "Some have insurance but not enough to prevent them from having financial difficulty from the cost of care. Others have no insurance."

Each U.S. state has options for people without insurance, such as a state-funded plan or high-risk insurance pool. Your cancer center may also be able to help with payment plans, reduced rates, patient assistance, or connections with charitable organizations.

#### No health insurance?

People without health insurance may apply for public insurance, such as care through the state where they live, Medicaid, or Medicare. However, applying and being accepted takes time and quite a bit of work. This can be difficult for someone who is not feeling well, has relatively low health literacy, is not a fluent English reader and speaker, or is not a computer user. Waiting to be accepted into an insurance program can also cause risky delays in getting cancer treatment, according to Dr. Wadlow. Many cancer centers have financial counselors on staff who can help walk patients through their options to pay for cancer care and connect them to resources for additional support. Some health-care systems have charity care, so that may be worth exploring before deciding where to receive treatment.

## An oncologist's advice

Dr. Wadlow offers this advice to reduce or avoid financial toxicity:

- **First, learn** what financial toxicity is. Even if you have health insurance, don't assume cancer and treatment cannot affect your finances.
- Then, talk with your health-care team about what your cancer care may cost. They want to know if you have financial concerns regarding treatment! If you have other specific financial needs, such as paying for a child's college tuition or being on a fixed income in retirement, share this with your cancer care team. A social worker or financial counselor may be able to assist.
- Finally, understand that integrative treatments, which support the mind and spirit as well as the body, are an important part of cancer care. Your health-care team may be able to help you find these types of treatments free or at low cost, such as from a community acupuncture clinic. You may also receive financial assistance for your regular cancer care, such as a discount on medications from the pharmaceutical company that makes them. Some arrangements make it easier to incorporate integrative health options into your treatment plan.

"You're much better off bringing the question of finances to your health-care team's attention than trying to avoid it," says Dr. Wadlow. This is particularly true if you are already facing some financial challenges, such as going without insurance or coping with another health condition. Dr. Wadlow says, "There are resources available! It is much easier for us to personalize your care for maximum benefit if we hear about your needs and concerns."

#### More finance and insurance tips

Our top tips to lessen the financial impact of cancer include:

- If you're insured, check out your benefits online. Learn what your deductible, co-payments, co-insurance rate, and cancer care benefits are, and let your main health-care providers know.
- 2. Ask to talk with a financial counselor (they are also called financial navigators) at the hospital, clinic, or cancer center where you will be treated. They can go over your insurance information, help you apply for public insurance if you need it, and help you find other ways to pay for care. For example, you may qualify for financial assistance from the hospital or clinic if you have financial need. This can reduce the amount you need to pay out of your personal funds.
- 3. WWTalk with a social worker at the cancer center or clinic. They can help you find low-cost or free options for everything from transportation to integrative care. For example, some hospitals offer free yoga classes for people with cancer. Many organizations offer free or low-cost rides, which can help cut the cost of going to treatment.

- 4. If you get Medicare, sign up for Part D, which helps with the cost of prescription drugs. You may want to purchase insurance that supplements Medicare, too. This can pay for things Medicare does not cover or pick up the remaining cost after Medicare pays their part.
- 5. Ask if group visits are available to access supportive services. Some organizations offer free or reduced-fee acupuncture, nutrition counseling, exercise, or Zumba classes. Some services are even available online.
- 6. You may be eligible for disability benefits. The Social Security and Supplemental Security Income disability program is an option for those who have paid into Social Security. Up to \$1,200 per month is available, and those who are dealing with cancer may have their application processed more quickly.

## The impact of out-of-pocket costs

Many people with health insurance are accustomed to paying a modest amount for appointments, tests, and prescriptions. But cancer is one of the most expensive medical conditions to diagnose and treat.<sup>5</sup> Staging scans alone may run thousands of dollars, and these tests occur well before any expensive treatment is delivered.

Factors that make cancer treatment especially costly include:

- Newer chemotherapy and other treatments are more expensive than in the past.
- New drugs enter the market at higher price points, with many cancer medications priced in the most expensive "specialty" tier of prescriptions.
- Prices continue to increase after drugs and treatments are on the market.
- Insurance companies charge consumers higher insurance premiums, deductibles, co-payments, and co-insurance rates.<sup>6</sup>

Providers may assume that because someone with cancer has health insurance, the cost of treatment won't be a concern. Unfortunately, it can be, even for people with "good" insurance. Someone with a high deductible may have to pay \$3,000 to \$6,000 out of their own pocket before insurance begins paying any part of the cost. With a short-term health insurance plan, the policy may pay very little.

Co-insurance is the percentage of each bill the insured person must pay (the insurance company pays the rest). If someone's co-insurance rate is 20 percent, their out-of-pocket cost is modest for a treatment that costs \$100. But if a cancer medication costs \$10,000 per month, the person with cancer just acquired a new monthly bill of \$2,000—more than the average mortgage payment in some parts of the country. According to the National Cancer Institute, prices higher than \$10,000 a month for individual drugs are "common."

## Talking with health-care providers

Asking questions about cost can help you avoid overwhelming financial impacts. You may need to bring this up with your oncologist and other team members. Dr. Wadlow says most providers don't realize how big a financial burden cancer places on the people they care for.

"Doctors don't know much about this, and patients often don't tell them much," he says. "People may be apprehensive about sharing financial concerns with the cancer care team because they are wary of having the 'budget' option recommended. They want to hear about the best care, not the lowest-cost option, because that may seem like it's less effective."

Financial toxicity may lead some to skip supportive services, such as physical therapy or nutrition counseling, without first talking with their doctor. This may be an opportunity to ask about integrative options that are low cost or even free. See our chart, Free and Low-Cost Integrative Health Resources, for examples of services that support healing.

## Integrative care and finances

Research shows that most people who choose integrative health options such as massage, acupuncture, chiropractic, or biofeedback pay for them personally. Insurance often does not cover them. In addition to buying higher-quality foods, such as fresh fish and organic produce, paying for these types of care takes a bite out of the family budget.

"There is a barrier to leveraging the benefits of integrative medicine if you have financial stress," says Dr. Wadlow. "You have stress related to paying for your regular care. This may keep you from taking advantage of integrative approaches that would help your stress—so even more stress builds up."

Bringing integrative care further into the mainstream can help. When insurance companies begin to cover these treatments, doctors are more likely to prescribe them in addition to standard

cancer care. "Integrative treatment should be integrated into the care plan, so everyone understands that it is every bit as important as chemotherapy or surgery in terms of whole-person care—not an added luxury," says Dr. Wadlow. "When that happens, financial stress can be distributed across the whole spectrum of treatment, so it is less likely to prevent people from choosing integrative modalities." Doing this will require changing some government rules. For example, Medicare does not cover treatments it considers "alternative," such as acupuncture, except for very specific purposes.

# More financial assistance options

Some cancer centers offer financial assistance programs. One such program at the Karuna Precision Wellness Center in Indiana offers financial assistance to clients regardless of income level.

Unite for HER, a Philadelphia-based organization, recently launched a wellness program that covers the cost of integrative health services for breast and ovarian cancer patients. The national program is available for those within 18 months of diagnosis or who have been diagnosed with metastatic disease. Patients receive a care box with educational resources as well as a \$2,000 passport that covers the cost of integrative therapies such as nutritional counseling, virtual fitness and yoga classes, sexual health counseling, and meditation.

# **Crowdfunding**

Many patients use crowdfunding platforms such as <u>GoFundMe</u> to ask friends, family, coworkers, and others to assist with the costs of cancer treatment. This provides the patient with an easy link to share through social media, text, or email that can be an easy and non-awkward way to ask others for financial assistance.

Another way that friends and family can offer help is through <u>Meal Train</u>. This platform creates an easy, organized tool for friends and family to plan meals for a loved one who is going through cancer treatment or surgery or just needs help planning meals.

Free and Low-Cost Integrative Health Resources				
Good nutrition	Mediterranean Diet Pocket Guide	The Nutrition Cancer Center	Pocket Guide to Nutrition and Cancer	
Better sleep	Guided meditation via HealthJourneys	CBT-i Coach app		
Journaling	Journaling through Pain and Trauma	Healing with Words: Journaling and Reflecting Throughout Treatment from www.cancercare.org	<u>CaringBridge</u> – offers free, private and ad-free personal health journey website	
Mindfulness meditation	Breathing Healing Meditation with Dr. Wayne Jonas	Free mindfulness courses via Mindfulness Exercises		
Acupuncture	Search "community acupuncture near me" online	Ask your health-care provider for an acupuncture clinic recommendation	Explore whether your community offers acupuncture in a group setting for a reduced fee	

Free and Low-Cost Integrative Health Resources				
Art therapy	Art Therapy Pocket Guide	Oncology on Canvas from Lilly Oncology	Smith Center for Healing and the Arts	
Music therapy	Free music therapy library from the University of Michigan Rogel Cancer Center			
Pain relief	<u>Curable</u> app	Nutrition for Chronic Pain Guide	Watch For Grace's free event on "The Pain-Cancer Connection"	
Therapeutic yoga	Therapeutic Yoga Pocket Guide	Healing Yoga Foundation	Yoga4Cancer	
Moving meditation (tai chi or qi gong)	Moving Meditations: Tai Chi and Qi Gong Pocket Guide	Tai Chi Video with Dr. Wayne Jonas	Memorial Sloan Kettering Cancer Center Tai Chi Instructional Video Series	
Connection to social services	Call 211 — Help with food assistance, health expenses, and more - www.211.org	American Cancer Society Support Programs and Services	National LGBT Cancer Network	
Exercise	Maple Tree Cancer Alliance free online workout videos and YouTube Channel			
My notes				

#### For health-care providers

Let everyone with cancer know that financial counselors or navigators are available and can be helpful in planning to meet the cost of cancer care. Also let them know social workers can help them locate free or low-cost care resources and practical support connect them with other organizations that offer free or low-cost help for people with cancer.

Knowing that the very latest chemotherapy drug or treatment is extremely expensive "creates a lot of anxiety," says Dr. Wadlow. His approach? Talking about financial options with every person who needs treatment, without guessing who might face financial challenges. "I simply say, 'We could do this treatment, or here are some other less costly options." This can help start a discussion about which treatment is the best choice overall.

#### A cancer survivor's advice

Jenny Leyh, a breast cancer survivor and mother of two, felt the strain of financial toxicity after having to quit her job following her diagnosis in 2016. Her advice is to keep a binder of important documents and tap a family member to play the role of patient advocate and manage the medical bills.

"A cancer diagnosis is an overwhelming experience and cannot be solely managed by an individual. It's important to ask for help in areas where you need assistance. Explore free or less expensive options such as online yoga classes, going for walks, imagery and mindfulness apps, or books on meditation. Complementary practices are so important in supporting healing during treatment, and they do not have to add to the financial burdens of cancer care," says Leyh.

#### **Resources**

<u>CancerCare.org offers a Helping Hand tool</u> — a searchable database of organizations that help people with cancer. You can search by your type of cancer and the type of assistance you're interested in, such as meal delivery, help paying for prescriptions, and much more.

A magazine called <u>CONQUER: the patient voice</u>, from the Academy of Oncology Nurse and Patient Navigators, offers a <u>wealth of</u> information on financial issues and cancer.

The <u>HealthWell Foundation</u> offers assistance to people who are underinsured and dealing with a serious illness. They also provide coverage for some medications.

<u>Triage Cancer</u> offers a tool to help guide patients through the potential financial burdens of cancer care.

#### References

- Cancer Support Community. Access to Care in Cancer: The Patient Experience. Survey results (2016).
- John GM, Hershman DL, Falci L, Shi Z, Tsai WY, Greenlee H. Complementary and alternative medicine use among US cancer survivors. J Cancer Surviv. 2016;10(5):850-864. doi:10.1007/s11764-016-0530-y
- Zheng Z, Han X, Guy GP Jr, Davidoff AJ, Li C, Banegas MP, Ekwueme DU, Yabroff KR, Jemal A. Do cancer survivors change their prescription drug use for financial reasons? Findings from a nationally representative sample in the United States. Cancer. 2017 Apr 15;123(8):1453-1463. doi: 10.1002/cncr.30560. Epub 2017 Feb 20. PMID: 28218801; PMCID: PMC6080209.
- National Cancer Institute. Financial Toxicity (Financial Distress) and Cancer Treatment. (PDQ) – Patient Version. September 20, 2019. Available at https:// www.cancer.gov/about-cancer/managing-care/track-care-costs/financialtoxicity-pdq Accessed November 2, 2021.
- Soni A. Trends in the five most costly conditions among the US civilian institutionalized population, 2002 and 2012. Statistical Brief 470. Rockville, Md: Agency for Healthcare Research and Quality, 2015. Available at https://meps. ahrq.gov/data\_files/publications/st470/stat470.shtml. Accessed August 12, 2021.
- National Cancer Institute. Financial Toxicity Associated with Cancer Care Background and Prevalence. In: Financial Toxicity and Cancer Treatment (PDQ) – Health Professional Version. Available at https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq Accessed November 2, 2021.

