



Oncology Nurse Navigator Toolkit

Helping Patients Navigate Financial Issues

2	Background
4	Why Is Cancer Care Costing Patients So Much?
7	Risk Factors for Financial Distress
8	Affordable Care Act Tip Sheet
9	Available Tools for Financial Toxicity and Burden
9	Resources/Websites That Are Helpful With Insurance and Cost Lingo
10	Costs of Cancer Care
11	Disability Resources
12	Financial Assistance
15	General Financial Support and Drug Assistance Resources
16	Financial Issues FAQs
20	References



Background

Cancer-related financial burden in survivors has been linked to lower health-related quality of life (HRQOL), increased risk of depressed mood, and an increased frequency of worrying about cancer recurrence (Kale & Carroll, 2016).

In 2013, Zafar and Abernethy coined the term **financial toxicity**, which is the unintended financial consequences of cancer treatment, including objective financial burden and subjective financial distress. Out-of-pocket expenses related to cancer treatment are like a physical toxicity in that they can decrease quality of life (QOL) and impede delivery of the highest quality care. This financial burden has been linked with several clinically relevant patient outcomes, including decreased HRQOL, increased symptom burden, decreased compliance, and decreased survival (Lathan et al., 2016; Neugut et al., 2011; Ramsey et al., 2016; Zafar & Abernethy, 2013a; Zafar et al., 2015).

High Costs of Cancer Care

- In 2013, cancer care had the **fourth highest estimated spending of \$125 billion** among all medical conditions. (*Larner, 2016*)
- With the growth and aging population of the United States, the National Institutes of Health expect medical costs for cancer to reach at least **\$158 billion in 2020**. This is an **increase of 27%** from 2010. (*National Institutes of Health, 2011*)
- Drugs for the treatment of cancer account for **7 of the 10 highest priced therapies** available, and cost as much as \$40,000 per month or more. (*Young, 2015*)
- To obtain high-quality and safe cancer care, patients often face **very high costs and bear a disproportionately large financial burden** compared to those without cancer. This financial hardship may cause some patients to become nonadherent to their treatment plan. (*Fitzner, Oteng-Mensah, Patrick, & Heckinger, 2017*)
- Per the U.S. Census Bureau, about **29 million people (9.1%) in the United States were uninsured in 2015**. The percentage of uninsured people ranged from 2.8% in Massachusetts to 17.1% in Texas. (*Barnett & Vornovitsky, 2016*)
- Although most patients with cancer are insured, the high cost of cancer drugs can result in high out-of-pocket costs for patients, which may be unmanageable even for those with medical insurance. The Medical Expenditure Panel Survey revealed that \$1.3 billion (6.5%) of the \$20.1 billion spent on cancer care each year by nonelderly populations comes directly from the patients themselves. Patients with cancer **may spend an average of \$10,000 a month on chemotherapy alone**, causing a financially toxic and often highly unsustainable circumstance. (*Goodman, 2014*)
- High treatment costs affect patients financially and may lead to patients filing for bankruptcy. **More than one quarter of cancer survivors report financial burden**. The literature on the financial hardship that patients with cancer experience shows that these patients are less likely to work and more likely to file for bankruptcy than others. Moreover, high treatment expenses may play a part in patients forgoing or delaying medical care after cancer diagnosis. (*Goodman, 2014; Zafar & Abernethy, 2013b*)
- Of patients with cancer who declared bankruptcy, **79% had a greater mortality risk** compared to those who had not declared bankruptcy. (*Bansal et al., 2015*)
- The degree to which cancer caused financial issues was the **strongest independent predictor of QOL** compared to several other factors, including age, race, education, insurance status, and family income. (*Fenn et al., 2014*)
- Three factors might explain the relationship between heavy financial distress and a greater risk of mortality: **(a) poorer subjective well-being, (b) impaired HRQOL, and (c) subpar quality of care**. (*Zafar, 2016*)



Why Is Cancer Care Costing Patients So Much?

Patients are paying more out of pocket because of more expensive cancer treatments. Expensive treatments are overused; therefore, these excess costs are the responsibility of the patient. The cost of cancer is increasing because of the aging population, more patients with access to treatment, innovation, and overutilization. *(Zafar & Abernethy, 2013a)*

What happens when patients have financial burden and need to save money during cancer treatment?

- They do not adhere to drug/treatment regimen.
- They avoid recommended procedures.
- They skip healthcare appointments.

This is where the role of the oncology nurse navigator (ONN) comes in!

It doesn't matter if patients are insured, underinsured, or uninsured—all are at risk for financial burden and concerns!

Patients are often reluctant to talk about their financial issues because:

- If patients expect cancer treatment to work, they may be more likely to accept the financial burden.
- They want or might feel pressured to receive the best care, regardless of the cost.
- They might not think their healthcare providers are the right people to discuss cost concerns with.
- They might think their healthcare providers do not have the time to discuss financial issues.
- They might feel embarrassed about bringing up financial issues and distress with their healthcare providers.

(Zafar & Abernethy, 2013b)

Medicare, the “Donut Hole,” and Cancer Care

- Medicare Part A and Part B may cover certain cancer treatments, including but not limited to chemotherapy and radiation therapy. A patient’s Medicare costs will depend on whether they receive chemotherapy as an inpatient or outpatient.
- Medicare Part A covers chemotherapy and other cancer treatment that is given to the patient as an inpatient in the hospital, after the patient pays the Part A deductible.
- Medicare Part B generally covers outpatient chemotherapy treatments, such as in a freestanding clinic or doctor’s office. In this case, the patient pays 20% of the Medicare-approved amount, after paying the Medicare Part B deductible.
- Medicare Part B may also cover some cancer screenings (e.g., mammograms for breast cancer).
- Medicare Part B may cover limited prescription drugs, including some oral prescription drugs used in cancer care. Some antiemetic drugs may be covered as well. Typically, in these situations, the patient is responsible for 20% of the Medicare-approved amount, after the annual Medicare Part B deductible is applied. However, if the patient is admitted to a hospital, Medicare Part A typically covers the prescription drugs given to the patient as part of their inpatient care and treatment.
- For medications not covered by Medicare Part A or B, patients may require Medicare Part D coverage, or may be expected to pay the full cost of their prescription drugs.
- Medicare Part D adds drug coverage to other Medicare plans. Each Medicare prescription drug plan has its own formulary or list of drugs that are covered. Many Medicare drug plans place drugs into different “tiers” on their formularies, and each tier has a different cost.
- Patients should be instructed to routinely check their formulary (list of covered prescription drugs) of the plan they have or are considering to see if the medications they need are included. Patients should know, though, that their Medicare plan’s formulary may change at any time.
- Even with original Medicare coverage, there are still costs for the patient for their cancer treatment, such as coinsurance and deductibles. Some patients who are enrolled in Medicare Part A and B may be eligible to sign up for a Medicare Supplement (Medigap) plan to help pay for Original Medicare’s out-of-pocket costs.
- People on Medicare who also have low income and limited resources may get help paying for out-of-pocket medical expenses from their state Medicaid program.
- Coverage gap (also called the “donut hole”)
 - ▷ Most Medicare prescription drug plans have a coverage gap. This is a temporary limit on what the drug plan will cover for drugs.
 - ▷ Not everyone will enter the coverage gap. The coverage gap begins after the patient and their prescription drug plan has spent a certain amount for covered drugs.
 - ▷ For example, in 2017, once the patient and the prescription drug plan have spent \$3,700 on covered drugs, the patient is in the coverage gap. This amount may change each year.
 - ▷ For more information on coverage gap, visit the Medicare website:
<https://www.medicare.gov/part-d/costs/coverage-gap/part-d-coverage-gap.html>

(Hardy, 2016; Medicare.gov, n.d.)

Medicare, the “Donut Hole,” and Cancer Care *(continued)*

- High cost of cancer drugs
 - ▷ The cost of new cancer drugs has been escalating in recent years. Patients with cancer often have large out-of-pocket expenses (thousands of dollars in drug expenses annually) for the drugs used to treat their disease.
 - ▷ For some patients with inadequate insurance coverage, high drug costs simply make cancer treatment unrealistic.
 - ▷ Oral drugs for cancer treatment, as opposed to IV drugs, are usually not fully reimbursable by insurers and require a copayment that can be a fixed amount or a percentage of the total cost of the drug. Many of the newer oral drugs for cancer are quite expensive, which can lead to exorbitant out-of-pocket costs.
 - ▷ Oral cancer drugs are covered through a patient’s “pharmacy benefit,” whereas IV chemotherapy is covered through what is known as a “medical benefit.” Medical benefits for IV chemotherapy usually require patients to pay a flat copayment for care in an outpatient setting, which can include the administration of IV medications. The cost of IV chemotherapy for patients is usually very modest. Pharmacy benefits for oral chemotherapy are a very different animal. They often have a leveled copayment structure and other requirements that increase cost-sharing for more expensive medications.
 - ▷ Oral parity laws state that the reimbursement benefit for oral chemotherapy drugs cannot be any lower than the benefit for IV cancer therapy drugs, which will hopefully offer more affordable and accessible cancer care to patients. Medicare is excluded from oral parity laws.

(National Cancer Policy Forum, Board on Health Care Services, & Institute of Medicine, 2014)

The bottom line is that access to quality health insurance is vital to make cancer care affordable for patients and survivors. To learn more about the tremendous financial impact of cancer, review the *Costs of Cancer Report: Addressing Patient Costs*, recently published by the American Cancer Society Cancer Action Network. <https://www.acscan.org/policy-resources/costs-cancer>



Risk Factors for Financial Distress

Several identified factors can influence a patient's susceptibility to financial distress. These include:

- Wage-earner status of the household member with cancer (primary, secondary, etc.)
- Pre-illness debt load (a term that is used to describe a consumer's amount of debt)
- Assets (any item that is owned that increases net worth)
- Illness-associated costs (e.g., copayments, medication costs, travel expenses, etc.)
- The influence of the illness and its treatment on the patient's ability to work
- The presence and terms of the health and disability insurance of the patient
- Incomes of others in the household

(National Cancer Institute [NCI], 2016)

The following factors may determine the risk of long-term financial hardship for patients at the time of cancer diagnosis:

- The general health and noncancer comorbidities of the patient
- Assets
- Existing debt
- Household income
- Income from other sources (e.g., spouse or family member who works outside the home)

(NCI, 2016)

Risk factors identified for developing financial hardship include:

- Younger age
 - ▷ Secondary to things like lack of savings and assets, competing financial obligations (e.g., children), and lack of protection from Medicare coverage
- Minority race
- Low income
 - ▷ There is no consensus on an absolute income threshold below which patients face higher financial hardship.
- Medicaid or lack of insurance
- Work disability
- Loss of productivity and unemployment
 - ▷ Considered a risk factor for but also a measurement of financial hardship
- Patients with advanced-stage cancers, with cancers requiring chemotherapy or radiation therapy, and with underlying comorbidities

(NCI, 2016; Shankaran, Jolly, Blough, & Ramsey, 2012)

Affordable Care Act Tip Sheet

The Patient Protection and Affordable Care Act (ACA)

- Also known as healthcare reform, the Affordable Care Act, or ACA
- Passed in March 2010
- Main points of the ACA include:
 - ▷ You cannot be denied insurance because of a preexisting condition.
 - ▷ Your company cannot charge you more for healthcare benefits because you are female or male or because you have a specific health condition.
 - ▷ If you join a group insurance plan, you are entitled to receive benefits in 90 days or less.
 - ▷ Private insurance companies cannot limit how much they pay for care in your lifetime (lifetime maximum benefit).
 - ▷ Your insurance company cannot stop paying its part of your bills.
 - ▷ A company cannot cancel your insurance if it finds a mistake in your application.
 - ▷ If the plan covers your children, they are covered until they turn 26.
- ACA and Cancer Prevention and Cancer Care
 - ▷ Some preventive screenings, tests, and services can lower your cancer risk. The ACA requires health insurance to pay for them. The following are recommended by the U.S. Preventive Services Task Force:
 - Colorectal cancer screening tests if you are aged 50–75 years
 - Mammograms every year or two for women older than age 40 years. Companies must also pay for some other services to prevent breast cancer. For example, women with a higher risk for breast cancer may see a genetic counselor to talk about breast cancer risk and talk to a doctor about medication to prevent breast cancer.
 - Regular screening for cervical cancer and the human papillomavirus (HPV) vaccine to prevent cervical cancer
 - Help to stop smoking, such as counseling and medication
 - Lung cancer screening for adults aged 55–80 years with high risk for lung cancer because they are either heavy smokers or have quit in the past 15 years
 - ▷ Participation in a clinical trial
 - Most insurance companies cannot limit what they pay for if you are in a clinical trial. They must pay for all the healthcare services related to the clinical trial. This is true for insurance starting January 1, 2014, or later.
 - Your company cannot stop your insurance if you are currently participating in a clinical trial.
 - If your insurance started before January 1, 2014, the insurance company can limit what it pays for your participation in a clinical trial. The insurance company can also stop paying for your health care.

(Cancer.Net, 2016; HealthCare.gov, n.d.)



Available Tools for Financial Toxicity and Burden

Comprehensive Score for Financial Toxicity (COST) tool

Validated in patients with advanced cancer receiving treatment

<https://costofcancercare.uchicago.edu/page/faqs>

American Society of Clinical Oncology (ASCO) Choosing Wisely Campaign

For practitioners to avoid unnecessary, costly testing and treatment

<http://www.choosingwisely.org/societies/american-society-of-clinical-oncology>

Financial Toxicity Grading Criteria

For an example, visit:

<http://ascopubs.org/doi/full/10.1200/JCO.2014.57.8740>

Functional Assessment of Cancer Therapy (FACT) questionnaires

HRQOL questionnaires often used in conjunction with financial measures (e.g., COST measure)

<http://www.facit.org/FACITOrg/Questionnaires>

Resources/Websites That Are Helpful With Insurance and Cost Lingo

Cancer.Net: Glossary or cost-related terms

<http://www.cancer.net/navigating-cancer-care/financial-considerations/glossary-cost-related-terms>

Cancer.Net: Health insurance

<http://www.cancer.net/navigating-cancer-care/financial-considerations/health-insurance>

CancerCare: Insurance glossary

<http://www.cancercare.org/publications/296-insurance-glossary-terms-to-know>

Leukemia and Lymphoma Society:

Insurance coverage

<https://www.lls.org/managing-your-cancer/finances-and-insurance-coverage/insurance-coverage>

Association of Community Cancer Centers (ACCC):

The Financial Advocacy Toolkit includes helpful PDFs on:

- Insurance basics (Cancer Insurance Checklist):
<http://acc-cancer.org/resources/pdf/FAN/FAN-Cancer-Insurance-Checklist.pdf>
- Medicare and Medicaid:
<http://acc-cancer.org/resources/FinancialAdvocacy-Toolkit.asp>
- Patient assistance and copayments:
<http://acc-cancer.org/resources/FinancialAdvocacy-Toolkit.asp>
- Financial toxicity:
<http://acc-cancer.org/resources/FinancialAdvocacy-Toolkit.asp>

Costs of Cancer Care

How are a patient's out-of-pocket costs determined?

A patient's out-of-pocket expenses are dependent on several factors:

- What cancer treatment they will be receiving
- How long they will need to be treated
- Where they will be receiving treatment
- What type of health insurance coverage they have
- Whether they have supplemental healthcare insurance

Extra expenses a patient needs to be aware of include:

- Copayments (copays) for doctor visits
- Payments for laboratory tests, blood work, and other testing
- Payments for care received while undergoing cancer treatment (e.g., radiation therapy)
- Medication copayments
- Transportation and travel expenses (e.g., gas, parking, tolls, bus or taxi fares)
- Family expenses (e.g., childcare or elder care) while receiving treatment
- Caregiving expenses (e.g., in-home care or extended care facility)
- Employment and legal expenses (e.g., loss of wages, writing a will)

(Cancer.Net, 2015)

Comprehensive information on patient costs and what questions the patient should ask can be found here:

Cancer.Net: Questions to ask about cost

<http://www.cancer.net/navigating-cancer-care/financial-considerations/questions-ask-about-cost>

National Cancer Institute: Questions the patient should ask their doctor about treatment clinical trials (including cost)

<https://www.cancer.gov/about-cancer/treatment/clinical-trials/questions>

American Cancer Society: Managing the costs of cancer treatment

<https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/the-cost-of-cancer-treatment.html>

Disability Resources

Social Security Income (SSI) program

The SSI program makes cash assistance payments to older adults and people who are blind or disabled who have limited income and resources. The federal government funds SSI from general tax revenues.

Social Security Disability Insurance (SSDI) program

The SSDI program provides benefits to people who are disabled or blind who are “insured” by workers’ contributions to the Social Security Trust Fund. These contributions are based on each person’s earnings (or those of their spouse or parents) as required by the Federal Insurance Contributions Act (FICA).

Compassionate Allowances Initiative (CAL)

The CAL is a way to expedite the processing of SSDI and SSI disability claims for applicants whose medical conditions are so severe that their conditions obviously meet Social Security’s definition of disability.

<https://www.ssa.gov/compassionateallowances/index.htm>

Resources:

Social Security 2016 Red Book

Includes a comparison table between the two programs (SSI vs. SSDI)

<https://www.ssa.gov/redbook/eng/overview-disability.htm>

AARP: “What’s the Difference Between SSDI and SSI?”

<http://www.aarp.org/work/social-security/info-06-2012/social-security-disability-insurance-supplemental-security-income.html>

Social Security Disability Resource Center: “What Is the Difference Between Social Security Disability and SSI?”

<http://www.ssdrc.com/disabilityquestions1-28.html>

Compassionate Allowances Conditions list

<https://www.ssa.gov/compassionateallowances/conditions.htm>

Cancer and Careers

Discusses the legal and financial issues with having a career while undergoing cancer treatment

<http://www.cancerandcareers.org/en/at-work/legal-and-financial>

Financial Assistance

Several types of financial assistance are available to patients:

Health insurance

If patients have health insurance, it should cover many of the costs of cancer care. Patients should be told to review their insurance policy to see what their policy covers. Sometimes, an insurance company will assign a patient a case manager. If the insurance company denies a payment or coverage, the patient should ask their insurance company what they need to do to appeal the denial of coverage.

Government programs (e.g., Medicare, Medicaid, Social Security)

Patients must qualify to receive financial help from these programs. Many of these programs are for people who are disabled or elderly or who have low income (those earning less than twice the federal poverty line). Many state governments also have available programs to assist qualified state residents with medical and living expenses. These government program applications often have long processing times and, therefore, should be completed as soon as possible.

Public and nonprofit hospitals

Hospitals that are operated by state or local government. Some nonprofit hospitals are an option for those who need care, regardless of ability to pay. Usually, a social worker or the local health department can help identify “charity care” or “indigent care” programs available in the community.

Copayment relief programs

Numerous voluntary organizations offer financial assistance to patients who cannot afford to pay insurance premiums, copayments, deductibles, and other out-of-pocket costs. Each individual organization offers a type of assistance and has its own eligibility criteria (e.g., specific cancer type). Patients should be referred to these organizations as necessary.

Patient assistance programs

Many pharmaceutical companies have patient assistance programs that offer help with insurance reimbursement, refer patients to copayment relief programs, and help with patients’ applications for assistance. Some drug companies also offer medications at little or no cost to patients who do not qualify for other help.

Assistance from voluntary organizations

Voluntary organizations aid with practical needs (e.g., child care, household help, transportation). Each organization offers a type of assistance and may have its own eligibility criteria, so patients should contact each organization directly.

Fund-raising

Fund-raising may be an option for some patients after they have explored all other sources of financial help. Patients should also make sure that fund-raising will not disqualify them from other benefits, such as Medicaid or Social Security. Patients should consider working with an organization that has experience raising funds for medical treatment.

Personal financial planning

Patients can also seek advice from a professional, such as an accountant or a financial planner. An accountant may be able to help patients save money on income taxes (e.g., may be able to deduct out-of-pocket medical expenses from income). A financial planner can offer guidance and plans for patients’ financial future.

What types of information and documentation might a patient need for a financial counselor or to complete a financial assistance application?

General Information

- **Names and birth dates** of all people living in their house
- **Social security numbers** (their own, their spouse's, and that of any family member who is younger than age 18 years)

Household Income

- Copies of their **current federal tax return** with all schedules, including W-2s
- **Employment income (gross):** Provide paycheck stubs for the last two pay periods or three months of bank statements.
- **Self-employment income (gross):** Provide three months of bank statements.
- **Pension, retirement, Social Security income:** Provide their pension or retirement statement and/or Social Security award letter.
- **Unemployment, disability income, etc.:** Provide unemployment, disability award letter, or three months of bank statements.
- **Child support, alimony:** Provide a copy of their divorce decree, legal separation notice, or custody agreement.
- **Other:** Provide three months of bank statements with an explanation of their income source(s).
- **No income:** Provide a letter verifying support from family or friends.



Assets

- **Cash:** Total amount
- **Savings account(s):** Financial institution and total balance amount (may need to provide recent bank statement)
- **Checking account(s):** Financial institution and total balance amount (may need to provide recent bank statement)
- **Stocks, bonds, 401(K), and IRA:** Statement from bank or broker showing current value
- **Personal letter:** Personal explanation of why requesting financial assistance and any additional information that might help explain the inability to pay medical expenses

Personal Property

- **Vehicle(s), etc.:** Tax statement showing assessed value of vehicle(s) and other items (e.g., trucks, motorcycles, mobile homes, campers, etc.) claimed with the amounts owed
- **Real estate property:** Most current tax statement showing acreage and value along with the mortgage statement from the bank

Additional Documents

- **Life insurance:** Policy or statement specifying cash-in value
- **Custody:** A copy of custody papers
- **Financial assistance:** View the following application examples (provided for reference only with permission by the identified organization; not to be altered or used for other purposes without express consent):
https://www.ons.org/sites/default/files/FiancialAssistanceApp_LVHN_English.pdf
https://www.ons.org/sites/default/files/FiancialAssistanceApp_LVHN_Spanish.pdf





General Financial Support and Drug Assistance Resources

The following include general financial assistance resources, as well as prescription drug, lodging, travel, clinical trials, etc., assistance.

Cancer.Net: “Financial Resources”

<http://www.cancer.net/navigating-cancer-care/financial-considerations/financial-resources>

CancerCare: “Sources of Financial Assistance”

<http://www.cancercare.org/publications/62-sources-of-financial-assistance>

Cancer Financial Assistance Coalition: “Resource Directory”

<http://www.cancerfac.org/>

Susan G. Komen: “How to Find Financial Assistance”

<http://ww5.komen.org/BreastCancer/FinancialResources.html>

American Cancer Society: “If You Have Trouble Paying a Bill”

<https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/if-you-have-trouble-paying-a-bill.html>

NCI: “Organizations That Offer Support Services”

<https://supportorgs.cancer.gov/home.aspx?js=1>

ACCC: “2017 Patient Assistance and Reimbursement Guide”

<https://www.accc-cancer.org/publications/PatientAssistanceGuide.asp>

ONNs’ Most Commonly Used Websites for Financial Assistance

AgingCare

www.agingcare.com

BenefitsCheckUp® by the National Council on Aging (includes prescription extra help program)

www.benefitscheckup.org

Cancer and Careers

<https://www.cancerandcareers.org/en>

Cancer Care

<http://www.cancercare.org>

Good Days

www.mygooddays.org

Needy Meds

<http://www.needymeds.org/>

Partnership for Prescription Assistance

<https://www.pparx.org/>

PAN Foundation

www.panfoundation.org

Patient Advocate Foundation

<http://www.patientadvocate.org/>

RxAssist

<http://rxassist.org/>

RxHope

www.rxhope.com

Financial Issues FAQs

Here are some of the more common financial questions that ONNs are asked:

1 Who in your facility/organization handles financial issues/concerns/counseling? What if there isn't a financial counselor in your organization to refer to?

Most organizations have a financial counselor who will assist with charity care programs, as well as setting up payment plans; seeking all methods of coverage, such as plans available through the ACA; and applying for disability/Medicaid.

If your organization does not have a financial counselor in your organization to refer to, here are a few recommendations and resources to help guide you:

- **Speak with your healthcare team**, including the social worker, who may offer suggestions and direct you to private and public financial resources.
- **Social Security disability options:** Patients with advanced cancer may qualify for Social Security Disability. Patients should contact the Social Security Administration to determine whether they qualify. www.ssa.gov
- **Early life insurance payouts:** A life insurance policy ordinarily pays benefits to a beneficiary after the policy owner dies. Some life insurance policies offer early payments to policy holders who are chronically or terminally ill.
- **Individual pharmaceutical companies:** Almost every pharmaceutical company has a patient assistance program to help patients with copayments for specific drugs. The website is usually found easily under the name of the drug.
- **The Cancer Support Community** has published a booklet titled “Frankly Speaking About Cancer: Coping With the Cost of Care,” which discusses how to navigate health insurance, employment, disability, income, and debt issues and pay for medications, and includes a comprehensive list of national resources and support organizations for patients with cancer. www.cancersupportcommunity.org
- **CancerCare** has a web page dedicated to helping you find resources in your community. http://www.cancercare.org/publications/60-finding_resources_in_your_community

IMPORTANT: Always remember that not all patients will have Internet access at home. If this is the case, patients should be reminded that their local public library will most likely have computers and someone who can assist them with finding web-based resources.

2 What is the best way to start a conversation about finances with a patient to make them feel comfortable talking about their concerns?

Finances are a very personal matter. One of the most important elements of helping people feel comfortable talking about their finances is to have the conversation in a quiet and private setting. Additional elements of the setup include allotting enough time to develop rapport with patients and patients not feeling rushed during the discussion. Put patients and families at ease by using these additional financial conversation tips:

Prepare by gathering pertinent background information. Some of this information may be in the patient's medical records. If not, be prepared to fill in the blanks during the conversation.

- Is the patient insured? Primary or secondary?
- Has the patient already accrued financial charges from surgery or other diagnostic and staging studies?
- Is the patient employed?
- Does the patient have dependents still living at home?

Ask permission to discuss financial concerns. Let patients know that financial worry is one of the most common stressors patients with cancer face. Honor patients' readiness to talk about financial worries.

Know current local and national financial resources and educate patients on what is available. If patients do not want to discuss finances or they deny having financial concerns, they may be open to hearing about what resources are available should their situation change.

3 When or how should you refer a patient for financial counseling?

In the inpatient setting, the first financial screening assessment is performed by a case manager (RN). Questions they ask include:

- Does the patient work?
- Who does patient live with?
- What is the patient's retirement income, savings, SSI?
- Does the patient own a home?
- What are the patient's monthly bills?
- What is the patient's monthly rent/mortgage payment?
- Does the patient own a car?
- How does the patient pay for daily living expenses?
- How does the patient pay for medication?
- Does the patient have a credit card?

Based on the answers to these questions, the case manager makes referrals. When the ONN meets with each patient, they follow up on these questions and make separate referrals for medication assistance, food assistance, and other services. The ONN also receives referrals from social workers and counselors based on the results of distress screening, which indicate financial stressors.



Some outpatient infusion clinics may not have a financial counselor to perform a screening. The outpatient navigator may refer patients to the financial counselor for the following reasons:

- Patient has no job, or will not be receiving income during treatment
- Patient has difficulty paying bills
- Patient has no insurance, or is underinsured
- Patient has poor or no pharmacy coverage

In this case, the financial counselor or support person would inquire about insurance and refer patients to Medicaid or charity care, and the infusion RNs are sometimes the ones to follow up on referrals for assistance.

4 When is the best time to talk to my patient about financial concerns?

The best time to talk to your patient is at the beginning; however, patients may be in disbelief and overwhelmed by their diagnosis, so it may not be appropriate. You can still be proactive in addressing financial concerns and identifying potential gaps during your initial assessment. It is important to get to know your patient and what their role is in the household. The following questions may give insight into this:

- How many people live in your home?
- What are their ages?
- Have you been working full time?
- How has your daily routine changed since your diagnosis?

Very soon after that first visit, reality may set in, and patients may ask questions like “How am I going to afford this?” “How will this affect my family?”

This is the time to ask more direct questions and help your patient feel comfortable sharing financial concerns. This should be an ongoing process because financial toxicity, like treatment toxicity, is cumulative and may not peak until entering survivorship. ONNs need to constantly be in tune to patients’ financial concerns and readdress them often throughout the cancer experience.

5 What are the best patient advocacy groups to refer my patients to?

Patient Advocate Foundation

<http://www.patientadvocate.org>

National Patient Advocate Foundation

<http://www.npaf.org>

Leukemia and Lymphoma Society

<http://www.lls.org>

National Comprehensive Cancer Network advocacy and support groups

<https://www.nccn.org/patients/advocacy>

6 Where do I find or how do I access local organizations and resources in my area?

First, find out if there is someone in your organization who may be familiar with resources in your area. For instance, are there social workers, financial counselors, or case managers in your organization? You may be able to collaborate with them. Check with colleagues in other specialty areas, such as palliative care, hospice, or HIV services. If you have a local Oncology Nursing Society chapter, network with your oncology nursing colleagues about their knowledge of local resources.

Most national organizations like the American Cancer Society and Leukemia & Lymphoma Society can help you connect to their local services. Check their websites or call their toll-free numbers.

Many resources are available for people with specific cancer diagnoses, such as Pink Fund for patients with breast cancer. Search the terms diagnosis and financial assistance on the Internet to find many of these resources.

Statewide programs exist to assist people in applying for Medicaid and state assistance. Search www.medicaid.gov to find the contact information for your state.

Usually, many local resources exist to help people in need. Check with the leadership of your cancer program to find out if any grant funds are available to help your patients in need. Ask your patient to check with their utility company to assist with utility payments. Rental assistance may be available through the Agency on Aging, the Department of Welfare, or the Council of Churches. Public transportation in your area may offer aid through Medicaid. Local groups like the Rotary or the Lions Club may offer aid as well, particularly if the patient is tied to the organization. Other local resources include the local housing authority, food banks, the Salvation Army, and churches.

References

- Bansal, A., Ramsey, S.D., Fedorenko, C.R., Blough, D.K., Overstreet, K.A., Shankaran, V., & Newcomb, P.A. (2015). Financial insolvency as a risk factor for mortality among patients with cancer. Abstract presented at the American Society of Clinical Oncology Annual Meeting, Chicago, IL.
- Barnett, J.C., & Vornovitsky, M.S. (2016). *Health insurance coverage in the United States: 2015*. Retrieved from <https://www.census.gov/content/dam/Census/library/publications/2016/demo/p60-257.pdf>
- Cancer.Net. (2015). Understanding the costs related to cancer care. Retrieved from <http://www.cancer.net/navigating-cancer-care/financial-considerations/understanding-costs-related-cancer-care>
- Cancer.Net. (2016). Cancer and the Affordable Care Act. Retrieved from <http://www.cancer.net/navigating-cancer-care/financial-considerations/cancer-and-affordable-care-act>
- Fenn, K.M., Evans, S.B., McCorkle, R., DiGiovanna, M.P., Puzstai, L., Sanft, T., . . . Chagpar, A.B. (2014). Impact of financial burden of cancer on survivors' quality of life. *Journal of Oncology Practice*, 10, 332–338. doi:10.1200/JOP.2013.001322
- Fitzner, K., Oteng-Mensah, F., Patrick, D., & Heckinger, E.A.F. (2017). Safety of cancer therapies: At what cost? *Population Health Management*. Advanced online publication. doi:10.1089/pop.2016.0097
- Goodman, A. (2014). Financial toxicity potentially harmful treatment-related effect. Retrieved from <http://www.ascopost.com/issues/november-15-2014/financial-toxicity-potentially-harmful-treatment-related-effect>
- Hardy, B. (2016). Does Medicare cover cancer treatment? Retrieved from <https://medicare.com/coverage/does-medicare-cover-cancer-treatment>
- HealthCare.gov. (n.d.). Health coverage rights and protections. Retrieved from <https://www.healthcare.gov/health-care-law-protections>
- Kale, H.P., & Carroll, N.V. (2016). Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer*, 122, 283–290. doi:10.1002/cncr.29808. Epub 2016 Mar 14.
- Larner, L. (2016). Health Affairs web first: In 2013, US spent more on mental disorders than on any other medical condition. Retrieved from <http://healthaffairs.org/blog/2016/05/18/health-affairs-web-first-in-2013-us-spent-more-on-mental-disorders-than-on-any-other-medical-condition>
- Lathan, C.S., Cronin, A., Tucker-Seeley, R., Zafar, S.Y., Ayanian, J.Z., & Schrag, D. (2016). Association of financial strain with symptom burden and quality of life for patients with lung or colorectal cancer. *Journal of Clinical Oncology*, 34, 1732–1740. doi:10.1200/JCO.2015.63.2232
- Medicare.gov. (n.d.). What drug plans cover. Retrieved from <https://www.medicare.gov/part-d/coverage/part-d-coverage.html>
- National Cancer Institute. (2016). Financial toxicity and cancer treatment (PDQ®)—Health professional version. Retrieved from https://www.cancer.gov/about-cancer/managing-care/financial-toxicity-hp-pdq#link/152_toc

National Cancer Policy Forum, Board on Health Care Services, & Institute of Medicine. (2014). *Ensuring patient access to affordable cancer drugs: Workshop Summary*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK268684>

National Institutes of Health. (2011). Cancer costs projected to reach at least \$158 billion in 2020. Retrieved from <https://www.nih.gov/news-events/news-releases/cancer-costs-projected-reach-least-158-billion-2020>

Neugut, A.I., Subar, M., Wilde, E.T., Stratton, S., Brouse, C.H., Hillyer, G.C., . . . Hershman, D.L. (2011). Association between prescription co-payment amount and compliance with adjuvant hormonal therapy in women with early-stage breast cancer. *Journal of Clinical Oncology*, 29, 2534–2542. doi:10.1200/JCO.2010.33.3179

Ramsey, S.D., Bansal, A., Fedorenko, C.R., Blough, D.K., Overstreet, K.A., Shankaran, V., & Newcomb, P. (2016). Financial insolvency as a risk factor for early mortality among patients with cancer. *Journal of Clinical Oncology*, 34, 980–986. doi:10.1200/JCO.2015.64.6620

Shankaran, V., Jolly, S., Blough, D., & Ramsey, S.D. (2012). Risk factors for financial hardship in patients receiving adjuvant chemotherapy for colon cancer: A population-based exploratory analysis. *Journal of Clinical Oncology*, 30, 1608–1614. doi:10.1200/JCO.2011.37.9511

Young, R.C. (2015). Value-based cancer care. *New England Journal of Medicine*, 373, 2593–2595. doi:10.1056/NEJMp1508387

Zafar, S.Y. (2016). Financial toxicity of cancer care: It's time to intervene. *Journal of the National Cancer Institute*, 108(5), djv370. doi:10.1093/jnci/djv370

Zafar, S.Y., & Abernethy, A.P. (2013a). Financial toxicity, part I: A new name for a growing problem. Retrieved from <http://www.cancernetwork.com/oncology-journal/financial-toxicity-part-i-new-name-growing-problem>

Zafar, S.Y., & Abernethy, A.P. (2013b). Financial toxicity, part II: How can we help with the burden of treatment-related costs? Retrieved from <http://www.cancernetwork.com/oncology-journal/financial-toxicity-part-ii-how-can-we-help-burden-treatment-related-costs>

Zafar, S.Y., McNeil, R.B., Thomas, C.M., Lathan, C.S., Ayanian, J.Z., & Provenzale, D. (2015). Population-based assessment of cancer survivors' financial burden and quality of life: A prospective cohort study. *Journal of Oncology Practice*, 11, 145–150. doi:10.1200/JOP.2014.001542

Funding for the development of this toolkit was provided by **Genentech**



ONS is solely responsible for the criteria, objectives, content, quality and scientific integrity of its programs and publications.