



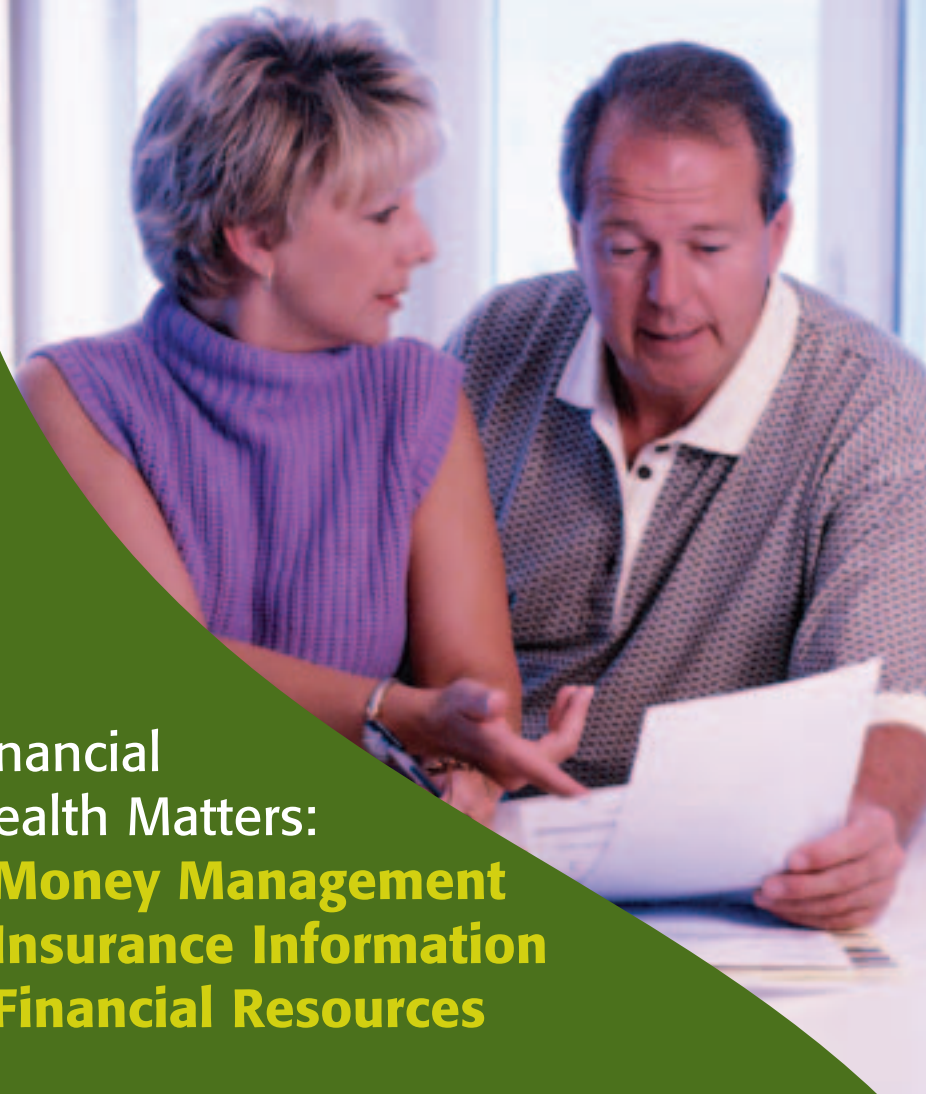
We hope you have found this booklet helpful in learning about some of the financial challenges facing those diagnosed with CML.

If you have any questions about anything you have read in this booklet, The Leukemia & Lymphoma Society is here to help.

For further information and support services, contact The Leukemia & Lymphoma Society's Information Resource Center at **(800) 955-4572**. Speak to a CML information specialist **Monday through Friday, 9 am to 6 pm EST**, or visit us online at <http://cml.tlls.org>

Models used for illustrative purposes only.

3/03



Financial Health Matters:

- **Money Management**
- **Insurance Information**
- **Financial Resources**

The third in a series of CML teleconferences featuring:
Diane Pammenter Tolley, Author of *Finding the Money:*

A Guide to Paying Your Medical Bills

Erin Moaratty, *Patient Advocate Foundation*

Jocelyn D'Antonio, MS, RN, *The Leukemia & Lymphoma Society*

*Created especially for people with CML
and those who care for them through
an unrestricted grant from:*



Diane Pammenter Tolley

Author

As the parent of a child with non-Hodgkin lymphoma who has spent the last 15 years helping patients and families find the money to pay for medical costs, Diane Pammenter Tolley has developed a unique perspective on what it takes to cope with the financial pressures of a serious illness. Her book, *Finding the Money: A Guide to Paying Your Medical Bills*, offers explicit advice on dealing with insurers and raising funds for medical expenses that insurance does not cover. Copies of the book may be ordered by e-mailing Diane at tolley@bendcable.com.

Erin Moaratty

Patient Liaison Representative

Patient Advocate Foundation

An expert on resolving insurance, job discrimination, and debt crisis matters related to serious illness, Erin Moaratty educates patients on how to communicate effectively with their insurers and health care providers. She helps patients learn how to negotiate with insurance representatives and medical providers to obtain access to care. Erin also monitors trends on health care issues and trains Patient Advocate Foundation case managers to ensure that patient needs are addressed promptly and accurately.

Jocelyn D'Antonio, MS, RN

Oncology Nurse

Information Specialist, The Leukemia & Lymphoma Society

As an Information Specialist for The Leukemia & Lymphoma Society, Jocelyn D'Antonio provides disease information, support, and referrals to patients and families from around the world. Prior to joining the staff of the Information Resource Center, Jocelyn worked as an oncology and hospice nurse at Mercy Medical Center in Rockville Centre, New York. A graduate of Molloy College and Adelphi University, Jocelyn is also a certified clinical nurse specialist in mental health and psychiatric nursing.



Preserving financial health

Financial concerns can add to the stress of living with cancer. Patients who do not have adequate health insurance worry about how they will pay for care. Those who have insurance often find that it does not cover all the costs related to their illness. The process of filing claims and dealing with insurers can also overwhelm patients. Unfortunately, there are not always simple solutions to the challenge of coping with the financial impact of cancer treatment.

As frustrating as it can be to deal with these issues, there are ways to reduce the financial burden. With persistence, it is possible to obtain some financial support. It also helps to have an advocate who can assist the patient in accessing resources and resolving problems that may arise.

How this booklet can help

This booklet introduces some of the major financial issues confronting people with blood-related cancers and their families. It suggests resources that may be helpful in relieving fiscal stress and preserving financial health. These include:

- Understanding health insurance coverage
- Enrolling in entitlement programs
- Obtaining financial assistance
- Finding an advocate

Understanding health insurance coverage

Having health insurance coverage is important for people with cancer. It pays for costly medical treatment and helps protect patients and their families from financial hardship. Yet millions of Americans do not have adequate medical coverage at the time they are diagnosed with cancer. Many people find out after they are diagnosed that the insurance they have does not cover the expensive medicines or experimental treatments they may need. Or they may be denied coverage if their cancer is considered a **preexisting condition**, that is, a medical condition for which they had received treatment prior to enrolling in a health plan. Some may lose their insurance coverage or let it lapse when they leave or change jobs. Others may not be able to afford the cost of private insurance but do not realize that they may qualify for government programs or other types of assistance.

Knowing what is covered

People who have health insurance need to read their policy carefully to learn what services are covered and what portion of the medical expenses they are responsible for paying. These may include:

- **Premium** – the cost of participating in the plan
- **Deductible** – the amount that must be paid each year before the covered benefits become available
- **Co-payment** – the fee paid by the patient to the provider at the time of service
- **Coinsurance** – the percentage of the bill that is the patient's responsibility

The policy will also state the **lifetime cap**, the maximum benefits that will be paid for each individual enrolled in the plan.

Getting organized

Start by checking to make sure that the personal information about all individuals covered under the health insurance plan is correct. This information can be found on the **Declarations** page (often the first page of the policy). Then, review the **Summary of Benefits**, paying particular

attention to any exclusions or limits to the coverage. Do not overlook any endorsements; these are the periodic updates to the plan. In addition to reading the policy, there are three other steps that can help people with cancer get the most from their coverage:

- Keep a copy of all bills and statements and a written record of any conversations with insurers.
- Pay premiums on time to avoid any lapse in coverage.
- Learn what to do if a claim is denied. (See the Take Action plan at the back of this booklet.)

Keeping insurance coverage

Cancer survivors who lose, leave, or change jobs may be able to remain on the company plan if they are eligible for **COBRA** coverage. This federal law requires some employers to offer continuous health coverage to employees for a limited time after they leave their jobs. Even though employees must pay the premiums themselves, COBRA generally provides better coverage than they could obtain through an individual plan. Cancer survivors who are not eligible for COBRA, or those who are job hunting, may want to consider seeking employment at a large company that offers health insurance as a job benefit. That's because it can often be more difficult to obtain insurance as an individual after being diagnosed with cancer.

Where to learn more

Patient Advocate Foundation (PAF)
(800) 532-5274 www.patientadvocate.org

PAF draws upon the expertise of case managers, attorneys, and doctors who work with patients and their insurers, employers, and creditors to resolve insurance problems, job discrimination issues, and debt crisis matters. The PAF Web site features a comprehensive state-by-state directory of financial resources for housing, utilities, food, transportation, medical treatment, and children's needs. Also available on the Web site is *Your Guide to the Appeals Process*, step-by-step instructions on how to appeal an insurer's denial of coverage.

Enrolling in entitlement programs

Cancer survivors who meet certain criteria may qualify for health insurance, disability benefits, or cash payments provided through government “entitlement” programs. These programs are open to anyone who qualifies, regardless of his or her medical condition.

Many people are not aware that they may be entitled to these valuable benefits, which include:

- **Medicare** – Medical coverage for people age 65 and older, younger people with disabilities, and people on kidney dialysis. (800) 633-4227 or www.medicare.gov
- **Medicaid** – Medical benefits for those with limited income and assets. Visit <http://cms.hhs.gov/medicaid/tollfree.asp> for a list of state Medicaid hotline numbers.
- **SCHIP** – Low-cost health insurance offered in every state for uninsured children up to age 18. (877) 543-7669 or www.insurekidsnow.gov
- **Hill-Burton** – Free or low-cost treatment for patients who are unable to pay at hospitals and health facilities that receive federal funding. (800) 638-0742 or www.hrsa.gov/osp/dfcr
- **Veteran’s Benefits** – Comprehensive health care and other benefits for veterans with service-connected disabilities and financial need. (800) 827-1000 or www.va.gov
- **Social Security Disability** – Income replacement program for people who are unable to work because of a disabling condition. (800) 772-1213 or www.ssa.gov
- **Supplemental Security Income** – Monthly cash benefit for low-income people who are disabled, blind, or age 65 or older. (800) 772-1213 or www.ssa.gov

Accessing entitlement programs

The single most important consideration for enrolling in entitlement programs is to apply early. Many of these programs have waiting lists or waiting periods before covered benefits and services take effect.

Obtaining health insurance coverage

Patients who do not have adequate health insurance can check with their local Social Security office to see if they may be eligible for any of the entitlement programs described on these pages. People with cancer may also contact their State Department of Insurance to find out if the state has a **high-risk pool**, a program that makes health coverage available to people who are considered medically uninsurable. To find consumer health insurance guides by state on the Web, go to www.healthinsuranceinfo.net.

How The Leukemia & Lymphoma Society can help

The Leukemia & Lymphoma Society offers a wealth of information, guidance, and support to patients and families coping with CML and other blood-related cancers. For general information on entitlement programs and sources of financial assistance, call The Leukemia & Lymphoma Society’s Information Resource Center at (800) 955-4572.

Practical advice and information on insurance, managed care, employment issues, and financial aid are available online at <http://cml.tlls.org> in the section on Patient/Caregiver Services.

Additional support is provided through the Society’s network of more than 60 chapters nationwide. Patient services managers based in each chapter can help patients and caregivers research and access local and state resources.

Obtaining financial assistance

Even a comprehensive health insurance plan may not cover all the costs of cancer care.

Prescription drugs

People who do not have insurance to cover the cost of prescription medications for cancer treatment may want to explore the following options with their doctor or social worker.

- **Patient assistance programs** sponsored by major pharmaceutical manufacturers that provide free or reduced-cost medications to patients who cannot afford them. For example, Novartis sponsors such a program to help patients pay for Gleevec™. For more information, call (877)-GLEEVEC.
- **Prescription savings programs**, such as Together Rx, which offers substantial discounts on widely prescribed medications to Medicare enrollees who meet the income requirements.
- **Participation in clinical trials** for promising cancer drug therapies. To determine whether a study drug is available free or at a reduced cost, check with the patient's health care provider, insurance representative, or the study contact.

Cancer survivors who do have a prescription drug plan may find that it does not cover certain costly medicines. By negotiating with the insurance company, they may be able to get a particular drug added to the **formulary** (the insurer's list of covered medications).

Where to learn more

Pharmaceutical Research and Manufacturers of America (PhRMA)
(800) 762-4636 www.phrma.org

Maintains a directory of patient assistance programs for prescription drugs. Through these programs, PhRMA member companies supply free medicines to millions of eligible low-income patients.

Stem cell transplantation

Stem cell transplants are expensive. In addition to the procedure itself, which may not be fully covered by insurance, patients may incur significant expenses for travel, lodging, meals, phone calls, child care, donor testing, and posttreatment care. Patients and caregivers may need to employ multiple strategies to secure enough funding to cover these costs. These strategies may include:

- **Working closely with the transplant center** to obtain maximum reimbursement from the insurance company.
- **Applying for grants and financial aid** from employers, labor unions, community service agencies, religious and fraternal groups, or cancer support organizations.
- **Forming a committee of volunteers to conduct fund-raising events**, sales, raffles, canister collections, and letter-writing and publicity campaigns.
- **Negotiating with health care providers** to reduce or waive medical fees or adjust the payment schedule in cases of financial hardship.
- **Cashing in life insurance through viatical settlements or accelerated benefits**, which provide cash payouts to seriously ill policyholders. It is important to discuss this strategy with a financial professional before pursuing either of these options.

Blood & Marrow Transplant Information Network (BMT InfoNet)
(888) 597-7674 www.bmtinfonet.org

National Foundation for Transplants
(800) 489-3863 www.transplants.org

These two nonprofit organizations provide assistance and advocacy to help patients and their families raise funds for transplant costs.

Finding an advocate

Staying on top of medical bills, obtaining financial relief, and dealing with insurance problems can be tedious and trying. Having an advocate to support and guide the patient can be extremely valuable in preserving financial and emotional well-being.

What family and friends can do

In addition to managing the kinds of fund-raising efforts described on page 7, friends and relatives may be especially helpful in:

- Setting up a record-keeping system to keep track of bills and insurance claims
- Calling public and private agencies to determine eligibility for financial assistance, entitlement programs, and other benefits and services
- Gathering documents to support insurance claims and appeals, and following up with the insurance company

One caveat: Be sure to delegate time-sensitive tasks only to those who can be trusted to meet the deadlines.

What professionals can do

The professionals who staff the national organizations that support people with cancer can provide expert advice on preserving assets, reducing debt, accessing community resources, handling employment issues, minimizing insurance problems, and utilizing legal remedies if necessary. This type of guidance can be invaluable in helping patients learn how to advocate for themselves more effectively.

How Cancer Care can help

Cancer Care
(800) 813-4673 www.cancer.org

This national nonprofit agency provides emotional support, information, and practical help to people with cancer and their loved ones. All services are provided free of charge.

Take-Action Plan

If the insurance company refuses to pay for a treatment your doctor has recommended, you may be able to get the decision overturned by filing an appeal. To improve your chance of success, be courteous and honor deadlines for obtaining key documents and submitting all necessary paperwork. Also, whenever you speak with an insurance representative, be sure to record the date and time as well as the name, phone number, and extension of the person who handled the call.

Questions to ask your insurer if you are appealing a denial of coverage

1. Can you send me a copy of the denial letter? Yes No
2. Please tell me the *specific reason* why the claim was denied?
(This information should be included in the denial letter.)

3. How can I get a current copy of the plan document and plan summary? (You may have to request these documents in writing.)

4. Whom can I contact at the insurance company to discuss the denial? May I have that person's direct phone number?
Name _____

Telephone number _____
5. Is there anyone else I can speak to if I have questions about the appeals process?
Name _____

Telephone number _____