



**The Leukemia &
Lymphoma Society®**
Fighting Blood Cancers

Financial Health Matters

INSURANCE INFORMATION & FINANCIAL RESOURCES

LEUKEMIA

LYMPHOMA

MYELOMA



Introduction

Healthcare costs are a key concern for many people with leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative diseases. Patients and families need to determine how they will pay for treatment. Some patients do not have health insurance. Even for those with coverage, certain treatments and charges may not be included or paid in full. Patients may need help filing or appealing health insurance claims. Additionally, patients need to plan for indirect costs, including lost time from work, added child care and transportation and travel expenses.

There are steps you can take to manage your finances before, during and after treatment. For example, you can

- Speak with your physician and ask for a timeline for your treatment
- Learn your insurance plan's oncology benefits, mail-order pharmacy benefits, preauthorization, referral and claims appeal rules
- Assess your anticipated medical expenses and whether your income might be reduced
- Consider reducing unnecessary expenses
- Speak with creditors early if you expect difficulty making payments
- Check to see if you have home mortgage or car payment insurance to help cover expenses during your illness
- Take advantage of disability plans if needed during your treatment and recovery
- Seek access to co-payment programs that help insured patients meet their pharmaceutical co-payment expenses.

The Leukemia & Lymphoma Society's (LLS) Information Resource Center offers guidance about health insurance, government programs, disability benefits, financial assistance programs and health advocacy. LLS chapters' patient services staff can help patients and caregivers connect with LLS programs and community resources.

This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society, with the understanding that LLS is not engaged in rendering medical or other professional services.

Inside This Booklet

Managing Health Insurance Coverage	2
Navigating Public Programs	8
Applying for Financial Aid	11
Taking Action	15

Managing Health Insurance Coverage

Health insurance helps pay for costly medical treatment and can protect patients and their families from financial hardship. There are different types of private and public health insurance programs. Some people have private health insurance coverage either through an employer (often called a “group plan”) or through an individual policy that they have purchased. Some patients qualify for public or government-funded health insurance programs, including Medicare, Medicaid, State Children’s Health Insurance Program (SCHIP) and other special interest programs (see *Navigating Public Programs* on page 8 for more details about these programs).

Millions of people living in the United States do not have health insurance or do not have enough medical coverage. Some people may lose their insurance coverage or let it lapse when they leave or change jobs. Others who cannot afford the cost of private insurance may not realize that they qualify for government programs or other types of assistance. Or, patients may find out after they are diagnosed with cancer that their insurance does not cover the prescription drugs or treatments they need.

Know what is covered

It’s important for patients with health insurance to know what is covered and how to protect their benefits. This is not only important for newly diagnosed patients, but also for survivors who will need follow-up visits.

Protecting Patients' Rights

A patient may be denied coverage for a period of time if his or her cancer is considered a pre-existing condition. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides several protections for patients who have pre-existing conditions. The law defines a pre-existing condition as a condition for which medical advice, diagnosis, care or treatment was recommended or received during the 6-month period prior to an individual's medical coverage enrollment date. HIPAA limits these exclusions and bans discrimination against employees and dependents based on their health status. In most cases, group health plans cannot exclude a condition from coverage for longer than 12 months. Here are some possible scenarios:

- If an individual was previously uninsured, but takes a job with an employer offering health coverage, the maximum waiting period for medical coverage is 12 months.
- If a patient has "creditable" health insurance (coverage in a group health plan, COBRA continuation coverage, Medicare, Medicaid, a state health benefits risk pool, a public health plan, and certain other health plans and programs) for 12 continuous months, with no lapse in coverage of 63 days or more, a new group or individual health plan cannot impose the pre-existing exclusion. This has helped to ease the issue of "job-lock," whereby people are reluctant to switch to a different job or company for fear of losing their health coverage. In this case, there cannot be a waiting period or breaks in dependent coverage for a pre-existing health condition. Certificates that document prior health coverage periods are issued to individuals by insurance carriers when coverage is terminated.

Cancer Legal Resource Center (CLRC)

(866) 843-2572 • Click on the "About DLRC" menu at www.disabilityrightslegalcenter.org to see information about the CLRC program.

CLRC provides free information and resources on cancer-related legal issues to cancer patients, families, caregivers and healthcare professionals.

People with health insurance need to read their policies carefully to understand the health and medical services that are covered. They also need to know the portion of medical expenses that they are responsible for paying. These expenses may include

- Premiums—the cost of participating in the plan; premium payments are usually made monthly.
- Deductibles—a fixed amount of money that must be “met” or paid by a patient each year before the insurance carrier will cover medical expenses.
- Co-payments—a set dollar amount paid by the patient at the time of service for certain medical services and prescription drugs. Co-pay amounts are not applied against the insurance plan deductible amount(s). The co-pay amount may vary depending on whether the patient is seeing a specialist (e.g., hematologist/oncologist) or a primary care provider.
- Coinsurance—the percentage of medical expenses shared by the patient and the health plan. For example, for some types of plans, the insurer pays 80 percent of covered expenses and the remaining 20 percent of the medical charges are the patient’s responsibility. This cost is in addition to any deductibles and co-payments. Coinsurance may apply to hospital services, certain laboratory tests and for managed care plans, instances when a patient receives medical care from a health provider outside of the plan’s network.
- Lifetime maximum or “cap”—the maximum benefits that will be paid for each individual enrolled in the plan during the individual’s lifetime.

Some plans, such as health maintenance organizations (HMOs), limit patients’ choice of providers to those within the plan’s approved network. Other types of health insurance plans are fee-for-service plans, point-of-service (POS) plans and preferred provider organizations (PPOs). PPOs sometimes offer more choices than HMOs, but may cost more.

Health Insurance Plans

The following general descriptions may vary from your coverage, so always check your own plan description.

Health Maintenance Organizations (HMOs) provide plan members with reduced costs and little paperwork for medical services from specific doctors, hospitals, and clinics. These specific providers must be used for medical services in order to be covered under the plan. Plan members choose a primary care physician and must get a referral from the primary care physician to see a specialist.

Preferred Provider Organizations (PPOs) also provide plan members with reduced costs. Members pay a standard co-pay amount for an office visit. They can choose between a plan or non-plan provider instead of being restricted to designated providers. A member may go to a specialist without permission from the primary care physician, as long as the specialist is part of the PPO network. A network specialist would be the least expensive choice. If a member sees an out-of-network specialist, he or she may have to pay the entire bill first, then submit a claim for reimbursement. There may be a deductible for out-of-network medical services, or members may have to pay the difference between what network doctors charge and what out-of-network doctors charge.

Point-of-service (POS) plans blend the features of HMO and PPO plans. Plan participants can choose the type of provider network best suited to their needs each time they seek care. This type of plan enables participants to obtain care from a network provider for one type of care and at the next “point of service,” to see a provider who has contracted with the POS plan to provide services at a discount. In a POS plan, the plan member would usually see his or her chosen primary care physician first for any medical issues. If needed, he or she would be referred to a specialist. A plan member may visit a licensed provider outside the network and still receive coverage, but substantially less than if he or she stayed within the network.

Health Insurance Plans (*cont'd.*)

Fee-for-service (FFS) plans are more flexible, but involve higher premiums and out-of-pocket expenses, as well as more paperwork. Plan members can choose their own doctors and hospitals. They may visit a specialist without getting permission from a primary care physician. There is usually a deductible amount before the insurance company starts paying claims, and then doctors are reimbursed a percent of the bill, typically 80 percent; members must pay the remaining 20 percent. Members of an FFS plan may have to pay up front for medical services, then submit a claim for reimbursement. FFS plans pay for “reasonable and customary” medical expenses. If a doctor charges more than the average, the plan member has to pay the difference.

Get organized

Patients, responsible family members or advocates should start by checking to make sure the personal information about all individuals covered under their health insurance plan is correct. For individual policy holders, this information can be found on the “Declarations” page (often the first page of the policy). They should then review the Summary of Benefits and note any exclusions or limits to coverage. It is important for patients not to overlook any riders or endorsement forms. These are developed as updates to the initial plan and describe changes to the plan benefits that may affect medical coverage.

There are steps that patients and families can take to manage their health finances and get the most from their coverage. They can

- Keep a copy of all claims and related paperwork, such as letters of medical necessity, bills, receipts, requests for sick leave, as well as a written record of any phone conversations with insurers
- Check health policies often to determine what services and medications are covered
- Obtain proof of previous health insurance coverage from former employer and/or insurers (called a “certificate of creditable coverage”)
- Pay premiums on time and in full to avoid a lapse in coverage

- Learn what to do if a claim is denied (see *Get Information* on page 17)
- Know the laws designed to protect patients and provide continuation of medical coverage (for example, COBRA, HIPAA, Family and Medical Leave Act, Americans with Disabilities Act).

Keep insurance coverage

Cancer survivors who lose, leave or change jobs may be eligible to remain in their employers' plan under COBRA, a federal act that requires some companies to offer continuous health coverage to employees and their covered dependents for up to 18 to 36 months. Even though individuals must pay the entire premium (including the portion that the employer used to pay on their behalf), COBRA may be a better choice than an individual medical insurance plan. The COBRA plan may not be the least expensive option but it will provide continuation of coverage.

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 an employment benefit. This is because obtaining individual medical insurance coverage after being diagnosed with cancer may involve a waiting period before medical coverage begins.

For more information about COBRA, including a list of qualifying events for employees, spouses and dependent children, see www.dol.gov/ebsa or contact the Information Resource Center at LLS ([800] 955-4572).

Navigating Public Programs

Cancer survivors who meet certain criteria may qualify for health insurance, disability benefits or cash payments provided through government-funded programs. Many times patients are not aware that they may qualify for these benefits. The eligibility requirements and enrollment process can be complicated, but financial case workers and social workers can advise and help patients through the process. The single most important consideration for enrolling in public programs is to apply as soon as patients think they may qualify for benefits. Many programs have waiting lists or waiting periods before covered benefits and services take effect.

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, under *PAF Publications*, is *Your Guide to the Appeals Process*, a step-by-step guide to appealing a denied insurance claim. The PAF Co-Pay Relief Program offers financial assistance for qualified persons. Call (866) 512-3861 or visit www.copays.org for more information.

Public health and financial assistance programs include:

• **Medicare**

Medicare provides medical coverage for people 65 years and older, people under 65 years with certain disabilities (as defined by the Social Security Administration) and anyone with end-stage renal disease requiring kidney dialysis. Medicare pays for basic medical coverage and is divided into the following parts or benefits:

- Part A (hospital insurance) helps pay for inpatient hospital care, home health, skilled nursing facility, psychiatric hospital and hospice care services.
- Part B (medical insurance) helps pay for medical services, physician visits, outpatient therapy and other professional services.
- Part D (prescription drug coverage) provides coverage to enrollees for both brand name and generic prescription drugs. Patients must elect and enroll in a stand-alone prescription drug plan (PDP) or Medicare Advantage prescription drug (MA-PD) plan. Patients generally pay a monthly premium, which varies by plan, and a yearly deductible (between \$0-\$275 in 2008). Coinsurance or co-payments also apply. Assistance with drug benefit premiums, deductibles and co-payments is available to beneficiaries with low incomes and limited assets.

Medicare doesn't cover all medical expenses. Patients can apply for supplemental insurance, sometimes called "Medigap". Call (800) MEDICARE ([800] 633-4227) or visit www.medicare.gov for more information.

• **Medicaid**

Medicaid provides medical benefits for certain individuals and families with limited income and assets. It is important for you or your advocate to apply for Medicaid in person. There are programs for which eligibility cannot be determined by phone. Bring proof of income and medical diagnosis and your physician's contact information. Be sure to get the business card of the Medicaid employee who is handling your application. Each state has its own Medicaid program with its own rules about eligibility and coverage. Visit www.cms.hhs.gov/home/medicaid.asp or contact the state or local department of social services (or welfare office) for eligibility requirements.

- **State Children’s Health Insurance Program or SCHIP**

SCHIP provides free or subsidized health coverage for eligible children. SCHIP is part of Medicaid in many states. Most states cover children with family income of up to 200 percent of the federal poverty level. Call (877) 543-7669 or visit www.insurekidsnow.gov for more information.

- **Hill-Burton Program**

Under this program, hospitals and other nonprofit medical facilities that have received federal aid for construction purposes are required by law to offer free or low-cost medical services to patients who are unable to pay. Call (800) 638-0742 or visit www.hrsa.gov/hillburton for more information.

- **Veterans Benefits**

Veterans benefits provide comprehensive healthcare and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. Call (800) 827-1000 or visit www.va.gov for more information.

- **Social Security Disability Income (SSDI)**

SSDI is an income replacement program for people who are unable to work because of a disabling condition. Call (800) 772-1213 or visit www.ssa.gov for more information.

- **Supplemental Security Income (SSI)**

SSI provides a monthly cash benefit for low-income people who are disabled, blind or 65 years or older. Call (800) 772-1213 or visit www.ssa.gov for more information.

Obtaining or adding to healthcare coverage

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. High-risk pools generally have strict eligibility requirements and may be more expensive than other health plans. To find consumer health insurance guides by state on the Web, go to www.healthinsuranceinfo.net.

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 public programs described on these pages.

Applying for Financial Aid

Health insurance plans may not cover all of the costs of cancer care.

LLS Offers Financial Assistance

The Patient Financial Aid Program provides financial assistance to people with blood cancers who are in need. The program will reimburse up to \$500 per year for cancer-related treatment costs that are not covered by a patient's insurance. Examples include chemotherapy and most medications, radiation therapy, blood and marrow lab tests and certain travel expenses. Contact a local LLS chapter or the Information Resource Center at (800) 955-4572 for more information.

The Co-pay Assistance Program offers financial assistance to eligible patients who find it difficult to afford their health plan co-pays for treatment or health insurance premiums. Funds are available for specific blood cancer diagnoses. Visit www.LLS.org/copay or call (877) LLS-COPAY ([877] 557-2672) for more information, including a current list of available co-pay assistance funds.

The Information Resource Center provides general information about other sources of financial assistance. Patients and caregivers can call an information specialist at (800) 955-4572. Information about insurance, managed care, employment issues and financial aid is available online at www.LLS.org/finances.

LLS is part of the Cancer Financial Assistance Coalition (C-FAC) of organizations joining forces to address cancer patients' needs by facilitating communication and collaboration among its members; educating patients and providers about resources and linking to other organizations providing information about C-FAC's collective resources; and advocating for cancer patients regarding the financial burdens of cancer care.

Prescription Drugs

There are a growing number of resources to find assistance to help pay for prescription drugs.

Patients who have prescription drug plans may find that their plan's "formulary" does not cover certain drugs they need. A formulary is a list of prescription drugs that has been approved by a state, health plan or hospital. Formularies typically include procedures that enable access to nonformulary drugs when they are documented as medically necessary. A plan sponsor must have an exceptions process for these situations, and denials of exceptions must be subject to an appeals process.

Those without adequate insurance to cover the cost of prescription medications for cancer treatment may want to explore the following options:

- Patient assistance or prescription assistance programs, sponsored by major pharmaceutical manufacturers that provide free or reduced-cost medications to patients who cannot afford them. Contact Rxassist at www.rxassist.org for a current listing of patient prescription assistance programs.
- Prescription savings programs, such as Together Rx. Together Rx offers a free prescription savings card for individuals who are not eligible for Medicare, do not have prescription drug coverage and meet certain household income levels. Most card holders save between 25 and 40 percent on more than 300 brand-name prescription products. For more information, visit www.TogetherRxAccess.com. The National Association of Counties (www.naco.org) and other state programs also provide ways to cut drug costs.
- Some patients are participants in clinical trials for promising cancer drug therapies. To determine whether a study drug is available for free or at a reduced cost, check with the healthcare provider, insurance representative or study contact. What an insurer will cover varies significantly depending on the health plan and clinical trial. Patients may be able to gain access to investigational drugs through "Expanded Access" or "Special Exception/Compassionate Exemption" programs, which are sometimes offered by drug companies. Patients may be able to negotiate with their insurance company to get a particular drug added to the formulary.

Co-pay assistance programs and foundations will help pay costs for prescription drug insurance plan premiums or co-pay obligations. Funds are disease specific. Contact LLS for information about our Co-pay Assistance Program, (877) LLS-COPAY ([877] 557-2672) and for information about other co-pay assistance programs.

Partnership for Prescription Assistance (PPA)

(888) 4PPA-NOW ([888] 477-2669) • www.pparx.org

PPA brings together pharmaceutical companies, doctors, other healthcare providers and patient advocacy and community groups to help eligible patients who lack prescription drug coverage get needed medicines for little or no cost. The partnership offers access to many public and private patient assistance programs, including programs offered by pharmaceutical companies.

NeedyMeds

www.needyeds.com

NeedyMeds is a central source of information for people who cannot afford medicine or other healthcare expenses. New programs such as assistance for specific diseases and conditions, application assistance, state-sponsored programs and Medicaid sites are also available online.

Stem Cell Transplantation

Stem cell transplantation is expensive and may not be fully covered by health insurance. In addition to the cost of the treatment, patients may have significant expenses for travel, lodging, meals, phone calls, child care, donor testing and aftercare. Patients and caregivers may need to use multiple strategies to secure enough funding to cover these costs. Strategies may include

- Working closely with the transplant center to obtain maximum reimbursement from the insurance company
- Negotiating with healthcare providers to reduce or waive medical fees or adjust the payment schedule in cases of financial hardship
- 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 fundraising events, sales, raffles, canister collections, and letter-writing and publicity campaigns
- Cashing in on benefits from life insurance policies through “viatical settlements” (selling a life insurance policy at a discount to someone else who will collect the face value when the policy holder dies) or accelerated benefits, which can provide cash payouts to seriously ill policyholders. It is important to discuss this strategy with a financial advisor 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

National Marrow Donor Program

(888) 999-6743 • www.marrow.org

These three nonprofit organizations provide information, support, financial support services and patient advocacy for transplant candidates, recipients and their families.

Taking Action

Talk about insurance and financial issues

Healthcare providers do not always ask patients about their insurance coverage or their ability to pay out-of-pocket for cancer care. Many patients are reluctant to share personal financial information with their healthcare providers. Some patients may not want to divert attention from their treatment. However, it is important to resolve financial issues that increase stress and limit access to needed treatments, prescription medications or support services. Discuss payment options with members of your healthcare team or the treatment centers' patient financial services department. Patients and providers can work together to devise ways to reduce costs without compromising treatment.

Speak to the members of the healthcare team about switching from a brand name drug to the generic, reviewing a medication list to see whether the patient is taking nonessential drugs, enrolling in a Prescription Assistance Program (PAP) or referring patients to a public agency or social worker. Social workers and caseworkers can help patients better understand their insurance coverage, submit claims, refer patients to assistance programs to help meet the cost of remaining bills and offer guidance on submitting all the necessary paperwork for Medicare or Medicaid. The Homes & Communities Web site of the United States Department of Housing and Urban Development (HUD) at www.hud.gov may have helpful information for patients and caregivers with concerns about housing expenses.

Find an advocate

Staying on top of bills, dealing with insurance and managing other financial matters takes time and energy. Having an organized and reliable advocate from diagnosis to recovery is extremely valuable. This person can help manage the patient's financial health, while also offering ongoing emotional support. For more information about coping with cancer, see the free LLS booklet, *Each New Day: Ideas for Coping with Leukemia, Lymphoma or Myeloma* at Free Materials, Support at www.LLS.org.

What family and friends can do

Patients can delegate time-sensitive tasks to reliable family members or friends who can be counted on to be thorough and meet deadlines. In addition to organizing the fundraising efforts listed on page 14, friends and relatives may be especially helpful with

- Setting up a record-keeping system to track bills and submitted, pending and paid 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.

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 using legal remedies, if and when necessary. This type of guidance can be invaluable in helping patients learn how to advocate for themselves more effectively.

CancerCare

(800) 813-HOPE ([800] 813-4673) • www.cancercares.org

This national nonprofit agency provides free services, support, information and practical help to anyone affected by cancer, including individuals with cancer. The organization offers guidance on financial issues and gives financial assistance to help with some types of costs.

Get information

Patients may be able to get a decision overturned by filing an appeal if their insurance company denies payment for a recommended treatment. Courtesy, honoring deadlines for obtaining key documents and submitting all necessary paperwork are important elements in improving the likelihood of a successful appeal. Also, patients or their advocates should record the date and time of each call to the insurance company, and the name, phone number and extension of the insurance company representative who handles the call.

Questions to ask an insurer when appealing a denial of coverage:

1. Can you send me a copy of the denial letter?
2. What is the specific reason 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? (It may be necessary 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?
5. How can I request a physician peer review? (A peer review provides the opportunity for the patient's physician to discuss the patient's treatment in detail with other physicians, usually within the same geographic area and medical specialty.)
6. Is there anyone else I can speak to if I have questions about the appeals process?
7. If a particular drug is not on the prescription plan's covered drug list (formulary), is there a process by which an exception can be made? Can my doctor submit a letter explaining why the drug is necessary in order to gain approval?

Call Our Information Resource Center

The Leukemia & Lymphoma Society's (LLS) Information Resource Center (IRC) provides patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our information specialists – master's level oncology professionals – are available by phone (800.955.4572) Monday through Friday, 9 am to 6 pm (ET). Callers to the IRC may request the services of a language interpreter. The IRC can also be contacted via email (infocenter@LLS.org); or chat online at www.LLS.org (click on "Live Help").

Call 800.955.4572 for a complete directory of our patient services programs.



800.955.4572 • www.LLS.org

LEUKEMIA

LYMPHOMA

MYELOMA

For more information, please contact:



or:

Home Office

1311 Mamaroneck Avenue

White Plains, NY 10605

Information Resource Center (IRC) 800.955.4572 (Language interpreters available upon request.)

www.LLS.org

Our Mission: Cure leukemia, lymphoma,

Hodgkin's disease and myeloma, and improve the

quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.



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Lymphoma Society**
Fighting Blood Cancers