

7 FINANCIAL AND LEGAL

Visit www.LLS.org/CaregiverWorkbook to access all chapters and worksheets.

Balancing Work. The many responsibilities of caring for someone often leads to job conflicts. Work is a financial necessity and a major source of personal satisfaction, but for many caregivers, it is often difficult to balance the twin responsibilities of caregiving and working. Each caregiver's working conditions are different. Talk to your supervisor and look in the employee handbook or other human resources publications to learn about your company's policy on caregivers.

- Ask your employer if there is an employee assistance program.
- Ask your human resources or personnel department to give you information about the Federal Family and Medical Leave Act (FMLA). Have a copy sent to your supervisor as well, if appropriate. Read more about FMLA in *Family and Medical Leave Act (FMLA) for Caregivers*, below.
- Take advantage of flex-time policies. Consider asking for a flexible schedule if a formal policy is not in place.
- Offer to work a less desirable shift or be willing to make up time taken for caregiving by working days or shifts when most people want to be off. This flexibility on your part shows your employer that you are committed to the company and your job.
- Consider job sharing or working part time, if possible.
- Avoid mixing work with caregiving responsibilities. If you need to make phone calls or search the Internet for information related to your loved one's needs, do it on a lunch break.
- Manage your time well. When you must take time off for caregiving, set priorities and accomplish the most important things first. Delegate responsibilities when you can. Pace yourself; don't do so much in one area that you can't be effective in another.
- Get all the support you can from family members, friends and community resources.
- It's a personal choice about whether to disclose information about a medical situation to your employer. People have the right to keep the information to themselves. There are some instances when disclosing some information about a medical condition is necessary, but it doesn't have to be everything or even a specific diagnosis. Visit www.triagecancer.org/QuickGuide-Disclosure for more information.

You may find that the people you work with treat you differently because you are spending less time at work. You can tell your coworkers either as little or as much as you want to about your situation. In most cases, your coworkers will probably be understanding. Most people know someone or have a loved one who has been in a similar situation. However, do not feel obligated to share details, except with your supervisor. Be sure to thank people at work for their consideration and assistance.

Family and Medical Leave Act (FMLA) for Caregivers. In order to care for your loved one, it may become necessary for you to take a leave from work. There are laws in place to help protect caregivers in these types of situations.

What is the Family and Medical Leave Act (FMLA)? Eligible employees (who have worked at least 1,250 hours over the last 12 months for private companies with 50 or more employees) can take unpaid, job-protected leave for specified family and medical reasons under the provisions of FMLA. Employees would continue to receive their group health insurance coverage under the same terms and conditions as if they had not taken leave.

The information within the section is current as of June 2018.

Eligible employees are entitled to

- Twelve workweeks of leave within a 12-month period to care for the employee's
 - Own serious health condition that prevents the employee from performing the essential functions of his or her job
 - Spouse, child or parent who has a serious health condition
- Twenty-six workweeks of leave within a 12-month period to care for a covered service member with a serious injury or illness who is the spouse, child, parent or next of kin to the employee (military caregiver leave).

Note: As of February 2015, the US Department of Labor's Wage and Hour Division announced a Final Rule to revise the definition of "spouse" under the Family and Medical Leave Act of 1993 (FMLA). The Final Rule amends the definition of spouse so that eligible employees in a legal same-sex marriage will be able to take FMLA leave to care for their spouse or family member, regardless of where they live.

There are three kinds of FMLA leave. They are

- Continuous FMLA leave: An employee is absent for more than 3 consecutive business days and has been treated by a doctor.
- Intermittent FMLA leave: An employee is taking time off in shorter blocks of time due to a serious health condition that qualifies for FMLA. Intermittent leave can be in hourly, daily or weekly increments. Intermittent FMLA leave is often taken when an employee needs ongoing treatment or must go to follow-up appointments for his or her condition.
- Reduced-schedule FMLA leave: An employee needs to reduce the amount of hours he or she works per day or per week, often to care for a family member or to reduce fatigue or stress.

WANT MORE INFORMATION?

To access more information about this program, please visit the Department of Labor website at www.dol.gov/whd/fmla or call **(866) 487-9243**.



Contact an LLS Information Specialist for more information about FMLA and for a referral to appropriate organizations for additional assistance.



Want more information and suggested resources? You can view, print or order the free LLS booklet *Cancer and Your Finances* at www.LLS.org/booklets or contact an Information Specialist at **(800) 955-4572**.

Managing Health Insurance. 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.

Private health insurance coverage can come from

- An employer
- A union
- Another association
- An individual policy that has been purchased from an insurance company.

Government-funded health insurance programs include

- Medicaid
- State Children's Health Insurance Program (S-CHIP)
- Medicare
- Other government programs.

Know the Patient's Coverage. Newly diagnosed patients need to know exactly what medical treatment and services are covered by their insurance, how to protect their benefits, what resources are available to deal with gaps in insurance coverage, and what out-of-pocket expenses there will be. Cancer survivors who will need follow-up care also need to know what is covered by insurance.

Tips for Navigating the Patient's Health Insurance

- Be proactive and be informed. Pay premiums on time and in full to avoid either a lapse in or cancellation of coverage. Check health policies often to determine what services and medications are covered.
- Request a case manager from the insurance company. He or she will be your contact person and will be able to answer questions about claims or the policy. When many medical treatments are necessary, it can be useful to have a designated person to speak to at the insurance company. You can also find out whether your employer has a benefits' advisor or an advocate who can assist you or you can call organizations (including The Leukemia & Lymphoma Society) to get help.
- Create a filing system that works for you. This will allow you to find information quickly and easily. Keep a copy of all claims and related paperwork in an organized folder, by category. The folder would store letters of medical necessity, bills, receipts, requests for sick leave, etc. Also, keep a written record of any phone conversations with insurers; be sure to include the name of the person you were speaking to, what was said and the date.
- Keep track of all unreimbursed medical expenses. This may include the dates of each service, the amount paid and the name of the medical provider. It may be possible to claim these expenses for tax purposes.



Use **Worksheet 14: Insurance Call Log** to keep a record of communications with the insurance company.

Understanding Terms and Expenses. People with health insurance need to read their policies carefully to understand the health and medical services that are covered. Familiarize yourself with the following health insurance terms:

- **Premiums.** The monthly cost of participating in the plan
- **Deductible.** A fixed amount of money that must be "met" or paid out-of-pocket by a patient each year before the insurance plan will cover medical expenses
- **Co-payments/Co-pays.** A set dollar amount that is paid by the patient at the time of service for certain medical services and prescription drugs. Co-pays do not count toward the deductible. The co-pay amount may vary, depending on whether the patient is seeing a specialist or a primary care provider (PCP).
- **Co-insurance/Cost share.** Certain percentages of medical expenses shared by the patient and the health plan. This cost is in addition to any deductibles and co-payments. For example, if Patty has an 80/20 plan, the insurer pays 80 percent of covered expenses and Patty pays the remaining 20 percent of the medical or prescription drug charges.
- **Out-of-Pocket Expenses.** The total amount of medical expenses that the patient is responsible for paying.
- **Out-of-Pocket Expenses Maximum.** The limit on the total amount a health insurance company requires a patient to pay in deductible and co-insurance per year. After reaching an out-of-pocket maximum, the patient no longer pays co-insurance because the plan begins to pay 100 percent of covered medical expenses. Members are still responsible for services that are not covered by the plan. They must also continue to pay their monthly premiums.
- **In-Network Provider.** An in-network provider is contracted with an individual's health insurance company to provide services to plan members at a predetermined rate. The amount paid for an in-network provider is usually much less than the amount that you would pay for an out-of-network provider
- **Out-of-Network Provider.** An out-of-network provider is not directly contracted with an individual's health insurance plan.

- **Lifetime and Annual Maximums or “Caps.”** The maximum benefits that will be paid for each individual enrolled in the plan during each year or during the individual’s lifetime.
 - Under the The Patient Protection and Affordable Care Act, (ACA), for plan years that began either on or after September 23, 2010, plans can no longer impose lifetime caps, and as of January 1, 2014, plans cannot impose annual limits on essential health benefits.

Types of Health Insurance Plans. The following is a list of different types of health insurance plans.

Private Plans. The following general descriptions of the different types of plans and the coverage that they provide may not be exactly the same as the description of the coverage in your loved one’s plan, so always check the coverage in his or her plan.

Health Maintenance Organizations (HMOs)

A health maintenance organization is a network of providers (doctors, hospitals and clinics) who provide the HMO plan members with reduced costs for medical services. When they belong to an HMO

- Plan members choose a primary care provider (PCP) who oversees their needs.
- Plan members who need access to a specialist are often required to get a referral from their PCP.
- Patients may need precertification before nonemergency hospital visits and some types of specialist care.
- Patients requiring emergency care may be required to notify their HMO within 24 hours of receiving care.

Preferred Provider Organizations (PPOs)

A preferred provider organization is a group of doctors, hospitals and other healthcare professionals who agree to provide healthcare services for PPO plan members at a reduced fee. When they are enrolled in a PPO plan

- Members may pay a standard co-pay amount for an office visit.
- Members can choose between either an in-network or an out-of-network provider instead of being restricted to designated providers.
- A member may go to a specialist without a referral from the primary care doctor. An in-network specialist is usually the least expensive choice. A member can still go to an out-of-network provider, but the visit may not be covered at the lower rate that insurance coverage pays for an in-network provider visit.
- If a member sees an out-of-network specialist, he or she may have to pay the entire bill first, and then submit a claim for reimbursement.
- There may be a separate deductible for out-of-network medical services, or members may have to pay the difference between in-network charges and out-of-network charges; this practice is referred to as “balance billing.”
- Members may need to get precertification (preauthorization) for some types of care, especially if the facility or doctor is out of network. Some types of services may not be covered.

Exclusive Provider Organizations (EPOs)

The EPO and PPO plans both provide their members with reduced costs and charge members a co-pay amount for an office visit; however, when they are enrolled in an EPO plan

- Members may not need a referral to see a specialist. However, members must select providers from a limited list.

- A plan member visiting an out-of-network doctor may incur from 20 to 100 percent of the costs.
- Patients who require a number of unique specialists may find an EPO plan problematic.

Point-of-Service (POS) Plans

The POS plans blend the features of HMO and PPO plans. If they are enrolled in a POS plan

- Members of the plan can choose the type of provider network that is best suited to their needs each time they seek care.
- Plan participants designate an in-network provider to be their primary care doctor.
- Plan members usually see their chosen primary care provider first for any medical issues. If necessary, the member would then be referred to a specialist.
- A POS plan member may need a referral to see a specialist.
- Members may visit a licensed provider outside the network and still receive coverage, though at higher cost to the patient.

Fee-for-Service (FFS) plans

Fee-for-service plans are more flexible than the other plans, but they involve higher premiums and higher out-of-pocket expenses, as well as requiring more paperwork. If they are enrolled in an FFS plan

- Plan members can choose their own doctors and hospitals.
- Members may visit a specialist without getting permission from a primary care provider (PCP).
- Members of an FFS plan may have to pay up front for medical services and then submit a claim for reimbursement.
- Participants in an FFS plan get only limited coverage for routine care.

Medicaid. Medicaid provides coverage for certain individuals and families with limited income and assets. Each state has its own Medicaid program with its own rules about eligibility and coverage.

Visit www.medicaid.gov/state-overviews/index.html to learn more about your state's Medicaid program.

State Children's Health Insurance Program (S-CHIP). This program provides free or subsidized health coverage for eligible children. It is part of the Medicaid program in many states. Most states cover children with family income up to 200 percent of the federal poverty level. Call **(877) 543-7669** or visit www.insurekidsnow.gov for more information.

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

- **Part A (hospital insurance)** helps pay for inpatient hospital care, some home healthcare services, care at a skilled nursing facility, psychiatric hospital care and hospice care services.
- **Part B (medical insurance)** helps pay for medical services; doctor visits; laboratory testing; outpatient therapy; and other professional services, as well as some preventative services.

- **Part C Plans (Medicare Advantage Plans)** are offered through private companies approved by Medicare. These plans cover all the services provided by Medicare Part A and Part B and usually include prescription drug coverage (Part D) as well. Different Medicare Advantage Plans can charge different out-of-pocket costs and have different rules for how to get services, such as whether a referral is needed to see a specialist.
- **Part D (prescription drug coverage)** provides coverage for both brand-name and generic prescription drugs. Patients may elect and enroll in a stand-alone prescription drug plan (PDP) or a Medicare Advantage prescription drug (MA-PD) plan. Patients are charged a monthly premium, which varies by plan, and they must pay a yearly deductible. Co-insurance or co-payments apply.
 - Assistance with drug benefit premiums, deductibles and co-payments is available to beneficiaries with low incomes and limited assets (more information about the Low Income Subsidy [Extra Help] program is available at www.cms.gov/limitedincomeandresources).
 - The “donut hole,” which limits drug coverage so that patients have to pay out-of-pocket, is being phased out. The ACA will gradually decrease the amount patients pay for all prescriptions once they reach the donut hole. The donut hole is supposed to be phased out by 2019.

Medicare does NOT cover some services, such as long-term care, most dental care, eye examinations related to prescription glasses, dentures, cosmetic surgery, acupuncture, hearing aids, and routine foot care. These services may be covered by some Medicare Advantage (Part C) or Medigap plans. Call **(800) MEDICARE ((800) 633-4227)** or visit www.medicare.gov for more information.

Veterans Affairs (VA) Benefits. Veterans’ benefits provide comprehensive healthcare and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. TRICARE® is the healthcare program serving uniformed service members, retirees and their families. For information about TRICARE, visit www.tricare.mil. Veterans who were exposed to Agent Orange while serving in Vietnam or Korea and have a diagnosis that the VA recognizes as associated with Agent Orange exposure, may be able to get help from the United States Department of Veterans Affairs. For information call the Department of Veterans Affairs at **(800) 749-8387** or visit www.publichealth.va.gov/exposures/agentorange. For general VA information call **(800) 827-1000** or visit www.va.gov.

COBRA (Consolidated Omnibus Budget Reconciliation Act)

Coverage. Cancer survivors who lose, leave or change jobs, or children who “age out” of their parent’s health insurance plan may be eligible to remain on their employer plan under COBRA. This federal law also applies to dependents (spouse or child) who experience divorce or legal separation from a covered employee, dependents of an employee who becomes Medicare eligible, and dependents of a deceased employee.

The individual is required to pay the entire premium (including the portion that the employer used to pay on his or her behalf and a 2 percent administrative fee). COBRA may not be the least expensive option, but it will provide continuation of coverage and allows the enrollee time to explore other options without a gap in coverage.

Flexible Spending Accounts (FSAs) and Health Savings Accounts (HSAs). These are special accounts that allow people to save pre-tax dollars and then use them to pay their medical expenses. Many employers provide FSAs or HSAs to employees who are enrolled in private health insurance plans. These accounts give participants the opportunity to plan for specific medical expenses and accrue tax benefits.

At the start of the health-plan year, people can deposit money in an FSA and then use it later to pay for all their anticipated out-of-pocket medical expenses. Funds must be used before the end of the year. However, employers can provide a roll-over option of up to \$500 or give employees a 3-month extension, during which they can use any remaining funds. Check with the employer to learn the specific policies of the FSA.

TIP:

When looking for a new health insurance plan, remember, cost is not the only consideration. You need to think about the quality of coverage, as well, or you may end up paying more in medical expenses overall.

Health savings account (HSA) funds (unlike the FSA funds) do not expire. An HSA can only be used along with a high-deductible health insurance plan. In high-deductible plans, the patient is responsible for paying for the total amount of the costs of his or her care until the high deductible amount is met. Once the patient meets the out-of-pocket maximum, the insurance plan will pay 100 percent of the in-network covered services. The money in an HSA account can also be either invested or, if it is necessary, taken with the owner to another job.

Understanding the Health Insurance Plan. To estimate the cost of medical care, you must understand your loved one's health insurance plan. Use this chart to view all the plan specifics in one place.

Plan Name		
Type of Plan		
Primary Care Provider	Covered In Network <input type="checkbox"/>	Covered Out of Network <input type="checkbox"/>
Specialists	Covered In Network <input type="checkbox"/>	Covered Out of Network <input type="checkbox"/>
Treatment Center	Covered In Network <input type="checkbox"/>	Covered Out of Network <input type="checkbox"/>
Other Medical Service Providers (Lab Tests, Infusions, Radiology)	Covered In Network <input type="checkbox"/>	Covered Out of Network <input type="checkbox"/>
Premium	Per Month: \$ _____	Per Year: \$ _____
Maximum Out-of-Pocket Expense	Per Individual Per Year: \$ _____	Per Family Per Year: \$ _____
Co-pays and/or Co-insurance	Primary Care Visits: \$ _____ % Specialist Visits: \$ _____ % Hospitalization: \$ _____ % Emergency Room: \$ _____ % Urgent Care: \$ _____ % Prescription Drugs: \$ _____ %	Co-Pay Co-Insurance \$ _____ _____ % \$ _____ _____ %
Plan Status as of this Date: _____	\$ _____ of patient's \$ _____ individual deductible has been met \$ _____ of patient's \$ _____ family deductible has been met \$ _____ of patient's \$ _____ individual maximum out-of-pocket expense has been met \$ _____ of patient's \$ _____ family maximum out-of-pocket expense has been met	



Use **Worksheet 15: Understanding the Health Insurance Plan** if the insurance plan changes.

Denial of Insurance Coverage. If an insurance company denies coverage for a recommended treatment, procedure, or prescription medication, a patient may be able to get the decision overturned by filing an appeal. Before you file an appeal, you may want to contact your loved one's insurer to find out why payment was denied. The reason may be a mistake, such as a coding error.

However, if the payment was denied for another reason (for example, because the insurer did not think the treatment was medically necessary), then you can appeal the decision. Submitting all necessary paperwork and key documents by stated deadlines are important elements in improving the likelihood of a successful appeal. You should keep track of

- The date, time and method of any correspondence to the insurance company (by phone, email or in writing)
- The name and contact information of any insurance agent or claim reviewer with whom you communicate
- Summaries of your conversations and any written documents issued by the insurance company.



Use **Worksheet 16: Health Insurance Appeal Tracking Form** to keep track of appeals as you work through the process.

Beginning with healthcare-plan years starting after July 1, 2011, insurance companies that deny payment for a treatment or service are required to conduct internal appeals at the patient's request within the following specific timelines:

- 72 hours after receiving an appeal for urgent medical care
- 30 days for nonurgent care that the patient has not yet received
- 60 days for services that the patient has already received.

You can get information on the appeals process by calling the insurance company, visiting the insurer's website or reading the plan's documents or Explanation of Benefits.

Explanation of Benefits (EOB). Typically, after a person receives medical care, the provider sends a bill or claim to the insurance company. The insurance company handles the claim and sends the patient an Explanation of Benefits statement. This is a summary of the services the patient received, how much the provider charged the insurance company and how much the insurance company paid. The EOB may also include the amount the patient has paid toward his/or her deductible. Most EOB forms start with identifying information specific to the patient and the insurance plan, as well as a list of services received. If any of this information is incorrect, it is important that the patient notify his or her plan.

For each service that the provider is requesting reimbursement, there is a description of the service along with a corresponding code and the date the service was provided.

An EOB is not a bill, so no payments should be made based on the information found in that statement. The hospital or provider will bill the patient if there is a balance due.

The Appeals Process. If you choose to call your loved one's insurer, the following questions may be useful when appealing a denial of coverage:

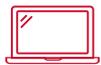
1. Can you send me a copy of the denial letter?
2. What is the specific reason the claim was denied? (This information should be included in the denial letter.)
3. Can I get a current copy of the plan document and the plan's Summary of Benefits and Coverage (SBC) on the Internet? If not, how can I get a copy of that information?

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 doctor peer review? (A peer review provides the opportunity for the patient's doctor to discuss the patient's treatment in detail with other doctors who are 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 obtain approval by submitting a letter explaining why the drug is medically necessary?

In most cases, there are three levels of appeals. They are

- An internal review by the insurer
- A second-level appeal to the insurer if the first is denied. That appeal will be reviewed by people who were not involved in the first appeal.
- If that appeal is also denied, a third-level appeal (external appeal), to an independent outside organization is made. To begin this type of appeal, you can contact your State Insurance Department. It may refer you to an independent organization that can handle this level of appeal. You may also choose to get help from a social worker or an attorney.

If your loved one gets health coverage through an employer, the plan may have to follow certain regulations set by a law called ERISA (Employee Retirement Income Security Act). This law has specific rules about the appeal timelines, your rights and the type of information that the insurer is required to provide. Your loved one's plan may have to follow specific state laws too.



Visit the Patient Advocate Foundation at www.patientadvocate.org and Triage Cancer at www.triagecancer.org for more information and resources regarding navigating the insurance appeal process.

Managing Finances. It is important to have a plan to understand expenses.

Budgeting. Planning a budget in advance and sticking to it is an important part of managing finances after a cancer diagnosis. If you and your loved one share finances, work together to create a budget. If you do not share finances, offer to help your loved one to create one. You may also want to create your own budget since caregiving can bring additional expenses, too.

Don't forget to consider all possible changes to expenses and income, such as

- Wages lost from time off work for treatment or recovery
- Transportation and lodging for you and your loved one if you live far from the treatment center
- Additional medical expenses, such as nutritional supplements, over-the-counter medications, hygiene products, wig, etc
- Childcare and/or pet sitter for when you are away.

When working on a budget, you should also look for ways to reduce expenses. Consider the following questions:

- Can any of the expenses be reduced by shopping for a different phone/cable plan or home insurance quote?
- Can you reach out to family members and friends to help with childcare or pet care?
- Is your loved one eligible for financial assistance programs or disability insurance?



Work together to complete **Worksheet 17: Budgeting** to begin budget planning.

Use the following example of a completed **Worksheet 17: Budgeting** as a guide.

Jane's Budget for August

Monthly Expenses	Expected	Actual
Health Insurance Premium and Estimated Medical Expenses	\$600	\$700
Rent/Mortgage	\$1,025	\$1,025
Utilities (Electric, Gas, Water)	\$135	\$130
Groceries/Food	\$325	\$350
Phone/Cell Phone	\$50	\$50
Cable/Internet/Streaming Services	\$150	\$150
Transportation (Car Payment, Gas, Bus Fare)	\$300	\$450
Debt Payments (Credit Cards/Loans)	\$200	\$200
Insurance Premiums (Car/Life)	\$75	\$75
Housecleaning/Landscaping		
Childcare	\$250	\$265
Other Expenses	\$55	\$70
Total Expenses	\$3,165	\$3,465

Jane used her last mortgage bill to fill in the exact amount for the category since the payment stays the same.

To estimate groceries and food, Jane checked last month's bank statement to see what she had spent at the grocery store and restaurants.

Jane ended up spending more on transportation than she anticipated. Driving to treatment meant more gas money and parking at the cancer center was costly.

Jane checked her last paystubs to determine her income.

Sources of Monthly Income	Expected	Actual
Salary (net income*)	\$3,500	\$3,500
SSI (Supplemental Security Income)/ SSDI (Social Security Disability Insurance) Supplemental Security Income		
Employment Benefits: Disability (Short- or long-term)		
Retirement (Private and/or Social Security Administration (SSA)		
Financial Assistance		
Other Forms of Income		
Total Income	\$3,500	\$3,500

*Net income is your take-home pay after taxes and other payroll deductions.

	Expected	Actual
Total Income	\$3,500	\$3,500
Total Expenses	\$3,165	\$3,465
After Expenses (Total Income— Total Expenses = After Expenses)	\$335	\$35

Financial Assistance. There are a number of ways to find financial assistance for expenses related to treatment or to replace lost income. Some organizations can also help with transportation costs, living expenses or prescription costs.

Disability Insurance Options. Disability insurance provides income replacement to people whose medical condition keeps them from being able to work for either a period of time or permanently. There are different types of disability insurance. There are private disability insurance plans that you can purchase directly from an insurance company or that may be available to you through an employer. A few states (CA, HI, NJ, NY, RI and Puerto Rico) have short-term disability insurance programs. There are also two federal long-term, disability programs: Social Security Disability Insurance and Supplemental Security Income.

If the patient is unable to work, consider applying for social security disability insurance.

- Social Security Disability Insurance (SSDI)
 - SSDI is an income replacement program for people who are unable to work because of a disability. Call **(800) 772-1213** or visit www.ssa.gov for information.
 - Compassionate Allowances. Social Security provides an expedited application process to applicants who have certain serious medical conditions that meet Social Security’s disability standards. Social Security has identified a list of these diseases and medical conditions. Several cancers, including acute leukemia, adult non-Hodgkin lymphoma and childhood lymphoma, are included in the list of conditions. For more information, visit www.ssa.gov/compassionateallowances or call **(800) 772-1213**.
- Supplemental Security Income (SSI)
 - SSI provides a monthly cash benefit for low-income people who are disabled, blind or aged 65 years and older. Call **(800) 772-1213** or visit www.ssa.gov for information.

Financial Assistance Programs

- Supplemental Nutrition Assistance Program (SNAP)
 - The Supplemental Nutrition Assistance Program benefits, more commonly referred to as “food stamps,” can help with food costs. To apply for benefits, or for information about the Supplemental Nutrition Assistance Program, contact the local SNAP office. You can find a list of local offices at www.fns.usda.gov/snap/snap-application-and-local-office-locators.
- Low Income Heating Energy Assistance Program (LIHEAP)
 - The Low Income Heating Energy Assistance Program provides help paying the electric bill. To learn more or to apply, contact the local LIHEAP office. You can find your local office at <https://liheapch.acf.hhs.gov/db/index.php> or call The National Energy Assistance Referral hotline at **(866) 674-6327**.
- *Co-pay Assistance Program*
 - LLS offers a *Co-Pay Assistance Program*. LLS offers insurance premium and medication co-pay assistance for eligible patients. For more information, please call **(877) 557-2672** or visit www.LLS.org/copay.
- Information Specialists at **(800) 955-4572** can provide information about other organizations and pharmaceutical companies that provide medication and financial assistance.

TIP:

If there is an expense you are struggling to pay, it may require some creative thinking. For example, you probably won’t be able to find financial assistance to cover your credit card bill. However, you may be able to find a financial assistance program that can help with the electric bill, which frees up more money in your budget to be applied to your credit card payments.



Other Possible Sources of Assistance

CancerCare

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

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

NeedyMeds

(800) 503-6897 or www.needymeds.org

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



If your loved one applies for financial assistance, you will want to keep record of this, as well. Use **Worksheet 18: Financial Assistance Record** to keep track of applications.



Want more information and suggested resources? You can view, print or order the free LLS booklet *Cancer and Your Finances* at www.LLS.org/booklets or contact an Information Specialist at **(800) 955-4572**.

Advance Directives. Advance directives are a patient's instructions about future medical care either if or when he or she can no longer speak for himself or herself. Ideally, advance directives should be in place before a person becomes ill or before a crisis.

If your loved one doesn't have an advance directive, choose a practical time and place to have this conversation with him or her. Let your ill relative set the pace of the conversation. Use good listening skills, but expect some initial resistance. Whatever your loved one's wishes are, acknowledge and sustain them, even if you don't agree.

An advance directive is generally made up of one or two legal documents: A living will and/or a medical power of attorney. You or loved one can obtain information about advance directive(s) (and the relevant documents) from the healthcare team.



You can also download information and blank templates for these documents from the National Hospice and Palliative Care Organization at www.caringinfo.org.

Each type of advance directive is regulated differently by state. For this reason, you may wish to consult with an attorney when preparing an advance directive.

Living Wills. A living will outlines a person's wishes about medical treatment if he or she is unable to communicate at the end of life. State law defines when a living will can go into effect and may limit treatments to which the living will applies. A person always, though, has the right to refuse treatment.

The patient's living will may address the following issues:

- Life support or use of equipment, such as dialysis machines, ventilators, and respirators
- Do-not-resuscitate orders (DNRs)
 - These orders instruct members of the healthcare team not to do cardiopulmonary resuscitation (CPR) if

the patient's heart stops beating or his or her breathing stops.

- Cardiopulmonary resuscitation (CPR)
 - This is the first aid that is used when the patient's heart stops beating or his or her breathing stops. Cardiopulmonary resuscitation can include chest compressions, electric shock, or medication.
- Do not intubate (DNI) orders
 - These orders instruct members of the healthcare team that they must not pass a tube through the patient's nose or mouth to help with breathing.
- Artificial nutrition and hydration
 - If the patient is unable to eat or drink, instructions must be given to the healthcare team so that they know whether or not they can provide nutrition and/or fluids either intravenously or through a feeding tube.
- The provisions for organ and/or tissue donation.

Medical Power of Attorney. If someone becomes incapacitated and is unable to make decisions regarding his or her medical care for himself or herself, he or she can appoint someone (who is given a medical power of attorney) to make those decisions on his or her behalf. This individual is sometimes called a "healthcare proxy" or "healthcare agent." In many states, the appointed person may speak for a patient at any time that someone is unable to make decisions, not just at the end of life.

Financial Matters. The costs of end-of-life care can be considerable. Financial stress at this time is common, and financial issues are important. Families deal with terminal illness and finance concerns in different ways. It's important to not feel guilty if you and your loved one have concerns.



Although no single resource exists that fully address a family's financial concerns, an Information Specialist at **(800) 955-4572** from The Leukemia & Lymphoma Society (LLS) can provide information and referrals to help you.
