



# Health Insurance and Financial Assistance for the Cancer Patient

## You may not want to think about money right now, but it could become a problem

There are financial resources available to help people with cancer deal with the mounting costs that come with this disease. These resources can be health insurance, government programs, disability benefits, aid from voluntary organizations, and living benefits from life insurance policies, including viaticals (these will be explained later on). Even if you have health insurance, you will soon find out that it doesn't cover everything. And even if you are well-insured, cancer can cause financial problems.

If you have no health insurance, it can be really scary. But there are some other options you may want to think about.

Here we will cover:

- Private health insurance
- Government-funded insurance plans
- Options if you are uninsured
- Financial issues and possible sources of help
- Other resources

## Private health plans

Health insurance coverage helps with the medical costs that come with the diagnosis and treatment of an illness. It is important to have and keep good medical coverage. This can help you avoid major money problems. Many people have private insurance through employee group plans or individual plans.

A *group plan* is a policy that covers a group of people, usually employees of the same company, and often their dependents. In general, employees do not have to prove that they are healthy to be insured with their job's plan. Group plans usually cost less, and some employers pay part of the premium costs for employees.

*Individual plans* may check into your personal and family health and require physical exams or lab tests before they will insure you. They often charge higher rates or premiums based on age or health conditions, and in some cases, may not be willing to insure you at all. Some individual policies may also cover family members.

It is important to have accurate, up-to-date information and a good understanding of your financial situation and insurance coverage. And, if your insurance cost is not deducted from your paycheck, it is very important to pay your monthly insurance premiums on time.

## Types of health plans

There are many types of health insurance and health service plans. Here are very brief descriptions of those that are most often used:

### **Fee-for-service plans**

Fee-for-service plans are also called *indemnity* or *traditional* health plans. If you have this type of health insurance, you can choose any doctor, change doctors any time, and go to any hospital anywhere in the United States. You pay a monthly fee, called a *premium*. Each year, you also have to pay a certain amount of your medical costs (known as the *deductible*) before your insurance will start to pay. After you have met your deductible, your insurance will pay a set percentage of the bill for the rest of the year. You may have to fill out forms and send them to your insurer to get reimbursed (paid back) for medical costs you have already paid. Sometimes the doctor's office will do this for you, and then send you a bill for the amount your insurance didn't cover. You also need to keep receipts of drugs and other medical costs. You are responsible for keeping track of your own medical expenses. This can help you greatly if there is a dispute about payments or other problems in the future.

### **Managed care plans**

There are different types of managed health care plans. Most of them have lower premiums and co-payments (co-pays) than fee-for-service insurance. (Co-payments are sometimes called *co-insurance*. This is the amount you must pay at the time of service.) These amounts can differ between managed care companies and between services within the same company. There is usually no need to file claim forms.. Here are the most common types of managed care plans.

- **Health maintenance organizations (HMOs):** The HMO will usually cover most expenses after a small co-pay. HMOs often limit your choice of providers to those within their approved provider network. This means you have to check their listing to

be sure the doctor you want to see is one of their doctors. If not, you may have to change to a different type of health plan to have the doctor's services covered. Or, you may have to switch to one of the approved doctors on their list.

- **Point-of-service plans:** A point-of-service plan (POS) is a type of HMO. The primary care doctors in a POS plan usually refer you to other doctors in the plan or network. If your doctor refers you to a doctor who is not in the plan (out of network), the plan will still pay all or most of the bill. But if you choose a doctor outside the network, you will have to pay co-insurance, even if the service is covered by the plan. Co-insurance is what you must pay in addition to what the insurance company pays for each service. It is usually a certain percentage of the cost. For example, the insurance company may pay 80% of the bill and you have to pay the other 20%.
- **Preferred provider organization:** The preferred provider organization (PPO) is a hybrid of fee-for-service and an HMO. Like an HMO, there are only a certain number of doctors and hospitals you can use to get the most coverage. When you use those doctors (sometimes called *preferred* or *network* providers), most of your medical bills are covered. When you don't use these providers, the PPO makes you pay more of the bill out of your own pocket. So you pay more to choose providers that are not in the network.

## **Know your managed care plan**

Some plans employ their own doctors and run their own hospitals. Others require that members use a primary care provider who coordinates all of the patient's care and serves as a "gatekeeper" for care from specialists. The gatekeeper is usually a primary care doctor who is responsible for the overall medical care of the patient. This doctor organizes and approves medical treatments, tests, specialty referrals, and hospitalizations. For example, if you need to see an expert like a lung specialist, you would need a referral from the primary care doctor before the specialist sees you. Otherwise your plan may not pay.

Under some plans, members must use only the services of certain providers and institutions that have contracts with the plan. Some plans do not require prior approval (also called *pre-authorization*), but do require that members choose providers from a particular list or "network" of providers. When you choose to go outside the network for care, you may have to pay an extra fee, or even pay for the full service with no help from your health insurance plan.

Many different types of institutions and agencies sponsor managed care plans, not just insurance companies. These include employers, hospitals, labor unions, consumer groups, the government, and others. It helps to know all the ins and outs of the plan and how it will affect your care.

## Other things to know about health insurance

### **Catastrophic illness or major medical clauses**

Treating and managing most cancers costs a lot of money. Some insurance plans provide for extra coverage under a "catastrophic illness" clause. These are policies that cover major medical care needs. The policies usually have very high deductibles and fairly low premiums. They can be good for people with chronic illnesses. Check to see if your plan includes such coverage.

### **Health Savings Accounts**

If you have or plan to enroll in an insurance plan that has a high deductible, you may want to set up a Health Savings Account (HSA). You don't have to pay federal income taxes on the contributions you make to the HSA if the money is used to pay for qualified medical expenses. If you use it for anything else, you will be required to pay the tax and a penalty.

Note that an HSA is different from a Flexible Spending Account (FSA); for instance, you can have an FSA even if you don't have a high deductible health plan. FSA funds are set up to be used for both medical and child care expenses. But the FSA money you don't use goes away at the end of each year, while the HSA money is yours until you take it out. For more information about setting up an HSA you can contact your employer, bank, or credit union.

### **Pre-existing condition exclusions**

A *pre-existing condition* is a health problem that you had *before* you joined your medical plan. If you are a cancer patient and join a new health insurance plan, you may face a *pre-existing condition exclusion period*. A pre-existing condition exclusion period means your plan will make you wait before they pay the costs of the pre-existing medical problem. The wait may be as long as a year for insurance you get through an employer.

If you refuse health insurance when it is first offered and then sign up later, the pre-existing condition exclusion can climb to 18 months after you sign up. And the time can be longer for independent policies and those not through an employer. In fact, some insurance may not cover certain illnesses at all.

If you get health insurance through your job, Federal law prevents the employer from imposing an exclusion period for a pre-existing condition in some situations. For instance, you may be able to avoid the exclusion period if you have had health insurance with a previous employer and have not been without health insurance coverage for more than 63 days. Some states require an employer-based insurance company to cover your pre-existing condition even if you were without insurance for a bit more than 63 days. You can call the US Department of Labor at 1-866-444-3272 to find out more about your specific situation. (See the section, "The Health Insurance Portability and Accountability Act of 1996" for more information.)

But if you are joining a plan that is not group coverage (including some high risk pools), the pre-existing condition exclusion period can be many years or even unlimited. If you are getting a plan through someone other than an employer, the insurance provider can impose an *elimination rider* that would keep that disease, body part, or body system from ever being covered by that policy. It's important to know these things before you sign up.

It's also important to know that the Affordable Care Act (ACA) passed in 2010 affects pre-existing condition exclusion periods, among many other aspects of health insurance. The ACA does not allow insurance companies to deny coverage for pre-existing conditions (such as diabetes or cancer) in children as of September 2010 and in adults starting in 2014. See the section called "The federal law that is changing health insurance: The Affordable Care Act of 2010" for more on this.

### **National law prohibits discrimination based on genetic testing or test results**

The Genetic Information Nondiscrimination Act (GINA) does not allow health insurers to turn down individuals or charge higher premiums for health insurance based on genetic information or the use of genetic services, such as genetic counseling. GINA defines genetic information as any of these:

- A person's own genetic tests
- The genetic tests of family members
- One or more family members with a genetic disease or disorder

GINA bars group health plans, individual plans, and Medicare supplemental plans from using genetic information to limit enrollment or to change premiums. It also forbids these insurers to request or require genetic tests. GINA applies to all health insurance plans (including federally regulated plans, state-regulated plans, and private individual plans).

The law also forbids discrimination by employers based on genetic test results or genetic information. GINA states that employers must not discriminate on the basis of genetic information (no matter how they got the information) in hiring, firing, layoffs, pay, or other personnel actions such as promotions, classifications or assignments.

### **Look carefully at health insurance options at work**

Look closely and compare plans if you are trying to decide among several insurance or managed care options. Sometimes there is a chance to look at and consider different types of coverage during open enrollment periods. (Open enrollment is the time period when you are able to make changes in your coverage. It usually happens once a year). Sometimes it is possible to add yourself, your spouse, or a child to a work health insurance policy outside the open enrollment period if you've had a major change in situation; for instance, if you've gotten married or your spouse has been laid off. Check with your health insurance administrator at work about this.

## **Hospital indemnity policies**

Hospital indemnity policies, sometimes called *supplemental medical policies*, pay a fixed amount for each day a person is hospitalized. There may be a limit on the total number of hospital inpatient days it will pay for in a calendar year, or a cap on the total number of days it will pay. The money received from this type of policy can be used as the insured wishes. It is often used for medical costs not paid by the insurance company, or the other expenses that families face when one member is ill.

## **Case managers and financial assistance planners**

Hospitals, clinics, and doctors' offices often have someone who can help you fill out claims for insurance coverage or reimbursement. A case manager or a financial assistance planner may be able to help guide you through what can be a complicated process.

## **How to manage your health insurance**

- DO NOT let your health insurance expire.
- If you are changing insurance plans, don't let one policy lapse until the new one goes into effect -- this includes when you are switching to Medicare.
- Pay premiums in full and on time. It is often difficult and expensive to get new insurance.
- Know the details of your individual insurance plan and its coverage. Get a copy of your plan's summary description (SPD), which tells you how the plan works, what benefits it provides, and how to get the benefits or file your claim. If you think you might need more insurance, ask your insurance carrier if it is available.
- Submit claims for all medical expenses even when you are not sure if they are covered.
- Keep accurate and complete records of claims submitted, pending (waiting), and paid.
- Keep copies of all paperwork related to your claims, such as letters of medical necessity, explanations of benefits (EOBs), bills, receipts, requests for sick leave or family medical leave (FMLA), and correspondence with insurance companies.
- Get a caseworker, a hospital financial counselor, or a social worker to help you if your finances are limited. Often, companies or hospitals can work with you to make special payment arrangements if you let them know about your situation.
- Send in your bills for reimbursement as you get them. If you become overwhelmed with bills, get help. Contact local support organizations, such as your American Cancer Society or your state's government agencies, for extra help.

# Getting answers to insurance-related questions

Questions about insurance coverage often come up during treatment. Here are some tips for dealing with insurance-related questions:

- Speak with the insurer or managed care provider's customer service department.
- Ask the cancer care team social worker for help.
- Talk with a hospital financial counselor.
- Talk with the consumer advocacy office of the government agency that oversees your insurance plan. (See the section "Who regulates insurance plans?")
- Learn about the insurance laws that protect the public. The Agency for Healthcare Research and Quality has a section entitled "Questions and Answers About Health Insurance." You can find this at [www.ahrq.gov/consumer/insuranceqa](http://www.ahrq.gov/consumer/insuranceqa).

# Keeping records of insurance and medical care costs

It can be hard to keep track of all the bills, letters, claim forms, and other papers that begin flowing into your home after a cancer diagnosis. But keeping careful records of medical bills, insurance claims, and payments helps families manage their money better and lower their stress levels. Some families already have a system for tracking their finances and records and only need to expand it and create new files. Others may have to come up with a plan to handle all of the paperwork.

Record-keeping is also important for those who wish to take advantage of the deductions available in filing itemized tax returns. The Internal Revenue Service (IRS) can give you information and free publications regarding tax deductions for cancer treatment expenses (see the "To learn more" section). These rules change from time to time, so the IRS is the best source of the newest information.

Keep records of the following:

- Medical bills from all health care providers -- write the date you got the bill on each one
- Claims filed, including the date of service, the doctor, and the date filed
- Reimbursements (payments from insurance companies) received and explanations of benefits (EOBs)
- Dates, names, and outcomes of calls, letters, or emails to insurers and others

- Medical costs that were not reimbursed, those waiting for the insurance company, and other costs related to treatment
- Meals and lodging expenses
- Travel to and from doctor's appointments and treatments (including gas, mileage, and parking)
- Long-distance phone calls related to medical or other types of care, including psychosocial care
- Admissions, clinic visits, lab work, diagnostic tests, procedures, and treatments
- Drugs given and prescriptions filled

Here are some ideas to help you with record-keeping:

- Decide who in the family will be the record-keeper or how the task will be shared.
- Get the help of a relative or friend, if needed. This may be especially important for people who are single or who live alone.
- Set up a file system using a file cabinet, drawer, box, binders, or loose-leaf notebooks.
- Review bills soon after getting them and note any questions about charges.
- Check all bills and explanations of benefits paid to be sure they are correct.
- Pay bills by check if possible so that you will have a record of payment.
- Save and file all bills, payment receipts, and canceled checks (If you do not normally get copies of canceled checks, talk to your bank or credit union about how to get them when you need them.)
- Keep a daily log of events and expenses; a calendar with plenty of writing space is useful.
- Keep a list of cancer care team members and all other contact persons with their phone and fax numbers and email addresses.
- Find out what is tax deductible and be sure the original copies of those records are kept. (See the "To learn more" section for the IRS phone number.)

## **When you have problems paying a medical bill**

Many people go through times when they find it hard to pay their bills on time. Most hospitals and agencies are willing to discuss and help resolve these problems. To keep a

good credit rating, pay attention to notices that say the bill will soon be turned over to a collection agency. You want to avoid this if at all possible. Families can do the following:

- Explain the problem to the hospital or clinic financial counselor or the doctor's office secretary.
- Work out a payment delay or an extended payment plan.
- Talk with the team social worker about sources of short-term help.
- Think about asking relatives or friends to help out with money on a short-term basis.

## **Handling a claim denial -- what to do when insurance won't pay for a prescribed service**

It is not unusual for some claims to be denied or for insurers to say they will not cover a test, procedure, or service that your doctor orders. If this happens, it is important to have a working relationship with a customer service representative or case manager with whom you can talk about the situation. Before you appeal, you may want to take these steps:

- Ask for a full explanation of why the claim was denied.
- Review your health insurance plan's benefits.
- Contact your health plan administrator to find out more about the refusal.
- Ask the doctor to write a letter explaining or justifying what has been done or has been requested.
- Talk to your state insurance department or the agency that regulates your insurance company to learn more (see the section "Who regulates insurance plans?").

You can then re-submit the claim with a copy of the denial letter and your doctor's explanation, along with any other written information that supports using the test or treatment that has been denied. Sometimes the test or service will only need to be "coded" differently. If questioning or challenging the denial in these ways does not work, you may need to:

- Put off payment until the matter is resolved.
- Re-submit the claim a third time and request a review.
- Ask to speak with a supervisor who may have authority to reverse the decision.
- Request a written response. (Keep the originals of all the letters you get; the team may be able to help you make copies if you need them.)
- Keep a record of dates, names, and conversations you have about the denial.

- Formally appeal the denial in writing, explaining why you think the claim should be paid. Your cancer care team members (doctor, nurse, social worker) may be able to help with this.
- Get help from the consumer services division of your state insurance department or commission. Check the blue pages of your phone book or the National Association of Insurance Commissioners (contact information is in the "To learn more" section).
- Do not back down when trying to resolve the matter.
- Consider legal action.

You can learn more about the appeals process from the Kaiser Family Foundation through "A Consumer's Guide to Handling Disputes with Your Employer or Private Health Plan" which can be found on their Web site at [www.kff.org/consumerguide](http://www.kff.org/consumerguide). The Patient Advocate Foundation also has "Your Guide to the Appeals Process" which can be found on their Web site at [www.patientadvocate.org/resources.php?p=13](http://www.patientadvocate.org/resources.php?p=13). A detailed guide from America's Health Insurance Plans (AHIP) has information about internal and external review of denied claims. It has details on each state's review process, which can be found at [www.healthclaimappeals.org/home.html](http://www.healthclaimappeals.org/home.html).

## **Keeping employer-sponsored health insurance coverage when you leave your job**

There are federal laws which give people the chance to continue employer-sponsored medical insurance coverage when a person has a "qualifying event" (defined under the "COBRA" section).

### **COBRA (Consolidated Omnibus Budget and Reconciliation Act of 1986)**

COBRA gives you the right to choose to keep your health insurance coverage at the employer's group rates, but you usually pay much more than you paid while employed. In most cases, you can keep the insurance for up to 18 months. Some people may be able keep it a few months longer.

COBRA is available when insurance coverage is lost due to certain "qualifying events," such as stopping work, reducing work hours, divorce or legal separation, the covered person becoming entitled to Medicare, a dependent child no longer considered to be dependent according to the terms of the plan, or the death of the employee.

How long COBRA allows people to keep their group medical insurance depends on the qualifying event. For example:

- Up to 18 months of coverage is allowed if you stop working or reduce the number of hours you work.

- 29 months of coverage is possible if a beneficiary is considered disabled. (This determination of disability is made by the Social Security Administration.)
- 36 months of coverage is available for the spouse or child in cases of divorce or legal separation, the covered person becoming eligible for Medicare, death of the employee, or when a dependent child is no longer considered to be a dependent.

If a person is fired for gross misconduct, he or she is not eligible for COBRA.

COBRA is not provided automatically but must be chosen by the former employee within 60 days of getting the written COBRA "election notice" (this is not always within 60 days of when you stopped working). The employer must notify an employee in writing that COBRA is available after work is stopped or hours are reduced.

But there is also a deadline for notifying the plan administrator of the qualifying event, which varies according to the qualifying event. Whose responsibility it is to notify the plan administrator also depends on the qualifying event. In cases of family changes, the beneficiary must do it, as in these situations:

- Divorce
- Legal separation
- An employee's child reaches the status of non-dependent

This means it may be the employee, the employee's spouse, or the employee's adult child who needs to notify the plan administrator of the qualifying event. If this notice is not done within the deadline, the spouse or child may lose their COBRA rights. But if a family member gets COBRA due to one of these changes in family situation, it can be extended to 36 months. Contact the employer's human resources person, your insurance company, or check your policy to find out the details of what must be done and who should do it.

You can keep your health insurance if the premium is paid, and until the person becomes covered under another group policy, up to a certain time limit. Premiums cannot be more than 102% of the cost of the plan for employees in similar situations who have not had a "qualifying event." COBRA coverage may be lost if you go above the limits of the coverage, your former employer stops offering all health plan coverage, or you become entitled to Medicare after you choose COBRA.

COBRA is administered by the US Department of Labor and they can give you more detailed information about how it works. (See the section called "To learn more") Families often are concerned about being able to pay the premium for COBRA. If this is the case, talk to your team social worker who may have suggestions about how to help with these costs.

For more information, read our document, *What is COBRA?*

## The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

This bill has many clauses that can help cancer patients:

- It allows a person who has had health insurance for at least 12 months with no long loss of coverage (usually more than 63 days) to change jobs and be guaranteed other coverage with a new employer who also offers group insurance. In this case there may be no waiting period and the pre-existing condition exclusion may be reduced or not applied. Also, the employee and his or her partner cannot be denied coverage because of a pre-existing health problem. (See "Pre-existing condition exclusions" under the section, "Other things to know about health insurance.") For dependent children and many young adults up to age 26, there are new protections under the Affordable Care Act that do not allow pre-existing condition exclusion periods. (See the section "The Federal law that is changing health insurance: The Affordable Care Act of 2010" and "Health insurance options for young adults" under the section "Options for the Uninsured" for more information.)
- If a cancer patient is uninsured, and takes a job with an employer offering group insurance, the pre-existing condition exclusion period for the employee and his or her partner cannot be longer than 12 months. Pre-existing condition exclusion periods cannot be applied to dependent children and some young adults under the Affordable Care Act, as noted above.
- HIPAA requires insurers to renew coverage for all employers and individuals when premiums are paid on time.
- It also guarantees that group insurance coverage is available for employers with 2 to 50 employees. But it does not require these small employers to buy the insurance that is offered.
- HIPAA also helps protect anyone left out of group health coverage after COBRA has run out. If you are eligible and act within 63 days of losing COBRA coverage, HIPAA guarantees that you can buy some type of coverage and that you will have a choice of at least 2 options. But it is important to know that no one will notify you that you are eligible or of the 63 day time limit. Contact your state insurance department or commission to find out what is available to you, or call us.

For more information about HIPAA ask for our document, *What is HIPAA?* or contact your state department or commission of insurance. See the section called "To learn more."

## The Family and Medical Leave Act of 1993

The Family and Medical Leave Act (FMLA) requires employers (with at least 50 employees) to provide up to 12 weeks of unpaid, job-protected leave to eligible employees for certain family and medical reasons. Employees are eligible if they have worked for a covered employer for at least 1,250 hours in the previous 12 months. For the

time period of the FMLA leave, the employer must maintain the employee's health coverage.

This act is regulated by the US Department of Labor's Wage and Hour Division. They can give you more information. Check your local phone book under US Government, Department of Labor for contact information, or find it in the "To learn more" section.

## The Americans With Disabilities Act of 1990

The Americans With Disabilities Act offers protection against discrimination in the workplace to anyone who has, or has had, certain disabilities, including any diagnosis of cancer. Parents of dependent children with cancer and spouses of people with cancer are also protected under this law. The ADA requires private employers who employ 15 or more people, labor unions, employment agencies, and government agencies to treat employees equally, including the benefits offered them, without regard to their disabling condition or medical history. It also does not allow employers to screen out potential employees who have children with disabilities.

This act, along with the Health Insurance Portability and Accountability Act makes it easier to change jobs and move from one group insurance plan to another. This law is administered by the US Equal Employment Opportunity Commission (EEOC). They can answer questions and give you more information on a special phone line (1-800-514-0301). You can also get more information in our document called *Americans With Disabilities Act: Information for People Facing Cancer*.

## The federal law that is changing health insurance: The Affordable Care Act of 2010

Many people with cancer are afraid they will lose their health coverage if they lose their jobs. Others worry about having their coverage canceled because they got sick. Some face dollar limits on the amount of care their health plan will cover. The Affordable Care Act, passed in 2010, changes health care in many ways that help people with cancer. For instance, the new law:

- Removed lifetime dollar limits and restricted yearly dollar limits on health benefits starting in September 2010. It will remove all yearly limits in 2014.
- Does not allow insurance companies to deny coverage for pre-existing conditions (such as cancer) in children as of September 2010. Pre-existing condition exclusions will not be allowed in adults starting in 2014.
- Does not allow insurance plans to stop coverage when a patient gets sick
- Created state or federal run Pre-Existing Condition Insurance Plans (PCIPs) in every state to cover people who have not had insurance for 6 months or more and have cancer or another pre-existing condition

- Makes coverage available for patients who take part in clinical trials

To learn more, please read our brochure called *The Affordable Care Act: How It Helps People With Cancer and Their Families*. You can also get up-to-date information online from the US Department of Health & Human Services at [www.healthcare.gov](http://www.healthcare.gov).

## Government-funded health plans

### Medicare

Medicare is a federal program funded through the Social Security system. It provides health insurance for US citizens and other eligible people who meet certain criteria. Young people with cancer may get Medicare benefits after collecting Social Security benefits for 2 years under the Supplemental Security Income program. You can get more information from the Social Security Administration (check the blue pages of your phone book or the "To learn more" section in this document), or by talking with your cancer care team social worker. Medicare is also federal health insurance for people who meet any of these requirements:

- Are age 65 or older
- Have been permanently disabled and are getting disability benefits from Social Security
- Have permanent kidney failure treated with dialysis or a transplant

Medicare is divided into parts:

**Part A** pays for hospital care, home health care, hospice care, and care in Medicare-certified nursing facilities. For most people, there is no monthly premium, but you pay a yearly deductible for your health care before Medicare pays anything. After that's paid, Medicare pays its share, and you pay your share (your co-insurance or co-payment) for covered services and supplies. You can go to any doctor or supplier that accepts Medicare and is accepting new Medicare patients, or to any hospital or other facility. You may have a Medigap policy or other supplemental coverage that may pay deductibles, co-insurance, or other costs that aren't covered by the Medicare Part A (see below, "Private insurance coverage that can be added to Medicare").

**Part B** covers diagnostic studies, doctors' services, durable medical equipment used at home, and ambulance transportation. Part B is optional, and there is a monthly premium which is based on your income. Each year, before Medicare pays anything, you must pay your own medical expenses to equal the deductible, based on Medicare's approved "reasonable charge," not on the provider's actual charge. And you must still pay co-insurance or a co-payment on the rest of the covered charges for that year.

**Part C** is actually a combination of Parts A and B but it is provided by private insurers. These private insurance companies must be approved by Medicare, and must provide all hospital and medical benefits covered by Medicare. Called *Medicare Advantage*, these private insurers charge a monthly fee and some include the Part D prescription drug coverage (see "Part D" below), as well as vision, hearing, and dental coverage. Part C is

not available everywhere. Medicare Advantage plans can be PPOs, HMOs, or fee-for-service plans. (See the section "Types of health plans" for more on these different plans.) There is also a Part C Medicare Special Needs plan, which is designed for people with long-term health problems. These plans must include Parts A, B, and D coverage.

**Part D** is optional. It helps pay for prescription drugs that are usually bought at a retail pharmacy. If you join, you pay a monthly premium, which varies by plan, and a yearly deductible. You will also pay a part of the cost of your prescriptions, including a co-payment or co-insurance. Costs vary based on which drug plan you choose. Some plans may offer more coverage and a wider choice of drugs for a higher monthly cost. If you have limited income and resources, you may qualify for extra help and you may not have to pay a premium or deductible. You can apply or get more information about the extra help by contacting the Social Security Administration (see "To learn more" for contact information). You can find out more about Medicare Part D and how it applies to people with cancer in our document, *Medicare Part D: Things People With Cancer May Want to Know*.

Medicare provides basic health coverage, but it won't pay all of your medical expenses. It may cover the costs of prostheses or bras, and the number covered per year may vary from state to state. Medicare also limits the number of items for ostomy supplies used per month. If you have questions about Medicare, call 1-800-633-4227 or contact your local Social Security office.

### **Private insurance coverage that can be added to Medicare (Medicare Supplement Insurance or Medigap)**

If you are enrolled in standard Medicare, you may be able to add more coverage with a Medicare Supplement Insurance policy (commonly called Medigap). There are 10 standard Medigap policies. Each offers a different combination of benefits and is offered in all 50 states, but the plans may not be the same in all states. The plans are identified by letters A through J. It is important to compare Medigap policies because premiums and other costs can vary, and some of the plans expect you to use only certain doctors or hospitals.

## **Medicaid**

Medicaid is another government program that covers the cost of medical care. To get Medicaid, your income and assets must be below a certain level. These levels vary from state to state. Not all health providers accept Medicaid. Some examples of people who are eligible for Medicaid include:

- Low-income families with children
- Supplemental Security Income (SSI) recipients
- Infants born to Medicaid-eligible pregnant women
- Children under age 6 from low-income families may be eligible in some states (even if other family members are not)

- Pregnant women whose income is below the family poverty level

Medicare beneficiaries who have a low income and limited resources may get help paying for their out-of-pocket medical expenses from their state Medicaid program. For more information, contact your state Medicaid office (see the "To learn more" section).

## State-sponsored children's health insurance programs

There is a special state and federal partnership that pays for medical services for children called the Children's Health Insurance Program (CHIP). CHIP offers some type of low-cost health insurance to uninsured children and pregnant women in families with incomes too high to qualify for state Medicaid programs, but too low to pay for private coverage. Within federal guidelines, each state sets up its own CHIP program, including eligibility guidelines, benefits offered, and cost. The program covers doctor visits, medicines, hospitalizations, dental care, eye care, and medical equipment. It is funded by state tax dollars. People enrolled in Medicaid usually are not eligible for state sponsored health insurance programs.

To find out more about CHIP, call 1-877-543-7669. You can also go to the CHIP Web site, [www.insurekidsnow.gov](http://www.insurekidsnow.gov), to learn more about the program and find your state's CHIP.

## Veterans' and military benefits

**Veterans:** If you have ever been on active duty in the military, you may qualify for Veterans Administration (VA) health benefits. The VA looks at how long you served, the type of discharge you received, disability, income, availability of VA services in your area, and other factors to decide if you are eligible. Veterans' benefits change often, and the number of veterans' medical facilities has been declining in recent years. See the "To learn more" section to learn how to contact the Department of Veterans Affairs to get the latest information.

**Active duty, reservists, retirees, survivors, and family:** TRICARE is the Department of Defense's health insurance program for those in the military, as well as some family members, survivors, and retirees. It offers 9 different plan options to cover people in the US and overseas, and includes family plans as well as plans for certain reservists. Pharmacy plans, dental plans, and other special services are available for some beneficiaries.

Each TRICARE plan has its own limits and requirements. Choose your plan carefully and know how it works. Contact TRICARE for complete and current information on TRICARE benefits for those who have been in the military and their families, including eligibility, plan details, and cost, as well as how to find providers in your area. You can find this information online at [www.tricare.mil](http://www.tricare.mil) or call 1-800-538-9552.

**Widows or widowers, and spouses or children of military members with service-related disabilities:** Another program called Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) is available to certain spouses or

widows(ers) and their children who are not eligible for TRICARE. CHAMPVA can cover the spouse or widow(er) and the children of a veteran who:

- Is permanently and totally disabled due to a service-connected disability as determined by a VA regional office
- Was rated permanently and totally disabled due to a service-connected condition at the time of death
- Died from a service-connected disability
- Died in the line of duty and the family members are not eligible for TRICARE benefits

CHAMPVA is a comprehensive health care program in which the VA shares the cost of covered health care services and supplies with eligible beneficiaries. The program is administered by the VA Health Administration Center. You can find out more about CHAMPVA, including things like eligibility, benefits, finding a provider, and filing claims by calling 1-800-733-8387, or visiting their Web site, [www.va.gov/hac](http://www.va.gov/hac) (select CHAMPVA under "Special Programs").

**Activated reservists and their employee health benefits:** Members of the military reserve units who are called up for active duty from private employment have specific rights about the health care coverage they get from their employers. They are allowed to pay the full cost of insurance, very much like COBRA, during their time away. When they return to work, their coverage must be re-instated without any waiting period. See the "To learn more" section for US Department of Labor contact information.

## Breast and cervical cancer screening and treatment for low-income women

Medically underserved women can get tested for breast cancer for free or at very little cost through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This program provides breast and cervical cancer early detection testing for women who are uninsured, or in some cases under-insured. The NBCCEDP tries to reach as many women in medically underserved communities as possible, including older women, women without health insurance, and women who are members of racial and ethnic minorities. Every state offers the program, and the Centers for Disease Control and Prevention (CDC) helps support the state program.

Although the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) can help women find cancer early, uninsured women still need help getting treatment. In 2000, the Breast and Cervical Cancer Prevention and Treatment Act was signed into law. This Act provides money to pay for breast and cervical cancer treatment for certain uninsured women who are under age 65. As in the NBCCEDP, each state must adopt the program to get the matching federal funds. Even though the money is channeled through each state's Medicaid program, it helps women who are not eligible for Medicaid.

Information on the NBCCEDP can be found at the CDC Web site, [www.cdc.gov/cancer/nbccedp/index.htm](http://www.cdc.gov/cancer/nbccedp/index.htm), or you can call 1-800-232-4636 to learn more.

## Who regulates insurance plans?

The *private group plans* (or *fully insured plans*) purchased from insurance carriers by employers as a benefit for employees are overseen by the insurance commission or department of insurance in each state. You can find your state's insurance department in the blue pages of your local phone book, or contact the National Association of Insurance Commissioners (see "To learn more" for contact information).

Self-funded plans (or *self-insured plans*) are health plans that employers or unions create rather than purchase. They are overseen by the US Department of Labor's Employee Benefits Security Administration. (See the "To learn more" section for the Web site and phone number.) You may have to ask your employer if their health plan is fully insured or self-insured.

Managed care plans are regulated by several state and federal agencies. Your state insurance commission or department of insurance can provide specific information about an individual plan.

Medigap policies (Medicare Supplement Insurance policies) are regulated by federal agencies, as well as some state laws. Contact Medicare (CMS) and/or your state department of insurance for problems.

Medicaid is controlled by your state health department.

Medicare is run by the US Social Security Administration.

TRICARE is overseen by the US Department of Defense.

The Veteran's Health Care system (including CHAMPVA) is regulated by the US Department of Veteran's Affairs.

## Options for the uninsured

### Shopping for insurance coverage

If you are not already insured, here are some things to think about when looking for coverage:

- An independent broker may be able to help you find a reasonable benefit package. Group insurance is better for most people than individual insurance.
- Getting a job with a large company is the surest way to get access to group insurance.
- As of 2010, your state should offer some type of Pre-Existing Condition Insurance Plan (PCIP) to cover people who have not had insurance for 6 months or more and

have cancer or another pre-existing condition. Also, some states have health insurance options for low-income residents, in which the state pays for part of the coverage.

- Find out if there are health maintenance organizations (HMOs) or health care service plans in your community. You can sometimes get very good coverage through these plans. Many have an open enrollment period each year during which applicants are accepted regardless of past health problems.
- If you have been covered under your employer-sponsored plan for at least one day you should be able to keep your medical insurance through COBRA. Your employer should be able to tell you, in writing, about your COBRA option. For more information, please see the section, "COBRA (Consolidated Omnibus Budget and Reconciliation Act of 1986)"
- Find out if you can apply for group insurance through fraternal or professional organizations (such as those for retired persons, teachers, social workers, realtors, etc.). Look for a "guaranteed issue" plan.
- Look into Medicare, which covers most people who are 65 or older, or children who are permanently disabled and have been getting Social Security benefits for 2 years.
- See if you are eligible for state or local benefits, such as Medicaid if you are in a low-income bracket or are unemployed.
- If you are employed, don't leave your job until you have found out if you can convert your group insurance to an individual plan. Some group plans have a clause that allows people to convert to individual plans, but premiums may be much higher. These individual plans usually must be applied for within 30 days of leaving a job. (This is different from COBRA, which allows you to stay with the group insurance but only for a limited time.)

In looking at insurance options, find out about differences in coverage. Ask about choice of doctors, protection against cancellations, and increases in premium costs. Find out what the plan really covers, especially in the event of a catastrophic illness (a serious illness, like cancer, that can add up bills quickly). How much will the deductibles and co-pays cost you? (Sometimes higher deductibles go along with better or more complete coverage.)

If you feel an insurance company has treated you unfairly, contact your state insurance commission for more information. See the "To learn more" section to find your state insurance department.

## Health insurance options for young adults

If you're age 18 to 25, you may think you're young and healthy and don't have to worry about health insurance. Maybe you can't afford it anyway. But even young adults have accidents and serious illnesses, and find themselves needing health care. There are some health insurance options for this age group.

When choosing a plan, ask about coverage for common tests young people need, like blood tests or x-rays. Also, if you have any medical condition that you are concerned about, you may want to check with the insurance company about its policy on pre-existing conditions (medical conditions that you already have). (If you are under the age of 19 you cannot be denied coverage for pre-existing conditions.) Here are some of the health insurance options for young adults.

**Through your parent's health coverage:** The Affordable Care Act of 2010 provides coverage for young adults up to the age of 26 under their parent's health insurance (if the plan has dependent or family coverage). This means that adult children can join or stay on a parent's plan whether or not they are:

- Married
- Living with a parent
- In school
- Financially dependent on a parent (the young adult does not have to be listed as a dependent on the parent's tax return)

The only exception is if the parent has an existing job-based plan and the young adult can get their own job-based coverage.

The cost of the insurance for young adults cannot be any higher than for dependent children under the age of 18.

**Individual insurance:** There are individual health insurance plans from private companies that are offered to young adults. Some of these insurers will turn you down, charge more, or not offer certain benefits if you have a pre-existing health condition. But in some states insurers aren't allowed to turn you down because of your health condition. This is called "guaranteed issue." Contact your State Department of Insurance to see if this protection applies to you. You can find your state's insurance department in the blue pages of your local phone book, or see the "To learn more" section to contact the National Association of Insurance Commissioners. Be sure you understand the coverage offered and yearly or lifetime limits on the plan before you buy it.

**Through your work or your spouse's work:** If your employer offers coverage, you generally can't be turned away or charged more because of your health status. But employers may refuse or restrict coverage for other reasons (such as part-time employment), as long as these reasons are not related to your health and are applied to all employees.

**Student health insurance programs (SHIPs):** Some colleges or universities may offer a reduced-cost student health insurance. Be sure you understand the coverage and payout limits. For example, coverage may be limited to \$500,000 or even less per year. This may not be enough to treat a serious illness. Also make sure that you understand how long you are covered and if coverage is only active as long as you are enrolled in classes. Often an advantage of plans like this is that it is integrated to cover any charges from the Student Health Service, which may provide basic health care on campus. Keep in mind that many

colleges and universities even offer counseling centers where students can get short-term therapy at no cost or for low cost co-pays at each visit.

**Uninsurable risk programs:** There are some states that provide special coverage for people who have a pre-existing condition (one you had before you applied for coverage) and do not qualify for individual health coverage. Your state's department of health insurance can give you more information about your state.

**Pre-Existing Condition Insurance Plans:** A Pre-Existing Condition Insurance Plan (PCIP) is now offered in every state because of the Affordable Care Act. It can be administered by either the state or the federal government. You may qualify for PCIP coverage if you have been uninsured for at least 6 months, you have a pre-existing condition, and you have been denied coverage (or offered insurance without coverage of the pre-existing condition) by a private insurance company. In some states you no longer have to wait for a private company to deny you coverage. Instead, you can get a letter from your health care provider stating that you have a pre-existing condition, disability, or illness.

PCIP cost isn't based on your income. It covers major-medical and prescription drug expenses, but you must pay premiums, deductibles, and co-pays. PCIP won't cost you more just because of your medical condition.

**Medicaid, Indian Health Services, dependents of active duty US military, or other government aid programs:** These types of programs are available for young adults, but some states exclude full-time students from these programs if the programs work mostly with low-income people.

## While you are looking for health insurance

**Check into Hill-Burton funds:** A few hospitals and other non-profit medical facilities get Hill-Burton funds from the federal government so they can offer free or low-cost services to those who can't pay. Each facility chooses which services it will provide at no or lowered cost. Medicare and Medicaid services aren't eligible for Hill-Burton coverage. But Hill-Burton may cover services that other government programs don't.

Eligibility for Hill-Burton is based on family size and income. You will need to find out if there is a facility in your area that has any Hill-Burton obligation for which you may qualify. If you are cared for at such a facility, you may apply for Hill-Burton help at any time, either before or after you receive care. Call the Hill-Burton Program for more information on this program at 1-800-638-0742. Or visit their Web site, [www.hrsa.gov/hillburton](http://www.hrsa.gov/hillburton), for a listing of Hill-Burton-obligated facilities, eligibility criteria, and frequently asked questions about the program.

**Compare your drug list to low-cost prescription programs:** Some drugstores and discount stores now offer certain generic drugs at very low prices. Most of the time, these do not include cancer drugs -- although some offer tamoxifen in their programs. Even people with insurance may be able to lower their co-payments and save money by getting some of their medicines at very low cost (often \$4 to \$10 for each refill).

See the section "Financial issues: Getting help with living expenses" for ideas on help with non-medical expenses.

## State coverage and health insurance options for the hard-to-insure

People with health problems are often denied private health insurance or have trouble finding affordable coverage. The Affordable Care Act (ACA), passed in 2010, does not allow insurance companies to deny coverage to children with pre-existing conditions (such as diabetes or cancer) as of September 2010. Starting in 2014, it will not allow adults to be denied coverage for pre-existing conditions. But in the meantime, there are some options available for those who have had trouble getting health insurance.

For a number of years, some states have sold comprehensive health insurance to state residents with serious medical conditions who can't find a company to insure them. These state programs, sometimes called *risk pools*, serve people who have pre-existing health conditions.

Now, under the Affordable Care Act (ACA), every state must have a Pre-Existing Condition Insurance Plan (PCIP) for people who have not had insurance for 6 months or more and have cancer or another pre-existing condition. Whether the state or the US Department of Health and Human Services runs the PCIP program depends on the state. The program name and design may vary, too, depending on which state you live in. (Go to [www.healthcare.gov/law/provisions/preexisting/index.html](http://www.healthcare.gov/law/provisions/preexisting/index.html) for the most current information on what is available in your state.)

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides nationwide standards and a guarantee of access to individual health insurance for some people who are losing their group health insurance coverage (see the section on HIPAA). But this doesn't mean that you can afford it or that it will cover what you need.

All states are different. Some have special laws requiring that insurers offer health insurance to anyone who applies. This is called *guaranteed issue*. A few states also limit the premium the insurance company can charge, even if a person has a pre-existing condition. This is called *community rating*. If you live in a state that requires community rating, you are not likely to need insurance risk pools or PCIPs.

To find out which public, private, or community health insurance programs best meet your needs, please see the "Find Insurance Options" tool on the US Department of Health & Human Services Web site at <http://finder.healthcare.gov/>. This tool was created to help consumers under the health insurance reform law, the Affordable Care Act. You can also call your American Cancer Society for answers to your insurance questions. Other resources that may be helpful are listed in the "To learn more" section.

# Financial issues: Getting help with living expenses

The major costs of a cancer diagnosis and treatment are for things like time in the hospital, clinic visits, medicines, tests and procedures, home health services, and the services of doctors and other professionals. Insurance, managed care, or public health care programs pay most of these costs if you are covered in such a plan.

But families face many indirect costs or "out-of-pocket" expenses, too, along with their usual bills. These costs can be for things like:

- Travel (gas and parking)
- Lodging (a place for the patient and/or family to stay) during treatment done away from home
- Meals during travel or clinic visits
- Extra child care costs
- Communication (phone calls, faxes, copies of medical records, etc.) with doctors, friends, and relatives
- Special foods and nutritional supplements
- Special equipment or clothing

Also, a cancer treatment plan can cause family members to lose time at work and, in some cases, all or part of their salary. Even more money is lost if a family member has to quit a job or take an extended leave of absence. Of course, costs increase as treatment is extended, if there are treatment complications, or if the cancer comes back (recurs). This section offers just a few ideas of where you might be able to get some help dealing with the costs of cancer. See the "To learn more" section for other resources that may be useful to you.

## Viaticals and living benefits from life insurance policies

Life-threatening illnesses and problems that need a lot of medical care often lead to a need for immediate cash income. In many states, your life insurance policy may be a source of income through the acceleration of the policy's death benefit, known as "living benefits." You can get these benefits in different ways, such as viaticals (sale of the life insurance policy) and loans against the face value of the life insurance policy (from the original insurance company or from a third party). The Life Insurance Settlement Association can give you more information on ways you may be able to use your life insurance policy. Visit them online at [www.thevoiceoftheindustry.com](http://www.thevoiceoftheindustry.com), or call 407-894-3797.

## **Viaticals**

A *viatical* is the sale of a life insurance policy for cash. The person insured (called the *viator*) sells his or her life insurance policy to a third party. As with any sale, both sides must agree on what is being sold and how much it is being sold for.

A viatical transaction usually takes place when someone has a limited time to live. The person's life expectancy may be less than 6 months or as long as several years and must be certified by a doctor. The insured person is probably unable to work and is likely to have a low income. To reduce money worries, the person sells the life insurance policy for a lump-sum cash payment. The payment is often between 60% and 80% of the face value of the policy, and is usually tax-free. This payment is given only to the person who holds the policy.

A viatical insurance company buys policies from people with terminal illnesses. The viatical company becomes the new owner and the only beneficiary of the policy. It pays the premiums on the policy as long as the patient is alive. When the person dies, the death benefit (payout) from the policy goes to the viatical company.

Reasons for choosing a viatical:

- To pay for food, shelter, doctor visits, or other pressing needs
- To ease the stress of money worries
- To fulfill a life-long dream

Drawbacks of a viatical:

- Your heirs get no insurance money.
- You may not make the best trade available.
- Decision-making may be difficult.
- Once a policy is sold, the sale is usually not reversible.

## **Line of credit from a finance company**

People with cancer who are not expected to live a long time can transfer their life insurance's death benefit to a finance company. The company reviews your health status, then makes "cash advances" on the expected benefit. This is actually a loan, and as with all loans, interest rates vary. You may borrow up to 35% to 75% of your insurance's death benefit depending on your situation. The death benefit is then reduced by the loan amount, the premiums the company pays on the policy, fees, and the interest on the loans you have taken out. Not all life insurance is eligible, and this type of loan is not offered by all companies.

## **Living benefits and other choices**

You also have other choices. For instance, you may be able to get a personal loan, or, instead of selling your policy outright to a third-party viatical company or transferring

your death benefit, you may be able to get more money from the original insurance company. Many insurance companies make it possible for life insurance policy owners to collect part of their death benefits early -- before dying -- to cover extraordinary expenses. A life insurance policy usually pays benefits to a beneficiary after a policy owner dies. But in certain cases, those benefits are accelerated and are paid directly to a chronically or terminally ill policy owner before he or she dies. These are called *living benefits* or *accelerated benefits*.

In general, living benefits can range from 25% to 95% of the death benefit. The payment depends on your policy's face value, the terms of your contract, and the state you live in. Ask your insurer to provide you with a quote before you use your accelerated death benefit option. Living benefits are not intended to replace health insurance or long-term care insurance. But they can give you extra help with needs that result from terminal or catastrophic illness. Contact your insurance agent or life insurance company for details on your policy's accelerated benefits plan.

For more information regarding living benefits from life insurance, please contact the American Council of Life Insurers Web site at 202-624-2000 or [www.acli.com](http://www.acli.com).

Another choice is to get a loan from a third party. Some companies will lend money to terminally ill people who have a life expectancy of between 6 months and 5 years. The patient's life insurance policy is used as collateral. The company will lend a portion of the policy's face value, usually ranging from 35% to 85%, which will be paid back from the proceeds of the policy at the time of the patient's death. Any surplus funds then go to the original beneficiary. The interest rates on the loans are often high, but there are no restrictions on how the borrowed money may be used.

**Signing a contract for a viatical or living benefits:** Before you make a final decision, think about the points below. Talk to a lawyer or a financial planner to help you decide what is best in your case.

- Get a clear picture of what's involved. Read about viaticals, loans, and living benefits. Ask questions.
- Get professional advice about the types of living benefits available and the pros and cons of each.
- Decide whether a viatical is really the best course of action for you.
- Talk to your doctor about how long you can expect to live.
- Find out if Medicaid or other benefits will be affected.
- Shop around. Get several bids. Bids can vary a lot.
- Find out if the company is a broker. Some companies use their own money to buy policies, but others are brokers. A broker gets a commission from the company and may not act in your best interest.
- Negotiate; you might get a better deal.

## Outside sources of financial help

Most families find it hard to turn to others or to public agencies and funds for financial help. The extra expenses of cancer may be the first time a family has had problems with money. Families should remember that their problems in this situation are often short-lived and not unique. In the future, they may be the ones who can offer help to others.

Here are just a few of the many possible sources of help for families who need extra financial support at this time:

- Income assistance for low-income families through Supplemental Security Income (SSI) benefits.
- Income assistance for needy families from the Temporary Assistance for Needy Families (TANF) program.
- Help with treatment-related travel, meals, and lodging from public and private programs.
- Help with basic living costs (such as rent, mortgage, insurance premiums, utilities, and telephone) from public and private programs.
- Help from church, civic, social, and fraternal groups in the community.

Help may also be available from groups like the Salvation Army, Catholic Social Services, the United Way, Jewish Social Services, and other groups that can be found in the yellow pages.

Though it is not available in all areas, the United Way of America and the Alliance of Information and Referral Systems have set up a 211 service in many parts of the country. You can call 211 to find out what help might be available in your area, or visit them on the Web at [www.211.org](http://www.211.org).

There are National Association of Area Agencies on Aging offices in many areas that can help older people with cancer. Call 1-800-677-1116 for their Eldercare Locator to learn what is in your area, and whether you might be able to get help. You can also check on the Web at [www.n4a.org](http://www.n4a.org).

The American Cancer Society also has many helpful services. Call us to find out more about them and to see if there are other local resources in your area.

## Sources of help with short-term housing

Many treatment centers have short-term housing centers or discount programs set up with nearby motels and hotels. The clinic social worker or oncology nurse may have suggestions for low-cost housing during hospital or clinic treatment.

The American Cancer Society has a limited number of Hope Lodges throughout the United States which give families a place to stay during cancer treatment. Contact us to find out if there is a Hope Lodge near you.

Most major pediatric treatment centers have a Ronald McDonald House nearby. These houses provide low-cost or free housing to patients and their immediate families. Ronald McDonald houses are designed to offer a nice break to any family with a seriously ill child, not just those with limited funds. Although partly funded by McDonald's Children's Charities, each house has its own management, sets its own admission standards, and operates according to its own rules. Check with your health care team's social worker or nurse to learn more, or contact Ronald McDonald House Charities at 630-623-7048 or [www.rmhc.org](http://www.rmhc.org). Families must be referred by medical staff and/or social workers at the treatment facility.

Another possible option is the National Association of Hospital Hospitality Houses, Inc. This group of more than 150 non-profit organizations throughout the US provides free or low-cost family-centered lodging to families getting medical treatment far from home. They can be contacted at 1-800-542-9730 or online at [www.nahhh.org](http://www.nahhh.org) to see if there is a location that works for you.

### **Sources of help with housing needs or mortgage payments**

The extra costs of treatment or major loss of family income may make it hard for families to pay their mortgage or rent on time. To keep a good credit rating, talk with your creditor or landlord about your situation and try to make special arrangements. Family, friends, or church members may be able to give you short-term help if they are told about the problem. Talk about your situation with your cancer team social worker who may know of special resources.

Families who need to move out of housing after a cancer diagnosis should talk with their county department of social services to find out if they qualify for government supported housing programs.

### **Sources of help with driving and ground transportation costs**

People who have Medicaid are entitled to help with travel to medical centers and doctors' offices for treatment. This may take the form of payment or being paid back (reimbursed) for gas, payment of bus fare, or may mean using a vanpool. County departments of social services in each state arrange for help with transportation, but families must ask for it by talking to their Medicaid case worker.

The American Cancer Society Road to Recovery program is available in some areas. Volunteers drive patients and families to hospitals and clinics for treatment. In some parts of the country, the ACS may also provide some limited help with the cost of gas. Contact your local American Cancer Society office for more information on what type of transportation program is available in your area.

The Leukemia & Lymphoma Society (LLS), through its Patient Aid program, can help some families with the cost of gas and parking for outpatient treatment. There is a limit on the amount of financial help given to each patient and family for each year. Check with your team social worker about this program or see contact the LLS at 1-800-955-4572 or [www.lls.org](http://www.lls.org).

Community and church groups may be sources of help with travel or its costs, too. Also, talk to your team social worker about getting help with hospital or clinic parking fees.

### **Sources of help with air transportation costs**

The ACS Air Miles Program is a joint effort between Mercy Medical Airlift (MMA)/National Patient Travel Helpline (NPATH) and the American Cancer Society. The program is designed to help patients with the costs of air travel for cancer-related reasons. Call us at 1-800-227-2345 to find out if you are eligible for help with air travel. MMA/NPATH helps set up the travel on behalf of ACS, through the ACS call center staff.

### **Sources of help with telephone service**

Help with the cost of basic charges for phone service may be available from Temporary Assistance for Needy Families (TANF -- see "To learn more" for contact information). Speak with the eligibility worker in your county department of social services for more information. Families that have problems controlling charges may want to think about buying pre-paid calling cards, pre-paid cell phones, or plans with pre-paid minutes. If you call your cell phone carrier before you go over your limit, sometimes they can help you avoid going over your minutes limit for the month.

The Universal Service Administrative Company (USAC) is another resource that may help if your income is very low. Visit their Web site at [www.usac.org/li/low-income](http://www.usac.org/li/low-income) to learn more about phone service help that's available in your state. Or you can call 1-866-873-4727 and follow the low-income prompts.

You may also want to call the ACS to find out about other local sources of help with telephone service.

### **Sources of help with food and food costs**

Some government programs help with food costs. These programs include:

- School meals, such as
  - National School Lunch Program
  - Fresh Fruit & Vegetable Program
  - School Breakfast Program
  - Special Milk Program
  - Team Nutrition
- Supplemental Nutrition Assistance Program or SNAP (formerly called the Food Stamp Program)
- Women, Infants and Children (WIC)
  - Farmers' Market Nutrition Program

- Senior Farmers' Market Nutrition Program
- Summer Food Service Program
- Food Distribution
  - Commodity Supplemental Food Program
  - The Emergency Food Assistance Program

These programs are run by the US Department of Agriculture. You can learn more about what is covered and how to apply on their Web site at [www.fns.usda.gov/snap/](http://www.fns.usda.gov/snap/) or by calling 1-800-221-5689.

**Meals on Wheels:** This program is designed more for people who are disabled, homebound, or elderly. Volunteers deliver ready-to-eat meals to your home. You can contact them at 703-548-5558 or visit their Web site at [www.mowaa.org](http://www.mowaa.org).

## **Other kinds of help**

You may also get general help from special funds in your medical center or community. Or maybe you can get help through fundraising done for you or your family. Your cancer team social worker can give you more information about resources that might help. There are organizations and written materials that can give you ideas on ways to raise money, too (see "To learn more").

## **About Internet access**

You may notice that many groups and organizations now have a lot of information on the Internet and may be harder to call or reach in person. When you do call, you may find that they encourage you to find the information you need on their Web site. For many groups, this is a way to save money and they can focus funds on services to those in need.

For many people, especially families who are having financial troubles, Internet access may not be available at home. This may make it seem harder to find what you need. But if you must check something on the Internet, many public libraries offer free Internet access.

Still, you do not need Internet access to find help. Many organizations provide toll-free phone numbers so that people without Internet service can learn about and ask for services. Don't be embarrassed to tell people that you don't have Internet access or that you can't check their Web site.

And you can always call us, day or night, to find out about getting the help you need.

## **Disability benefits**

If you get to the point that you cannot work, find out if your employer has a long-term disability insurance policy before you leave your job. This type of policy often replaces 60% to 70% of your income. Read your policy closely. Find out the definition of

"disabled," the monthly benefit amount, the benefit period, the waiting period, and whether you must pay taxes on the money you get. Some companies also have a short-term disability option that can help replace income during part or all of the waiting period of the long-term disability policy.

## Social Security Disability Income

If you have been working for many years, you probably have contributed to Social Security. If so, you may qualify for disability benefits. But you must meet Social Security's definition of disability, which is very strict. If you get turned down, appeal the decision. Some cases that are turned down the first time get approved after an appeal. When approved, benefits do not begin until the sixth full month of disability.

With certain serious illnesses, it may take less time to be approved. The Social Security Administration can speed up their processing of disability applications for people with a diagnosis that is on their Compassionate Allowances list. You can check the list online at [www.socialsecurity.gov/compassionateallowances/](http://www.socialsecurity.gov/compassionateallowances/).

Your income has nothing to do with whether or not you qualify for Social Security Disability Income (SSDI). To find out how to apply, call the Social Security Administration. (See the "To learn more" section for phone numbers.)

Keep in mind that after getting SSDI for 24 months you become eligible for Medicare. Also if you have a dependent child or children they may be eligible to receive benefits under your SSDI.

## Supplemental Security Income benefits

Supplemental Security Income (SSI) is designed to supplement the income of an eligible person or family in which there is a disabled person. The family or the person must have a low income and limited assets. If you have not worked much or if your income was very low before you became unable to work, you may be eligible for SSI. To get SSI, your income and assets must fall below a certain level and you must be disabled, over 65, and/or blind. Like SSDI, certain illnesses are allowed faster processing under the Compassionate Allowances program. If you do qualify, SSI pays you a monthly income. The amount you could get varies from state to state. It also varies from year to year, because of cost of living increases.

Children can qualify for SSI if they meet Social Security's definition of disability. Income criteria are checked by the local Social Security Administration office. Disability evaluation specialists at the state Social Security office decide whether or not you are disabled. Children with certain cancer diagnoses are considered disabled.

In many states Medicaid is given to any adult or child who gets SSI, but you may need to apply for it separately. You can get more information about SSI from your team social worker. Or you can get it from the nearest Social Security Administration office listed in the US Government section of your local phone book. See "To learn more" for more information.

## Temporary Assistance for Needy Families

Temporary Assistance for Needy Families (TANF) is a grant program that provides monthly cash payments to help pay for food, clothing, housing, utilities, transportation, phone, medical supplies, and other basic needs not paid for by Medicaid. TANF also helps states provide training and jobs to the people in their welfare programs. A social worker can tell you about your state's plan or see the "To learn more" section for TANF contact information.

## To learn more

### More information from your American Cancer Society

The following related information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345.

[What Is COBRA? \(also available in Spanish\)](#)

[What Is HIPAA?](#)

[The Affordable Care Act: How It Helps People With Cancer and Their Families](#)

[Prescription Drug Assistance \(also available in Spanish\)](#)

[Children Diagnosed with Cancer: Financial and Insurance Issues](#)

[Medicare Coverage for Cancer Prevention and Early Detection \(also available in Spanish\)](#)

[Medicare Part D: Things People With Cancer May Want To Know](#)

[Family and Medical Leave Act \(FMLA\)](#)

[Americans with Disabilities Act: Information for People Facing Cancer](#)

[Clinical Trials: State Laws Regarding Insurance Coverage](#)

[Financial Guidance for Cancer Survivors and Their Families: In Treatment \(also available in Spanish\)](#)

[Financial Guidance for Cancer Survivors and Their Families: Off Treatment](#)

[Financial Guidance for Cancer Survivors and Their Families: How to Find a Financial Planner Sensitive to Cancer Issues](#)

[Financial Guidance for Cancer Survivors and Their Families: Advanced Illness](#)

[Financial Guidance for Families: Coping Financially With the Loss of a Loved One](#)

[Financial Guidance for Those With Concerns About Cancer: Can I Be Prepared If Cancer Occurs?](#)

National Breast and Cervical Cancer Early Detection Program

## National organizations and Web sites\*

Along with the American Cancer Society, other sources of information and support are listed here.

### **Association of Community Cancer Centers**

Web site: [www.accc-cancer.org](http://www.accc-cancer.org)

To find a cancer treatment program and see program details, including contact information, treatments offered, and specialized services. Also lists patient assistance programs for medicines, travel, and financial aid for other oncology-related services

### **Cancer Legal Resource Center (CLRC)**

Toll-free number: 1-866-843-2572 (may need to leave a number for a call back)

Web site: [www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

Provides free legal information about laws and resources for many cancer-related issues including health insurance issues, denial of benefits, and government benefits

### **Department of Veterans Affairs**

Toll-free number: 1-800-827-1000

Web site: [www.va.gov](http://www.va.gov)

For information on Veteran's medical benefits and whether you qualify for them use:

Toll-free number: 1-877-222-8387

Web site: [www.va.gov/healtheligibility](http://www.va.gov/healtheligibility)

### **Financial Planning Association**

Telephone: 1-800-322-4237

Web site: [www.fpanet.org](http://www.fpanet.org)

Offers free information on personal finance, answers general financial planning questions, makes referrals to FPA members who are Certified Financial Planners™, and sets up free financial planning services to qualified people and families in need

### **Georgetown University Health Policy Institute**

Web site: [healthinsuranceinfo.net](http://healthinsuranceinfo.net)

Offers free online information including guides for getting and keeping health insurance for each state, how to manage medical bills and avoid debt, and understanding health insurance

### **Internal Revenue Service**

Toll-free number: 1-800-829-1040

TTY: 1-800-829-4059  
Web site: [www.irs.gov](http://www.irs.gov)

Has answers to tax questions, tax forms, and referrals to free tax help for those who qualify

**Medicaid -- US Department of Health and Human Services**

Toll-free number: 1-800-633-4227  
Web site: [www.cms.gov/home/medicaid.asp](http://www.cms.gov/home/medicaid.asp)

To learn more about Medicaid coverage and eligibility. Your state social service or human service agency can give you the best answers to questions about your benefits, eligibility, and fraud. To get contact information for your state go to [www.cms.gov/apps/contacts/](http://www.cms.gov/apps/contacts/)

**Medicare -- US Department of Health and Human Services**

Toll-free number: 1-800-633-4227  
TTY: 1-877-486-2048  
Web site: [www.medicare.gov](http://www.medicare.gov)

Answer questions, provides literature, and gives referrals to state Medicare offices and local HMO's with Medicare contracts.

**Medicare Rights Center (for those with Medicare)**

Toll-free number: 1-800-333-4114  
Web site: [www.medicarerights.org](http://www.medicarerights.org)

This service can help you understand your rights and benefits, work through the Medicare system, and get quality care. They can also help you apply for programs that help reduce your costs for prescription drugs and medical care, and guide you through the appeals process if your Medicare prescription drug plan denies coverage for drugs you need

**National Association of Insurance Commissioners (NAIC)**

Toll-free number: 1-866-470-6242  
Web site: [http://naic.org/state\\_web\\_map.htm](http://naic.org/state_web_map.htm)

To find your state's Insurance Commissioner

**Patient Advocate Foundation (PAF)**

Toll-free number: 1-800-532-5274  
Web site: [www.patientadvocate.org](http://www.patientadvocate.org)

Works with the patient and insurer, employer and/or creditors to resolve insurance, job retention and/or debt problems related to their diagnosis, with help from case managers, doctors, and attorneys. For cancer patients in treatment or less than 2 years out of treatment

**Social Security Administration (SSA)**

Toll-free number: 1-800-772-1213

TTY: 1-800-325-0778

Web site: [www.socialsecurity.gov](http://www.socialsecurity.gov)

Has general information, qualification criteria, and information about how to apply for program benefits (such as Social Security Disability Income and Supplemental Security Income if you cannot work). Makes referrals to local SSA and Medicare/Medicaid offices

### **TANF and State Health Departments -- US Department of Health and Human Services**

Toll-free number: 1-877-696-6775

Web site: [www.acf.hhs.gov/programs/ofa/states/st\\_index.html](http://www.acf.hhs.gov/programs/ofa/states/st_index.html)

Provides contact information for each state's health department, including Temporary Assistance for Needy Families (TANF) in your state

### **US Department of Health & Human Services**

Web site: [www.healthcare.gov](http://www.healthcare.gov)

For the most current information on health care and insurance laws and how they might affect you

### **US Department of Labor, Employee Benefits, Security Administration (EBSA)**

Toll-free number: 1-866-444-3272

Web site: [www.dol.gov/ebsa](http://www.dol.gov/ebsa)

Information on employee benefit laws, including COBRA, FMLA, and HIPAA requirements of employer-based health coverage and self-insured health plans. Also has and information on recent changes in health care laws. Information for military reservists who must leave their private employer for active duty can be found at: [www.dol.gov/elaws/vets/userra/mainmenu.asp](http://www.dol.gov/elaws/vets/userra/mainmenu.asp)

### **US Equal Employment Opportunity Commission (EEOC)**

Toll-free number: 1-800-669-4000

TTY: 1-800-669-6820

Web site: [www.eeoc.gov](http://www.eeoc.gov)

For information on all federal equal employment opportunity regulations, practices, and policies; publications; how to file charges of workplace discrimination; and how to find EEOC offices in your area

### **Other publications\***

Landay, David. *Be Prepared: The Complete Financial, Legal, and Practical Guide for Living with a Life-challenging Condition*. New York: St. Martin's Press, 1998.

*\*Inclusion on these lists does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit [www.cancer.org](http://www.cancer.org).

## References

America's Health Insurance Plans (AHIP). Health Claim Appeals: A guide to resolving health insurance disputes. Accessed at [www.healthclaimappeals.org/home.html](http://www.healthclaimappeals.org/home.html) on December 2, 2010.

Centers for Medicare & Medicaid Services. National CHIP Policy Overview. Accessed at [www.cms.gov/NationalCHIPPolicy/](http://www.cms.gov/NationalCHIPPolicy/) on November 29, 2010.

US Department of Veterans Affairs. CHAMPVA. Accessed at [www4.va.gov/hac/forbeneficiaries/champva/champva.asp](http://www4.va.gov/hac/forbeneficiaries/champva/champva.asp) on November 29, 2010.

Hudson KL, Holohan MK, Collins FS. Keeping Pace with the Times — The Genetic Information Nondiscrimination Act of 2008. *New Eng J Med.* 2008;358:2661-2663.

Health Insurance Resource Center. Accessed at [www.healthinsurance.org](http://www.healthinsurance.org) on November 19, 2010.

National Cancer Institute. *Facing Forward: A Guide for Cancer Survivors.* (NIH Publication No.94-2424, Revised July, 1994).

TRICARE Management Activity. Quick Links. Accessed at [www.tricare.mil](http://www.tricare.mil) on November 30, 2010.

US Department of Health & Human Services. Information for You: Young Adults. Accessed at [www.healthcare.gov/foryou/youngadults/need/index.html](http://www.healthcare.gov/foryou/youngadults/need/index.html) on November 30, 2010.

US Department of Health and Human Services. Medicare Basics. Accessed at [www.medicare.gov/navigation/medicare-basics/medicare-basics-overview.aspx](http://www.medicare.gov/navigation/medicare-basics/medicare-basics-overview.aspx) on November 30, 2010.

US Department of Health & Human Services. Take health care into your own hands. Accessed at [www.healthcare.gov](http://www.healthcare.gov) on December 3, 2010.

Last Medical Review: 1/5/2011

Last Revised: 6/27/2011

2011 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society  
1 · 800 · ACS-2345 or [www.cancer.org](http://www.cancer.org)