



Children Diagnosed With Cancer: Financial and Insurance Issues

When a child is diagnosed with cancer, families and parents will need to know about and cope with many problems. This document, which offers ideas for managing the costs of a cancer diagnosis, is one in a series of documents for parents and loved ones of a child with cancer. The other documents have information on how to cope with the cancer diagnosis, understanding the health care system, returning to school, and the late effects of cancer treatment.

If your child has been diagnosed with cancer, the last thing you want to think about is money. But families are usually forced to think about this issue sooner rather than later. There are financial resources that may be able to help you with the mounting costs that often come with this disease. These resources can be health insurance, government programs, disability benefits, and aid from voluntary organizations. Even if your child has health insurance, you will soon find that it doesn't cover everything. And even if your child is well-insured, cancer can cause financial problems.

If your child isn't covered by health insurance, it can be really scary. But there are other options you may want to think about.

What we'll cover

We will try to answer common questions about insurance and financial concerns, with information about:

- Keeping and managing private health plans or health insurance
- Government-funded insurance plans
- Options if your child is uninsured or hard to insure
- Getting help with living expenses
- Other resources you can look into

This information is not meant as expert professional advice for any person, family, or insurance situation. If you need help for your situation, it's best to use a financial professional.

Insurance can be complicated

Health insurance or some kind of health coverage is a key work benefit. Having it eases some of the worry that comes with a major medical problem. Everyone knows that hospitalization, surgery, radiation therapy, chemotherapy, medicines, state-of-the-art equipment and procedures, and a medical professional's time are all costly. But no health plan has benefits that cover all the costs of treatment. Very few families know exactly what their insurance or managed care plans provide. Many are surprised to find that, even for a major illness, not everything that is ordered or prescribed will be approved or paid for by the health insurance plan.

In the effort to control medical costs, there are rules and guidelines that require hospital admissions, tests, treatment, and specialized care be approved ahead of time. And since health insurance is becoming more and more expensive for employers, they often limit benefits and pass along some of the extra costs to their employees. Families must be ready to deal with many phone calls, lots of paperwork, ongoing follow-up, and careful record keeping. This is a lot to add to your schedule. And it's even harder when you are worried about your sick child and all the other problems illness can cause.

There are also new expenses that come with illness. Transportation, a place to stay during treatment, food, and child care for the other children in your family are not part of your health plan. A parent may have to take unpaid time off work or give up a job because of treatment schedules. (See our information *Family and Medical Leave Act* for more about taking time off but still keeping your job. You can find it on our Web site or call us to get a copy.) Missed time at work for one or both parents may cause a serious loss of income.

Parents who do not have health insurance are even more concerned with how this might affect their child's treatment. Whether families have insurance or other sources of payment, most families worry about the out-of-pocket costs they will face and how family income may be affected by their child's illness.

Private health plans

Health insurance coverage helps with the medical costs that come with the diagnosis and treatment of a child's illness. It's important to have and keep good medical coverage. This can help families avoid major money problems. Many parents are insured 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 and their families 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 the employees.

Individual plans may check into your and your family's 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, though some may not cover children.

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 keep paying your monthly insurance premiums on time.

Types of health plans

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

Indemnity, fee-for-service, 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 the medical costs (known as the *deductible*) for yourself and each family member before your insurance will start to pay. After you have met your child's deductible, your insurance will pay a set percentage of the bill for the rest of the year. You are responsible for the rest, which is called a co-payment or co-insurance.

You might 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. Keep receipts of your child's drugs and other medical costs to keep track of these medical expenses. This can help you greatly if there is a dispute about payments or other problems in the future.

After your stated deductible is met, the insurance company will pay a percentage (75% to 80% is common) of the costs or claims submitted to them. Some policies have a limit or cap on the total costs that the beneficiary (a person who gets benefits) must pay in a calendar year. This means that, after you pay a certain amount (the cap), the company pays 100% of "usual and customary" charges. Since the insurance company decides what is usual and customary, there are often still uncovered costs that families must pay beyond the co-pay and their out-of-pocket limit for the year. Always ask if the insurance company will waive (or not make you pay) the amount above the usual and customary charges.

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 may

also be called *co-insurance*. This is the amount you must pay at the time of service.) These amounts can differ among managed care companies and among 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 co-pay. HMOs often limit your choice of providers to those in their approved provider network. This means you have to check their listing to be sure the doctor you want your child 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.
- **Preferred provider organizations:** 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 your child can use to get the most coverage. When your child uses those doctors (sometimes called *preferred* or *network* providers), most of the 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.
- **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 child's 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 to take your child to 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%.

Know your managed care plan

Some plans employ their own doctors and run their own hospitals. Others require plan members to 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 a child needs to see an expert like a lung specialist, you would need a referral from the primary care doctor before the specialist sees the child. If this is not done the 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 parents choose to go outside the network for their child's care, they may have to pay an extra fee, or even pay for the full service with no help from their 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's important to know all the ins and outs of the plan and how it will affect your child's 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.

Pre-existing condition exclusions

A *pre-existing condition* is a health problem that a person had BEFORE joining the health plan. A pre-existing condition exclusion period means the plan will make you wait before they pay any costs of the pre-existing medical problem.

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 younger than 19 as of September 2010. See the section called "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 your 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 you can 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. Not all indemnity policies cover children, and some that do pay a lower rate for days that children are in the hospital than they do for adults. There may also be a limit on the total number of hospital inpatient days a policy will pay in a calendar year or a cap on the total number of days it will pay. The money received from such policies 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 a 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.

What if my child is a young adult?

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 ages 18 through 25 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 young adult can get their own job-based coverage, then they cannot be covered by the parent's plan.

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

How to manage your child's health insurance

DON'T let your child's health insurance expire. If you are changing insurance plans, don't let one policy lapse until the new one goes into effect. Pay premiums in full and on time. It can be difficult and expensive to get new insurance.

The following are ideas to help you and your family better understand your child's health coverage:

- Read and review any booklets explaining the plan under which your child is covered. You may find more on the company's or the insurance carrier's Web site.
- Ask for written information on benefits if you do not have it, and be sure you understand the details. 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.
- Talk with the employee benefits person at your job (usually a person in the human resources department) if you have questions or do not understand what you're reading.
- Make a list of any questions about benefits, deductibles, and coverage.
- Get answers directly from the insurer or managed care group that covers your child.
- Be sure you understand what you need to do to make sure that services are covered.
- Identify one contact person (if possible) in customer service at the insurance company with whom you can discuss claims and services. It will help to have one person who becomes familiar with your situation. This person may be a case manager.
- Meet with a hospital or clinic financial counselor or a person from the patient accounts office where your child is being treated to learn about billing procedures and what you can expect.
- Discuss any concerns about your insurance with your child's cancer team social worker. He or she can help you understand how the system works and where to get help.
- Ask for help from a trusted friend if you feel overwhelmed in dealing with these matters.
- Develop a system for keeping records. For example, you may keep records arranged by visit date or by health provider, whatever works for you.

Dealing with medical bills

- 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 FMLA leave 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 child's 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 (ACS) or your state's government agencies, for extra help in finding resources.

Where can families get answers to questions about insurance?

Questions about insurance coverage often come up when families are making decisions about their child's care. 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 called "Who regulates insurance plans?")
- Learn about the insurance laws that protect the public. The US Department of Health & Human Services has a section called "The Health Care Law & You." You can find it online at <http://finder.healthcare.gov>.

What records should be kept for insurance and medical costs?

It can be hard for a family to keep track of the bills, letters, claim forms, and other papers that start flowing into your home after a child is diagnosed with cancer. But keeping careful records of medical bills, insurance claims, and payments helps families better manage their stress levels and their money. 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 exemptions for cancer treatment expenses (see “To learn more”). These rules change from time to time, so the IRS is the best source of current information.

Records to keep

It can be hard to know which papers are important and should be kept. Try to keep records of these things:

- 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 date it was 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 and other costs related to treatment that your insurance hasn't paid or doesn't pay
- Costs for meals and lodging
- 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, treatments
- Drugs given and prescriptions filled

Some tips for record-keeping

- Decide who will be the family 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 single parents.
- 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 or the copies of canceled checks that come with your statement. (If you do not get copies of canceled checks, talk to your bank or credit union about how to get legal copies when you need them.)
- Keep a daily log of events and expenses; a calendar with space for writing is useful.
- Keep a list of cancer care team members and all other contacts with their phone and fax numbers and e-mail addresses.
- Find out what is tax deductible and be sure the originals of those records are kept. (See the “To learn more” section to contact the IRS.)

When you have problems paying a medical bill

Many families 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 help 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:

- 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’s not unusual for insurers to deny some claims or say they will not cover a test, procedure, or service that doctors order. If this happens, it’s important to have a working relationship with a customer service representative at the insurance company 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 child’s 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 with these methods 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 a 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 visit 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.

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.

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.

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 (including for their children) when a person has a “qualifying event” (defined below in the “COBRA” section).

COBRA (Consolidated Omnibus Budget and Reconciliation Act of 1986)

COBRA gives you, your spouse, and/or your dependents the right to temporarily continue health insurance coverage. Though you still get group rates, you usually pay much more than when you were working. You must now pay the portion that your employer paid plus a small administrative fee.

This law makes insurance available when coverage would normally be lost because of certain events (called *qualifying events*), such as stopping work, reducing work hours, divorce or legal separation, the covered person becoming entitled to Medicare, a dependent child is 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 continued 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 – and neither are the children or spouse.

COBRA is not given automatically but must be elected by the former employee or beneficiary 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 actual 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
- The employee becomes eligible for Medicare

If this notice is not done within the deadline, the spouse or child may lose their COBRA rights. If coverage for dependent(s) is ending for any of these reasons or because of the employee's death, their coverage may be continued for up to 36 months. Contact the employer's human resources person, the insurance company, or check the 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, until you, your child, or your spouse becomes covered under another group policy, but only up to a certain time limit. Premiums cannot be above 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 your former employer stops offering all health plan coverage.

COBRA is overseen 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 details, read our document called *What is COBRA?*

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

This bill has many clauses that can help parents of children or teens with cancer:

- It allows a parent who has had group medical insurance for at least 12 months with no loss of coverage longer 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. 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 called "The Affordable Care Act of 2010.")
- HIPAA requires insurers to renew coverage for all employers and individuals when premiums are paid on time.
- HIPAA 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 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's 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 visit our Web site or call and ask for *What is HIPAA?* You can also contact your state department or commission of insurance. Go the “To learn more” section for contact information.

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 for eligible employees for certain family and medical reasons. Having a child with cancer is certainly a reason to take family leave.

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 (including coverage for dependents).

Your child’s pediatric oncologist and the team social worker can help with the paperwork your employer needs for FMLA leave. 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 (ADA) 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 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 for a parent to change jobs and move from one group insurance plan to another. This law is overseen 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 Affordable Care Act of 2010

Many people are afraid they will lose their health coverage and their family’s coverage if they lose their jobs. 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 families 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 younger than age 19 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 person gets sick
- Created state or federal run high-risk pools or Pre-Existing Condition Insurance Plans (PCIPs) in every state to cover anyone who has not had insurance for 6 months or more and has cancer or another pre-existing condition
- Makes coverage available for patients who take part in clinical trials

To learn more, please read our document 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.

What if my child's medical care is covered by more than one insurance company?

Children who are covered under both parents' group health insurance plans have one plan considered their primary insurance, while the other is considered their secondary insurance. The primary insurance pays the cost of claims first. The secondary plan pays the rest of the costs not covered by the primary plan, if the treatment is a covered benefit. When a child or teen is covered by the group policies of both parents, the primary insurance usually is the one belonging to the parent whose birthday comes earlier in the calendar year. There are exceptions to this and families should check the details of each policy.

When 2 policies are used, record-keeping becomes much more involved. But depending on how much coverage you get, it may be worthwhile to keep both if you can. If the second coverage is better, fills in gaps to pay for treatments that the primary insurance doesn't cover, or if the primary has a low annual maximum limit, it may be worth keeping the second one. There are many factors to think about, and each situation is different.

Government-funded health plans

What is Medicaid?

Medicaid is a government program that covers the cost of medical care for eligible people who meet certain criteria. To get Medicaid, your family's income and assets must be below a certain level. These levels vary from state to state. Not all health providers take 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 certain federal poverty guidelines

Medicaid pays only a percentage of the direct cost of medical care to hospitals and doctors, but families are not billed for the rest. Children that Social Security determines to be disabled are usually eligible for Medicaid. Having insurance coverage does not make a person ineligible for Medicaid. Some children who are not eligible for Medicaid when they are diagnosed become eligible after the family's medical debt affects their income and assets.

In some situations, being eligible for Medicaid can help a child or family, even if it's not used to pay direct medical costs. For example, most medical centers make their own determination of a family's ability to pay medical bills. A family with an income low enough to qualify for Medicaid may get special consideration that could result in a discounted hospital bill. Medicaid funds may also be used in some states to help pay the cost of transportation to hospitals and clinics and for food and lodging if a family has to travel for treatment or follow-up care.

Your team social worker can give you more information on applying for Medicaid, or you can find out how to apply by contacting your county social service or health department. These numbers can be found in the blue pages of your local phone book, or contact your state Medicaid office (see the "To learn more" section).

Can Medicare help with medical care costs for children?

Medicare is a federal program funded through the Social Security system. It provides health insurance for those who meet certain criteria. Young people with cancer who are disabled may get Medicare benefits after collecting Social Security benefits under the Supplemental Security Income (SSI) program for 2 years. In order for your child to get SSI, you must apply for it on behalf of the child, complete with household income and the child's medical and school information. Social Security will then determine if the child is disabled. You can get more information on SSI and Medicare from the Social Security Web site (www.ssa.gov); click on "Disability." Or you can call 1-800-772-1213, or talk with your team social worker.

Low-income Medicare beneficiaries with limited resources may get extra help paying their out-of-pocket medical expenses from their state Medicaid program (see the section called, "What is Medicaid?").

What other public assistance programs might help pay for my child's medical care?

State-sponsored children's health insurance programs (CHIP)

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's 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, to learn more about the program and find your state's CHIP.

Children's Special Health (Care) Services (CSHS or CSHCS)

This is a state-run program, financed by state and federal money. It may help pay some health care costs for children, usually those 21 and younger with certain chronic conditions, including cancer. In many states these programs may have different names. To find out if such programs can help you, talk to a hospital or clinic financial counselor or talk with the team social worker. Or you can try calling your state health department.

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 your child is 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 at 1-800-638-0742 or visit their Web site, www.hrsa.gov/hillburton, for a listing of Hill-Burton-obligated facilities, eligibility criteria, and frequently asked questions about the program.

Can children who are not US citizens get Medicaid or Children's Special Health Services?

There are situations in which children who are not citizens of the United States, but are legal immigrants, may be able to get Medicaid, CHIP, or Children's Special Health Services (CSHS) to pay for some of their treatment. All questions about Medicaid eligibility rules and regulations should be discussed with your county Medicaid specialists. Talk to the hospital or clinic financial counselor about CHIP or CSHS coverage. The services of an interpreter can usually be arranged if speaking or understanding English is a problem.

Will children covered by Medicaid, CHIP, or Children's Special Health Services be treated the same as children covered by private health plans?

Children and teens should get the same care, the same state-of-the-art treatment, and any other services available – no matter who pays for their treatment. If parents have any questions or concerns about this, they should speak with the pediatric oncologist in charge of their child's care or with another member of the cancer care team.

Veterans' and military benefits may help children

What if the child's parent has TRICARE?

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.

The service member must register eligible family members, including children, in the Defense Enrollment Eligibility Reporting System (DEERS) to get health coverage for them. Records can be kept up to date by the service member or the family members through the nearest military personnel office or ID card-issuing facility, or online at www.tricare.mil/mybenefit/home/overview/Eligibility/DEERS.

Each TRICARE plan has its own limits and requirements. Choose your plan carefully and know how it works. You can find out more on TRICARE at www.tricare.mil, including a way to compare different plans to find one that best suits your family. You can also get help by calling 1-800-538-9552.

What if a parent is a military reservist who has been called to active duty?

Members of the military reserve units who are called up for active duty from private employment have certain rights about the health care coverage they get from their employers. They are allowed to pay the full cost of their health plan, very much like COBRA, during their time away. When they return to work, their health coverage must be re-instated without any waiting period. See “To learn more” for US Department of Labor contact information to find out more about this.

What if the child’s parent died in the military or became permanently disabled due to military service?

A program called the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) is available for certain spouses, widows, or widowers 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 of a service-connected disability
- Died on active 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 (select CHAMPVA under “Special Programs”).

Who regulates insurance plans?

The *private group plans* (or *fully insured plans*) that employers purchase from insurance carriers 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 run by the US Department of Labor’s Employee Benefits Security Administration. 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 give you specific information about an individual plan.

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 uninsured children

What if my child is not listed as a beneficiary under either parent's health insurance?

Sometimes even if a parent has group insurance coverage through an employer, family members are not covered because the premiums would cost too much. You will want to talk about this with the team social worker, who should know more about financial resources that may offer help.

If possible, the insured parent should talk with their employer (or their employee benefits person at work) about how to enroll their child. Some plans have annual or semi-annual "open enrollment" provisions that permit coverage despite current medical problems.

Cancer treatment can go on for long time and cost a lot. Insurance issues can be very complex and many families need help not only in finding answers, but even knowing the right questions to ask.

What can we do when work does not offer us group medical insurance?

Families that do not have medical insurance through an employer can explore several options:

- See if you and your family can get group insurance through an organization in which you have, or can arrange, membership. This may be a group like an alumni association, a fraternal organization, a farmers' cooperative group, a labor union, a professional organization, or a group such as the American Automobile Association (AAA).
- As of 2010, your state should offer some type of high risk pool or 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.

- Decide if one parent should look for a job with a large company that offers health insurance.
- Look into buying individual health insurance to cover your child. Although this is costly, rates have become more competitive with private insurance companies who see this as a business opportunity.
- 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 offer a period of open enrollment each year during which applicants are accepted regardless of past health problems.
- If a parent and child have recently been covered under an employer-sponsored plan for at least one day, and the employer still offers insurance coverage, the parent should be able to keep their medical insurance (or just the child's, if the parent went part time, lost or left the job, died, got divorced, or became eligible for Medicare) through COBRA. The employer should tell you, in writing, about this COBRA option. For more information, please see "COBRA (Consolidated Omnibus Budget and Reconciliation Act of 1986)" in the section called "Keeping employer-sponsored health insurance coverage when you leave your job."
- Look into your child's eligibility for Medicare, which covers people who are permanently disabled and have been getting Social Security (SSI) for 2 years.
- See if your child is 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 for your family. Some group plans have a clause that allows people to convert, 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.)

When looking into insurance options, find out about differences in coverage. Ask about choice of doctors, protection against cancellations, and increases in premiums. Find out what the plan really covers, especially in the event of catastrophic illness (a serious illness, like cancer, that can add up bills quickly). What are the deductibles and co-payments? (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.

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.

Under this Act, every state must have a high risk pool or 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 for the most current information on what is available in your state.)

What sources are available to help with treatment costs if my child doesn't have insurance and there's no public assistance available?

No child will be denied treatment in a non-profit hospital if a family is unable to pay. If insurance coverage cannot be arranged, and if a child cannot be covered under Medicaid or another program, a family may have to look at other options to meet some of the costs of treatment. These options could include programs through the Salvation Army; church related organizations, such as Lutheran Social Services, Jewish Social Services, and Catholic charities; or the Lions Clubs. The Patient Advocate Foundation may also be helpful. Here are some other things you can try:

- Talk with hospital or clinic financial counselors or the patient accounts office to see if you can arrange to pay bills over an extended time period.
- Seek financial assistance from special funds or from organizations like the National Children's Cancer Society (NCCS). The NCCS provides direct assistance with medical care and other costs of a child's cancer. Other groups may be able to help with specific costs in some parts of the country or help you find other sources of support. Some drug companies help with drug costs for patients in financial need. And special medical center and community funds often exist to help families with the costs of medical care. The team social worker should have information on these and other potential resources.
- Fundraising can be done to help with medical bills and related expenses. Families often need help from relatives, friends, church members, schools, or community groups to carry out successful fundraising efforts. Parents should give permission for

others to raise funds for their child. Caring for their ill child and managing the needs of family and work usually takes all their time and energy. In any fundraising effort, parents should consider their child's and their own need for privacy.

- Often it's best to set up a simple trust fund into which donations can be placed. A trustee is then named to approve spending from the fund. This way parents can avoid even a hint of any improper use of the fund. Parents may find it most helpful to check with an accountant, attorney, or bank officer about setting up such a trust. Ask whether money in a trust fund will affect eligibility for public assistance programs.
- Explore the possibility of free treatment through the Pediatric Branch of the National Cancer Institute or St. Jude's Children's Research Hospital in Memphis, Tennessee. Patients accepted for treatment at these institutions must meet specific criteria. Ask your child's oncologist for more information.

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, services of doctors and other professionals, and treatment (surgery, chemotherapy, radiation treatment, and bone marrow or peripheral stem cell transplant). Insurance, managed care, or public health care programs pay most of these costs if you are covered in such a plan.

But families also have many indirect costs or "out-of-pocket" expenses when a child has cancer, 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 treatments 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 child's treatment plan can cause parents and family members to lose time at work and, in some cases, all or part of their salary. Even more money is lost if one parent 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. 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.

What help is available with short-term housing near the treatment center?

Most major pediatric treatment centers have a Ronald McDonald House nearby. These houses provide low-cost or free housing for patients and their immediate families. These houses are designed to offer a nice break for 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 admissions 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. Families must be referred by medical staff and/or social workers at the treatment facility.

Many treatment centers also have other short-term housing possibilities or discount arrangements with nearby motels and hotels. The clinic social worker or oncology nurse may have ideas for low-cost housing during hospital or clinic treatment.

Where can families find help with housing needs or mortgage payments?

The extra expenses of a child's 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 the team social worker who may know of special resources.

Families who need to move out of housing after a child's cancer diagnosis should talk with their county department of social services to find out if they can get into government-supported housing programs.

Where can families get 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 reimbursed (paid back) for gas, payment of bus fare, or it may mean using a van pool. County departments of social services in each state arrange for help with transportation, but families must ask for it by talking with their Medicaid case worker.

The American Cancer Society's (ACS) program, Road To Recovery, 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 ACS office for more information on what 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 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.

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.

Where can families get help with air travel?

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.

Is there any help available for the cost of telephone service?

Help with the cost of basic charges for phone service may be available from Temporary Assistance for Needy Families (TANF). Speak with the eligibility worker in your county department of social services for more information. Families that have problems controlling phone charges may want to think about buying pre-paid calling cards, pre-paid cell phones, or plans with pre-paid minutes. If you call them before you go over your limit, sometimes they can help you avoid going over your minutes 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 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 American Cancer Society to find out about other local sources of help with telephone service.

What help is available for 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's covered and how to apply on their Web site at www.fns.usda.gov/snap/ or by calling 1-800-221-5689.

How 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.

Families who are having financial troubles may not have Internet access available at home. This may make it seem harder to find what you need.

But Internet access is not usually required to find help – and a lot of information is not available on the Internet at all. Because of this, many organizations still 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. Finally, if there is something that you must check on the Internet, many public libraries offer free Internet access.

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

Where else can families get financial help?

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

Here are some possible sources of help for families who need some extra financial support at this time:

- Income assistance for low-income families through Supplemental Security Income (SSI) benefits (see below)

- Income assistance from the Temporary Assistance for Needy Families (TANF) program (see below)
- Help with treatment-related travel, meals and lodging from public and private programs
- Help with basic living costs (like rent, mortgage, insurance premiums, utilities, and telephone) from public and private programs
- Help from church, civic, social, and fraternal groups in the community
- General help from special funds in the medical center or community
- Help from targeted fundraising for an individual patient or family

The team social worker may be able to give you more information about resources that might help your family. There are also organizations and written materials that can provide information on fundraising strategies (see “To learn more”).

What are Supplemental Security Income (SSI) benefits?

Supplemental Security Income (SSI) is designed to supplement the income of eligible families with low incomes and limited assets in which there is a disabled individual. Children qualify if they meet Social Security’s definition of disability. To get SSI, your income and assets must fall below a certain level.

Children can qualify 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 if the child is disabled. Not every child with a cancer diagnosis is considered disabled.

In most states, Medicaid is given to children getting SSI, but you must apply for it separately. You can get more information about SSI from the team social worker or from the nearest Social Security Administration office listed in the US Government section of your local phone book. See the “To learn more” section for more information.

Temporary Assistance for Needy Families (TANF)

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 for 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.

More on coping

Children Diagnosed With Cancer: Dealing With Diagnosis (also in Spanish)

Children Diagnosed With Cancer: Understanding the Health Care System (also in Spanish)

Children Diagnosed With Cancer: Returning to School

Children Diagnosed With Cancer: Late Effects of Cancer Treatment

Treatment aid

Prescription Drug Assistance (also in Spanish)

Clinical Trials: State Laws Regarding Insurance Coverage

Clinical Trials: What You Need to Know (also in Spanish)

Learn more about how federal laws can help you

What Is COBRA? (also in Spanish)

What Is HIPAA? (also in Spanish)

The Affordable Care Act: How It Helps People With Cancer and Their Families (also in Spanish)

Family and Medical Leave Act (FMLA) (also in Spanish)

Americans With Disabilities Act: Information for People Facing Cancer (also in Spanish)

National organizations and Web Sites*

Along with the American Cancer Society, other sources of information and support include:

Government resources

Department of Veterans Affairs

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

Web site: www.va.gov

For information on Veteran's medical benefits and whether your child qualifies for them:

Toll-free number: 1-800-733-8387

Web site: www.va.gov/healtheligibility

Internal Revenue Service

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

TTY: 1-800-829-4059

Web site: www.irs.gov

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

Medicaid – Centers for Medicare & Medicaid Services (CMS) – US Department of Health and Human Services

Toll-free number: 1-800-633-4227

Web site: 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/

National Association of Insurance Commissioners (NAIC)

Toll-free number: 1-866-470-6242

Web site: http://naic.org/state_web_map.htm

To find your state's Insurance Commissioner

Social Security Administration

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

TTY: 1-800-325-0778

Web site: www.ssa.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

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

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

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

US Equal Employment Opportunity Commission (EEOC)

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

TTY: 1-800-669-6820

Web site: 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 sources of help and legal resources

2-1-1 Program Information and Referral Search

Toll-free number: 211

Web site: www.211us.org

May be able to find help in your local area

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

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

Childhood Cancer Ombudsman Program

Toll-free number: 1-877-217-4166 (may need to leave message for return call)

Web site: www.childhoodbraintumor.org

Provides information and other options so that families may better exercise their rights to make decisions about medical treatment, school, rehabilitation, employment, and insurance reimbursement/coverage. This program is offered by the Childhood Brain Tumor Foundation, but services are provided for children and adult survivors of ANY type cancer.

National Association of Personal Financial Advisors

Toll-free number: 1-800-366-2732

Web site: www.napfa.org

Offers objective financial advice on a “fee-only” basis (neither the advisor nor any related party gets paid based on the purchase or sale of a financial product). Also has a listing of fee-only planners in the person’s area.

National Foundation for Credit Counseling (NFCC)

Toll-free number: 1-800-388-2227

Toll-free Spanish number: 1-800-682-9832

Web site: www.nfcc.org

For referrals to local Consumer Credit Counseling Services and answers to questions about bankruptcy, credit, and debt collection practices

National Transplant Assistance Fund and Catastrophic Injury Program (NTAF)

Toll-free number: 1-800-642-8399

Web site: www.transplantfund.org

Offers patients’ families and contributors free guidance and support in setting up community fundraisers to help pay for cancer treatment

Patient Advocate Foundation (PAF)

Toll-free number: 1-800-532-5274

Web site: www.patientadvocate.org

Works with the patient’s parents and insurer, employers and/or creditors to resolve insurance, job retention and/or debt problems related to their child’s diagnosis, with help from case managers, doctors, and attorneys. Also has co-pay relief programs for some types of cancer, a scholarship fund for young survivors, and educational materials on many cancer-related topics.

St. Jude Children’s Research Hospital

Toll-free number: 1-866-278-5833 (doctor referral number)

Web site: www.stjude.org

Covers all costs of care beyond those that are reimbursed by insurance. Total costs are covered when the child does not have insurance. After an initial evaluation, assistance with transportation and local living expenses may also be provided. Web site has information for patients seeking treatment, such as the admission policy, a guide for parents, and directions to the hospital. Patients are accepted by doctor referral only.

Childhood cancer-specific information resources**American Childhood Cancer Organization (ACCO)**

Phone number: 855-858-2226

Web site: www.acco.org

Has parent support groups in most states, offers insurance and legal guidance, and books for kids, caregivers, and teachers. All are without cost to the families of children with cancer.

CureSearch National Childhood Cancer Foundation (NCCF)

Toll-free number: 1-800-458-6223

Web site: www.curesearch.org

Provides up-to-date information about childhood cancer from the world's top pediatric cancer experts. Has sections for patients and families and a section for friends and the community to help them ease the burden of cancer and show support

National Children's Cancer Society, Inc. (NCCS)

Toll-free number: 1-800-532-6459

Web site: www.children-cancer.org

Online support, education, and financial assistance for children with cancer and their parents

Other resources*

Cancer Survival Toolbox™ By the National Coalition for Cancer Survivorship. Available at www.cancersurvivaltoolbox.org or by calling 1-877-NCCS-YES (1-800-622-7937).

Mapping the Maze: A Personal Insurance and Financial Guide to Marrow and Cord Blood Transplant. Available at www.marrow-donor.org. National Marrow Donor Program.

Surviving Childhood Cancer: A Guide for Families by Margot Joan Fromer. Published by New Harbinger Publications, 1998.

United States Department of Health and Human Services: Families & Children Web site. Covers many topics, including sources of financial assistance and information on Medicaid and other health insurance. Available at www.hhs.gov/children/index.shtml.

**Inclusion on this list 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.

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