



The  
National  
Children's  
Cancer  
Society

25 years of serving kids and their families

# HEALTH INSURANCE OPTIONS AND CONCERNS

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## Issues related to your child's coverage.

As if the experience of childhood cancer wasn't tense enough, the cost of treatment is often an added stress. Naturally, parents want what's best for their child, but in some cases, that translates to higher healthcare costs. Because of this, it's very important that you thoroughly understand your health insurance coverage. Your child may be covered by a private insurance plan, a public assistance program such as Medicaid, or both. Maintaining continuous healthcare coverage is vital at this time. Any lapse in coverage greater than 63 days can result in refusal of a new policy to cover a pre-existing condition.

A customer service representative from your health insurance plan can help you better understand what your plan covers with regard to your child's cancer treatment. Your hospital social worker or a member of the hospital's finance department can further assist you. Remember, a well-informed parent is a child's best advocate.

## How can I become better informed?

Becoming a better advocate for your child requires you to educate yourself on every aspect of your child's treatment and coverage. Here are some good tips to speed along your learning.

- 1) **Ask questions.** Take notes on the answers you receive and keep accurate records you can refer back to in the future.
- 2) **Request a case manager.** Contact your insurance company and ask for a person to serve as your consistent point of contact and source of information.
- 3) **Be prepared to spend time on the phone.** Being informed often means being put on hold.
- 4) **Learn the company's referral policy.** Know if and when referrals are needed before scheduling appointments.
- 5) **Ask about co-payments and deductibles.** Inquire about organizations that can assist with these and other treatment-related expenses not covered by insurance.
- 6) **Know what medications are covered by your insurance plan.** Know the insurance company's formulary or tiered pricing system and whether it only covers generic medication.
- 7) **Ask about non-medical expenses.** Find out if your plan covers things such as lodging, meals and transportation. If not, ask about organizations such as the NCCS that can help with these expenses.
- 8) **Know the cap on your insurance coverage.** Caps on how much the insurance company is willing to pay can be placed on occurrence, person, procedure and time period.
- 9) **Ask about home healthcare and medical supplies.** Not all insurance covers these.
- 10) **Look closely at bills.** You may discover costly billing or reimbursement mistakes on hospital bills and insurance company explanations of benefits.
- 11) **Understand the appeal process.** Learn how and when to appeal to insurance companies if necessary.

## How do legislation changes affect insurance?

Everyone needs dependable health insurance coverage, but it's especially important for cancer survivors. It's also critical that you thoroughly understand your policy and know your rights. Current health care reform policies have changed the way a person can obtain coverage. There are too many changes to list here, but an outline of the many provisions passed in legislation can be found at [healthcare.gov](http://healthcare.gov).

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## Understanding your health insurance options.

### MANAGED CARE

Most employer-provided health insurance is a form of managed care. This model provides healthcare services in the most cost-effective manner. There are several common types of managed care. These include Preferred Provider Organizations (**PPO**), Point of Service Plans (**POS**), Health Maintenance Organizations (**HMO**), and Health Savings Accounts (**HSA**). Your employer's human resources manager can help you better understand which type of policy you are covered under.

### GROUP INSURANCE

If your employer does not offer healthcare coverage, or if you are self-employed, investigate group healthcare policies through other organizations such as labor unions, fraternal organizations, and professional/business organizations. Also check into policies through student associations, religious groups or special interest groups. Most public libraries make The Encyclopedia of Associations available to residents so you can find information on different groups offering health insurance coverage. Be sure to investigate any carrier with your state's regulatory office before purchasing a policy. As with any industry, you should be wary of fraudulent insurance providers.

### STATE AND FEDERAL PROGRAMS

You may also qualify for state or federal health insurance. **Medicaid** and **State Children's Health Insurance Programs (S-CHIP)** are two government-sponsored programs you may qualify for. Currently, state and federal laws offer cancer survivors very limited help in obtaining health insurance, but advocates are working toward improving this situation. Pre-Existing insurance is now available in every state as part of the Affordable Care Act of March 2010.

### DRUG COVERAGE PROGRAMS

Recently, both the private and public sector have introduced programs to assist with the ever-increasing cost of prescription drugs. Two such programs are the **Medicare Prescription Drug Discount Card** and the **Together Rx Access Card**. These programs are updated frequently so if you choose to use these programs, visit their websites often to be sure you have the most current information. You should also regularly check with your current health insurance to be certain you are receiving the proper coverage based on current legislation.

The NCCS also offers a Discount Prescription Drug Card program. The NCCS card is available at medical clinics, hospitals, and pharmacies nationwide for individuals with limited or no prescription drug coverage. Not only does using the card provide you significant savings, it also generates contributions to the NCCS. Visit [theNCCS.agility.com](http://theNCCS.agility.com) to print a card and locate participating pharmacies.

## Battling with your insurance company.

If your insurance company refuses to pay for a given treatment or medication, don't take no for an answer. Fighting any insurance company can be time consuming and tedious, but it is important and can save you money. Many companies decline a claim simply because treatment for childhood cancer is unfamiliar ground. By questioning their call, you may make them reevaluate their policies. This can benefit your child, as well as other childhood cancer patients down the road.

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Should you start having problems with your health insurance, contact the nonprofit Patient Advocate Foundation at 800-532-5274. Your senator or congressperson may also have caseworkers who deal specifically with state insurance questions. To locate your state representative, visit [house.gov](http://house.gov), or get your state senator's contact information at [senate.gov](http://senate.gov). If you don't have Internet access, ask your hospital social worker to assist you.

### Your rights during time away from your job.

To care for a child with cancer, many parents must work reduced hours or take a leave from their job. There are laws to protect parents in this situation. You'll find these acts discussed in detail below. Should you need help paying for your health insurance premiums while you're away from your job, ask your child's hospital social worker to provide you with resources.

#### **Family Medical Leave Act (FMLA)**

The Family and Medical Leave Act of 1993 stipulates that a covered employer must grant an eligible employee up to 12 work weeks of unpaid leave during any 12-month period to care for an immediate family member (spouse, child or parent) with a serious health condition.

A covered employer is required to maintain group health insurance coverage for an employee on FMLA leave whenever such insurance was provided before the leave was taken and on the same terms as if the employee had continued to work. FMLA applies to all public agencies, local education agencies (schools) and private sector employers who employed 50 or more employees in 20 or more work weeks during the current or preceding calendar year. To learn more about the FMLA, go to [dol.gov](http://dol.gov).

#### **Americans with Disabilities Act (ADA)**

The ADA was enacted in July of 1990 to protect people with disabilities from discrimination, and to ensure equal access to employment and public facilities. This act may benefit parents of children with cancer. While the ADA defines the term disability, it doesn't include a list of conditions that are always considered disabilities. Each case is examined on an individual basis. According to the Equal Employment Opportunities Commission (EEOC), cancer isn't always considered a disability. Cancer is a disability under the ADA when it or its side effects substantially limit one or more of a person's major life activities. To learn more, call the Department of Justice at 800-514-0301 or visit [usdoj.gov/crt/ada/adahom1.htm](http://usdoj.gov/crt/ada/adahom1.htm).

#### **COBRA**

In 1985, The Consolidated Omnibus Budget Reconciliation Act (COBRA) was enacted to supply continued coverage of health insurance to workers who lost eligibility for health insurance because they were relocated or changed jobs, or because their work hours had been reduced. This coverage is temporary, and the employee is responsible for the cost. Ask your employer's human resources manager if you are eligible for continued coverage through COBRA. Or learn more through the Department of Labor at [dol.gov/dol/topic/health-plans/cobra.htm](http://dol.gov/dol/topic/health-plans/cobra.htm). Or call the Employee Benefits Security Administration's toll-free Employee and Employer Hotline at 866-444-EBSA.

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### HIPAA

The Health Insurance Portability and Accountability Act of 1996 was designed to protect access to health insurance in a variety of situations. HIPAA may help you:

- Get health coverage for yourself and your dependents if you start a new job
- Lower the risk of losing existing healthcare coverage, whether you have that coverage through a job or through individual health insurance
- Maintain continuous healthcare coverage for yourself and your dependents when you change jobs
- Buy health insurance on your own, should you be dropped from an employer's group plan and have no other healthcare coverage available

Your state's commissioner of insurance can provide you with more information. Or visit the Centers for Medicare and Medicaid Services website at [cms.hhs.gov/hipaa](https://www.cms.hhs.gov/hipaa).

### Just Between Us | Survival Tips from other Survivors

"Always make sure you are educated about your personal insurance coverage. Spend lots of time on the phone and ask lots of questions. Pay close attention to itemized bills."

- Shannon, mother of Olivia (Retinoblastoma)

"It's so important to just ask if changes are possible! We asked our insurance company to do an end of year audit for us to make sure we paid the bills in the correct order of date to meet our deductible."

- Linda, mother of Sam (Neuroblastoma)

### Keep your child insured continuously.

Being a cancer survivor means monitoring your health insurance coverage very carefully— even into adulthood. Whether your child is still in treatment or finished years ago, your child must always have health insurance. Without it, you and your child's health and financial future will be at risk.

Young adults are one of the fastest growing groups without health insurance. Children are often dropped from their parents' plans or from public insurance plans when they turn 19 or graduate high school. But in September of 2010, the Affordable Care Act was passed, requiring all private health insurance companies offering dependent coverage allow parents the ability to cover their children until age 26 at open enrollment time. Many companies are offering this protection already. Your adult children don't need to live with you to be eligible. However, if your adult children are eligible for health benefits from their own jobs, they can't be covered under your existing job-based plan.

As this brochure goes to print, current legislation is being determined. Changes are still being updated, so visit [healthcare.gov](https://www.healthcare.gov) to learn more about the current healthcare reform provisions passed in legislation.

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As your child reaches adulthood, be sure he or she understands the importance of maintaining continuous coverage. Encourage them to seek employers who offer health insurance and suggest they explore individual health insurance plans. It is critical that they always have health insurance coverage. Any gaps may result in the refusal of a new policy to cover a pre-existing condition. A lapse in coverage is a lapse in good judgment.

## BIBLIOGRAPHY

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- Arroyave, Whitney D., Elizabeth C. Clipp, Paige E. Miller, Lee W. Jones, Dianne S. Ward, Melanie J. Bonner, Philip M. Rosoff, Denise Clutter Snyder, and Wendy Demark-Wahnefried. "Childhood Cancer Survivors' Perceived Barriers to Improving Exercise and Dietary Behaviors." *Oncology Nursing Forum* 35.1 (2008): 121-30. Print.
- "Childhood Cancer: Late Effects of Cancer Treatment." *Cancer.org*. American Cancer Society, 19 June 2009. Web. 15 Dec. 2010.
- Cohen, Jennifer, Claire E. Wakefield, Catharine A. K. Fleming, Rebecca Gawthorne, Linda C. Tapsell, and Richard J. Cohn. "Dietary Intake after Treatment in Child Cancer Survivors." *Pediatric Blood & Cancer* (2011): N/a. Print.
- Hunsinger, Deborah Van Deusen. *Pray without Ceasing: Revitalizing Pastoral Care*. Grand Rapids, MI: William B. Eerdmans Pub., 2006. Print.
- Hudson, Melissa M., Sally Wiard, and Allison Hester. "Health Link: Finding and Paying for Healthcare after Treatment for Childhood Cancer." *Survivorshipguidelines.org*. Children's Oncology Group, Mar. 2006. Web. Jan. 2011.
- Jalonick, Mary C. "Food Pyramid Out, 'My Plate' in for Healthy Eating." *Boston Globe* 2 June 2011. *Boston.com*. Boston Globe. Web. 22 Sept. 2011.
- Kadan-Lottick, Nina S., Leslie L. Robison, James G. Gurney, Joseph P. Neglia, Yutaka Yasui, Robert Hayashi, Melissa Hudson, Mark Greenberg, and Ann C. Mertens. "Childhood Cancer Survivors' Knowledge About Their Past Diagnosis and Treatment." *Journal of the American Medical Association* 287.14 (2002): 1832-839. Print.
- Keene, Nancy. *Educating the Child with Cancer: a Guide for Parents and Teachers*. [Kensington, Md.]: Candlelighters Childhood Cancer Foundation, 2003. Print.
- Keene, Nancy, Wendy Hobbie, and Kathy Ruccione. *Childhood Cancer Survivors: a Practical Guide to Your Future*. Beijing: O'Reilly, 2007. Print.
- Klassen, Anne F., David Dix, Michael Papsdorf, Robert J. Klaassen, Rochelle Yanofsky, and Lillian Sung. "Impact of Caring for a Child with Cancer on Single Parents Compared with Parents from Two-parent Families." *Pediatric Blood and Cancer* (2011). *Onlinelibrary.wiley.com*. Wiley, 19 Jan. 2011. Web. Spring 2011.
- Landier, Wendy. "Health Link: Introduction to Long Term Follow Up after Treatment for Childhood, Adolescent, or Young Adult Cancer." *Survivorshipguidelines.org*. Children's Oncology Group, Oct. 2008. Web. Dec. 2010.
- Learning & Living with Cancer: Advocating for Your Child's Educational Needs*. White Plains, NY: Leukemia & Lymphoma Society, 2006. Print.
- MacLellan, Scott Neil. *Amanda's Gift: One Family's Journey through the Maze of Serious Childhood Illness*. Roswell, GA: Health Awareness Communications, 1999. Print.
- Martin, Terry L., and Kenneth J. Doka. *Men Don't Cry-- Women Do: Transcending Gender Stereotypes of Grief*. Philadelphia, Penn.: Brunner/Mazel, 2000. Print.
- Nutrition and the Cancer Survivor*. Washington DC: American Institute for Cancer Research, 2001. Print.
- Oeffinger, K. C., and M. M. Hudson. "Long-term Complications Following Childhood and Adolescent Cancer: Foundations for Providing Risk-based Health Care for Survivors." *CA: A Cancer Journal for Clinicians* 54.4 (2004): 208-36. Print.
- "Questions to Ask My Doctor about My Cancer." *Cancer.org*. American Cancer Society, 27 Apr. 2011. Web. Spring 2011.
- Raiss-Dana, Deborah. *Diamonds or Dust: Keeping Your Marriage Together When Your Child Fights for Life*. 2004. Print.
- Weiner, Susan Lipschitz, and Joseph V. Simone. *Childhood Cancer Survivorship Improving Care and Quality of Life*. Washington, D.C.: National Academies, 2003. Print.

# RESOURCES

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## Help for the climb

For additional resources, visit [beyondthecure.org](http://beyondthecure.org) or talk to a member of your child's medical team.

### Medical

#### National Cancer Institute

800-4-CANCER [cancer.gov](http://cancer.gov)  
Provides state-of-the-art information about the treatment of individual types of cancer, clinical trials and late effects.

#### CureSearch

800-458-6223 [curesearch.org](http://curesearch.org)  
Funds research and provides information to those affected by childhood cancer.

#### Chemo Care

[chemocare.com](http://chemocare.com)  
Provides information about chemotherapy and side effects.

### Insurance/Legal

#### HealthCare.gov

[healthcare.gov](http://healthcare.gov)  
A government sponsored web site on healthcare information.

#### Patient Advocate Foundation

800-532-5274 [patientadvocate.org](http://patientadvocate.org)  
Solve insurance and healthcare access problems.

#### Social Security Administration

800-772-1213 [ssa.gov](http://ssa.gov)  
Provides answers to questions regarding social security benefits.

### Support, Advocacy and Financial Assistance

#### The National Children's Cancer Society

800-5-FAMILY [theNCCS.org](http://theNCCS.org)  
Emotional support, advocacy, education, and financial assistance to parents of children with cancer and an online community for parents and survivors.

#### American Cancer Society

800-ACS-2345 [cancer.org](http://cancer.org)  
Information on parental issues such as coping with diagnosis, understanding the health care system, financial and insurance information, and transitioning your child back into school.

#### Association of Cancer Online Resources (ACOR)

[acor.org](http://acor.org)  
Electronic support groups to patients, caregivers, and survivors.

**Cancercare** 800-813-HOPE [cancercare.org](http://cancercare.org) Individual and group counseling both on-line and via their toll-free counseling line.

#### Supersibs

888-417-4704 [supersibs.org](http://supersibs.org)  
Support for brothers and sisters of children with cancer.

#### First Hand Foundation

816-201-1569 [applications.cerner.com/firsthand](http://applications.cerner.com/firsthand)  
Financial assistance for treatment, equipment, displacement and vehicle modifications for children with health problems.

#### United Healthcare Children's Foundation

952-992-4459 [uhccf.org](http://uhccf.org)  
Financial help for medical services such as speech, physical or occupational therapy, prescriptions, and medical equipment such as wheelchairs, orthotics and hearing aids.

### Healthy Living

#### American Institute of Cancer Research

800-843-8114 [aicr.org](http://aicr.org)  
Offers specific nutrition information for the cancer survivor.

#### SmokeFree

877-448-7848 [smokefree.gov](http://smokefree.gov)  
Help for those who want to quit smoking

#### Sun Safety Alliance

703-481-1414 [sunsafetyalliance.org](http://sunsafetyalliance.org)  
Provides information on sun safety.

### Learning Disabilities

#### National Center for Learning Disabilities

888-575-7373 [nccd.org](http://nccd.org)  
Solutions and opportunities for individuals with learning disabilities.

### Survivorship

#### Beyond the Cure Survivorship Program

Sponsored by The National Children's Cancer Society  
800-5-FAMILY [beyondthecure.org](http://beyondthecure.org)  
Information on all aspects of cancer survivorship, a late effects assessment tool and college scholarships.

#### Livestrong

866-673-7205 [livestrong.org](http://livestrong.org)  
Awareness, advocacy and support for the cancer community.