



Psychosocial Services *Resources for Families*

 The Children's Hospital
of Philadelphia®

CANCER CENTER

c a n c e r . c h o p . e d u

We Are Here for You

Children and families coping with a cancer diagnosis benefit immensely from the comprehensive psychosocial support programs offered at The Children’s Hospital of Philadelphia’s Cancer Center. Our multidisciplinary [Psychosocial Services](#) team includes social workers, psychologists, child life specialists, creative arts therapists, teachers, and others who help children and families through this difficult time in their lives.

We emphasize a team approach. Each newly diagnosed family is assigned a member of the psychosocial staff, who provides a psychosocial assessment and other supportive services as needed over the course of treatment. Psychosocial staff can help you understand the impact that the stress of serious illness may have on your family, as well as on your relationships with each other. Your social worker or psychologist can also direct you to the many resources available within the Hospital and in the community.

This handbook contains information about lodging and transportation options as well as the support services the Hospital offers to patients and families. We have also included a list of websites and books that you may find helpful.

If you have any questions or would like to speak to someone on our staff, contact Lamia Barakat, Ph.D., director of Psychosocial Services, at 1-877-403-2149. We look forward to getting to know you and your child.

Table of Contents

Transportation, Food and Lodging	2
Resources at CHOP	4
Financial Matters	4
Other Resources	5
Books	10

Transportation, Food and Lodging

Following is a list of resources that may be helpful to you as you plan your trip to The Children’s Hospital of Philadelphia. For more information, contact the psychosocial staff member assigned to work with your family.

Transportation and Parking

Directions

Call 215-590-7275 or visit <http://www.chop.edu/visitors/directions-maps-and-parking/main-campus-maps.html> for directions to CHOP via car or public transportation.

Parking

Families of children who are inpatient may park in the Hospital’s Main Building parking lot. Visitors and families with outpatient appointments can park in the Richard D. Wood Pediatric Ambulatory Care Center garage. For a discount, get your parking ticket stamped at the oncology clinic’s registration desk or at the Welcome Center desk. If your child receives radiation at the Perelman Center for Advanced Medicine, free parking is provided during treatment there. Contact the Registration Desk at the HUP Department of Radiation Oncology for further details at 215-615-5662.

Local Cab Companies

All City Taxi — 215-467-6666

Crescent Cab Co. — 215-365-3500

Yellow Cab Co. — 215-333-3333

Airport Shuttles

Super Trans — 1-800-309-2000

Dave’s Best — 1-800-255-2378

Call the Philadelphia International Airport’s Ground Transportation Hotline at 215-937-6958 for other airport transportation options.

Main Campus Maps

[Maps](#) of CHOP’s Main Campus, and of each floor in the Main Building, the Wood Center and Children’s Seashore House, are available at www.chop.edu/directions.

Food

Main Building Food Court

Located on the first floor of the Main Building, the Food Court offers pasta, pizza, soups, sandwiches, sushi, salads, hot entrees and much more. Open seven days a week from 6:30 a.m. to 7:30 p.m.

C3 Convenience Store

Located on the first floor of the Wood Center. Open Monday through Friday from 6:30 a.m. to 5:00 p.m.

The Shops at CHOP

Located on the first floor of the Main Building. Open Monday through Friday from 7:00 a.m. to 12:30 a.m. and Saturday and Sunday from 9:00 a.m. to 12:30 a.m.

Abramson Cafeteria

Located on the first floor of the Leonard and Madlyn Abramson Pediatric Research Center, across from the Wood Center. Open Monday through Friday from 7:30 a.m. to 2:30 p.m.

Au Bon Pain

Located outside, across from the Wood Center and next to the Abramson Research Center.

McDonald's

Located on the first floor of the Main Building. Open 24 hours a day.

Hours of operation are subject to change.

Additional information about local food/restaurant options is available in the Connelly Resource Center for Families, located on the eighth floor of the Main Building.

Lodging

In-room

Each patient room is equipped with a couch that can be used as a bed for one parent.

Parent Sleep Rooms

Sleep rooms for inpatient families are available in the Connelly Center and in other areas of the Hospital. Priority is typically given to ICU families. Distance from home is also considered. Stop by the Connelly Center or ask your social worker for assistance requesting a room. Requests must be submitted by noon on the day the room is needed.

The Ronald McDonald House (Philadelphia and Camden, N.J.)

The Ronald McDonald House offers families who travel long distances for treatment a place to stay at night. The room charge is \$15/night (rate is subject to change). There may be a waiting list.

There are two Ronald McDonald Houses in the Philadelphia area:

Philadelphia Ronald McDonald House

- 3925 Chestnut St. (215-387-8406)

Ronald McDonald House of Southern New Jersey

- 550 Mickle Blvd., Camden, N.J. (856-966-4663)

Hosts for Hospitals

Hosts for Hospitals provides free lodging and support at volunteer-host homes to patients and their families who come to the Greater Philadelphia area for specialized medical care.

Call 215-472-3801 or visit www.hostsforhospitals.org for more information.

Chai House Philadelphia

Located at 3434 Sansom St. in Philadelphia, the Chai House is a place for children and their families to stay while undergoing treatment. Call 1-877-CHAI-LIFE and ask to speak with the social worker.

Sheraton Philadelphia University City Hotel

Special rates are available at the [Sheraton Philadelphia University City Hotel](#) for patients referred from the Ronald McDonald House when the House is full. Also, a special rate is available for families of patients who are being treated at CHOP. The hotel is located at 3549 Chestnut St. Call 215-387-8000 for more information.

Art Museum Guest Houses

Fully furnished short-term rentals are available in Philadelphia's friendly Art Museum neighborhood. Call 215-236-4664 for rates and availability.



Resources at CHOP

The Children’s Hospital of Philadelphia provides support for the entire family. Following are just a few of the resources we offer. For more information on how we can help you, contact the psychosocial staff member assigned to work with your family.

The Connelly Resource Center for Families

The Connelly Center, located on the eighth floor of CHOP’s Main Building, welcomes families 24 hours a day, seven days a week. The center has a living room, kitchen and laundry area. There is also a library for adults and children with a librarian who can help you locate books and use the computers. The library hours vary. Call 215-590-4YOU (4968) for information.

Chaplaincy Service

A full-time Hospital chaplain is available for pastoral support and sacramental ministry. The chaplain maintains a directory of 30 visiting clergy from various denominations who are available on a referral basis. Please ask the nurse or social worker to contact the chaplain. There is also a nondenominational chapel located on the first floor of the Hospital. Call 215-590-1137 for more information.

Ronald McDonald Family Room (for inpatient families)

The Ronald McDonald Family Room, located on the 3 South inpatient unit, provides families with a cozy environment where they can interact with other families, watch television, eat meals, do laundry and store food in the kitchenette. Activities such as haircuts, massages and parent dinners are often held here.

Financial Matters

CHOP staff are available to answer your insurance and billing questions and to help you apply for financial assistance. For more information, visit www.chop.edu/visitors/financial-assistance.

Billing Questions

For help with billing issues, call Khadidrah Barco, financial counselor, Division of Oncology, at 215-590-4184.

Financial Assistance

CHOP’s Family Health Coverage Program is a resource for families who need assistance paying for their child’s medical care. You will be assigned a Family Health Coverage Coordinator who will assist you with applying for available public assistance programs that you may qualify for. The program’s office is located on the first floor of the Main Building (Room 1190) for inpatients and on the first floor of the Wood Building (Room 1433) for outpatients. They can also be reached at 1-800-974-2125 or at 267-426-0359.

Other Resources

Following is a list of resources that other families have found to be helpful. There are many other programs, agencies and organizations that we have not listed that may be able to assist your family as well. For more information, contact the psychosocial staff member assigned to work with your family.

American Cancer Society (ACS)

www.cancer.org
1-888-227-5445

The ACS sponsors support groups for patients, parents and siblings and may also be able to help with nonmedical expenses such as wigs, transportation, wheelchairs, hospital beds and nonmedical bills. The ACS also offers something called the Look Good...Feel Better program, which teaches cancer patients hands-on cosmetic techniques to help them cope with appearance-related side effects from chemotherapy and radiation treatments. The ACS is based in each county and services may vary from chapter to chapter.

American Society of Clinical Oncology (ASCO)

www.cancer.net
1-888-651-3038

The ASCO website has oncologist-approved information on more than 120 types of cancer and cancer-related syndromes.

Association of Cancer Online Resources (ACOR)

www.acor.org/ped-onc

ACOR offers information and e-support groups to patients, caregivers or anyone else looking for answers and support related to cancer. ACOR also hosts several pediatric discussion groups. The ACOR website has descriptions of diseases and treatments and links to pertinent information.

CancerCare

www.cancer.org
1-800-813-HOPE (4673)

CancerCare provides professional counseling and guidance to families and financial assistance to eligible families for certain home care, transportation, medical treatment and child care costs.

CarePages – CHOP

www.carepages.com/chop

This simple-to-use online service helps family and friends stay in touch during a child's hospitalization and recovery.

With a CarePage, you can share news and updates about your child, receive messages of support from friends and family on your own message board, post visiting hours and contact information, and share photos with friends and family.

CaringBridge

www.caringbridge.org

This user-friendly site allows parents to create a free Web page about their child and keep a virtual diary about their experiences. It can be updated at any time and friends and family can access it from any Web browser.

Chai Lifeline

www.chailifeline.org

Through programs that address the emotional, social and financial needs of seriously ill children and their families, Chai Lifeline restores normalcy to family life and better enables families to withstand the crises and challenges of serious pediatric illness.

CureSearch

www.curesearch.org
1-800-458-6223

This thorough website is sponsored by the National Childhood Cancer Foundation and the Children's Oncology Group. Information is available for specific cancer types, treatment stages and age groups. The site also has information on how to navigate the healthcare system.

Education Law Center

www.elc-pa.org
215-238-6970

The Education Law Center provides free legal assistance to parents, students and advocates on education law matters, and advises parents of their rights to special services under the law. The Center also publishes a free guide for parents called "The Right to Special Education in Pennsylvania: A Guide for Parents and Advocates."

Family and Medical Leave Act (FMLA)

www.dol.gov/whd/fmla/index.htm

FMLA mandates that covered employers must grant eligible employees up to a total of 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.

Fertile Hope

www.fertilehope.org

This national nonprofit organization provides reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Gilda's Club

Gilda's Club provides a meeting place for families who are learning how to live with cancer. Services include groups, activities and workshops for all age groups. All services are free. There are two Gilda's Clubs in the Philadelphia area:

- Delaware Valley (Bucks/Montgomery Counties) — 200 Kirk Rd., Warminster, Pa., 215-441-3290, www.gildasclubdelval.org
- South Jersey — 700 New Rd., Linwood, N.J., 609-926-2699, www.gildasclubsouthjersey.org



Hair Loss

ChemoCare HeadWear

www.chemocareheadwear.com

Provides hats, turbans, sleep hats, swim caps and wigs for hair loss due to cancer treatment.

Girl on the Go

www.girlonthego.biz

Provides private in-home wig consultations for girls and women going through cancer treatment.

Hair Club for Kids

www.hairclub.com/hc_for_kids.php

Provides free hair restoration for children battling hair loss as a result of illness.

Headcovers Unlimited

www.headcovers.com

Provides hats, turbans and wigs for hair loss and cancer patients.

Hip Hats With Hair

www.hatswithhair.com

Provides hats with human or synthetic hair attached for girls with hair loss that is due to chemotherapy.

Locks of Love

www.locksoflove.org

Provides hair pieces to financially disadvantaged children under age 18 suffering from long-term medical hair loss from any diagnosis.

Stylish Noggins

www.stylishnoggins.com

A non-cancer-specific site that offers a unique selection of soft, cute hats for kids.

Wigs for Kids

www.wigsforkids.org

A nonprofit organization that provides wigs and accepts hair donations.

Wiggalicious

www.wiggaliciouswigs.com

Provides free or low-cost wigs to women and girls who have lost hair due to chemotherapy.

Imerman Angels

www.imermanangels.org

This federally registered 501(c)(3) not-for-profit organization provides one-on-one cancer support, connecting cancer fighters, survivors and caregivers. Imerman Angels partners a person fighting cancer with someone who has beaten the same type of cancer. One-on-one relationships give a fighter the chance to ask personal questions and get support from someone who is uniquely familiar with their experience.

The Leukemia & Lymphoma Society (LLS)

www.lls.org

The LLS has a Patient Financial Aid program (\$500 per year) that can help with things such as transportation costs to and from medical appointments or medications not covered by insurance. LLS also offers a co-pay assistance program for certain diagnoses. Call and ask for the patient services manager.

Southern New Jersey: 856-638-1250 • Eastern Pennsylvania: 610-238-0360

Lotsa Helping Hands

www.lotsahelpinghands.org

Lotsa Helping Hands allows you to create a free, private, Web-based community to organize family, friends, neighbors and colleagues — a family’s “circles of community” — during times of need. You can easily coordinate activities and manage volunteers with an intuitive group calendar, and communicate and share information using announcements, message boards and photos.

Medical Assistance (MA)

www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance

This is a state program that helps families that qualify pay for medical expenses. Due to a provision in the laws regarding Medical Assistance, children with serious disabilities who live in Pennsylvania are eligible for Medical Assistance (also known as Medicaid) regardless of their parents’ income. Thus, those children whose parents’ income is too high for SSI can qualify for Medicaid under this provision. To apply, contact your local County Assistance Office or CHOP’s [Family Health Coverage Program](#) (1-800-974-2125).

National Cancer Institute (NCI)

www.nci.nih.gov

1-800-4-CANCER (422-6237)

The NCI website has information about cancer for patients, the public and the media. The site features research updates and advice on prevention and early detection.

National Children’s Cancer Society (NCCS)

www.nationalchildrenscancersociety.com

1-800-532-6459

NCCS can help to provide financial assistance to families for nonmedical expenses such as travel, meals for inpatient hospital stays, phone cards and lodging.

The Never-Ending Squirrel Tale

www.squirreltales.com

This website provides practical tips and encouragement for the parents of kids with cancer.

OncoLink

www.oncolink.org

OncoLink offers a variety of cancer-related information, including articles and writings by patients and their families. The site also has a children’s art gallery.

Public Health Management Corporation (ChildLink)

www.phmc.org (click on “Programs & Affiliates”)

215-731-2110

This agency coordinates services in Philadelphia to help children from birth to age 3 who have special needs or who may have developmental delays. ChildLink can help families receive a wide range of early intervention services in Philadelphia.

The Special Kids Network

www.helpinpa.state.pa.us/children.aspx

(click on “The Special Kids Network”)

1-800-986-4550

This agency provides information to families in Pennsylvania about special health issues and community resources. It also links families facing similar experiences.

Starlight Children's Foundation

www.starlight.org

The Starlight Children's Foundation has dedicated itself to improving the quality of life for children with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope with the pain, fear and isolation of prolonged illness.

Summer Camps

There are several camps for cancer patients, siblings and entire families. Contact the psychosocial staff member assigned to work with your family for more information.

Supplemental Security Income (SSI)

www.ssa.gov

SSI is a federally funded program that provides monthly payments to the elderly and to blind and disabled children and adults if medical and financial eligibility criteria are met. If a child is eligible he/she also automatically qualifies for Medical Assistance (MA) to help pay for medical expenses. You can apply at your local Social Security Administration office, by phone at 1-800-772-1213 or online.

Wish Foundations

There are many wish foundations that may be able to grant your child a special wish. Contact the psychosocial staff member assigned to work with your family for more information.

For Children and Teens

2bMe

www.2bme.org

This site for teens with cancer provides information on nonmedical topics, from skin and hair issues to fitness and friends.

Cancer Kids

www.cancerkids.org

This site tells the personal stories of children fighting many different types of cancer.

Chemo Angels

www.chemoangels.net

Your child can apply to be "adopted" by a Chemo Angel who, through cards, cheerful notes and small gifts, will provide support and encouragement throughout treatment.

Group Loop

www.grouploop.org

This site provides online support as well as information and resources for teens living with cancer and their families.

Next Step

www.nextstepnet.org

This organization for teens and young adults with cancer and life-threatening blood diseases offers retreats and workshops around the country.

Songs of Love

www.songsoflove.org

Songs of Love creates free personalized songs for chronically ill children and young adults. Ask your social worker for an application or download one from the website.

Starbright World (part of the Starlight Children's Foundation)

www.starbrightworld.org

Starbright World is an online social network for teens with chronic and life-threatening illnesses and their siblings.

Teens Living with Cancer

www.teenslivingwithcancer.org

This site for teens with cancer has information on coping with hair loss, friends, family, school and much more.

For Young Adults (18+)

CancerCare – Young Adult Program

www.cancercare.org/get_help/special_progs/young_adults.php

CancerCare offers specialized services for young adults, caregivers and those who have lost a loved one.

First Descents

www.firstdescents.org

First Descents provides whitewater kayaking and other outdoor adventure experiences to promote emotional, psychological and physical healing for young adults with cancer.

I'm Too Young for This! Cancer Foundation

<http://i2y.com>

I'm Too Young for This! is an all-inclusive young adult cancer community.

LIVESTRONG Young Adult Alliance

www.livestrong.org

(click on “What We Do,” then “Programs & Partnerships”)

The LIVESTRONG Young Adult Alliance is a coalition of organizations with the goal of improving survival rates and quality of life for young adults (ages 15 to 40) with cancer.

Next Step

www.nextstepnet.org

This organization for teens and young adults with cancer and life-threatening blood diseases offers retreats and workshops around the country.

Planet Cancer

<http://planetcancer.org>

Planet Cancer is an online community for young adults with cancer.

Prepare to Live

www.preparetolive.org

Prepare to Live is a source of help, hope, information and inspiration for young adult patients, survivors and caregivers coping with cancer worldwide.

Rise Above It (RAI)

www.raibenefit.org

RAI provides meaningful support to adolescents and young adults affected by cancer. RAI also provides financial assistance to patients ages 15 to 39 who are either undergoing or actively pursuing Phase I, II or III clinical trial treatment options.

The Ulman Cancer Fund for Young Adults

www.ulmanfund.org

The Ulman Cancer Fund provides support programs, education and resources for young adults with cancer, as well as their families and friends.

Young Cancer Spouses

www.youngcancerspouses.org

The emotional and logistical issues a young spouse of a cancer patient faces are vastly different from those faced by spouses of older cancer patients. This is a place to get practical information from other young cancer spouses.

For Siblings

Sibshops Sibling Support Project

www.siblingsupport.org

A part of the Sibling Support Project, Sibshops are interactive workshops for siblings of kids with special needs. Sibshops focus on peer support and celebrate the many contributions made by brothers and sisters of kids with special needs. Ask your social worker for more information.

SuperSibs!

www.supersibs.org

This national organization honors, supports and recognizes siblings of children with cancer. Ask the psychosocial staff member assigned to work with your family for more information.

Books

For Parents

Hilden, Joanne, M.D., and Tobin, Daniel, M.D., with Karen Lindsey. *Shelter from the Storm: Caring for a Child with a Life-Threatening Condition*. Perseus Publishing, 2003.

Janes-Hodder, Honna and Keene, Nancy. *Childhood Cancer: A Parent's Guide to Solid Tumor Cancers*. O'Reilly & Associates, 1999.

Keene, Nancy. *Childhood Leukemia: A Guide for Families, Friends and Caregivers*. O'Reilly & Associates, 2002.

Keene, Nancy and Prentice, Rachel. *Your Child in the Hospital: A Practical Guide for Parents*. O'Reilly & Associates, 2002.

Shiminski-Maher, Tania; Cullen, Patsy McGuire; and Sansalone, Maria. *Childhood Brain & Spinal Cord Tumors: A Guide for Families, Friends & Caregivers*. O'Reilly & Associates, 2002.

For Children and Teens

Baker, Lynn S., M.D. *You and Leukemia: A Day at a Time*. W.B. Saunders Company, 2002.

Dorfman, Elena. *The C-Word: Teenagers and Their Families Living with Cancer*. NewSage Press, 1998.

Foss, Karen. *The Problem with Hair: A Story for Children Who Are Learning About Cancer*. Centering Corporation, 1996.

Keene, Nancy and Romain, Trevor. *Chemo, Craziness, and Comfort: My Book About Childhood Cancer*. Candlelighters Childhood Cancer Foundation, 2002.

Krisher, Trudy. *Kathy's Hats: A Story of Hope*. Albert Whitman & Company, 1992.

Peterkin, Allan. *What About Me?: When Brothers and Sisters Get Sick*. Magination Press, 1992.

Sonnenblick, Jordan. *Drums, Girls, and Dangerous Pie*. Scholastic Books, 2004.

A fictional story about a sibling's experience with childhood cancer.

The psychosocial staff member assigned to our family is:

Phone number:

Pager:

E-mail: