

PARENT'S GUIDE

Special resources to assist families
going through cancer



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INTRODUCTION

Cancer can be unsettling to any family. It's already hard enough to raise a child - to add a cancer diagnosis on top of it all can feel overwhelming. According to the U.S. Census, approximately 2.85 million children under 18 live with a parent who is a cancer survivor.

The purpose of this guide is to assist parents and their children with information, resources, and suggestions during their cancer journey. At the end, it identifies local Maryland resources and services for households with cancer and their children. If you have any comments or concerns, please email contact jiam@jhmi.edu. We hope this guide will be of benefit for all those who use it.

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TABLE OF CONTENTS

INTRODUCTION.....	2
PARENT’S ADVICE.....	4
HELPING KIDS COPE.....	5
Explaining Cancer to Children.....	5
Answering Questions.....	6
Support Teams at Home and School.....	6
When the Child Becomes the Parent.....	7
Risky & Rebellious Behavior.....	7
When the Future Doesn’t Look Good & Delivering Bad News.....	7
LOCAL CANCER SUPPORT RESOURCES.....	9
Direct Services for Children Affected by Cancer.....	9
Education Scholarship Funds.....	10
Home Services.....	11
Counseling & Family Support.....	13
OTHER RESOURCES.....	16
Web Sites.....	16
Books for Children.....	18
Books for Parents.....	18
APPENDIX: FOR PARENTS WITH CANCER.....	19
General Tips.....	19
Patient File.....	20
Doctor Visits.....	21
Medications.....	22

Parent's Advice

While every child and family is unique, there are certainly ways to strengthen family togetherness during difficult times.

1. **Maintain communication** within the family. Even if your child may not be asking for details, it is important to offer updates on the cancer and treatment.
2. **Your child needs you.** Spend time together and focus your attention on your child and his or her interests.
3. **Keep family life and daily schedules as close to normal** as you can. It may be helpful to explain how treatment may alter your typical routines so that your child is prepared for the changes.
4. **Don't hide the bad news.** Children are perceptive and can sense the change in mood and facial expressions.
5. **Respect your child's feelings** and understand that feelings of anger, worry, confusion, and disinterest are all normal.
6. If your child is doing something that normally would make you worry, **address it** (i.e. avoiding people, taking risks, failing in school).
7. **Express your gratitude and appreciation to your child** for his or her contributions in the home.
8. If your **child wants to come to an appointment** with you, allow him or her to do so.
9. If your child apologizes for saying something he or she regrets, **accept the apology.** Everyone says things they do not mean.
10. **Appoint a go-to adult** your child can spend time with or confide in when you're not available.
11. Children **use different methods to cope with their stress.** If they seem to be playing video games, going to the mall, listening to music, spending time with friends more often, it may be their way of dealing with a difficult time.
12. Remind your child that it is okay to have sad days and to **feel the way you do.**
13. **Tell your children you love them.**

Helping Kids Cope

Explaining Cancer to Children

- **Find Out What Your Child Knows Already**

Take time to figure out how much he or she already knows, heard, noticed, or perhaps imagined about your cancer. This lets you clear up any misinformation and gives you an idea of where to start the conversation.

- **Asking Them What They Want to Know**

Sometimes it is hard to know what your child needs and wants to know about your cancer. It is best to ask them what they want to know. Be sure to follow up by asking if they still have questions.

- **Using Terms they Understand**

When explaining cancer to a child, use words that he or she understands. Foreign terms like “malignancy”, “chemotherapy”, and “radiation” may not only confuse, but scare a child. Describing cancer using story-telling format or using a toy animal/picture to show where the cancer is may help the child understand. Let your child know that while there are a lot of unknowns, you will keep your child updated as you and the doctors learn more. Tailor the story to the age of the child so that they can fully understand.

Sample Script: The body is made up of cells that have different functions. “These are the normal cells the body needs to work the right way. Cancer cells do not look like or function like these normal cells. They grow so fast that they crowd out normal cells and prevent the normal cells from functioning properly. When these cancer cells grow on a certain part of the body, a doctor might have to operate to remove the cells. Other people have to take special chemicals or get treated with radioactive rays to get rid of the cancer cells. Some people lose their hair when they have these treatments, but that is because the chemicals and radioactive rays also kill normal cells. After the treatment ends, the hair grows back.

If the concept of explaining cancer to your child is not something you want to do, it is okay to look elsewhere for an expert's help. Cancer centers or support organizations often have social workers or child life specialists who could meet with you and your child to help answer questions.

Answering Questions

Children often have a lot of questions when first told about a parent's cancer. Therefore, giving kids enough information to ease their concerns can be very helpful. It may be hard for children to ask questions and they may keep those worries inside. Create a safe place for your child to ask questions and follow up with your child on his or her understanding. If you don't know the answer, it's best to admit you don't know.

Common questions young children ask include:

- How did you get cancer?
- Can I catch cancer?
- Why did you get cancer? It's not fair!
- Why did you lose your hair?

Creating Support Teams at Home and School

Provide your child with a role in choosing his or her support team at home. It is helpful to have a to-go adult for the times when you may not be available. While it may not be possible to have their first choice, try to respect their preferences as much as possible.

Adults at school can also be an important component of your child's support team. Start with meeting with your child's teacher, guidance counselor, and school nurse to let them know your current situation and provide them with concrete examples on how they can support your child. With your child, decide whether you want the teacher to keep the information private or if it is okay for classmates to know.

During your meeting with the adults at the school, you can explain your desire for school to be an escape for your child from the medical uncertainties. Suggestions include enthusiastic and energetic greetings in the morning.

When the Child Becomes the Parent

When a parent is ill, a child can assume the roles of that ill parent, such as: acting like a parent to their siblings, spending most of their time at home, or taking on too many chores for their age. When this happens, it is helpful to thank them for their help and to remind them to relax and have fun. A combination of saying thank you and reminding them to be a kid may help him or her feel less frustrated with his or her new-found role.

Engagement in Risky & Rebellious Behavior

At times, teenagers may engage in rebellious behavior during cancer treatment. If you see warning signs of inappropriate behavior that you normally wouldn't let slide, that's a good indication that your child may need help. It's okay to seek help from outside sources, such as a school counselor, child psychologist, hospital social worker, or psychiatrist. Many families look toward family therapy, even if the child may not believe in its merits. Convincing the child that seeing a therapist has value is important in order for him or her to benefit from the therapy sessions.

While cancer patients need to focus on their own needs first, don't neglect your child's needs. Some of the recommendations provided by teenagers coping with cancer include being there for them, participating in active listening, remaining consistent with household rules, and allowing their children to stay involved in their parent's care. Try to stay aware of your child's friend groups. Include family activities within your regular schedule to maintain normalcy and positivity during treatment.

When the Future Doesn't Look Good & Delivering Bad News

There may come a point in time when the future doesn't look hopeful. As hard as it is, it may be helpful to start by letting them know if the treatment isn't working and asking your child how much or little he or she wants to know in detail.

There will be times where it may be tempting to make promises of a good outcome to your child. Unfortunately, making such a promise can be impossible to keep, especially when a prognosis is not good.

Instead, explain to your child that you and your doctors are working as hard as possible, and that the best part of your day is feeling his or her love in your heart. It is okay to be hopeful as long as the dialogue is truthful. While you may feel worse from the medicine for the time being, you will hopefully be healthy again when the treatment is over.

If death is a likely outcome, it may be helpful create memories your child can keep of you (i.e. videos, documents, letters, etc.). This lets you express your love for your child even after your time. For single parents, it is especially important to plan for alternative guardianship. Don't wait for your child to bring up future living arrangements. Consider asking your kids for their input on who they want to live with if something were to happen.

Local Cancer Support Resources

Direct Services for Children Affected by Cancer

◇ Camp Kesem – Johns Hopkins University, Baltimore, MD

- Camp Kesem is a week-long student-run summer camp for children whose parents have or had cancer. It is a chance for these kids to have fun by just being kids, and an opportunity for them to develop lasting relationships with the counselors and other campers going through the same experience. The camp is completely free for its campers and is held in Pennsylvania for the 2014 year. Bus transportation will be provided from Baltimore City.
- Contact: Alice Tao at 978-290-7207 or <http://campkesem.org/jhu>

◇ Carol Jean Cancer Foundation's Beth's Children Program, North East, MD

- An overnight camp for children of cancer patients. The camp provides an opportunity for children to share their feelings and experiences with one another while participating in recreational activities.
- Contact: 410-531-0758 or <http://www.cjcf4kids.org/programs/bethsChildren.asp>

◇ HopeWell Kids/Teen Circle and Kids/Teen Grief Program, Lutherville, MD

- HopeWell Cancer Support offers two free six-week programs for children dealing with a parent's cancer diagnosis or the loss of a parent to cancer. The curriculum includes engaging and age-appropriate activities led by licensed and experienced health professionals.
- Contact: 410-832-2719 or <http://www.hopewellcancersupport.org>

◇ Justin's Beach House, Bethany Beach, DE

- A respite home for families with cancer to relax and to spend time away from doctors and hospitals. Any patient undergoing active treatment for cancer (up until he or she has been off active treatment for one year) is eligible to apply for a full week at the beach house.
- Contact: 302-261-2510 or <http://www.justinjennings.org>

◇ Wellness House of Annapolis, Annapolis, MD

- Provides services for anyone affected by cancer (patients, spouses, children, caregivers, and friends). Resources include age-based support groups for children and teens affected by cancer, yoga, therapeutic art, oncology massages, and meditation.
- Contact: 410-990-0941 or <http://www.annapoliswellnesshouse.org/>

Scholarship Funds for Education

◇ Audrey B. Mastroianni College Scholarship

- United Breast Cancer Foundation's College fund for college-bound students of single parent homes affected by breast cancer. Applications must be postmarked by mid-October to be reviewed.
- Contact: 1-8777-UBC-4CURE or <http://www.ubcf.info/college-scholarship/>

◇ Hope Scholarship Fund

- Scholarship fund promoting the educational development of children of breast cancer patients. Email application inquiries to the listed email and include state of residence.
- Contact: 888-470-7909 or <http://www.breastcancersociety.org/programs/hope-scholarship-fund/>

◇ The Komen Scholarship Program

- The Susan Komen Foundation program offers college scholarships to teens that have lost a parent to breast cancer. The application deadline is mid-October.
- Contact: contactus@applyvist.com or <http://ww5.komen.org/researchgrants/collegescholarshipaward.html>

◇ Ulman Cancer Fund for Young Adults Scholarships

- 12 educational scholarships for young adults (15 years or older) that have been diagnosed with cancer or were 15 years or older during the treatment of their parent or sibling. Applicants only need to submit one application to be considered for all that they are eligible for.
- Contact: julie@ulmanfund.org or <http://ulmanfund.org/gethelp/support-programs-resources/scholarships/>

Home Services

◇ American Cancer Society, White Marsh, MD

- Local American Cancer Society office in the Maryland area. It provides a variety of services including a wig room, peer support group, transportation to/from treatment, and Camp Sunshine. Call the local office number or the national number (1-800-227-2345) for the American Cancer Society's Cancer Information Specialists.
- Contact: 410-933-5197 or <http://www.cancer.org/>

◇ American Cancer Society Hope Lodge, Baltimore, MD

- An American Cancer Society program that provides free accommodations for cancer patients and caregivers. The Hope Lodge offers 26 guest rooms, common kitchen area, washers/dryers, transportation (within a 3 mile radius), cancer support programs and services, etc.
- Contact: 410-547-2522 or <http://www.cancer.org/treatment/supportprogramsservices/hopelodge/>

◇ Catastrophic Health Planners, Westminster, MD

- A nonprofit organization dedicated to helping clients through obstacles posed by catastrophic health problems. Services include driving patients to appointments, refinancing mortgages, preparing medical directives and wills, providing patient medical services (CT/MRIs) and medical equipment, identifying eye care and dental providers with reduced rates, filing disability income, assist in the acquisition of a vehicle, counsel patients, provide hay for the patient's livestock, and speaking for the patient.
- Contact: 410-871-0751 or <http://www.chp1.org>

◇ Cleaning for a Reason's Maid Services, MD

- Provides free maid services for patients undergoing treatment of any type of cancer. Maid services are provided based on geographical area. Applications are available online and ask for a physician note confirming treatment.
- Contact: 877-337-3348 or <http://www.cleaningforareason.org/patients>

◇ The Little Things for Cancer, MD

- Funds services that will improve the quality of life for cancer patients and caregivers that live or are being treated in Maryland. Services include prescription payment, complementary therapies, transportation, childcare, meals, co-payments, housecleaning, and entertainment.
- Contact: 443-228-8584 or <http://tlt4c.org/>

◇ **Moveable Feast, MD**

- Provides and delivers nutritious meals or groceries-to-go for individuals (and their families) struggling from a broad range of illnesses including cancer. Services are available for people throughout Maryland.
- Contact: 1-800-556-9417 or <http://www.mfeast.org>

◇ **The Red Devils, MD**

- Funds services that improve the quality of life for breast cancer patients and their families including treatment transportation, housecleaning, meals, family support, and medical services. Patients must be referred by a participating hospital to be eligible for such services.
- Contact: 1-877-643-0202 or <http://www.the-red-devils.org>

◇ **United Breast Cancer Foundation's Domestic Services, MD**

- Supports families and patients managing breast cancer by providing domestic services to help reduce the daily stresses of managing a health household. Services range from house cleaning assistance to grocery shopping services.
- Contact: 1-877-UBC-4CURE or <http://www.ubcf.info/domestic-services/>

Counseling & Family Support

◇ **Claudia Mayer Cancer Resource Center, Columbia, MD**

- A Howard County General Hospital Center is dedicated to providing services and resources to cancer patients and their families. It sponsors a support group for teens dealing with a parent's cancer.
- Contact: 410-740-5858 or <http://www.hcgh.org/cmcrcc>

◇ HopeWell Family Support Program, Lutherville, MD

- This HopeWell Cancer Support group is specifically for family members and significant others of individuals with cancer. These weekly sessions are led by licensed health professionals and provides a support network with a family focus. Sessions promote self-care and offer an opportunity to share techniques on how to deal with the stresses of cancer in the family.
- Contact: 410-832-2719 or <http://www.hopewellcancersupport.org>

◇ Imerman Angels, Nationwide

- A free national service that matches a person affected by cancer with someone who has fought and survived the same type of cancer. Matches are also available for cancer caregivers.
 - <http://www.imermanangels.org/>

◇ Johns Hopkins Medicine Cancer Counseling Center, Baltimore, MD

- Professional counseling available to Hopkins patients, families, and caregivers with regards to psychological, emotional, and spiritual wellbeing. A psychological assessment is made at the initial appointment to identify individuals that may benefit from supportive intervention. Every month, there is a breast cancer patient's support group. For women with metastatic disease, there is a weekly support group. The Cancer Counseling Center also provides one-on-one professional counseling for patients and/or family members.
- Contact: 410-955-1010 or http://www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/support_services_counseling.html

◇ Nueva Vida's Caring for Caregivers Program, Baltimore, MD

- A mental health service for relatives (spouses, partners, and children) of Latina women with any type of cancer. This workshop gives caregivers and family members essential techniques to provide crucial support during cancer treatment. The group meets every fourth Thursday
- Contact: 1-866-986-8432 or <http://nueva-vida.org/support-programs.php?idprogram=2> (En Español también)

◇ **Smith Center for Healing and the Arts, Washington DC**

- A nonprofit health, education, and arts center that promotes healing practices as well as physical, emotional, and mental resources for people affected by a cancer. Programs include yoga and stress reduction, nutrition and cooking, arts workshops, weeklong residential retreats, etc.
- Contact: 202-483-8600 or <http://www.smithcenter.org/>

◇ **The Ulman Cancer Fund for Young Adults, Baltimore, MD**

- A Maryland-based foundation that provides support programs, educational materials, patient navigation services, and a supportive community for young parents with cancer .
- Contact: 1-888-393-3863 or <http://ulmanfund.org/gethelp/>

Other Resources

Web Sites

◇ Caring Bridge

- Free health social network for families coping with illness to connect, share news, and receive support through personalized webpages and communities.
 - <http://www.caringbridge.org/>

◇ KidsCope

- A non-profit that helps children and families understand the effects of cancer and treatment within the family, provides coping suggestions, and creates programs and materials to communicate hope. A DVD and comic-book are available online as resources for children coping with a parent's cancer.
 - <http://www.kidscope.org/index.html>

◇ Kids Konnected's Youth Leadership Training

- A 3-day training program hosted in Southern California. Its purpose is to help Youth Leaders learn basic therapeutic skills (i.e. active listening), answer cancer-related questions, and develop supportive relationships among one another. There will also be moments for self-reflection and development.
 - <http://kidskonnected.org/support-services/>

◇ LIVESTRONG Foundation's Educational Resources

- A compilation of cancer information for the recently diagnosed. Articles include cancer basics, young adults with cancer, facing your fears, life expectancy, fertility preservation, emotions after a cancer diagnosis, telling others about your cancer, and finding/evaluation cancer information.
 - <http://www.livestrong.org/we-can-help/just-diagnosed/>

◇ **National Financial Resource Guide for Patients (Maryland Specific Resources pg. 231)**

- A guide to assist uninsured or underinsured patients on valuable medical resources, including medical debt, insurance access, job retention, children's resources, etc.
 - Contact: 1-800-532-5274 or <http://www.patientadvocate.org/resources.php>

◇ **Survivorship A to Z's Children Resource**

- A database website on the many aspects of support for patients living with cancer. There is a comprehensive section regarding issues related to children while their parent is living with breast cancer.
 - <http://www.survivorshipatoz.org/breastcancer/topics/children-101/>

◇ **Susan G. Komen Resource Guide - Maryland**

- A compilation of information gathered by the Maryland branch of Susan G. Komen to assist women with breast cancer in navigating the local available resources.
 - Contact: 410-938-8990 or <http://www.komenmd.org>

◇ **University of Cincinnati's Health Library: Cancer**

- A resource for parents with cancer on how to explain their diagnosis to their children by the University of Cincinnati Health Library. The site also provides tips and advice on how to answer children's questions regarding cancer.
 - <http://healthadministration.uc.edu/news-and-resources/articles/health-library-cancer>

Books for Children

- *Because Someone I Love Has Cancer: Kids' Activity Book* by American Cancer Society
- *Butterfly Kisses and Wishes on Wings* by Ellen McVicker
- *Hair for Mama* by Kelly Tinkham
- *My Parent Has Cancer and it Really Sucks: Real-Life Advice from Real-Life Teens* by Marc and Maya Silver
- *Our Dad is Getting Better* by Alex, Emily, and Anna Rose Silver
- *Our Mom Has Cancer* by Abigail and Adrienne Ackermann
- *Punk Wig* by Lori Ries
- *Sammy's Mommy Has Cancer* by Sherry Kolenberg
- *The Year My Mother Was Bald* by Ann Speltz

Books for Parents

- *Cancer in the Family: Helping Children Cope with a Parent's Illness* by Sue Heiney
- *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* by Maggie Callanan and Patricia Kelley
- *Helping Your Children Cope with Your Cancer* by Peter van Dernoort
- *How to Help Children Through a Parent's Serious Illness* by Kathleen McCue and Ron Bonn
- *My Parent Has Cancer and it Really Sucks: Real-Life Advice from Real-Life Teens* by Marc and Maya Silver
- *Raising an Emotionally Healthy Child When a Parent Is Sick: A Harvard Medical School Book* by Paula Rauch and Anna Muriel
- *Walking on Eggshells* by Amy Sales
- *When a Parent Has Cancer: A Guide to Caring for Your Children* by Wendy Schlessel Harpham

Appendix: For Parents with Cancer

General Tips

1. Keep yourself [healthy](#) so you can best help yourself and your family; do things to de-stress!
2. Join a [support group](#) or seek out online forums. There are many people in the same situation as you.
3. Be willing to [accept help](#) from others when they offer. You and your family don't have to be in this alone.
4. [Communicate](#) with your family about what is happening. Young and old, everyone plays a role in helping make things easier for the family and supporting you through your cancer treatment.
5. [File medical information and legal documents](#) so that they are easy to access when needed.
6. Look into [financial resources](#) to help you if you need them. It will be less stressful for you to do this before treatment begins.
7. Keep your mind open to [clinical trials](#) that could help you.

Maintain a Patient File

Create a file for yourself covering all medical information. Whether its paper or electronic, keep the file updated and handy. The [LIVESTRONG iPad App](#) is a useful tool for electronically storing all your medical information in a single location. The Caregiver Action Network has a list of what should be placed in this file. Feel free to add other documents to the file as you see fit, and make it your own:

◇ Your medical history

- Diagnosis
- Physician, care coordinator, and support staff contact information
- Allergies
- Health history (e.g. surgeries, other medical conditions)

◇ Medication List

◇ Insurance Information

- Medical insurance
- Prescription plan
- Medicare/Medicaid
- Long-term care insurance
- Dental and vision insurance

◇ Legal Documents

- Living will
- Durable Power of Attorney for health care
- Power of attorney for finances
- Contact information for your lawyer

Have this file ready for visits with a new physician and in case of emergencies.

Doctor Visits

1. Prep Before Each Visit

- Make sure your patient file and medicine record are up-to-date. You will want to bring these along with you to the doctor visits.
- Write down current symptoms you are experiencing.
- Write down your questions and concerns for the doctor.
- Confirm your appointment before attending.

2. During Visits

- Hand the doctor the updated medication list and patient file.
- Mention the symptoms you wrote down to prepare for the visit.
- Ask your questions, mention your concerns, and write down what the doctor says so you can refer back to it later if you'd like.
- Make note of the doctor's instructions and recommendations. Don't be afraid to ask questions if you have some in mind.
- Understand the follow-up process: when will the office be contacting you, when will the medication be ready for pick up, and when you should call in if you have not heard back from the doctor.

3. Wrapping Up

- Review the notes you took during the visit and add them to your patient file.
- Discuss the visit with your family. Make sure they're kept in the loop with what is happening and your progress. You're all in this together.
- Pick up any medication prescribed during or immediately after the appointment.
- Add upcoming doctor visits to your calendar if follow-up visits were scheduled.
- Get in touch with the doctor's office about your next visits (if not previously discussed), test results, or anything else you are waiting for.

Tracking Medications

When you have cancer, there can be various medications to keep track of along with dosage information and when to take them. It can be a bit overwhelming at first for those of us who have only had to balance one or two at a time. “Good health outcomes are 3 times less likely for patients who do not take medications correctly as compared to those that do. Improper use of medications causes 18 million emergency room visits per year.” Being organized and keeping medical information easily accessible, in case of emergency, can help to avoid this. These next steps show you how to organize and manage your medicine schedule. It is important to keep track of the medications you have and have not taken.

1. Keep a [medication list](#). Include all medications prescribed by doctors, over-the-counter medications and any other supplements used currently or that have been used previously. Record notes on whether they have been successful, your reaction to the medicine (if it was a positive or negative experience and specifically what the reaction was), and details of the medication such as the directions you were given for taking it (dosage, time period and frequency of use, and the purpose of that medication-- what was it for?)
2. Note any known [allergies](#).
3. List [emergency contact information](#).
4. [Make copies](#) for the patient file and the primary care doctor.
5. [Ask questions](#) when the doctor prescribes a new medication to ensure you know [what](#) the medicine is for and the [purpose](#) of taking it (will be added to the medication list). Also ask about the [expected side effects](#) and [drug interactions](#) to avoid.

6. If possible, [use the same pharmacy](#) for all prescriptions. If there is an emergency, they will have a record of all medications used past and present. Check to see if your pharmacy has an auto-refill program.
7. Find an easy method to manage medications, such as [pill boxes or medicine charts](#).
8. [Properly dispose of unused medications](#). Recommended steps are to crush or dilute the medicine. Put it in a plastic bag and add a material such as sawdust, cat litter or coffee grounds to the bag before sealing and placing it in the trash.

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