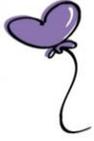




For Parents and Caregivers of Children with Cancer



Childhood Leukemia Foundation

Keeping Kids Connected Program

Dear Childhood Leukemia Foundation,

I cannot thank you enough for the gift of an iPad you gave to Abby Grace. Right after she got it she was admitted to the hospital for complications from chemo and it helped a TON with distraction and was a sound machine for noise so she could rest comfortably. Then we have had numerous inpatient chemotherapy treatments where she had to sit still. Today, I am once again reminded how thankful we are for this iPad as she completes puzzles, learns numbers and watches movies. I feel thanks is not enough but please know you have our sincere gratitude.

Love,

Abby's Mom



The information presented in this publication is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

Childhood Leukemia Foundation Program Services

Childhood Leukemia Foundation's services are free of charge and available to children under age 21 diagnosed with any type of cancer. All requests can be processed with the help of your social worker or child life specialist by visiting our website www.clf4kids.org

Here is a description of Childhood Leukemia Foundation's current programs...



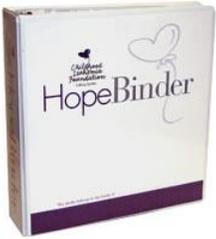
Hugs u Wear

One of the biggest obstacles to overcome is the loss of hair. Having to look different and worrying about fitting in should not be a part of the cancer battle. Childhood Leukemia Foundation provides thousands of custom made, 100% human hair wigs with detachable kid-friendly hats to children around the country. Limit one per child.



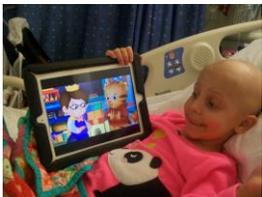
Wish Baskets

Everyone loves to receive a gift, especially a surprise package and young cancer patients are no exception. After receiving a grueling chemotherapy treatment or spinal tap, Childhood Leukemia Foundation offers Wish Baskets to "Lift the Spirits" of these very deserving children. The baskets are filled with age appropriate items and a \$75 Gift Card to purchase another wish item of their choice. Limit one per child.



Hope Binder

After the initial diagnosis of cancer is made, parents and care-givers are not equipped to handle and process the overwhelming amount of information related to their child's care. A Hope Binder documents a child's treatment and helps you keep track of treatment protocols, medicines, doctor's appointments, blood counts, physicians' names, hospitals, nutrition concerns, and insurance benefits, in a simple step by step layout. This binder helps restore a sense of control in a situation that is out of control.



Keeping Kids Connected

Childhood Leukemia Foundation's "Keeping Kids Connected" program was created to help young cancer patients stay connected to family, friends and school while actively receiving treatment. Laptops and iPads are successful tools that can be used to divert the child's attention during stressful and painful procedures. Hospitals and pediatric oncology patients are eligible to apply for an iPad or laptop gift.

Please contact Childhood Leukemia Foundation to learn more about the program eligibility and requirements.



"Can We Talk?"

Tips for Communicating with Your Health Care Professionals

Talking to your doctor can be difficult.

Confusing medical terminology can leave you feeling frightened and overwhelmed. Good communication with health professionals will help develop your level of understanding, and improve the quality and efficiencies in your child's healthcare.

Here are some tips:

Remember you are your child's healthcare advocate. As a parent/caregiver, it is important to know the best way to begin making difficult decisions is to educate yourself. This can be an overwhelming task, but ask questions and when you understand you will gain confidence in making necessary decisions.

Bring someone with you to your appointments. It is always helpful to have support, and having another person with you that can serve as a second set of ears. He or she may also be able to think of questions to ask your doctor, or remember details about symptoms you may have forgotten.

Prepare a list of questions beforehand. This way, you won't forget to ask about something that was important to you. Make your questions specific and brief because your doctor has limited time. Once you're at your appointment, ask your most important questions first.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses and instructions. It also allows you to go over the information later when you have more time to concentrate or do research.

If possible, tape-record your visit. Taping your conversation gives you a chance to hear specific information again, or share it with family members or friends.

Here are some questions to ask your health professionals regarding your child's treatment and follow-ups:

- What are our treatment options?
- What is the recommended treatment?
- How often is the treatment?
- What are the possible side effects?
- What are the possible benefits and risks of this treatment?
- How much will my treatment cost?
- If I have questions during my treatment and my doctor is not available, who can I ask? For example, is a nurse, social worker, or other specialist available?
- Is there any information I can read about this treatment or procedure?
- Is there anything else I should know?

HELPFUL TALKING HINTS

With planning and practice, most parents find they are able to talk to their kids about cancer. Sometimes it is hard and may not go exactly to plan, but the important thing is that you give it a go. Here are eight ways to help your kids cope with cancer and keep family communication channels open.

1 COMMUNICATE A LOT

At first it's difficult to know what to tell your children about cancer. Talking about it is not a one-off event; it's an unfolding story. Your kids need regular updates and to know they can talk to you at any time. Most parents know when their kids are more likely to open up. Try to tap into those times and be creative in finding creative ways to talk.

2 DON'T EXPECT TO BE PERFECT

Talking about cancer can be can be confronting and upsetting. It can be tricky to talk to kids, and you may feel you've made a mess of it. Don't panic. Kids will cope if a conversation doesn't go to plan. Take time to work out what you might do differently next time.

3 FIND OUT WHAT YOUR KIDS KNOW

It may be helpful to start with questions to find out your kids' level of understanding about cancer and where they've obtained their information from. This will help you clear up any of their misunderstandings and gauge how much to tell them.

4 LET YOUR KIDS ASK QUESTIONS

Try not to overload children with too many details. Give small amounts of information, wait and then ask if they have any questions. If they don't, leave it at that. They may ask questions later. Show your appreciation by saying something like "You have great questions".

5 BE HONEST AND MAINTAIN TRUST

You can't protect your children by avoiding the truth. Once you've established good communication about cancer, keep being open, even if the news isn't good. It's ok to say you don't have all of the answers. Make it clear that nothing the kids have said or done caused the cancer, and nothing they do can affect the outcome.

6 SHOW YOUR LOVE AND EMOTION

Let your children know that you love them. Assure that they will always be looked after, even if you can't always do it yourself. Don't be afraid to express your feelings or cry. This lets kids know it's okay to be emotional, and that you don't always know what to do or say.

7 PRESERVE FAMILY TIME AND ROUTINES

You may have many visitors or helpers, which is great, but don't let them take over. Try to set aside time for the whole family and for each of your kids. Continue normal routines as much as you can, and welcome the kids efforts to help at home but don't take it for granted.

8 LISTEN TO YOUR KIDS

Stop and listen to your children so you know how they really feel. Encourage them to tell you if they feel upset, and why. Let them know they don't have to worry alone. Talk about your kid's own activities as well, and make sure they know it's still ok to have fun.



YOU ARE THE ADVOCATE FOR YOUR CHILD

For any parent hearing the words "your child has cancer", life has changed forever. These life altering words are the beginning of an unknown and frightening journey for your family. Understanding complicated medical terminology, and taking the appropriate follow up action after procedures is daunting. The following tips are intended to empower your child's healthcare advocate and ease your burden of feeling overwhelmed. Remember KNOWLEDGE is power!

1. Learn everything you can about your child's diagnosis. Talk to your doctors, social workers, and other parents. Look up the diagnosis on the internet. If you lack a computer or can't use one, ask another parent, a teacher, or a teenager for help. In every community such as the public library, as well as within the hospital, computers are available with free internet access. The internet is a wealth of information for locating resources such as financial aid, free services, and important information regarding treatments.
2. Keep records of all phone calls, doctor visits, insurance bills, notices, and forms related to your child. Always take notes, including the date and person you spoke with. If you're not a good note taker, ask a friend or family member for help. Request copies of everything. Utilize the Hope Binder to organize all of this important information.
3. Become very familiar with your child's health insurance plan, whether private or Medicaid. Know the benefits covered. Read everything from your insurance company, managed care plan, or Medicaid.
4. Develop strong partnerships with the professionals in your child's life. Your knowledge about your child will help the health professionals practice family-centered care. Find one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.
5. Know that **YOU** are your child's best advocate. No one else can do the job as well. Use all your information, contacts, friends and skills to advocate with kindness and humor. Teach your child to be an advocate, or prepare a sibling or friend to do so whenever you are not able to be around and **NEVER** forget to take care of **YOU**, so that **YOU** remain healthy and strong.
6. As time goes by, you will become more experienced and confident with your knowledge. Be willing to share information to help another family. Although everyone's experience is different, the bond you can share with other between parents of having a child diagnosed with cancer is a journey you both share. Parent support groups can help you gain perspective, hope and information.
7. Be honest with your child. Children are very observant and no matter how hard you try you will not be able to keep them from knowing they have cancer. Allow them to talk to you and ask questions. This is journey you will be on together, let your child know you have their back and together you're a team that's going to **WIN!**



Strengthening the Spirit

Life changes in many ways when you or a loved one is diagnosed with cancer. You might find yourself turning to your spiritual side more often to help you to cope. Or, you may begin to question your faith. Both of these reactions are normal as you try to re-orient your life during a time of crisis.

How a Sense of Spirituality Can Help

A sense of meaning, purpose, and a connection beyond yourself can help you to have a better quality of life during cancer. Some studies show that people with cancer have less anxiety, depression and pain when they feel spiritually connected.

Spirituality can also help you to put your problems in perspective. Practices such as prayer, meditation and worship can help you to calm and restore yourself. Many people also find the support of other members of spiritual communities to be a great source of practical and emotional help.

Take time regularly to meditate or pray. This can bring a sense of calm and stability during difficult times.

Read spiritual writings. These can include the Bible, Torah, Koran or other faith-based texts. Delving into sacred texts can put you in touch with ancient traditions of wisdom and give you a sense of connection with a more divine reality. Recently published books on spirituality can also give new insights.

Retreat to spiritual spaces, natural settings, or concerts and museums. Visiting such places may help you cultivate a sense of peace. **Keep a journal to express your feelings, thoughts and memories.** This can contribute to your process of self-discovery and development. A diagnosis of cancer can start a process of looking inward for a stronger connection to what is most meaningful and sacred. Out of the turmoil of this crisis, you can find strength and deeper meaning in your life.

Discovering Your Spiritual Dimension - Whether or not you enter a church, synagogue, mosque, or temple, you are a spiritual person. Everyone holds certain beliefs and values about what makes life worthwhile, and many people have experienced moments when they have felt connected to a deeper meaning or reality. Spiritual moments can happen at any time — for example, when you feel close to nature, look into the face of a loved one, enter a house of worship, or sense a greater power.



Children with cancer have different dietary needs...

When a child is battling cancer eating can sometimes present a real challenge. Eating the right foods before, during, and after treatment can help a child feel better and stay stronger. Children with cancer need protein, carbohydrates, fat, water, vitamins, and minerals.

- **Proteins** - The body uses protein to grow; repair tissue and to maintain the skin, blood cells, the immune system, and the lining of the digestive tract. Children with cancer who do not get enough protein might break down muscle for the fuel their bodies need. This can make it take longer to recover from illness and can lower resistance to infection.
- **Carbohydrates** – They are a major source of the body’s energy. Carbohydrates give the body the fuel (calories) it needs for physical activity and proper organ function. Children being treated for cancer may need even more calories for tissue healing and energy.
- **Fat** - Fats play an important role in nutrition. Fats and oils are made of fatty acids and serve as a rich source of energy (calories) for the body. The body breaks down fats and uses them to store energy, insulate body tissues, and carry some types of vitamins through the blood.
- **Water** - All body cells need water to function. If your child does not take in enough fluids or loses fluids from vomiting or diarrhea, he may become dehydrated. Keep in mind that all liquids (soups, milk, even ice cream and gelatin) count toward your child’s fluid goals.
- **Vitamins & Minerals** - The body needs small amounts of vitamins and minerals for normal growth and development. It may be hard for a child in cancer treatment to eat a balanced diet because they are suffering from treatment side effects, such as nausea and vomiting. If your child has eating problems, ask your doctor, nurse, or dietitian for help.

Ask your doctor or nurse to refer you to a dietitian

A dietitian is the best person to talk with about your child’s diet. The dietitian can help choose foods and drinks that are best during treatment and after. If your child is already on a special diet it is even more important to speak a dietitian. Your doctor and dietitian can advise you how to follow a special diet while coping with eating problems caused by cancer treatment.



What You Should Know About Treating Cancer Pain

People who have cancer don't always have pain. Everyone is different. But if you do have cancer pain, you should know that you don't have to accept it. Cancer pain can almost always be relieved.

The key messages we want you to learn are:

- Your pain **can** be managed.
- Controlling pain **is part** of your cancer treatment.
- Talking openly with your doctor and health care team will help them manage your pain.
- The best way to control pain is to stop it from starting or keep it from getting worse.
- There are many different medicines to control pain. Everyone's pain control plan is different.
- Keeping a record of your pain will help create the best pain control plan for you.
- People who take cancer pain medicines as prescribed rarely become addicted to them.
- Your body does **not** become immune to pain medicine. Stronger medicines should not be saved for "later."

Palliative care and pain specialists can help.

Cancer pain can be reduced so that you can enjoy your normal routines and sleep better. It may help to talk with a palliative care or pain specialist. These may be oncologists, anesthesiologists, neurologists, surgeons, other doctors, nurses, or pharmacists. If you have a pain control team, it may also include psychologists and social workers.

Pain and palliative care specialists are experts in pain control. Palliative care specialists treat the symptoms, side effects, and emotional problems of both cancer and its treatment. They will work with you to find the best way to manage your pain. Ask your doctor or nurse to suggest someone. Or contact one of the following for help finding a specialist in your area:

- Cancer center
- Your local hospital or medical center
- Your primary care provider
- People who belong to pain support groups in your area
- The Center to Advance Palliative Care, www.getpalliativecare.org
(for lists of providers in each state)

** The information provided above is directly referenced from the National Cancer Institute's publication – Pain Control support for people with cancer.*



Art Therapy

Art therapy allows children use their creative process to explore their feelings, reconcile emotional conflicts, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem. Today, art therapy is widely practiced in many hospitals as a part of regular treatment schedules. Art therapy includes drawing, painting, sculpting and other art forms.

How “Art Therapy” differs from an average art class

Most art therapy sessions focus on personal experience, feelings, perceptions, and imagination. While art therapy may involve learning skills or art techniques, the emphasis is generally first on developing and expressing images that come from within the person. In addition, art therapy provides a wonderful distraction from boredom and lengthy hospital stays.

What is an Art Therapist?

Art therapists are professionals trained in both art and therapy. They use art in treatment, assessment and research, and provide consultations to allied professionals. Art therapists work with people of all ages: individuals, couples, families, groups and communities. They provide services, individually and as part of clinical teams, in settings that include mental health, rehabilitation, medical and forensic institutions; community outreach programs; wellness centers; schools; nursing homes; corporate structures; open studios and independent practices.

Make Art & Crafts a family affair

Parents, siblings and friends can spend time together creating individual masterpieces. Through art and play, children can talk about their problems by using their creativity and imagination. In a relaxed atmosphere children can learn to cope with overwhelming and painful feelings. With the love and support of their family and friends, children can develop perspectives to improve their outlook and emotional wellbeing.

For more information about Art Therapy talk to the child life specialist at your hospital.





Siblings

You've just learned that your brother or sister has cancer. You are probably experiencing a lot of different emotions including, shock, confusion, fear, loneliness and anger. To help you understand the situation better the best thing you can do is learn a little about your brother's or sister's cancer treatment. This may help you feel less afraid when you know what to expect. Right now it might seem like no one else in the world feels the way you do. In a way you're right. No one can feel exactly like you do.

Here are some very important things to know:

- ❖ Nothing you did, thought, or said caused your brother or sister to get cancer.
- ❖ You can't catch cancer from another person.
- ❖ Scientists are finding many new, and better ways to find and treat cancer.
- ❖ You're not alone. It might help to talk to other kids who have a brother or sister with cancer. Many hospitals have sibling support groups.

What Your Brother or Sister May Be Feeling

Just like everyone else, your brother or sister may be worried, scared, or confused. They may also feel tired and sick because of the treatment. Some kids feel embarrassed because treatment has changed the way they look and feel. You both may be having a lot of the same feelings. Knowing how your brother or sister feels can help you figure out how to help, or try to understand what they might be going through. Be there for each other and try to comfort one another. Laughing, smiling or just being silly is the best medicine in the world.

Everything changed with cancer

Once your brother or sister was diagnosed with cancer, everything in your family changed instantly. You may be the oldest, youngest, or middle child in your family. You may live with one parent or two. Whatever your family situation, you need to talk to the adults in your life, ask questions and even ask for a hug if that's what you need. Yes your brother or sister is sick, but never forget **You Still Matter** and your family loves you too.

Super Sibs is an organization dedicated to helping siblings of children with cancer.

Visit them at www.supersibs.org or call 847-462-4742

Free booklets are available from the National Cancer Institute (NCI). To learn more about cancer or to request other booklets, visit NCI's Web site (www.cancer.gov) or call NCI's Cancer Information Service at 800 4 CANCEER to talk with an information specialist.



Life after cancer

Once treatment is over, cancer survivors cope with their new life in different ways. While some prefer to put their experiences behind them, others choose to draw on them, and get involved by helping others. This is a personal choice and you need to take charge of your life again and live it however you want!

What Now?

For many families, life changed when the word “cancer” entered their lives. Now that your child has completed their treatments there is a sense of cautious happiness. For months or years your lives have been consumed by doctors, hospitals, treatments and fear, and now that it’s over you want to resume a normal life. Everything you're feeling is normal. So take time to acknowledge your feelings, and then take steps to understand your emotions and what you can do to reconcile with them.

Fear of recurrence

Fear of recurrence is very common. Even if many years go without a sign of disease, cancer survivors say the thought of recurrence is always with them. You might worry that every ache or pain is a sign of your cancer recurring. Eventually, these fears will lessen but they may never go away completely. Cope with your fear by being honest with yourself about your feelings. Try not to feel guilty about your feelings or ignore them, in hopes that they'll go away. Ask your doctor about what you can do to reduce your chance of a cancer recurrence. Once you've done all you can to reduce that risk, acknowledge your fears. Take control, and do what you can to influence your future health.

- **Take care of your body.** Eat a healthy diet with plenty of fruits and vegetables. Fit exercise into your day. Go easy at first, but try to increase the intensity and amount of exercise you get as you recover. Get enough sleep so that you wake feeling refreshed. These actions may help your body recover from cancer treatment, and also help put your mind at ease by giving you a greater sense of control over your life.
- **Go to all your follow-up appointments.** You may fear the worst when it's time for your next follow-up appointment. Don't let that stop you from going. Use the time with your doctor to ask questions about any signs or symptoms that worry you. Write down your concerns and discuss them at your next appointment. Knowing more may help you feel more in control.

Live - Laugh - Love
EVERY MOMENT EVERY DAY BEYOND WORDS

General information

American Cancer Society
800-227-2345
www.cancer.org

The Leukemia & Lymphoma Society's
Co-Pay Assistance Program
877-557-2672
www.lls.org/copay

National Cancer Institute
www.cancer.gov

Cancer Care
800-813-HOPE (4673)
www.cancercare.org

Cancer.Net
888-651-3038
www.cancer.net

Social Security
800-772-1213
www.ssa.gov

Cure Search
800-458-6223
www.curesearch.org

Children's Cancer Association
503 244-3141
www.joyrx.org

Candlelighters
713- 270-4700
www.candle.org

Parents/Caregivers Support Networks

Cancer Hope Network
800-552-4366
www.cancerhopenetwork.org

Alex's Lemonade Stand
Parent to Parent
610-649-3034
www.alexlemonade.org/parent-parent-network

Momcology
www.momcology.org

Brave Kids
800-872-5827
<http://www.bravekids.org>

OncoChat
www.oncochat.org

Cancer Support Community
888-793-9355
www.cancersupportcommunity.org

Financial Aid

Special Love, Inc.
888-930-2707
www.speciallove.org/financial-assistance

Cancer Care
800-813-HOPE (4673)
www.cancercare.org

Cancer Survivors Fund
281-437-7142
www.cancersurvivorsfund.org

Children's Cancer Association
503 244-3141
www.joyrx.org

Good Days
Chronic Disease Fund
877-968-7233
www.gooddaysfromcdf.org

National Children's Cancer Society
314-241-1600
www.thenccs.org

Children's Organ Transplant Assoc.
800-366-2682
www.cota.org

Children's Cancer Association
503 244-3141
www.joyrx.org

****Always check with local organizations in your community such as;** Elks, VFW, Kiwanis, Jr. Women's League, American Legion and Knights of Columbus

Sibling Support

National Cancer Institute
www.cancer.gov/Publications/patient-education/sibling-has-cancer

Alex's Lemonade Stand
Super Sibs
610-649-3034
www.alexlemonade.org/campaign/supersibs

Brave Kids
800-872-5827
www.bravekids.org

OncoChat
www.oncochat.org

Cancer Support Community
888-793-9355
www.cancersupportcommunity.org

Children's Cancer Association
503 244-3141
www.joyrx.org

Prescription Assistance

Patient Advocate Foundation
Co--Pay Relief Program
1-866-512-3861
www.copays.org

Cancer Care Co-Payment
Assistance Foundation
1-866-55-COPAY
www.cancercarecopay.org

Partnership for Prescription Assistance
888-4-PPA-NOW
888-477-2669
www.pparx.org

Chronic Disease Fund
877-968-7233
www.gooddaysfromcdf.org

The Leukemia & Lymphoma Society's
Co-Pay Assistance Program
877-557-2672
www.lls.org/copay

Children's Cancer Association
503 244-3141
www.joyrx.org

Transportation and Lodging

Angel Flight, Inc.
918-749-8992
www.angelflight.com

Make a Wish Foundation
80-722-9474
www.wish.org

Patient Airlift Services
631-694-PALS (7257)
www.palservices.org

Corporate Angel Network
914-328-1313
www.corpangelnetwork.org

Ground Transportation

American Cancer Society
800-227-2345
www.cancer.org

Cancer Care
800-813-HOPE (4673)
www.cancercare.org

Children's Hospice International
703-684-0330
www.chionline.org

Lodging

Ronald McDonald House
630-623-7048
www.rmhc.org

Joe's House
877-563-7468
www.joeshouse.org

Believe in Tomorrow
800-933-5470
www.believeintomorrow.org

Children's Cancer Association
503 244-3141
www.joyrx.org

Hope Lodges
American Cancer Society
800-227-2345
www.cancer.org/docroot/subsite/hopelodge/index.asp

Home Care

Pediatric Home Healthcare
770-441-1580
www.psahealthcare.com

Visiting Nurses Association
888-866-8773
www.vnaa.org

Caregiver.com
800-829-2734
www.caregiver.com

Hospice Foundation of America
800-854-3402
www.hospicefoundation.org

Greif and Bereavement Support

Cure Search
800-458-6223
www.curesearch.org

Baby Steps
905-707-1030
www.babysteps.org

Bereaved Parents of the USA
708-748-7866
www.bereavedparentsusa.org

Grieving Children
267- 437-3123
www.grievingchildren.org/grief-resources

Candlelighters
713- 270-4700
www.candle.org

Children's Cancer Association
503 244-3141
www.joyrx.org