

# *Holding on to Hope*

## **A Family's Handbook for Childhood Cancer Support**



# Navigating the Journey

## A Guide for Families Facing Childhood Cancer

The journey of caring for a child with cancer is often overwhelming, and filled with emotional, physical, and financial challenges. In times like these, having access to the right resources can make all the difference. These resources provide not only practical support such as financial assistance, medical guidance, and travel help but also emotional comfort, helping you feel less alone during a time when you need it most. The right resources can ease some of the burdens you face, allowing you to focus more on what matters most: your child's care, well-being, and future. Whether it's securing financial aid to cover mounting medical bills or finding a community of people who understand your experience, these resources are invaluable tools that can offer hope, healing, and a sense of relief. This guide is designed to help you navigate through this difficult time, empowering you with the knowledge and support needed to ease your journey. You don't have to face this alone help is available, and some people care and are ready to help every step of the way.



## "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 efficiency of 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 follow-ups:  
**your child's treatment and**

- 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?



# Strengthening Your Spirit

Caring for a child with cancer is an emotional and life-altering journey. It can challenge your beliefs or deepen your spiritual connection. Whether you find comfort in faith, nature, or personal reflection, nurturing your spirit can help you cope with stress, uncertainty, and exhaustion.

## How Spirituality Can Support You

### ***A strong spiritual foundation can:***

- Provide emotional strength and resilience.
- Reduce feelings of anxiety, depression, and isolation.
- Offer perspective and hope in difficult times.
- Connect you with a supportive community of faith or like-minded individuals.

### ***Ways to Nurture Your Spirit:***

- **Take Time for Reflection:** Daily prayer, meditation, or quiet contemplation can bring peace and clarity.
- **Seek Inspiration:** Read spiritual or uplifting texts, journal your thoughts, or listen to comforting music.
- **Find Strength in Community:** Attend worship services, join a support group, or connect with others who share your beliefs.
- **Embrace Nature and the Arts:** Walk in a peaceful setting, visit places of beauty, or find comfort in music and art.
- **Express Your Emotions:** Talking to a trusted friend, counselor, or faith leader can provide reassurance and guidance.
- **Discovering Meaning in the Journey**
- Spiritual moments can happen anywhere—watching a sunset, holding your child's hand, or hearing a kind word from a stranger.

Even in hardship, you can find moments of grace, strength, and deepened purpose. Whatever your beliefs, nurturing your spiritual well-being will help you navigate this journey with greater resilience and hope.



# How to Advocate for Your Child with Cancer

As a parent, you are your child's strongest voice. Navigating their cancer diagnosis can be overwhelming, but advocating for their needs ensures they receive the best possible care. Here's how you can be an effective advocate:

1. **Educate Yourself**- Learn about your child's diagnosis, treatment options, and potential side effects. Ask doctors, nurses, and social workers for clear explanations.

Research credible sources and connect with other parents for insight.

2. **Communicate Clearly with the Medical Team** -Take notes during appointments and ask questions until you understand.

Keep a record of symptoms, side effects, and concerns to share with doctors.

Build a strong relationship with a key medical contact, such as an oncologist or nurse navigator.

3. **Stay Organized** - Keep track of medical records, test results, and treatment plans in a binder or digital document. Log all conversations with healthcare providers, including dates and key details. Understand your insurance coverage and financial assistance options.

4. **Speak Up and Be Persistent** something doesn't feel right, trust your instincts and push for answers. Seek second opinions if necessary—advocating for the best care is your right.

Ensure your child's comfort by addressing pain management, emotional support, and accommodations for school or daily activities.

5. **Involve Your Child in Their Care**- Encourage them to ask questions and express their feelings. Provide age-appropriate explanations to help them understand their treatment. Empower them to make small choices where possible, fostering a sense of control.

6. **Lean on Your Support System** - Connect with other families facing childhood cancer for shared experiences and advice. Accept help from friends, family, and community resources—advocacy is easier with support. Consider joining a parent support group or seeking guidance from a counselor.

7. **Take Care of Yourself** -You can't be an effective advocate if you're exhausted prioritize rest and self-care. Set boundaries, take breaks, and ask for help when needed. Seek emotional support through therapy, journaling, or talking with trusted loved ones.

Being an advocate means ensuring your child's voice is heard, their needs are met, and their well-being is prioritized. Stay informed, speak up, and know that your dedication makes all the difference. ❤️

# 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.

Good nutrition supports a child's strength, immune system, and recovery during cancer treatment. Here's what to focus on:

## 1. Prioritize Protein & Calories

Helps maintain weight and muscle strength.

Sources: Eggs, dairy, lean meats, fish, beans, nut butter, and tofu.

## 2. Manage Treatment Side Effects

Nausea/Vomiting: Small, bland meals, ginger tea, and staying hydrated.

Mouth Sores: Soft foods like yogurt, mashed potatoes, and smoothies.

Taste Changes: Experiment with different flavors and food temperatures.

Weight Loss: High-calorie, high-protein foods, including nutritional shakes.

## 3. Stay Hydrated

Water, broth, electrolyte drinks, and fruit juices help prevent dehydration.

## 4. Encourage Fruits & Vegetables

Provide vitamins, minerals, and antioxidants.

Cook or blend if raw veggies are hard to eat.

## 5. Choose Healthy Fats

Avocados, nuts, seeds, and olive oil add energy and support overall health.

## 6. Follow Food Safety Precautions

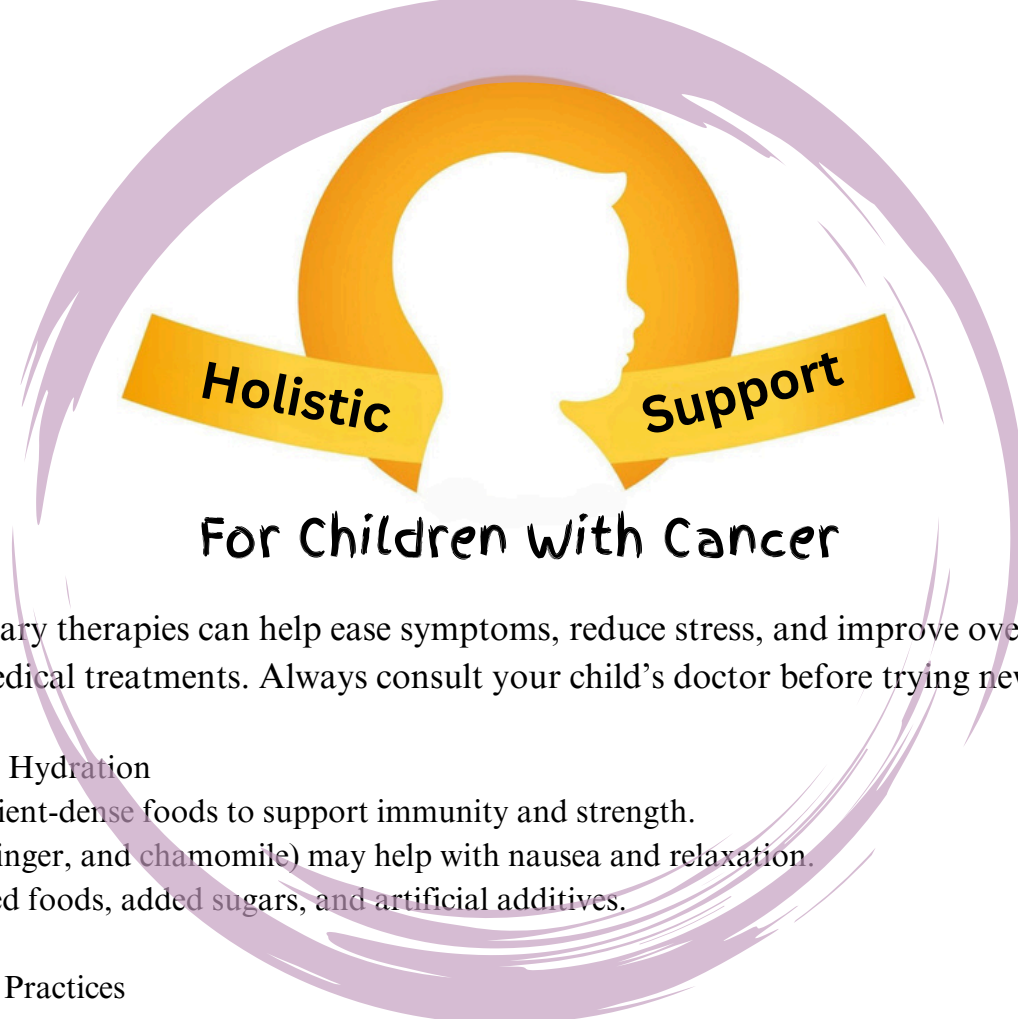
Avoid raw or undercooked foods to reduce infection risk.

Wash fruits and vegetables thoroughly.

## 7. Consider Supplements If Needed

***Consult a doctor before using vitamins or nutritional supplements.***

Every child's needs are unique—work with a healthcare provider or dietitian to create a personalized plan. ❤️



**Holistic**

**Support**

## For Children With Cancer

Complementary therapies can help ease symptoms, reduce stress, and improve overall well-being alongside medical treatments. Always consult your child's doctor before trying new approaches.

### 1. Nutrition & Hydration

Focus on nutrient-dense foods to support immunity and strength.

Herbal teas (ginger, and chamomile) may help with nausea and relaxation.

Limit processed foods, added sugars, and artificial additives.

### 2. Mind-Body Practices

Meditation & Deep Breathing: Helps with anxiety, pain, and sleep.

Guided Imagery: Encourages relaxation through storytelling or visualization.

Gentle Yoga & Stretching: Supports mobility and stress relief.

### 3. Acupuncture & Acupressure

May help with pain, nausea, and energy balance.

Always seek a practitioner experienced in pediatric care.

### 4. Massage & Therapeutic Touch

Light, child-friendly massage can ease pain, anxiety, and fatigue.

Reiki or energy healing may provide additional comfort.

### 5. Nutritionally-based treatment system

Gerson Therapy is a nutritionally-based treatment that involves a specialized diet, raw juices, coffee enemas, and natural supplements to activate the body's ability to heal itself.

### 6. Music & Art Therapy

Creative outlets can reduce stress, lift mood, and provide distraction during treatment.

### 7. Nature & Pet Therapy

Time outdoors or interaction with animals can boost emotional well-being.

Holistic approaches should complement, not replace, medical treatment. Work with your child's healthcare team to find safe and supportive therapies. ❤️



# Art Therapy

Art therapy allows children to 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.

## 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.





## *When Your Brother or Sister Has Cancer*



**Finding out that your sibling has cancer can be overwhelming. You may feel shocked, confused, scared, lonely, or even angry. All of these emotions are completely normal. While it may seem like no one else understands what you're going through, you are not alone.**

**One of the best ways to cope is to learn about your sibling's cancer and treatment. Understanding what to expect can help ease your fears and make you feel more in control.**

### **Helpful Tips for Coping:**

- ✓ **Ask Questions** – Talk to your parents, doctors, or nurses if you're unsure about what's happening. Knowing more can make things feel less scary.
- ✓ **Share Your Feelings** – It's okay to be upset, frustrated, or even jealous sometimes. Find a trusted friend, family member, or counselor to talk to. Writing in a journal can also help.
- ✓ **Take Breaks for Yourself** – It's okay to still do things you enjoy, like sports, art, or hanging out with friends. You deserve time to have fun and relax.
- ✓ **Be There in Your Own Way** – Whether it's sitting with your sibling, making them laugh, or drawing them a picture, small acts of kindness mean a lot.
- ✓ **Find Support** – You're not alone. Connecting with other siblings of kids with cancer through support groups or online communities can be helpful.

Remember, your feelings matter too. Taking care of yourself helps you be the best support for your sibling and your family. ♥

# HELPFUL TIPS

Talking to your family about cancer can be challenging, but open and honest communication can help everyone cope better. Here are some tips to guide you:

## 1. Be Honest and Age-Appropriate

Use simple, clear language based on your child's age and understanding. Explain what cancer is, how it's treated, and how it may affect daily life. Let them know it's okay to ask questions at any time.

## 2. Reassure and Address Fears

Let your child know cancer is not contagious and it's nobody's fault. If a sibling or parent is sick, reassure them that they are still loved and cared for. Be open about changes they may see, like hair loss, hospital visits, or mood shifts.

## 3. Encourage Questions and Feelings

Allow kids to express their emotions—whether it's sadness, fear, or anger. If they don't feel like talking, offer other outlets like drawing, journaling, or playing. Let them know there are no wrong feelings and that their emotions are valid.

## 4. Keep Communication Ongoing

This isn't a one-time conversation—keep checking in regularly. Encourage children to ask questions whenever they need to. Provide updates in a way that makes them feel informed but not overwhelmed.

## 5. Maintain Routine and Normalcy

Keeping up with school, activities, and family traditions can provide comfort. Let them know it's okay to still have fun and enjoy life.

## 6. Seek Outside Support

Books, support groups, and child life specialists can help children understand cancer. Therapy or counseling can be beneficial for the whole family.

## 7. Remind Them They Are Not Alone

Let your child know they are supported and loved no matter what. Encourage them to talk to other family members, teachers, or friends if they need extra support.

Talking about cancer isn't easy, but keeping the lines of communication open can help your child feel safe, supported, and less afraid. ❤️

# Courage & Care: Essential Support for Kids with Cancer

- *Hope Foundation for Cancer Research*  
Website: <https://hopecancerfoundation.org/>  
Offers emergency financial aid for families affected by cancer.
- *Cancer Financial Assistance Coalition*  
Website: <https://www.cancerfac.org/>  
Provides a searchable database of financial aid programs.
- *Hand in Hand: The Suzanne Renee Leider Memorial Assistance Fund*  
Website: <https://www.cancersupportcommunity.org/>  
Helps with non-medical expenses.
- *National Children's Cancer Society*  
Website: <https://thenccs.org/>  
Delivers financial support, advocacy, and resources for families.
- *Children's Oncology Group*  
Website: <https://www.childrensoncologygroup.org/>  
Supplies resources and information on childhood cancer treatment and support.

## Financial Assistance

- *The B+ Foundation*  
Website: <https://www.bepositive.org/>  
Provides financial aid for medical and household expenses.
- *The Assistance Fund*  
Website: <https://tafcares.org/>  
Covers co-pays, deductibles, and out-of-pocket medical expenses.
- *Pinky Swear Foundation*  
Website: <https://pinkyswear.org/>  
Helps with rent, car payments, and household bills.  
Provides financial assistance for basic needs, including rent, mortgage, utilities, and groceries, for families with children undergoing cancer treatment.
- *Family Reach*  
Website: <https://www.familyreach.org/>  
Services: Offers financial support to cover household expenses, transportation, and medical costs for families affected by childhood cancer.
- *UnitedHealthcare Children's Foundation*  
Website: <https://www.uhccf.org/>  
Services: Provides medical grants for families in need to help pay for child healthcare services not covered by insurance.

- *Kids Cancer Alliance*  
Website: <https://www.kidscanceralliance.org/>  
Services: Offers financial assistance, emotional support, and camp programs for children with cancer and their families.
- *National Pediatric Cancer Foundation*  
Website: <https://nationalpcf.org/>  
Services: Provides funding for pediatric cancer research and supports families through financial grants.
- *Joe Joe Bear Foundation*  
Website: <https://www.joejoebear.org/>  
Services: Provides comfort to children with cancer by donating teddy bears and offering financial assistance to families in need.
- *Leukemia & Lymphoma Society (LLS)*  
Website: <https://www.lls.org/>  
Services: Offers co-pay assistance, travel support, and financial aid for families dealing with blood cancers like leukemia and lymphoma.
- *Alex's Lemonade Stand Foundation*  
Website: <https://www.alexslimonade.org/>  
Services: Provides grants to help families cover travel expenses for treatment and supports child cancer research.
- *Tom Coughlin Jay Fund Foundation*  
Website: <https://tcjayfund.org/>  
Services: Provides financial relief for families, covering expenses such as medical bills, household costs, and transportation.

## Medical & Treatment Assistance

- *Pediatric Oncology Resource Center*  
Website: <http://www.ped-onc.org/financial/>  
Lists organizations aiding with medical treatment payments.
- *HealthWell Foundation*  
Website: <https://www.healthwellfoundation.org/>  
Provides grants to cover medical costs not paid by insurance.
- *Patient Advocate Foundation*  
Website: <https://www.patientadvocate.org/>  
Offers case management for medical bills and insurance challenges.
- *Ronald McDonald House Charities*  
Website: <https://www.rmhc.org/>  
Supplies housing and support near hospitals for families.

## Medical Bill Negotiation & Debt Forgiveness

- *Dollar For*  
Website: <https://dollarfor.org/>  
Services: Helps families apply for hospital financial assistance programs to reduce or eliminate medical debt.
- *RIP Medical Debt*  
Website: <https://ripmedicaldebt.org/>  
Services: A nonprofit that purchases and forgives medical debt for qualifying low-income families.
- *Civic Legal Aid*  
Website: <https://www.lsc.gov/>  
Services: Provides free legal assistance to help families dispute unfair medical bills and access financial aid programs.
- *Aunt Bertha (FindHelp)*  
Website: <https://www.findhelp.org/>  
Services: A search platform that connects individuals to local financial assistance programs, including help with medical expenses and hospital bills.

## Travel & Lodging Assistance

- *Air Care Alliance*  
Website: <https://www.aircarealliance.org/>  
Coordinates free medical flights for treatment.
- *Angel Flight*  
Website: <https://www.angelflight.com/>  
Arranges private flights for medical travel.
- *Mercy Medical Angels*  
Website: <https://www.mercymedical.org/>  
Provides free airline tickets and gas cards.
- *Corporate Angel Network*  
Website: <https://www.corpangelnetwork.org/>  
Secures free flights on corporate jets for treatment.

## Housing & Utility Assistance

- *Family Reach Foundation*  
Website: <https://familyreach.org/>  
Assists with rent, mortgage, and utility payments.
- *United Way 211*  
Website: <https://www.211.org/>  
Connects families to local housing and utility aid.
- *Modest Needs*  
Website: <https://www.modestneeds.org/>  
Offers short-term financial aid for housing costs.

- *Snowball Fund*  
Website: <https://www.snowballfund.org/>  
Helps with rent, mortgage, and household bills.
- *Ronald McDonald House Charities*  
Website: <https://www.rmhc.org/>  
Supplies housing and support near hospitals for families.

## Food & Daily Living Assistance

- *Feeding America*  
Website: <https://www.feedingamerica.org/>  
Operates a nationwide network of food banks.
- *Food for Families*  
Website: <https://www.foodforfamilies.org/>  
Provides free grocery assistance for families of sick children.
- *Delivering Hope*  
Website: <https://deliveringhope.org/>  
Sends meal kits and groceries to families.
- *Supplemental Nutrition Assistance Program (SNAP)*  
Website: <https://www.fns.usda.gov/snap/>  
Offers food assistance for low-income families.

## Additional Grants & Special Funds

- *The Samfund*  
Website: <https://www.thesamfund.org/>  
Provides grants for young adults who had childhood cancer.
- *The Mighty Millie Foundation*  
Website: <https://www.mightymillie.org/>  
Offers financial aid and fun experiences for kids in treatment.

## Emotional & Peer Support

- *CancerCare for Kids*  
Website: <https://www.cancercare.org/>  
Offers emotional support and counseling for children with cancer.
- *Stupid Cancer*  
Website: <https://stupidcancer.org/>  
Builds a support network for young cancer patients and survivors.
- *SuperSibs*  
Website: <https://www.alexstemonade.org/childhood-cancer/for-families/supersibs>  
Supports siblings of children with cancer.

- *Pediatric Brain Tumor Foundation*  
Website: <https://www.curethekids.org/>  
Provides family support programs and resources.

## Educational & Legal Support

- *Triage Cancer*  
Website: <https://tragecancer.org/>  
Guides families on insurance options and legal rights.
- *Cancer Legal Resource Center*  
Website: <https://thedrlc.org/cancer/>  
Offers legal advice on insurance, disability, and medical debt.
- *Scholarships for Childhood Cancer Survivors*  
Website: <https://www.pafcareline.org/scholarship>  
Provides college scholarships for cancer survivors.

## Special Wishes & Experiences

- *Make-A-Wish Foundation*  
Website: <https://wish.org/>  
Grants wishes to children with critical illnesses.
- *The Marty Lyons Foundation*  
Website: <https://www.martylyonsfoundation.org/>  
Fulfills special wishes for children with serious illnesses.
- *Special Spaces*  
Website: <https://specialspaces.org/>  
Creates dream bedroom makeovers for children with cancer.
- *CoachArt*  
Website: <https://www.coachart.org/>  
Services: Provides free arts and athletics programs for children with chronic illnesses, including cancer, to improve their quality of life and boost confidence.
- *Songs of Love Foundation*  
Website: <https://www.songsoflove.org/>  
Services: Creates free, personalized songs for children and teens facing serious medical conditions, including cancer, to bring them joy and comfort.
- *Starlight Children's Foundation*  
Website: <https://www.starlight.org/>  
Provides hospital wear, gaming, toys, and entertainment for seriously ill children.
- *A Special Wish Foundation*  
Website: <https://www.aspecialwish.org/>  
Grants wishes for children with life-threatening illnesses.

## Childhood Cancer Resources

- *Childhood Leukemia Foundation*  
Website: <https://clf4kids.org/>  
Provides educational and emotional support for kids with all types of cancer.
- *Leukemia & Lymphoma Society*  
Website: <https://www.lls.org/>  
Funds research and offers support services for leukemia patients.
- *CureSearch for Children's Cancer*  
Website: <https://curesearch.org/>  
Supports research and provides resources for families.

## Bereavement & End-of-Life Resources

- *Clayton Dabney for Kids with Cancer*  
Website: <https://www.claytondabney.org/>  
Financial support for end-of-life care.
- *The Compassionate Friends*  
Website: <https://www.compassionatefriends.org/>  
Description: Offers peer support groups, online communities, and resources for families grieving the loss of a child.
- *National Alliance for Children's Grief (NACG)*  
Website: <https://childrengrieve.org/>  
Description: Provides resources, education, and support for grieving children, teens, and their families.
- *Alex's Lemonade Stand Foundation – Travel for Care Bereavement Support*  
Website: <https://www.alexslimonade.org/>  
Description: Offers travel assistance for families facing the loss of a child due to cancer and connects them to grief support services.
- *Dougy Center – The National Center for Grieving Children & Families*  
Website: <https://www.dougy.org/>  
Description: Provides grief support groups, resources, and training for families who have lost a child.
- *Children's Bereavement Center*  
Website: <https://childbereavement.org/>  
Description: Offers counseling, peer support, and resources for families coping with the death of a child.
- *National Hospice and Palliative Care Organization (NHPCO)*  
Website: <https://www.nhpc.org/patients-and-caregivers/>  
Description: Provides end-of-life planning, palliative care, and hospice support resources for families.