

Parents to Parents





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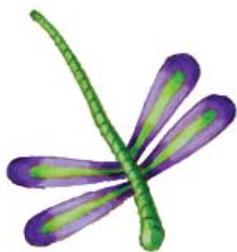
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Dear Friends,

This handbook has been written by parents and families, like you and yours, who have been through the challenging experience of caring for their children with cancer or a blood disease. Since most of what you and your child will be experiencing may be unfamiliar, we have collected practical tips and information that we hope will bring you comfort.

It's a shock, at first, being in the hospital. Every parent and caregiver you see in the halls is doing the best they can to manage a tough situation. As you go through this experience, you will learn the hospital's routine and how to manage your child's care. You will also learn how to get the information you need to make informed decisions.



We understand that your energy should be spent caring for your child, protecting your family and ensuring your own well-being. This booklet offers some practical tips and suggestions to help you along the way.

Please contact us if you have any suggestions to add to future editions of this booklet.

Know you are not alone.

Best wishes and a very big hug,
Rita Bradley and Shawna McDonough
Co-Chairs, The Buddy Team
The Dragonfly Foundation, a non-profit dedicated to providing comfort and joy to kids and young adults with cancer or a blood disease.

Email: info@TheDragonflyFoundation.org

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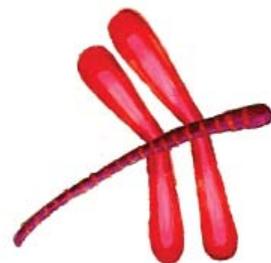




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Communicating With Your Child

Recognize and acknowledge feelings of sadness, anger, isolation and frustration.

Agree with them. Say things like, “yes, this really does stink” or “I am angry, too,” and then find ways to turn the moment into something positive.

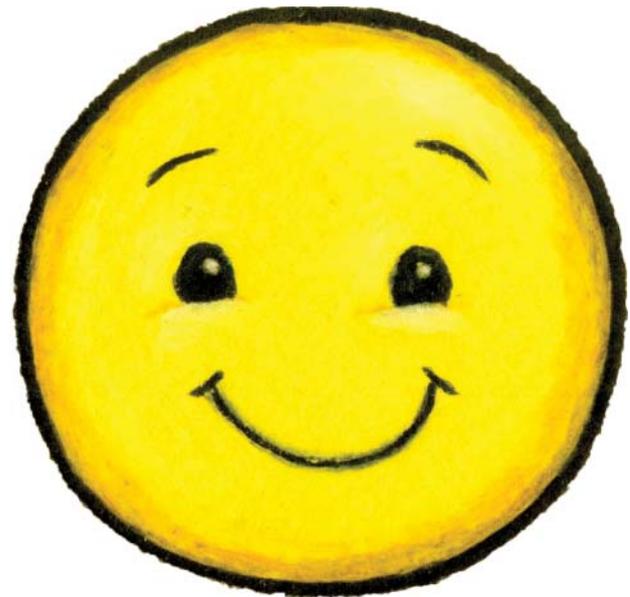
Let them have a chance to feel sad, but limit the amount of time. A positive attitude helps the healing process.

Be honest. For example, tell them if something is going to hurt – it will help your child cope and build trust. For younger children, use a word (e.g., “ouchy,” “boo-boo,”) that they can understand. This will help them be more relaxed at other medical checks or doctor visits.

Breathe with them or ask questions during procedures to help distract your child.

Provide a fun distraction. Talk to them about their Beads of Courage® (Ask your Child Life representative for more information about this program).

Find creative ways to communicate information and time. For example, create a paper chain with links equal to the number of days of chemotherapy. Kids love to tear up paper rings or make big Xs on a calendar or note pads as they count down to the end of their treatment. (Note: Be aware that the number of days a patient may have to stay in the hospital during treatment is never set in stone.)



Treatment

Consult with your physician about the possibility of crushing pills or opening capsules and mixing them into ice cream, pudding, applesauce or other food to help mask the taste. Another thing that might help is to coat it with hot fudge, a hardening ice cream topping or a small piece of rolled fruit wrap.

Check with the doctor about dietary restrictions. If possible, have your child drink white or chocolate milk when swallowing pills. It coats the throat and can help the pill go down easier. Whole milk works the best.

Ask for cooling sprays or other topical anesthetic to numb the skin before an IV or a shot.

Ask your Child Life Specialist for other techniques to try!

Check the site where the central line or IV infuses, so you know what that site should normally look like. Nurses can only check so often, so it helps to have another pair of eyes watch for abnormalities and potential complications.



Purchase or make cloth bags filled with dry rice to gently warm up in a microwave. They are great for tummy pains and for stiff necks and backs! Try one yourself. You'll be surprised how soothing and relaxing it can be.

Children are not little adults when it comes to their drug therapy. As a result, their dosages and how their bodies handle the drug may be different than an adult.



Challenges

Ease your child's fear of being alone in the hospital by using walkie-talkies or the room phone when you have to leave to go to the cafeteria, use the bathroom, go home, etc.

Help your child retain modesty and remain covered during procedures by creating custom clothes! Cut holes in leotards or open the side seams of a t-shirt to give staff access to central lines and to help your child remain covered during procedures. Try sewing four or five snaps along the side of the shirt to make it easier to take on and off.

Keep your child comfortable by asking for a consult with the hospital's Pain Management Service.

Work with the hospital to create a "care team." While your child will be receiving the best medical care at Cincinnati Children's, you might find that your child responds better to one person more than another.





Communicating With Staff

Always be honest.

Attend rounds every day.

Record rounds with a digital voice recorder, that way you can refer back to it later or ask specific questions related to information presented by the medical team.

Write questions for the doctor/nurse on a white board or in a notebook. It will help you remember what you want to ask and will help prompt a discussion when they come in for their next visit.

Don't be afraid of asking too many questions. Do everything you can to understand the situation. It will help you make informed decisions about your child's treatment.

Use a white board to keep charts of medications, dosages and schedules. Put a check box next to each item and record when it is administered. This way everyone involved knows what is happening each day. (It also makes "shift changes" from parent-to-parent smoother.)

Make signs that help staff understand your child's situation or attitude. (Ask your child to help you.) For example, one parent posted, "Child sleeping. Please respect her nap time." In another



example, one of our teen Dragonflies posted a sign that read, "Beware CHEMO Crankiness. (P.S. enter at your own risk.)"

Post a colorful, polite sign to hang on the IV pole as an extra reminder about the rate that certain medicines should be given.

Ask your medical team for suggestions on the most reliable online resources for information about your child's diagnosis, treatment path, etc. Misinformation will do nothing but increase your fear and anxiety. One good online resource is www.WebMD.com.

Contact Holistic Health. They can provide healing touch and massage services – even to infants! (They also give chair massages to parents!)

Distractions



Ask your social worker for The Dragonfly Foundation's application and information packet. Every Hematology and/or Oncology patient and their family can become a Dragonfly.

Register your child in the Beads of Courage™ program sponsored by The Dragonfly Foundation. Ask your Child Life Representative for the program application.

Introduce yourself to other parents/caregivers. You will meet incredible people who can be a source of comfort and friendship at a time when others might not understand your situation.

Celebrate holidays and create special occasions. Design snacks around a theme, play games and find other ways to make each day special and exciting.

Don't skip special days (birthdays, anniversaries, etc.) – even though you might be inpatient, there are creative ways to enjoy special times.

Encourage your child to use art, crafts, writing or music to express feelings. Your Child Life Therapist or Social Worker can help with these projects.

Make some popcorn and pretend you are at the movies!

Use sound machines or music players with white noise or natural sounds (i.e., rain, ocean, clothes dryer, wind, etc.) to create a calm atmosphere and drown out noise from pumps, machines that beep and staff visits.

Make a big deal about a new television show, an awards show, sporting event, etc.

Purchase an online movie membership.

Use a portable music player, phone, tablet, or computer to listen to music or play games.

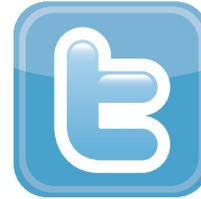
Visit the activity centers, when possible.
(There is a pool table on Location A-6.)

If siblings are allowed to visit, plan an in-room picnic with favorite outdoor picnic foods. Then plan some games they can play together.





Connectivity



Start a weblog (blog). (Care Pages and Caring Bridge are two free online blogging services to explore.) Entries on the blogs, whether hourly, daily, weekly or monthly can help connect you with people who care. It can also be a great stress reliever for you.

Post on Facebook or Twitter.
(Be sure to manage privacy settings.)

Join The Dragonfly Foundation's Facebook page, www.Facebook.com/TheDragonflyFoundation. Once you are registered as a Dragonfly, you will be invited to join our private page for Dragonfly Patients/Siblings/Parents.

Consider talking to your child's school about video conferencing. Ask your Bedside Teacher or School Interventionist how you can help move this process forward.

Ask to use a Dragonfly computer. They have webcams that can be used for video conferencing. (Be sure to include pets and other familiar people/items, when possible.)

Purchase an online gaming subscription to allow your child to connect with others outside of the hospital.

Consider getting your child a mobile phone that they can use to send and receive text and/or picture messages.

Attend a Dragonfly event after your child is released from the hospital! You will have a great time! You and your family will also have the opportunity to meet other families who are sharing a similar experience.



Food

Buy hospital/room service dining cards at the Location A Welcome Center or at the cash registers in the cafeteria. They are often the best value.

Let the child eat whatever sounds good to them – while following dietary restrictions and doctor's orders, of course. Now is not the time to worry about the nutritional value of food. (During treatment, there may be times when you will be grateful to watch your child drink a soda or eat a candy bar.)

Ask Guest Services or the staff for their recommendations for restaurants that deliver food to the hospital. (This is especially helpful for when your child is craving a specific food!)

Accept offers of food or ask relatives or friends to bring meals to the hospital when they visit, BUT – don't be afraid to politely and directly decline food help when it is overwhelming to you.

Seal items in brown paper bags and store them in the parents' lounges' main refrigerator. Label bags with your name and room number.



Ask your Social Worker about special meal programs for caregivers offered on holidays and other special occasions by the hospital, outside non-profits and others.

Tell well-meaning gift givers what kind of food your child prefers so that candy and other unwanted foods don't start to pile up.





Overnight Stays

Make the pull-out lounge bed (the vinyl, blue thing in the corner of your room) more comfortable by buying an air mattress or 4" memory foam mattress pad and put it on top of the pull-out lounge. [You may have to keep the chair's top cushion (under the pillow end) elevated to keep the air mattress flat.] In the morning, deflate it, roll it up, secure it with a luggage strap, place it in a lawn leaf bag and store it in a corner of the room.

Ask if the hospital will let you use a full-sized bed, called a Posey Bed. This will allow you to sleep or lay in bed with your child.

Ask for a picture ID of your child, as well as a bracelet. It will help staff verify your child's identity during naptimes.

Try your best to stay on schedule. During the day, open the blinds and let natural light in, to keep the room bright; close the blinds to darken the room at nap and bed times. Cover electronic equipment with blinking lights with washcloths or pillow cases to subdue their brightness.

Bring in their favorite things, such as movies, iPod, 2-3 small toys, a pillowcase or blanket, etc.

Use a 3-drawer plastic storage unit in the bathroom for personal care items. (Don't unpack the storage unit when you leave



the hospital. This way, if you have an unexpected admission, everything will be in one place.) These can be purchased at Target or Walmart.

Maximize space by moving the bedside table into the bathroom. It is a great place to keep supplies.

Keep extra plastic storage containers or storage bags handy.

Rearrange the room slightly – be sure that the medical team has access to the patient from all sides of the bed.

Use a nightlight in the bathroom.

Keep to a routine! Just as you would at home, move and store all items (toys, cords, clothes, etc.) that you may have out during the day to prevent a tripping problem during the night!

Exercise

Encourage your child to move or exercise with you; it's no fun to dance or exercise alone!

Stay fit, mentally and physically – though it can be a challenge even in the best of times. It will help your body and your mind.

Bend and stretch!!

Bring in a yoga mat and some small hand weights to keep in the room.

Go for walks as much as possible! It is important that you take time for yourself and recharge.

Explore hospital grounds on a nice day.

Throw a ball with your child.

Hang an over-the-door basketball hoop and shoot baskets with your child.



Dance or play active video games in your room or in the activity center.

Create a game by counting how many times you can pass a balloon without it hitting the floor.

Ask your Child Life Specialist or the Welcome Desk in Location D about local gyms – some offer free or reduced admission privileges to patients' families.





Important Notes



Insist that everyone wash or sanitize their hands before entering your child's room and follow the appropriate restrictions on visitors for gowns and gloves.

Remember, treatments and outcomes vary. Don't worry about or listen to war stories that may not apply to your situation.

Keep a sense of humor and try to find and do something positive every day.

Create a binder to hold all paperwork, such as labs, orders, discharge sheets, medication lists and contact information. Write everything down!

Direct your energy towards helping your child cope and get healthy. There is no sense asking for the meaning behind your child's illness.

Follow your instincts. If something doesn't seem right or you are concerned, speak your mind; ask for additional tests, request another opinion or ask your doctor to consult with other disciplines. Remember: 1) you are your child's best advocate, 2) you know your child better than anyone, and 3) you have power.

Record rounds or notes with a digital voice recorder. That way, if you need to refer back to something or give the information to another caregiver, you will have an audio recording of the important information.

Stay calm and make the best of every situation. There is no other experience that will test your patience more than an extended hospital stay.

Try not to get upset in front of your child. Kids feed off their parent's emotions. Getting down in the dumps and reacting negatively to situations brings everyone down and makes things more challenging.

Keep the same expectations of behavior and respect (with allowances for steroids, difficult procedures, illness, etc.). Illness does not have to change your values and goals, except for the better.

Inform friends and family about the hospital's visitation policy and tell them the best times to visit. There will be times when you and your child may feel that having a visitor is too tiring or adds to your stress. (Please note that the hospital has visitor restrictions during flu season.)

Contact Family Relations if you have a concern or complaint related to an experience you or a family member have while in the hospital. They can help.

Let Your Family, Friends, Congregation or Community Give Support & Comfort

Ask everyone to send your child “snail mail,” email or e-cards from online services or Cincinnati Children's Hospital's website, www.cincinnatichildrens.org.

Lighten your load by asking for and accepting help. It will allow you to focus on your child in the hospital and your family at home.

Designate one contact person for your family and another for your friends. This will help you spend less time answering phone calls, texts and/or emails.

Ask if trusted family and visitors would mind staying alone with your child to give you time to get a coffee, go home, take a walk, etc.

Ask friends to make and freeze a bit extra when they cook a meal. (Be sure they label the containers with the date and contents.) Consider providing them with freezer containers. You will be very glad to have something to heat up when you get home.

Provide a friend or relative a listing of restaurants (one that deliver are ideal) that your family enjoys. Busy people LOVE to give gift certificates.

Use a “Casserole Flag.” Put up a flag to show neighbors that meals are welcome. Put two ample-sized coolers in front of your home: one for hot items and one for cold. Neighbors, friends and family can drop off food at their convenience without having to ring the doorbell or disturb your family.

Check out some of the great websites that help organize meal donations and visitation schedules for you and your family. A couple of great examples are www.SignUpGenius.com and www.FoodTidings.com.

Accept offers to mow the lawn or clean the house. Give people a chance to do something to help.



Special Places At Cincinnati Children's

Shop till you drop at the hospital gift shop (Location C-1).

Seek out some quiet time at the little chapel under the stairs near Location B Welcome Desk.

Stop by the Family Resource Center in Location D-2. It is a place to relax, read, access the Internet, conduct personal business and obtain information about childhood conditions and more.

Visit the outdoor space that has statues of Alvin and the Chipmunks. It is located between Locations C and D, near the Family Resource Center.

Visit Guest Services at the Location A Welcome Desk, if you are from out-of-town or even if you are local. They have discounted tickets to local events and attractions.



Other Special Places To Visit While in Cincinnati

Tour University of Cincinnati's campus and Ludlow Avenue in Clifton, OH. Stop inside UC's Medical Building for a "real" Starbucks® experience.

Marvel at the beauty of Eden Park and Krohn Conservatory near downtown Cincinnati. They are worth the short drive.

Take in a movie at the Esquire Theater on Ludlow Avenue in Clifton (an easy walk from Cincinnati Children's), or you can drive to the quaint village of Mariemont, OH, near Cincinnati, to visit the theater there.

Taste test Cincinnati's best ice cream at Graeter's® in Clifton or Mariemont, Aglamesis Brothers in Oakley, OH or UDF® in Clifton.

Leave the hospital and visit the coffee houses in Clifton.

Take a quick bite at The Blind Lemon Cafe (this spot also has an outside eating area in nice weather and a fire pit for when temperatures start to cool) in historic Mt. Adams, OH, just above downtown Cincinnati.

Visit local specialty shops and malls. Favorites include: Rookwood Commons & Pavilion in Hyde Park, Target on Marburg Ave. in Oakley, and Newport on the Levee just over the river in Newport, KY.

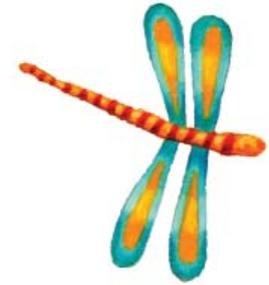


Enjoy fabulous views of Cincinnati from Devou Park in Covington, KY.

Take kids to the playground at Sawyer Point on the Cincinnati side of the Ohio River. Be sure to go for a stroll along the scenic walking path!

Visit the world-renowned Cincinnati Zoo & Botanical Garden. It is walking distance from Cincinnati Children's Hospital.

Before Your Child Comes Home



Make sure to have lots of hand sanitizer and disinfecting wipes available – put some in your purse, your pocket, your car and all around the house!

Hang laminated signs outside the door instructing visitors to remove their shoes and wash their hands upon entering your home. The sign should also state that a resident is a patient with an immune compromised disease – no one with flu or cold symptoms can enter.

Buy a pillbox organizer. A flashlight to keep in the bedroom near pumps for nighttime checks is also handy!

Clean your home thoroughly and wash or replace all air filters before your child comes home.

Use zip lock storage bags to hold medical items and to keep things organized.

Create a medical space and store everything in nearby plastic drawer sets with rollers. The space needs to accommodate your child's comfort and provide workspace for the nurse. Set up this area before your child is discharged from the hospital. Keep the area scrupulously clean.

At Home

Do not hesitate to call for help. The first few days and nights at home are always worrisome.

Verify and double check prescription dosages, dates and names, etc.

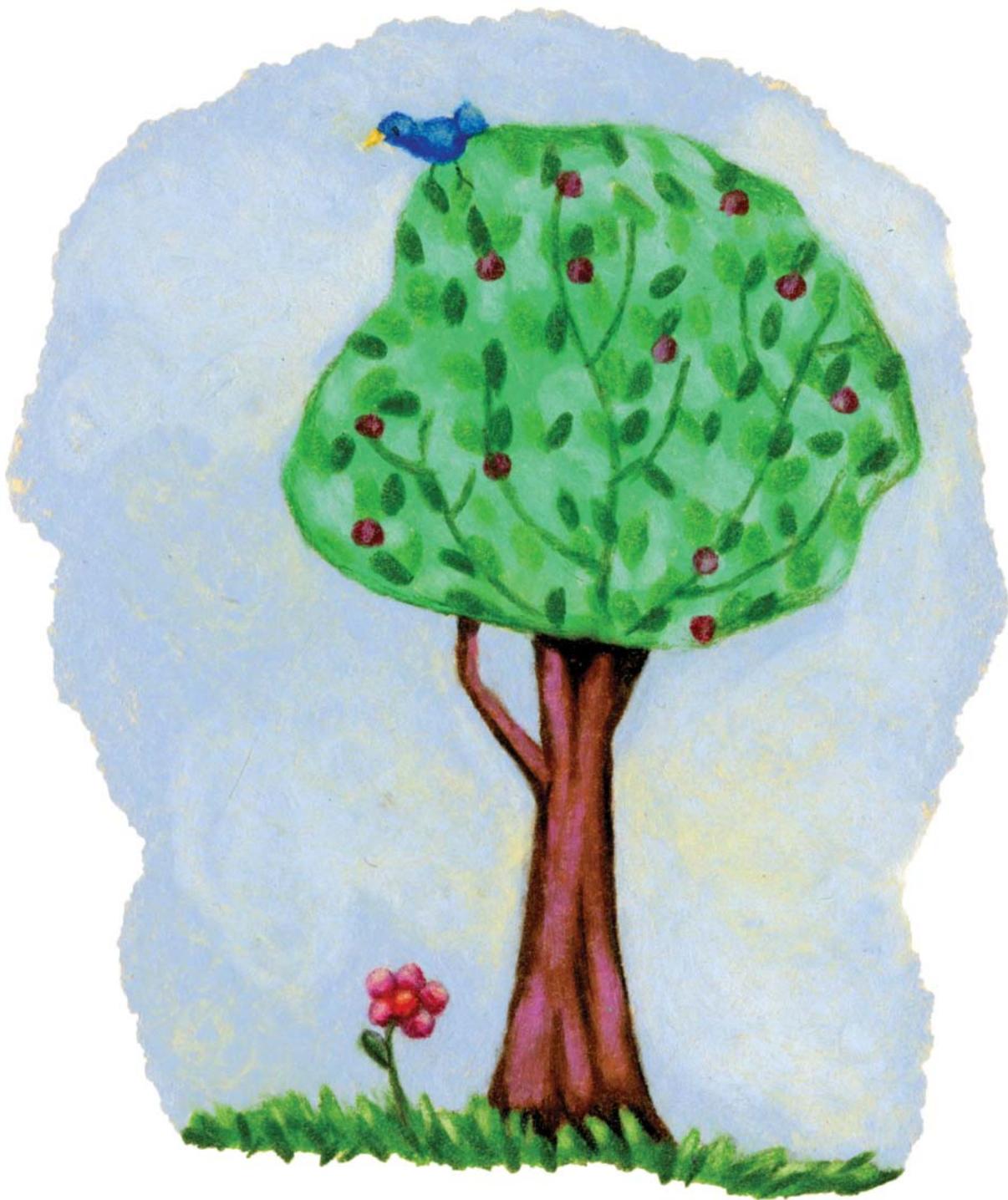
Use a small timer to help count the time for scrubbing lines.

Keep a log of medicines, times and temperatures.

Take notes and pictures of pills, as they can look similar. Keep these in the binder you started in the hospital.

Stock food and gift cards for meals.

Don't worry if your family has to survive on milk and cereal or peanut butter sandwiches for a few days.



Inspirational Quotes

"Never, never, never, never give up!" – Winston Churchill

"There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle." – Albert Einstein

"... also rejoice in our sufferings, because we know that suffering produces perseverance, character and hope. And hope does not disappoint us ... " – Romans 5: 3-5

"Leave your bubbly at the door, I don't feel like champagne today!" – Unknown

"Life by the inch is a cinch, life by the year is hard. Take one day at a time and remember that you are not alone in the journey. One day at a time, one day at a time, one day at a time ... " – Unknown

"You gain strength, courage and confidence by every experience in which you really stop to look fear in the face." – Eleanor Roosevelt



"We acquire the strength we have overcome."
– Ralph Waldo Emerson

"Don't count the days, make the days count."
– Muhammad Ali

"Never give up. Never surrender."
– Jason Nesmith from Galaxy Quest (1999 movie)

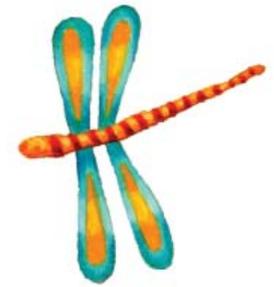
"Oh, my friend, it's not what they take away from you that counts - it's what you do with what you have left."
– Hubert H. Humphrey

"Life is not about waiting for the storm to pass; it is about dancing in the rain." – Unknown





Bringing Comfort and Joy to Kids and Young Adults with Cancer and Blood Diseases



The Dragonfly Foundation holds a unique place in the landscape of non-profit organizations focused on pediatric cancer and blood diseases. We call this **The Dragonfly Difference:**

☞ We embrace a family upon referral from their medical provider/hospital, and they remain with us until the patient is five years free of their disease or until the patient reaches 30 years of age. (If the patient joins Dragonfly at the end of their 5 years or at the age of 30, they will be a Dragonfly for one year from their date of application.) We understand that even though treatment may end, the post-traumatic stress of treatment, the challenges of side effects from treatment and the anxiety of reoccurrence continue to challenge families for years to come.

☞ We provide multiple, ongoing event opportunities (we average almost 2 events a week), distractions, gifts and entertainment for our Dragonflies and their families. The patients, as well as their siblings and parents/caregivers experience isolation, loneliness, fear and anxiety related to the diagnosis and treatment of cancer or blood disease. While only one person is receiving treatment, all affected benefit from our C.A.R.E. as we define it (**C**aring, **C**ommunity and **A**wareness that **R**esults in better **E**mootional Health).

☞ In many cases, the fundamental needs of a family are left to one organization and quality of life support to another. TDF is there to provide comprehensive C.A.R.E.

☞ With our army of supporters dedicated to the mission of bringing comfort and joy to our families, help is just a phone call, email, text or Facebook post away! We want patients and families to understand they are not alone.

Please ask your social worker for The Dragonfly Foundation application. We accept all applications from Cincinnati Children's Hospital Medical Center's Cancer & Blood Diseases Institute, regardless of permanent residency or income.

You and your family will love being Dragonflies.

For more information, please visit:

Email: info@TheDragonflyFoundation.org

Website: www.TheDragonflyFoundation.org

Facebook: www.Facebook.com/TheDragonflyFoundation

YouTube: www.youtube.com/user/DragonflyCincinnati

Notes To Keep And To Share

A series of horizontal dotted lines for writing notes.

The Dragonfly Foundation developed this booklet in cooperation with the Family to Family Support Parents of the Cancer & Blood Diseases Institute of Cincinnati Children's Hospital Medical Center. We are grateful to these parents, as well as the many Dragonfly families who contributed to this booklet.

We also would like to give special thanks to Tara Callahan King for donating her time and artistic talents to create all the original illustrations in this booklet.

We hope this book brings you comfort along your journey.

Sincerely,

Tara Callahan King
www.taracalahanking.com

Shawna
daughter- age 2
CVID, BMT

BMT Group

MaryBeth
son- age 12
HLH, BMT

Christine
son- age 10
Hodgkin's Lymphoma

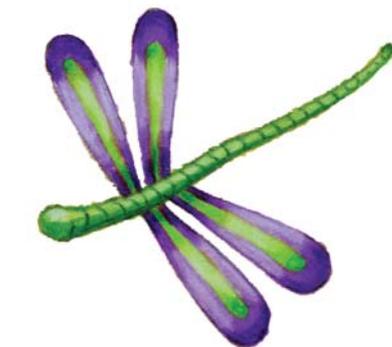
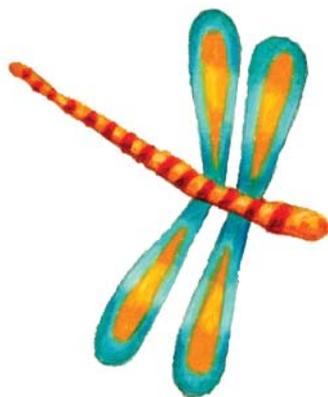
Elaine
granddaughter- age 2
CML

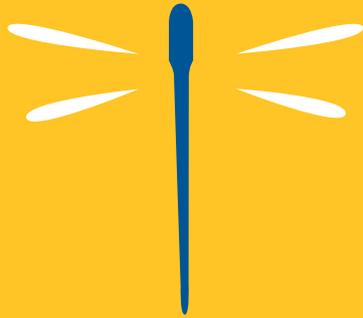
Rita
daughter- age 17
AML, BMT

Kim
son- age 15
ALL

Kristi
son- age 7
Severe Aplastic Anemia

Dee
son- age 11
Brain Tumor, PNET





THE
DRAGONFLY
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*Bringing Comfort and Joy to
Kids and Young Adults with
Cancer and Blood Diseases*

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