



Lighthouse

FAMILY RETREAT

Understanding Childhood Cancer

Below you will find some guidelines, suggestions, and general terms to know about childhood cancer. We encourage you to talk with your family—especially your kids—about the topics below, prior to attending a Lighthouse Family Retreat.

On-Retreat Expectations

- Some children have adverse physical effects and disabilities from their treatment that cause them to get stared at in public or even made fun of at school. One of the greatest gifts you can give them is not to pity what makes them appear different but to embrace their uniqueness with compassion. Sometimes the children appear weak and delicate, but few children are too fragile to be held or hugged!
- Children with cancer want to be treated normally—they want to run and play like other kids their age, even if it takes them a little longer to get something done. Please be sensitive and aware as you serve, as children with cancer typically don't want to be given "special treatment." While they may have some limitations, celebrate their accomplishments with authenticity.
- At the retreat, when we need to distinguish between a healthy child and a child with cancer, we identify the children with cancer as "the child on (or who has been on) treatment." If you are serving with your children, please make sure they don't refer to the children as "cancer" kids. Like all of us, the children we are serving just want to be normal kids called by their names, and not to be known or labeled by their disease.
- Childhood cancer has a devastating impact on the family. It causes emotional, financial, spiritual, and relational strain. Our weeklong retreats offer special attention for every member of the family. Understandably, the child with cancer often becomes the focus of concern, and this can leave the siblings feeling lonely, insecure, and left out. As we befriend them, we have the privilege and incredible opportunity to help restore their sense of significance and worth. For parents, the divorce rate is astounding—far greater than those without the challenges of childhood cancer. By taking care of their daily responsibilities such as cleaning, cooking, etc. and providing the family a "retreat" from their "battle," we give the families a chance to reconnect and restore much-strained relationships.
- If a parent shares their story with you, bear in mind that they are not looking for you to give them an answer. Sometimes a shared tear or hug can ease their pain or show you understand more than any word you can offer. Someone who is genuine and truly listens is an invaluable gift to them. Try to just listen to their story without going into a story about yourself.
- If a family is discussing their medical care with you or another family, do not offer any medical advice or assistance in any way. All of our families have medical teams they are working with to get the best care possible. Their medical team knows their medical details and their financial/insurance situation that we do not know about, nor should have any influence on. Please leave all of the medical and financial decisions to the family and their medical team. If they ask for advice, please direct them to their medical team.
- Immune system: Your body's defense against disease and illness. All our children on treatment have a compromised immune system due to the cancer and treatment they are on. They are very

susceptible to infection and illness. A simple cold for us can cause extreme illness and even death for these children. Because of this, we need to make sure we are not exposing them to any type of illness at all—including but not limited to a cold, strep throat, flu, Covid-19, stomach bug, etc. This includes exposing their siblings or parents to the same. If anyone in your family has any form of an illness during your time at Lighthouse or within 24 hours before arriving at Lighthouse, please notify your Retreat Medical Lead or someone on staff as soon as possible.

- Sunscreen: Because of the medications that the children take for their cancer treatment, they can be extremely sensitive to the sun and need frequent applications of sunscreen. We will have sunscreen available at the beach, the pool, and Flip Flop to screen the children before going outside. Remember to apply liberal amounts of sunscreen, even on a cloudy day.
- Hydration: It is important for everyone to stay well-hydrated at the retreat. The children need extra hydration when they're exposed to the sun and wind. Please remember to make sure ALL of the children drink plenty of fluids. We will have water at the pool during Flip Flop, the beach, and in the common areas.
- If you have any questions about a situation and think you need to do something, please talk to someone on staff and don't take any situation into your own hands.

General Cancer Facts

CANCER STATISTICS

- Research has not been able to determine why children develop cancer.
- Each year, more than 15,000 kids in the U.S. are diagnosed with cancer.
- More than 42 parents in the U.S. each day hear, "Your child has cancer."
- Each year, over 400,000 children aged 0 to 19 are diagnosed with cancer worldwide.
- Survival rates for childhood cancer depend on several factors: the type of cancer, the stage of the cancer when the child is diagnosed, and the child's response to treatment. Overall, the five-year survival rate is 85%; however, there are still around 2,000 children who die each year. Cancer continues to be the leading cause of death by disease in children.

FREQUENTLY USED TERMS

- Stages of Treatment
 - Untreated (new diagnosis)
 - In remission (treatment was given and now WBCs are in normal range)
 - Recurrent (treated, was in remission, and now the cancer is back)
 - Refractory (cancer is still present even after treatment)
- Treatment Phases
 - Remission induction chemotherapy (first stage of treatment that lasts one month)
 - Chemotherapy given to kill as many leukemic cells as possible to put child in remission
 - Consolidation/CNS prophylaxis (lasts one to two months)
 - Preventative treatment to prevent spread of cancer to brain and spinal cord
 - High dose chemo and possible radiation
 - Intensification therapy (lasts up to nine months)
 - Started once in remission
 - Multiple treatments that last two months each
 - High dose chemo to kill any remaining cancer cells
 - Maintenance therapy (Girls: two years; Boys: three years)
 - Chemo given to keep child in remission
- General terms
 - Oral or PO: Medicine is given by mouth

- Intravenous or IV: Medicine is given in a vein or through child's port
- Spinal tap or lumbar puncture (LP): Procedure to collect and look at cerebrospinal fluid surrounding the brain and spinal cord
- Stem cell transplant or bone marrow transplant (BMT): Replenishing the body with healthy cells and bone marrow after chemotherapy and radiation to help the body produce new cells and attack any remaining cancer cells
- Secondary effects: Side effects that occur due to chemo or radiation treatments
- Port: An internal device/IV where children receive chemotherapy and have blood drawn. You may see a small round bump under their skin located on their chest or abdomen, which is their port. Typically, the port does not hurt when touched and the kids don't mind explaining or showing it to you.
- ANC (absolute neutrophil count): This word refers to the child's ability to fight infection and is determined in part by their white blood cell count. When a child's ANC is <500, they are at greater risk for infection (the lower the number, the higher the risk).

CHILDHOOD CANCER TYPES

There are many types and subtypes of cancers that affect children. Below are the most common for the Retreat Families we serve. This is a broad overview. Each type of cancer may be called many different names depending on location, size, and prognosis.

- Leukemia: A cancer of the blood and bone marrow. The cancerous cells grow out of control and crowd out the healthy cells. There are 2,700 children diagnosed each year with leukemia, and it is the most common type of all childhood cancers. Two main types of leukemia:
 - Acute lymphoblastic leukemia (ALL): The most common childhood cancer that affects 75% of children with leukemia. ALL is a cancer that attacks the lymphoid cells in the bone marrow, which are part of the body's immune system.
 - Acute myeloid leukemia (AML): AML is a cancer of the myeloid blood cells, which are produced in the bone marrow and help fight bacterial infections.
- Cancers of the central nervous system
 - Brain tumors: The most common type of solid tumor cancers, brain tumors are named and classified according to their location on the brain. Medulloblastomas—malignant tumors on the cerebellum—are the most common.
 - Neuroblastoma: A cancer of the sympathetic nervous system, which most often originates in the adrenal glands above the kidney. They are the most common type of cancer in children under one year of age. Many times, this cancer has already spread before it is diagnosed.
- Sarcomas: Tumors of the bones and soft tissues
 - Osteosarcoma: the most common type of bone sarcoma. These tumors often are located at the growing end of the long bones of the extremities, close to the joints. Osteosarcomas are usually a primary cancer (they do not occur from other cancers in the body).
 - Ewing's sarcoma: a bone cancer that often appears in the middle of the bone. Commonly found in the thighs, hipbones, upper arms, and ribs.
 - Rhabdomyosarcoma: a soft tissue sarcoma that develops in muscles. Most often found in the head, neck, kidneys, bladder, arms, and legs.
- Lymphoma: A tumor of the lymph tissues, which are part of the immune system
 - Hodgkin lymphoma: Cancerous cells that reproduce uncontrollably in the lymph nodes that are in close proximity, such as the neck, shoulders, and chest, and they remain localized. Affects 15-35 year-olds and has the highest cure rate.
 - Non-Hodgkin lymphoma: Cancerous cells develop in peripheral lymph nodes and tend to spread throughout the body. There are many types of lymphoma, including Burkitt, non-Burkitt, and lymphoblastic lymphoma. This form of lymphoma can have a poor to excellent prognosis.

- Other types of cancer that are less common:
 - Hepatoblastoma: An abnormal growth/tumor in the liver
 - Wilms tumor: A solid mass found in the kidney, usually seen in children under nine years of age. 90% survival rate.
 - Retinoblastoma: A malignant tumor of the retina (a thin membrane in the back of the eye)
 - Germ cell tumors: Tumors that appear most commonly in the testes, ovaries, area at the bottom of the spine (sacroccygeal) and in the middle of the brain, chest, or abdomen

The information above was adapted from www.cureseach.org, www.hopkinsmedicine.org, www.childrenscancer.org, and www.lls.org.