We want to hear all about your journey. Share with us how you remained hopeful, what you learned that might be able to help other kids across the nation, what worked, or what didn’t. This toolkit is always growing and evolving as research and data advances and changes.

We need your help to make sure that we always have the most up-to-date information because so much of what we are able to learn comes from hearing real stories, like yours. If you would like to be featured in our toolkit to inform and inspire others, please contact us at nationalpcf.org/toolkit.

On this page, you will be able to share you or your child’s experience with pediatric cancer, upload photos, and offer additional advice to newly diagnosed pediatric cancer families.
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KEY PERSONAL
Information

Patient Name:

Parent/Guardian Name 1:

Address:

Phone Number 1:

Patient Name:

Parent/Guardian Name 2:

Address:

Phone Number 2:

Notes:
In 1991, two mothers faced every parent’s worst nightmare. Their children were diagnosed with cancer. Melissa Helms and Risa Tramel met at St. Joseph’s Children’s Hospital in Tampa, Florida while their infant daughters were undergoing cancer treatments. Through research advancements, both of their daughters survived and are now healthy young adults. However, through this experience, Melissa and Risa were inspired to continue fighting this disease.

Together, they founded the National Pediatric Cancer Foundation (NPCF), a non-profit organization whose mission is to fund research that will lead to the elimination of childhood cancer worldwide.

For the first 15 years, the NPCF funded seed grants at St. Joseph’s Children’s Hospital and Moffitt Cancer Center in Tampa, FL; All Children’s Research Institute in St. Petersburg, FL; the University of Florida in Gainesville, FL; and the University of Miami School of Medicine in Miami, FL.

In 2005, the NPCF formed the Sunshine Project, an innovative collaboration with one goal: to bring together the nation’s top doctors and researchers to fast-track new treatments and increase the survival rate for children battling cancer. Through the establishment of the Sunshine Project, the NPCF has developed a business model that capitalizes on the strengths of researchers from all different fields of science and streamlines the process to accelerate the development of new treatments.

Best of all, the NPCF has proven that this collaborative model works. Since 2005, through collaboration with leading hospitals across the nation, they have funded four Phase I clinical trials. New compounds have been, and continue to be, tested and hold great promise for children who have not experienced positive results under the standard treatment protocol. Despite the lack of advancement and funding towards research, the NPCF continues to raise funds and provide education through special events, corporate sponsorships, peer-to-peer/DIY programs, published research and literature pieces, and pediatric cancer ambassadors.

Since 1991, the NPCF has been a shining light for children who are battling cancer by yielding amazing discoveries that are saving their lives. The NPCF will continue to battle childhood cancer so that no child ever has to fight it alone. Together, we will rise up and fast-track a cure.
Our various programs and signature events help fund life-saving clinical trials that yield amazing discoveries. Every donation raised from these events directly supports our mission to eliminate childhood cancer and helps families like yours.

TOP-RATED CHARITY

Recognized as the Top-Rated Cancer Charity by Charity Navigator. Awarded a perfect 100% score for financial health and transparency.

$23 MILLION
We have donated more than 23 million dollars to pediatric cancer research.

14 INITIATIVES
Funding 11 clinical trials yielding amazing results, and saving children’s lives.

24 HOSPITALS
Collaborating with 24 leading pediatric hospitals nationwide for clinical trials.
ABOUT TRF

The Tyler Robinson Foundation (TRF) helps strengthen families financially and emotionally as they cope with the tragedy of a pediatric cancer diagnosis by providing grants specifically to offset out-of-pocket life expenses.

TRF is the nonprofit organization of the GRAMMY Award-winning band Imagine Dragons. TRF meets a critical need in communities across the U.S., Canada and Mexico. While many pediatric cancer organizations focus on growing awareness and support for families with the physical and emotional toll of a diagnosis, the huge financial hardship cancer treatment places on families is rarely discussed. More than 85-percent of every dollar TRF raises goes directly to families in need.

TRF is almost 7 years old, has raised almost 10 million dollars, and has supported over 500 pediatric cancer families.

WHERE DOES THE MONEY GO?

We are thrilled that over 85 cents from every $1 donated to TRF goes directly to our families!

**Signature Grants** - Grants made to families who have suffered financial hardship as a result of pediatric cancer diagnosis and treatment. These grants are issued to provide financial relief specifically for housing, utilities, and automobile expenses. Grant funds are paid directly to debtors in the amount of $1,000 monthly for one year.

**Fun Money** - Grants given to celebrate special occasions such as birthday parties or gifts and fun nights out together as a family. These grants are issued in the form of a retail gift card in denominations of $25 - 250 each. Families may apply for and receive unlimited fun vouchers each year with a maximum total value of $2,500 annually.

**Travel Grants** - Financial assistance to cover hotel and travel expenses for family members to accompany their child during travel incurred for medical treatment or therapy. Each TRF family qualifies for up to $5,000 per year.

**Path to Heaven** - For families faced with the exceptional burden and cost of laying their child to rest, TRF offers financial grants to pay funeral or burial expenses. Families receive up to $5,000 to supplement these costs.
# PRIMARY Contact

**Family Practitioner/Pediatrician:**

- **Address:**

- **Phone Number:**

**Hospital:**

- **Address:**

- **Phone Number:**

**Oncologist:**

- **Address:**

- **Phone Number:**

**Child Life Specialist:**

- **Address:**

- **Phone Number:**

**Primary Nurse:**

- **Address:**

- **Phone Number:**
MEDICAL Disclaimer:

All content in the educational toolkit is created and published for general informational purposes only. It is not intended to be a substitute for professional medical advice and should not be relied on as health or personal advice.

Always seek the guidance of your doctor or other qualified health professional with any questions you may have regarding your health or medical condition. Never disregard the advice of a medical professional, or delay in seeking it because of something you have read in this educational toolkit.

The information contained in this educational toolkit is not intended to recommend the self-management of health problems or wellness. It is not intended to endorse or recommend any particular type of medical treatment. Should any reader have any health care related questions, promptly call or consult your physician or healthcare provider. No information contained in this educational toolkit should be used by any reader to disregard medical and/or health related advice or provide a basis to delay consultation with a physician or a qualified healthcare provider.

In no event shall The National Pediatric Cancer Foundation be liable for any special, direct, indirect, consequential, incidental damages or any damages whatsoever, whether in an action of contract, negligence or other tort, arising out of or in connection with the use of the educational toolkit or the contents of the educational toolkit. The National Pediatric Cancer Foundation reserves the right to make additions, deletions, or modifications to the contents on the educational toolkit at any time without prior notice.
Tab 1
Record Keeping

A LOOK INSIDE

• Medical Treatment Summary
• Medical Imaging
• Medicine Log
• Exercise Log
• Diet Log
• Calendar
• Dictionary
• Stories of Hope
## MEDICAL TREATMENT
### Summary

<table>
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<tr>
<th>DATE</th>
<th>SURGERY</th>
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Notes:

Make copies of this page for weekly logs
What is mymedicalimages.com?

mymedicalimages.com is an easy to use, safe and secure platform for viewing, sharing and managing medical images. CDs are hard to keep up with and difficult to share when time is critical. Use the Referral Code NPCFKids to join today for FREE and start managing your family’s medical images.

Get started uploading your medical images to the cloud from CDs using our simple upload process.

Want us to upload them for you? Order our Starter Kit online.
Order our 
**Starter Kit**
Now you can view, share and manage your medical images on any device.

**Step 1**
Start your **free** subscription at mymedicalimages.com and begin uploading your images in the cloud with our easy to use uploader. If you don’t have access to a CD drive we can upload them for you with our starter kit.

Use referral code **NPCFKIDS**

**Step 2**
Just place CDs with your medical images in the starter kit and return the kit to us. Shipping is included.

Referral Code **NPCFKids**
Step 3
Once we’ve processed your CDs, you will receive an email or text. All your medical images will be available for you to view, share and manage in the cloud.

Referral Code NPCFKids
When our son was diagnosed with cancer in his femur at age 9, we were immediately scheduled for X-Rays, MRI’s with and without contrast, Nuclear Medicine Bone Scans and CT scans. In the first 3 months of his diagnosis we had already had over 20 different imaging CDs we were storing and keeping track of.

We are amazed at the ease and efficiency of storing all of these images on mymedicalImages.com. This is an amazing place to store these high tech DICOM images in their exact form so that they are at our fingertips for reviewing or sharing with other medical professionals.

We are excited to share mymedicalImages.com with other families whose children are being treated with cancer because we know this technology is a game changer in the way that each child can be treated. We understand that just like each person is different so is each diagnosis, treatment and reaction. mymedicalImages.com allows a family to share with a doctor an image that needs an extra look or may need to be discussed among colleagues with all of the qualities of a high tech DICOM image. This record keeping is amazing and we are so grateful to have it for our son.
Don’t Compromise Pediatric Patient Safety

Ben-Guard
Put on Love

Creating a new standard-of-care in wearable catheter securement

• Registered as an FDA Class 1 Medical Device
• Well-placed snaps, straps and front pocket secure and conceal CVC and other tubing devices during infusions and daily activities
• Soft bamboo, cotton and spandex fabric

• Easy access to wound site for inspection and cleaning
• Removable without disconnecting tubing
• Comfortable and washable
• Accommodates CVC, G/J and other tubing and ostomy scenarios
Ben-Guard’s proprietary and unique design provides comprehensive, 24/7 catheter securement, toward the prevention of serious and emergent complications.

Shoulder and side straps provide added securement.

Available in two styles and four colors:
- Bodysuit—0-3 months to 4T
- Tank Top—2T to small adult
- Light blue, navy, pink and red
- Special request sizes available

- Endorsed as a new protocol for catheter management by a top tier U.S. Pediatric Hospital
- Ben-Guard is collaborating with Healthcare and Insurance providers to establish robust coverage for our products, as a medical necessity
- Health Savings Account payments accepted

For questions or to order our products:
www.ben-guard.com or call us @ 833-BEN-LOVE
Facebook@benguardhealth/info@ben-guard.com
# WEEKLY MEDICINE Log

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## WEEKLY EXERCISE Log

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GROUNDHOG DAY

PRESIDENTS’ DAY

VALENTINE’S DAY
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Notes:
2020 NOVEMBER

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ELECTION DAY

VETERANS DAY

THANKSGIVING DAY

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**Notes:**

- National Cancer Survivors Day
- Father's Day
ANC (Absolute Neutrophil Count): the white blood cells that fight infections.

Anemia: a decrease in the amount of red blood cells (hemoglobin) in the body.

Anesthesia: a loss of feeling or awareness caused by drugs or other substances. Anesthesia keeps patients from feeling pain during surgery or other procedures.

- Local anesthesia is a loss of feeling in one small area of the body.
- Regional anesthesia is a loss of feeling in a part of the body, such as an arm or leg.
- General anesthesia is a loss of feeling and a complete loss of awareness that feels like a very deep sleep.

Antineoplastic: an agent that inhibits or ceases the growth of neoplasms.

Benign: non-harmful cell growth.

Bone Marrow: cavity within the bone where blood cells are produced.

Broviac: a central venous line placed into the body that is visible outside the body and used to deliver medications, such as chemotherapy.

Cancer: an abnormal growth of cells.

CBC (Complete Blood Count): blood test done to evaluate the cells in the body, such as hemoglobin, platelets, ANC, etc.

Chemotherapy: cytotoxic agents used to treat cancer, that inhibits cell growth of rapidly dividing and growing cells.

Cytotoxic: an agent that is toxic to living cells.

Dehydration: loss of water from an object, such as the body.

Fatigue: the sensation of being extremely tired as a result of illness, such as anemia.

Hemoglobin: the red blood cell responsible for carrying oxygen throughout the body.

Immunocompromised: an immune system that has been impaired, most commonly from chemotherapy.

Intrathecal: space within the spinal theca in which medication can be administered and cerebral spinal fluid can be removed.

Lumbar Puncture: a procedure to remove cerebral spinal fluid for diagnostic purposes.

Malignant: invasive cells that are not growth limiting and can spread to other tissue.

Mediport: a central venous line inserted into the body, in which a needle is used, to deliver medications, such as chemotherapy.
**Metastatic:** abnormal spread of cancer cells to other parts of the body, including organs.

**Mucositis:** a side effect of certain chemotherapy agents and radiotherapy that results in painful sores and inflammation of the mucosal cells of the mouth, throat, stomach, and intestines.

**Nadir:** the point at which blood counts are at their lowest.

**Neoplasm:** a characteristic of cancer in which a new or abnormal growth of tissue occurs in the body.

**Neuropathy:** a numbness or weakness of the limbs caused by dysfunction to one or more peripheral nerves.

**Neutropenia:** an abnormally low neutrophil count that increases the risk of infection.

**Petechiae:** reddish to purplish spots that appear on the skin resulting from localized hemorrhage, often accompanying low platelets.

**Platelets (also known as Thrombocytes):** cells in the body responsible for forming clots to stop bleeding.

**Prophylaxis:** an action or a specific means to prevent a disease process.

**Radiotherapy (also known as Radiation Therapy):** a form of treatment for cancer that involves high-energy ionizing rays that cause damage to cancer cells and inhibits their growth.

**Resection:** a surgical procedure to remove part, or all, of an organ or tumor.

**Thrombocytopenia:** a lower than normal platelet count that increases the risk of bleeding.

**Transfusion (also known as Blood Transfusion):** a procedure in which whole blood or parts of blood are put into a patient’s bloodstream through a vein. The blood may be donated by another person, or it may have been taken from the patient and stored until needed.

**Transplant:** a procedure in which an organ, tissue, or bone marrow is removed from one person and placed into another person.

**Tumor:** abnormal growth of tissue that can be benign or malignant.

**Tumor Lysis:** a complication that may occur during chemotherapy as a result of tumor cells being killed off and emitting their contents into the bloodstream.
Surviving Cancer from A to Z
by Grace Hamilton

My name is Grace Hamilton, and I was diagnosed with high-risk acute lymphoblastic leukemia at the age of 2, and I finished treatment right before my 5th birthday and right before my two little troublemaker sisters were born. They are now four years old but still troublemakers. I got thousands of doses of chemotherapy, countless spinal taps with chemo, and spent over 50 nights in Vanderbilt Children’s Hospital. I lost my hair and felt really bad at times, but it’s good to have a caring family, friends and medical providers.

A is for...Acute Lymphoblastic Leukemia: Cancer affecting the blood stream and almost three years of your life.

B is for...BFF: Everyone needs one of these to survive. My BFF is Montgomery Cate. She sat beside me while I got chemo and held my hand through the entire thing.

C is for...Cancer: I called my cancer a crazy adventure. It might not seem the same as a typical adventure, but we made it one just the same.

D is for...Doctor: Your supporter through all of the fight–from deciding how to best get rid of it to figuring out how to make you feel okay through it to becoming your friend. Mine are Dr. Ho and Maggie.

E is for...EKG: Worst thing in the world. Beware of the stickiness all over your chest. Eight sticky pads in fact.

F is for...Family: They make it bearable with lots of snuggle time, movie watching, book reading, and corn making when you’re craving CORN! Fudge is also important and might be the first store you get to go into after 9 months of only going to the hospital and home.

G is for...Grace: Survivor.

H is for...Hemoglobin: Magic red juice that will make you feel better immediately. (Hint: it’s a blood transfusion for low red blood cells if you can’t pronounce hemoglobin).

I is for...IV: Pole that gets in your way when you’re trying to dance...but necessary to keep you alive.

J is for...Jammies: Your wardrobe for nearly three years.

K is for...Kayla: Best nurse in the world. (also see D for Dara...the best nurse in the world as well).

L is for...Listen: Listen to all the words you don’t understand because you’re just a kid, but also listen for the love and laughter.

Having cancer is hard and definitely a challenge, so here is a dictionary guide to surviving and thriving:
M is for...Mommy: Someone who cares and is needed throughout for making up silly ideas like “crazy adventure,” “car picnics,” “gift closet,” and more. See also D for Daddy, N for Nana, M for Mimi, P for Papa and Pam. All good for things listed above.

N is for...Nose tubie: Almost inserted into nose but kept out with French fries. Lots of French fries.

O is for...Oncology Floor: The unit at Vanderbilt Children’s Hospital where you will fight and spend lots and lots and lots of energy and hours.

P is for...Port-a-catheter: Button in your chest that gets accessed weekly on Wednesdays to receive chemo. See also IV. . .the thing that gets in your way of moving around like a normal kid.

Q is for...Quack: The duck on the elevator that will distract you on the way into the Operating Room. Also, chemo duck who you will snuggle when you’re having a hard day. You always will try to be happy, but sometimes it won’t work.

R is for...Remission: Something you will be thankful for. I know I am.

S is for...Strawberry Shortcake: The movie you watch on repeat while receiving high-dose methotrexate. Believe me, you need to find a movie to watch on repeat.

T is for...Treatment: Could mean spinal tap with chemo, could mean IV chemo, could mean high-dose steroids (those taste AWFUL), could mean chemo by mouth, definitely means yuckiness.

U is for...Uncomfortable: How you feel a lot of the time...but see Jammies, Visitors, and Strawberry Shortcake. They will help with that.

V is for...Visitors: Only two allowed back while inpatient, Pam is a favorite because she colors Winnie the Pooh for hours, Nana because she is so snuggly, Papa because he plays hide and seek even though the hospital bed is always your hiding place, Mimi because she reads and reads and reads, or via car picnic where you get Chick-Fil-A through the drive-thru and park at your church and roll down your windows to greet visitors in the next car.

W is for...War: You will go to war with your own blood, and you will win.

X is for...X-ray: Beware of cold table, heavy drape (which is also cold), and your parents having to step out of the room. That part is not cool.

Y is for...Years: The amount of time it takes to beat the yuckiness. See also war, acute lymphoblastic leukemia, and crazy adventure.

Z is for...Zippedooda: Going on a Disney cruise for your Make-A-Wish trip, and that means it’s finally over.

Grace Hamilton
11 years old / In remission from High Risk Acute Lymphoblastic Leukemia

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Cancer can be a scary thing. I’ll admit it. When I was first diagnosed, I cried out all my tears, and wouldn’t listen to anybody else in this world. I went to school, and I was completely dazed. I thought I was in a nightmare: trapped and enclosed within a world of fear and despair. It’s been a little less than two years since my diagnosis now, and I just came back from a camp specifically for kids with cancer. I had so much fun, and made so many friends. When I was in the hospital, the nurses would always play the keyboard that my mom ordered for me and had delivered to my room. I got to participate in Uno and Monopoly games with the nurses there. The doctors were so kind, and still are. I aspire to be a surgeon when I am older, and one of the oncologists connected me with a cardiothoracic surgeon at the same hospital, and I was lucky enough to shadow her the day after I was discharged.

During scans (MRI, PET/CT, X-Rays, etc.), I was always a little nervous. It always helped me to think about all my friends, school, and my family. I also requested to listen to music during my scans. There was one place where I was even allowed to watch a whole movie during my MRI! Treatment was a little more different. Whenever I got a transfusion (blood products, mostly), I felt it was best if I distracted myself by watching TV, or maybe playing some games. It was over before I knew it! When I started chemo, I was nervous about getting a port in, and how much nausea and vomiting I would have. I was especially nervous about my hair loss. Thinking back on it now, I am so glad to have had the port placed. It is much better than an IV, especially since they can give you Lidocaine to put over it to numb up the area before they access it. To deal with nausea, I used Ativan (Lorazepam) mostly. I also used it during radiation. It worked really well. The scopolamine patch didn’t work for me that well and ended up hurting the back of my ear. Zofran (Ondansetron) also worked a bit for me for nausea and vomiting.

Being in the hospital was, at times, extremely boring. One of my favorite pastimes was knitting. I would knit all the time while watching TV, or even just sitting in the playroom while people-watching. If there are any Child Life specialists, I would definitely suggest asking about them and seeing if they can come play with you/your child. I also got a ChemoDuck (a stuffed animal duck) when I was inpatient, to help me further understand what my port was for and to have a buddy with me during treatment. Talking to my classmates during treatment, and telling them about my diagnosis was not an easy task. It was either sad, awkward, or just kind of weird to do. I would suggest telling them at a time that you think is right for you. If you don’t feel like telling them, that’s fine, too. If they ask, and you don’t want to tell them, don’t be afraid to be vague with your answer.

As I continue to stand up in the fight against pediatric cancer, I am still the happy, cheerful 17-year-old that I would have been without it. Cancer didn’t break me; it only made me understand how strong I really am. I wish everyone luck with their own journeys. Never give up, for difficult roads often lead to beautiful destinations.

• Make sure to be aware of all side effects of a drug, even side effects that don’t pop up until years later.
• I didn’t like taking senna (Senna glycosides, sennosides). It caused a lot of pain and didn’t work too well. Miralax is the best for constipation, in my opinion.
• Take each day as each day comes.
• Don’t be afraid to cry your eyes out.
Tab 2
Pediatric Cancer Information

A LOOK INSIDE
• Dear Parents and Caregivers
• Types of Pediatric Cancer
• Diagnosing and Stages
• Stories of Hope
As you begin to digest and process the monumental news that has just taken over your life, realize first that there are many, many professionals who are able to help you. Of course, there are the oncologists, surgeons, specialists, doctors, and nurses, but also social workers, clergy (even if you don’t consider yourself religious), child psychologists, child life specialists, and music and art therapists (for you as well as for your child).

Realize, too, that a palliative care team’s goal is to minimize discomfort. It’s a scary term and easy to think the worst, but by bringing them in right at the beginning, they can help minimize not only physical pain but psychological stress as well, both for you and for your child.

Everyone handles a new and serious diagnosis in a different way. Some caregivers spend hours into the night researching their child’s condition, the latest clinical trials, current research, and even speculative therapies. Others become quiet and pensive, leaving treatment entirely to the specialists. There is no right or wrong way to react, no right or wrong way to behave.

Don’t blame yourself. Yes, as parents, it is our responsibility and we do all we can to protect our children, especially from a serious, life-threatening peril. But nothing we could have done could have changed where we are now.

Know that you are not alone. Caregivers of pediatric cancer patients are a tight yet warmly welcoming community. You are family.

Richard Alpert
(FATHER OF MICAELA ALPERT)
Facts about Pediatric Cancer
• 43 children per day are expected to be diagnosed with cancer.
• 95% of children who survive cancer will end up having health related issues around age 45 as a result of being treated with drugs designed for adults.
• Only 4% of the billions of dollars that are annually spent on cancer treatments and research are directed towards pediatric cancer.
• Since 1980, fewer than 10 drugs have been created for children battling cancer, as compared to the hundreds that have been created for adults.
• Cancer is the #1 cause of death by disease among children.

What is Cancer?
Cancer is an abnormal growth of cells. It is caused by changes to genes that control the way our cells function, especially how they grow and divide.

Brain Cancer
• The brain and spinal cord make up the central nervous system (CNS). Brain and spinal cord tumors are growths of abnormal cells in tissues of the brain or spinal cord.
  — Tumors that start in the brain are called primary brain tumors.
  — A tumor that starts in another part of the body and spreads to the brain is called a metastatic brain tumor.
• Brain and spinal cord tumors may be either benign (not cancer) or malignant (cancer). Both benign and malignant tumors cause signs and symptoms and need treatment.
  — Benign brain and spinal cord tumors grow and press on nearby areas of the brain but rarely spread into other parts of the brain.
  — Malignant brain and spinal cord tumors are likely to grow quickly and spread into other parts of the brain.
• There are many types of brain and spinal cord tumors. They form in different cell types and in different areas of the brain and spinal cord.
• The signs and symptoms of brain and spinal cord tumors depend on where the tumor forms, its size, how fast it is growing, and the age of the patient.
• Brain and spinal cord tumors can occur in children. The types of tumors that form and the way they are treated are different in children. The prognosis (chance of recovery) depends on many factors, including age, tumor size, tumor type, and where the tumor is in the CNS.
Germ Cell Tumors

A germ cell is a type of cell that forms as a fetus develops. These cells later become sperm in the testicles or eggs in the ovaries. Sometimes, germ cells may develop into a germ cell tumor in other parts of the body, either before or after birth, often beginning in the testicles or ovaries; although, they can form almost anywhere in the body. These types of tumors include:

- **Extracranial Germ Cell Tumors:** A germ cell tumor that forms in parts of the body other than the brain, such as the gonads (testicles and ovaries), chest, abdomen, or tailbone.
  - Extracranial germ cell tumors are most common in teenagers 15 to 19 years of age.
- There are three types of extracranial germ cell tumors:
  - The most common type is mature teratoma, a benign tumor that is not likely to become cancer. Other types are immature teratomas (which may become cancer) and malignant germ cell tumors (cancer).
  - Extracranial germ cell tumors in children, especially ovarian germ cell tumors or testicular cancer, can usually be cured.
- **Central Nervous System (CNS) Germ Cell Tumors:** A germ cell tumor that forms in the brain or spinal cord.
  - The most common places for one or more CNS germ cell tumors to form is near the pineal gland and the area of the brain that includes the pituitary gland and the tissue just above it. Sometimes germ cell tumors may form in other areas of the brain.
  - The cause of most childhood CNS germ cell tumors is not known.
  - There are different types of CNS germ cell tumors. The type of CNS germ cell tumor depends on what the cells look like under a microscope. The two main types of CNS germ cell tumors are Germinomas and Nongerminomas.
  - Germinomas are the most common type of CNS germ cell tumor and have a good prognosis.
  - Nongerminomas either make or do not make hormones. CNS teratomas are a type of nongerminoma that do not make hormones. They may have different kinds of tissue in them, such as hair, muscle, and bone. Signs and symptoms may depend on where the tumor has formed, the size of the tumor, and whether or not the tumor makes hormones. They include unusual thirst, frequent urination, early puberty, or vision changes.

Leukemia

Leukemia is a cancer of the blood cells wherein immature blood cells formed in bone marrow become cancer. These cells do not work the way they should and crowd out the healthy blood cells in the bone marrow. Different types of leukemia depend on the type of blood cell that becomes cancer. For example, lymphoblastic leukemia is a cancer of the white blood cells. White blood cells are the most common type of blood cell to become cancer. However, red blood cells and platelets may also become cancer. Leukemia is the most common cancer in children younger than 15 years old.

- Leukemia can be either acute or chronic.
  - Acute leukemia is a fast-growing cancer that usually gets worse quickly.
  - Chronic leukemia is a slower-growing cancer that gets worse slowly over time.
- The treatment and prognosis for leukemia depend on the type of blood cell affected and whether the leukemia is acute or chronic.
Types of leukemia include:

- **Acute Lymphoblastic Leukemia (ALL):** the most common cancer diagnosed in children and represents approximately 25% of cancer diagnoses among children younger than 15 years old.
- **Acute Myeloid Leukemia (AML):** a cancer of the blood and bone marrow. Cancers that are acute usually get worse quickly if they are not treated. Cancers that are chronic usually get worse slowly. Also called acute myelogenous leukemia, acute myeloblastic leukemia, acute granulocytic leukemia, and acute non-lymphocytic leukemia.
- **Chronic Myeloid Leukemia (CML):** an indolent (slow-growing) cancer in which too many myeloblasts are found in the blood and bone marrow. Myeloblasts are a type of immature blood cell that makes white blood cells called myeloid cells.
  — CML may get worse over time as the number of myeloblasts increases in the blood and bone marrow. This may cause fever, fatigue, easy bleeding, anemia, infection, a swollen spleen, bone pain, or other signs and symptoms.
  — CML is usually marked by a chromosome change called the Philadelphia chromosome, in which a piece of chromosome 9 and a piece of chromosome 22 break off and trade places with each other. It usually occurs in older adults and rarely occurs in children.
  — Also called chronic granulocytic leukemia, chronic myelogenous leukemia, and chronic myeloid leukemia.
- **T-cell leukemia:** a type of leukemia in which large T lymphocytes (a type of white blood cell) that contain granules (small particles) are found in the blood. It is a chronic disease that may last for a long time and get worse. Also called T-LGL leukemia.

**Lymphoma**

- Lymphoma is cancer that begins in cells of the lymph system. The lymph system is part of the immune system, which helps the body fight infection and disease. Because lymph tissue is found throughout the body, lymphoma can begin almost anywhere.
- The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). These can occur in both children and adults.
  — Most people with Hodgkin lymphoma have the classic type. With this type, there are large, abnormal lymphocytes (a type of white blood cell) in the lymph nodes called Reed-Sternberg cells. Hodgkin lymphoma can usually be cured.
- There are many different types of NHL that form from different types of white blood cells (B-cells, T-cells, NK cells). Most types of NHL form from B-cells.
- NHL may be indolent (slow-growing) or aggressive (fast-growing).
- The most common types of NHL in adults are diffuse large B-cell lymphoma, which is usually aggressive, and follicular lymphoma, which is usually indolent. Mycosis fungoid and the Sézary syndrome are types of NHL that start in white blood cells in the skin. Primary central nervous system lymphoma is a rare type of NHL that starts in white blood cells in the brain, spinal cord, or eye. The treatment and the chance of a cure depend on the stage and the type of lymphoma.

**There are several types:**

- **Hodgkin’s Lymphoma:** a type of cancer that develops in the lymph system, which is part of the body’s immune system. The immune system protects the body from
foreign substances, infection, and diseases. If the Reed Sternberg cell is detected, the lymphoma will be classified as Hodgkin’s Lymphoma.

- **Non-Hodgkin’s Lymphoma**: a type of cancer that forms in the lymph system, which is part of the body’s immune system. The immune system protects the body from foreign substances, infection, and diseases.

- **Large B cell lymphoma**: a type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually aggressive (fast-growing). It is the most common type of non-Hodgkin lymphoma, and is marked by rapidly growing tumors in the lymph nodes, spleen, liver, bone marrow, or other organs. Other symptoms include fever, night sweats, and weight loss. There are several subtypes of diffuse large B-cell lymphoma.

- **Anaplastic large cell lymphoma**: an aggressive (fast-growing) type of non-Hodgkin lymphoma that is usually of the T-cell type. The cancer cells express a marker called CD30 or Ki-1 on the surface and may appear in the lymph nodes, skin, bones, soft tissues, lungs, or liver. Also called ALCL.

- **T-cell lymphoma**: a type of cancer that forms in T cells (a type of immune system cell). T-cell lymphomas may be either indolent (slow-growing) or aggressive (fast-growing). Most T-cell lymphomas are non-Hodgkin lymphomas. There are many different types of T-cell non-Hodgkin lymphomas. These include mycosis fungoides, anaplastic large cell lymphoma, and precursor T-lymphoblastic lymphoma. Prognosis and treatment depend on the type and stage of the cancer.

### Neuroblastoma (neural crest)

A disease in which malignant (cancer) cells form in certain types of nerve tissue. Neuroblastoma most often begins in the adrenal glands, which are on top of the kidneys. It can also form in nerve tissue in the neck, chest, abdomen, or spine. Neuroblastoma most often occurs in children younger than 5 years of age. Sometimes it forms before birth and is found during a routine pregnancy ultrasound. In children who are 6 months or younger, the disease sometimes goes away without treatment. Neuroblastoma is usually found when the tumor begins to grow and cause signs or symptoms. By the time it is diagnosed, the cancer has usually metastasized (spread to other parts of the body).

### Melanoma

A form of cancer that begins in melanocytes (cells that make the pigment melanin). It may begin in a mole (skin melanoma) but can also begin in other pigmented tissues, such as the eye or intestines.

### Sarcoma:

An uncommon group of cancers which arise in the bones and connective tissue, such as fat and muscle. In most cases, it is unclear what causes sarcoma. Family history and exposure to chemicals or radiation may increase risk. There are several types:

- **Ewing Sarcoma**: tumors that usually form in the hip bones, ribs, or middle of long bones. The disease occurs most often in teenagers. Ewing tumors are most common in bone but can also form in soft tissue.

- **Osteosarcoma**: the most common bone cancer. It starts in bone cells that make new
bone tissue. It usually forms at the end of long bones, such as the leg bones, but can form in any bone. It is most common in teenagers.

• **Soft Tissue Sarcoma**: a cancer that starts in soft tissues of the body, including muscle, tendons, fat, lymph vessels, blood vessels, nerves, and tissue around joints. The tumors can be found anywhere in the body but often form in the arms, legs, chest, or abdomen. Signs of soft tissue sarcoma include a lump or swelling in soft tissue. Sometimes there are no signs or symptoms until the tumor is big and presses on nearby nerves or other parts of the body. Children can develop soft tissue sarcoma. Treatment often works best in children, and they may have the best chance of being cured.

• **Rhabdomyosarcoma**: the most common type of soft tissue sarcoma in children. It begins in muscles that are attached to bones and help the body move. Most rhabdomyosarcomas are diagnosed in children younger than 10 years. Rhabdomyosarcomas usually form lumps near the surface of the body and are found early.

• **Wilms tumor and other childhood kidney tumors**: there are two kidneys, one on each side of the spine, above the waist. The kidneys clean the blood to take out waste and make urine. Urine collects in the renal pelvis, the area at the center of the kidney, and then passes through the ureter, into the bladder, and out of the body. The kidneys also make hormones that help control blood pressure and signal the bone marrow to make red blood cells when needed.

  — There are three main types of kidney cancer. Wilms tumors are the most common in children. Wilms tumors form in the tissues of the kidney that make urine. Certain inherited disorders can increase the risk of kidney cancer in children including von Hippel-Lindau syndrome, hereditary leiomyomatosis and renal cell cancer, Birt-Hogg-Dubé syndrome, and hereditary papillary renal cancer.

  — Kidney tumors may be benign or malignant.

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**Hepatoblastoma**
A type of liver tumor that occurs in infants and children.

**Retinoblastoma**
Cancer that forms in the tissues of the retina.
Cancer can cause many different symptoms. These are some of them:

- Skin changes, such as:
  - A new mole or change in existing mole.
  - A sore that does not heal.
  - A thickening or lump on or under the skin.
- Hoarseness or cough that does not go away.
- Changes in bowel habits.
- Difficult or painful urination.
- Problems with eating, such as:
  - Discomfort after eating.
  - A hard time swallowing.
  - Changes in appetite.
- Weight gain or loss with no known reason.
- Abdominal pain.
- Unexplained night sweats.
- Unusual bleeding or bruising and/or blood in urine.
- Feeling weak or very tired.

Most often, these symptoms are not due to cancer. They may also be caused by benign tumors or other problems. If symptoms last for a couple of weeks, it is important to see a doctor so that problems can be diagnosed and treated as early as possible.

**Diagnosis**

If symptoms occur or a screening test result suggests cancer, the doctor must find out whether it is due to cancer or some other cause. The doctor may ask about personal and family medical history and do a physical exam. The doctor also may order lab tests, scans, or other tests or procedures.

**Lab Tests**

High or low levels of certain substances in the body can be a sign of cancer. So, lab tests of the blood, urine, or other body fluids that measure these substances can help doctors make a diagnosis. However, abnormal lab results are not a sure sign of cancer. Lab tests are an important tool, but doctors cannot rely on them alone to diagnose cancer.

**Imaging Procedures**

Imaging procedures create pictures of areas inside the body that help doctors see if a tumor is present. These pictures can be made in several ways:

**CT scan**

An x-ray machine linked to a computer that takes detailed pictures of the organs.
**Nuclear scan**
A small injection of radioactive material, sometimes called a tracer, is administered. It flows through the bloodstream and collects in certain bones or organs. A machine called a scanner detects and measures the radioactivity and then creates pictures of bones or organs.

**PET scan**
An injection of radioactive material, sometimes called a tracer, is administered. Then, a machine makes 3-D pictures that show what the tracer collects in the body. These scans show how organs and tissues are working.

**MIBG scan**
Commonly used for detection of neuroendocrine tumors, such as neuroblastoma and phaeochromocytoma. It can also aid in the detection of carcinoid and medullary thyroid carcinoma.

**Ultrasound**
A device that sends sound waves, which people cannot hear, bounce from tissue to tissue inside the body. A computer uses these waves to create a picture of areas inside the body called a sonogram.

**MRI**
A strong magnet linked to a computer that makes detailed pictures of areas in the body.

**X-Ray**
Uses low doses of radiation to create pictures of the body’s interior.

**Biopsy**
In most cases, doctors need to do a biopsy to make a diagnosis of cancer. A biopsy is a procedure in which the doctor removes pieces of tissue to get a sample. A pathologist then examines the tissue to analyze if it is cancer. The sample may be removed in several ways:
- The doctor uses a needle to withdraw tissue, bone, marrow, or fluid.
- The doctor looks at areas inside the body using a thin, lighted tube called an endoscope. The scope is inserted through a natural opening, such as the mouth. Then, the doctor uses a special tool to remove tissue or cells through the tube.
- Surgery may be excisional or incisional.
  — In an excisional biopsy, the surgeon removes the entire tumor. Often some of the normal tissue around the tumor also is removed.
  — In an incisional biopsy, the surgeon removes just part of the tumor.

**Staging**
Stage refers to the extent of a cancer, such as how large the tumor is and if it has spread. Knowing the cancer stage helps the doctor:
- Understand how serious a cancer is and the chances of survival.
- Plan the best treatment.
• Identify clinical trials that may be treatment options.

A cancer is always referred to by the stage it was given at diagnosis, even if it gets worse or spreads. New information about how a cancer has changed over time gets added onto the original stage. So, the stage doesn’t change, even though the cancer might.

How Stage Is Determined
To learn the cancer stage, the doctor may order x-rays, lab tests, and other tests or procedures. See the section on Diagnosis to learn more about these tests.

Systems That Describe Stage
• There are many staging systems. Most include information about:
  — Tumor location.
  — Tumor size.
  — Cell type (such as, adenocarcinoma or squamous cell carcinoma).
  — If the cancer has spread to nearby lymph nodes.
  — If the cancer has spread to a different part of the body.
  — Tumor grade, which refers to how abnormal the cancer cells look and how likely the tumor is to grow and spread.

The TNM Staging System
The TNM (Tumor Nodes Metastasis) system is the most widely used cancer staging system. Most hospitals and medical centers use the TNM system as their main method for cancer reporting. You are likely to see cancer described by this staging system in a pathology report, unless the type of cancer uses a different staging system. Examples of cancers with different staging systems include brain and spinal cord tumors and blood cancers.

Other Ways To Describe Stage
The TNM system helps describe cancer in great detail. For many cancers, the TNM combinations are grouped into one of five main categories. This staging system is more commonly used by cancer registries than doctors, but you may still hear the doctor or nurse describe the cancer in one of the following ways:
• In situ: abnormal cells are present but have not spread to nearby tissue.
• Localized: cancer is limited to the place where it started, without signs that it has spread.
• Regional: cancer has spread to nearby lymph nodes, tissues, or organs.
• Distant: cancer has spread to distant parts of the body.
• Unknown: there is not enough information to determine the stage.

<table>
<thead>
<tr>
<th>Stage</th>
<th>What it means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Abnormal cells are present but have not spread to nearby tissue. Also called carcinoma in situ (CIS). CIS is not cancer, but it may become cancer.</td>
</tr>
<tr>
<td>Stage I, Stage II, and Stage III</td>
<td>Cancer is present. The higher the number, the larger the cancer tumor and the more it has spread to nearby tissues.</td>
</tr>
<tr>
<td>Stage IV</td>
<td>The cancer has spread to distant parts of the body.</td>
</tr>
</tbody>
</table>
About 17 months ago, our daughter was diagnosed at age 11 with AML (acute myeloid leukemia). To say our world turned upside down would be a massive understatement. We were unprepared, both physically and mentally, for the journey on which we were about to embark, but we knew we had to stay strong for the family...much easier said than done. Both my husband and I work full-time, so juggling work, 2 kids, a new home, a dog, and a cancer diagnosis were about to challenge us more than we ever knew.

The shock is truly debilitating, and there is a degree of grief that our bodies were experiencing during the onset of this journey. Every ‘first’ experience was emotionally and physically draining - the first hospital admission, first surgery for a port, first chemotherapy infusion, first blood transfusion and the first meeting with a plethora of doctors, nurses, residents, interns, therapists, nurse practitioners and physician assistants, all of whom asked probing and repetitive questions that left our brains and our hearts hurting. The overwhelming emotions were just too much to reconcile at the beginning, all on top of kind-hearted family members, friends, medical workers and complete strangers who burdened us with the innocent question, “what can I do to help?” How could we possibly know what we needed at that point? We didn’t – we had no clue.

We needed time to process, learn, adjust and grieve. We needed time to help our kids process, learn, adjust and grieve. And we needed time to help our family and friends process, learn, adjust and grieve. We thought we could do all of this very quickly - after all, the faster we did this, the faster we could move on and start fighting the horrible cancer battle. FALSE! As they say, “it's all about the journey, not the destination.”

The biggest piece of advice I can give to parents and caregivers is to stay true to yourself. Statement of the obvious? Yes! Trust your intuition – if your gut tells you something is wrong with your child, stay true to yourself and act like the fantastic parent/caregiver you are, and press the medical workers to determine the root cause. Just because you’re in a hospital and/or surrounded by medical professionals, doesn’t mean you stepped down from your job as a parent/caregiver. Your child is helpless in the world of hospitals and medicine, so be your child’s advocate, and don’t be afraid to stand up for their rights. If a medical worker comes into the hospital room at 6 AM to poke, prod and ask a hundred questions, stay true to yourself by protecting your child like you would outside the hospital, and ask them to return after 8 AM! Many people will tell you what to do in a loving and caring way (e.g., go outside for some fresh air, go home to rest, go out for lunch or dinner, etc.) – if you would like to follow their advice, go for it, and don’t feel guilty! If not, stay true to yourself and decline the offer. Everyone wants to participate by helping. If you don’t want to read the book someone offers, or call a stranger who knows someone who went through something similar, stay true to yourself, and don’t do it!

Some people rely heavily on support groups and talking to others who have had similar experiences - and others do not. It’s important for you to draw boundaries and ensure people know in which category you fall. If you fall in the former category, take lots and lots of notes on names, contacts, chat groups, books, etc., as you will never remember everything when you are of sound mind and body again. If you fall in the latter category, you may want to unanimously poke around in chat groups on social media and the internet, but otherwise rely on your closest confidants for support. Don’t be afraid to reach out for help and to ask questions – everyone around you is willing to help you in any way they can, and it doesn’t mean you have to make a long-term commitment to a support group. Support groups can be an incredible part of your journey, and they can also be emotionally draining – sharing your story over and over, listening to other families’ stories, re-living the most difficult moments, all the while staying strong for yourself and your family.
Being a total ‘foodies,’ I have to say this: Food is very important! Healthy eating is one of the most important components to maintaining your strength and energy! Unfortunately, it falls low on the priority list when you’re caring for a gravely ill child. When people offer you food, take it! Home-cooked meals are few and far between during hospitalization, so we learned to appreciate anything and everything people gave us to eat. When neighbors offer to bring meals in to your home (during or after hospitalization), graciously accept their generosity!

A lot of people talk about the impact their child’s cancer diagnosis has on their personal relationships and friendships. A little peek into online support groups will quickly enlighten you to the drama that can ensue during your journey. Your child’s cancer diagnosis is one of the biggest elephants that exists in any room you enter and any conversation you have. Human nature dictates that most people have no idea what to say and how to act around you – they want to be supportive, but they don’t want to say the wrong thing, and they don’t want to make you cry. You will encounter a lot of different types of people – some who will be there just for the hug or cry on their shoulder, some who jump in and start doing things (come to your house to do your laundry, clean your house, cook meals, run errands, etc.), some who simply tell you they love you but don’t want the emotional burden in their lives, and some who avoid you because they really don’t know what to do or say. Avoiding the elephant is easiest for a lot of people, so we need to accept them for who they are, or we can help educate them on what we need. If you know what you need from them, tell them! If not, don’t blame them for avoiding the subject.

Stay true to yourself and do what feels right. If making a list of things people can do to help you will ease your burden, make the list right now! If joining 10 support groups will make you feel more educated and more involved, join them today! If talking to a healthcare professional about your feelings will help you sort through your emotions, get a referral immediately and make an appointment right away! If you need some alone time and don’t want to engage in conversation about your child’s illness, take the time you need and let people know to call you next month! If you need time alone with your spouse/partner or other kids, arrange for someone to care for your ill child, and take the time! Don’t apologize for what you need, and please...don’t apologize for your feelings. We are human, and we can only do so much. The airlines were on to something when they decided to tell adults to put their oxygen mask on first, and then help their child – remember, you can’t take care of your child if you’re unable to take care of yourself first.
When my daughter was first diagnosed with cancer, my whole world stopped. I couldn’t believe the words I was hearing. As the doctors were coming and going, I watched how strong and calm my daughter was. She was 11 at the time. At one point the surgeon came in and explained what he was going to do and her response was “So you’re saying I’m going to have a cool scar?” He chuckled and responded that yes, she was going to have a cool scar and that it will be part of her story. We had no idea what was ahead of us, but whatever it was, it would be her story. In the days that followed, we all found a depth of strength I didn’t know was possible.

Something I found helpful from trying to keep fear from completely overtaking me was prayer and visualizing. During the long nights when I couldn’t sleep and was filled with worry, I would pray and visualize an army of tiny people inside my daughter carefully gathering cancer cells and putting them in sealed bags. I could have easily spent 100 hours doing this. Whether it actually helped I don’t know, but oddly it helped the helplessness I was feeling, which helped me stay strong for my kids.

When my younger daughter was struggling to deal with what was happening to her sister, it was hard for her to say what her concerns were. She was 7 at the time. I asked her to take some time and draw me a picture and maybe just write out a few words of what she was feeling. Her fear of her sister dying was something she was trying to understand, and as it turned out, she was feeling guilty for having these thoughts. We were able to talk about it and assure her she wasn’t wrong or alone with her concerns. Family and individual counseling has been very helpful for us. It can be really hard on siblings.

Something that seemed to help with mouth sores and general GI was L-Glutamine. We got it as a powder and added it to a drink. She would start it an hour before each round of chemo and sip on it through treatment time. It was something her doctor suggested, and I believe it helped things from being much worse.

She also had a very hard time taking the prednisone. Toward the end of her treatment, a nurse suggested we put the dosage in gelatin capsules. This was a game changer. It seems the chalky texture was just really hard for her to get down. I was able to make the pills a little smaller for her, and it made all the difference.

Through all the heartbreaking realities of childhood cancer there are angels who are there in the most unexpected ways. You will meet some of the best people in the world. You will come through this a changed person. We are now involved in a few organizations, and my daughter is an ambassador for two of them that raise awareness and funding for pediatric cancer.
Tab 3
Treatments

A LOOK INSIDE
• Cancer Treatment
• Side Effects of Cancer Treatment
• Common Drugs Used to Treat Pediatric Cancer
• Research and Clinical Trials
• Symptom Management Suggestions
• Stories of Hope
CANCER Treatments

Surgery
The treatment of injuries or disorders of the body by incision or manipulation.

Radiation Therapy
A treatment where high doses of radiation are used to kill cancer cells or shrink tumors.

Chemotherapy
A treatment that uses chemical substances, such as drugs, to kill off cancerous cells.

Immunotherapy
A treatment that helps your immune system to battle cancer.

Targeted Therapy
A treatment that targets the changes in the cancerous cell to stop them from growing or spreading.

Stem Cell Transplant
A procedure that restores blood-forming stem cells in cancer patients who have had theirs destroyed by very high doses of chemotherapy or radiation therapy.

Precision Medicine
An approach to cancer care that allows doctors to select treatments that are most likely to help patients based on a genetic understanding of their disease.

Common Effects of Cancer Treatments:
- Anemia
- Appetite Loss
- Bleeding/Bruising
- Constipation
- Delirium
- Diarrhea
- Edema
- Fatigue
- Hair Loss
- Infection and Neutropenia
- Lymphedema
- Memory or Concentration Problems
- Mouth and Throat Problems
- Nausea and Vomiting
- Pain
- Sexual and Fertility Problems (Male/Female)
- Skin and Nail Problems
- Sleep Problems
- Urinary and Bladder Problems
Fertility
Some treatments used may affect your child’s ability to have children in the future. Depending on your child’s treatment, you and your child’s doctor should discuss whether fertility preservation options should be pursued prior to starting treatment. The doctor may then refer you to a fertility preservation specialist. Often times fertility preservation is most easily addressed after puberty.

Effects of therapy will differ between males and females. Sperm production impairment is the easiest to predict for males and shortening of the fertility for females. These are the most common fertility effects with chemotherapy.

Many studies have found that learning about fertility prior to therapy, even if ultimately choosing not to go through any procedure, is helpful for patients and families.

Females: Egg cryopreservation can be used in females who have gone through puberty. It is relatively costly (thousands of dollars) and takes a few weeks. For younger females who have yet to go through puberty, the process of ovarian tissue cryopreservation is offered at some centers.

Males: For males who have reached puberty sperm banking is used (a few hundred dollars per year). For those males who have not reached puberty, testicular sperm extraction and testicular tissue cryopreservation are offered at some centers but are more complicated.

For additional resources providing more information regarding fertility preservation visit:

Alliance for Fertility Preservation
AllianceForFertilityPreservation.org

Critical Mass: The Young Adult Cancer Alliance
CriticalMass.org

National Cancer Institute
Cancer.gov

AYA Cancer Connect
AYACancerConnect.com/resources/fertility

ReproTech
ReproTech.com
COMMON DRUGS USED TO TREAT Pediatric Cancer

LEUKEMIA:

**Arsenic Trioxide**
Drug Type: Antineoplastic
Aim: Causes death of leukemia cells via morphological changes and DNA fragmentation in both acute promyelocytic leukemia (APL) and acute myeloid leukemia (AML) when previous treatments are not working.
Side Effects: Nausea, vomiting, fatigue, fever, headaches, rapid heartbeat, abdominal pain, diarrhea, shortness of breath, blurred vision, blood test abnormalities, swelling, sore throat, insomnia, rash, joint pain, itching, numbness of hands and feet, chills, anxiety, shivering, increase in white blood cell counts.
Administered/Taken: Intravenous injection.

**Asparaginase Erwinia Chrysanthemi**
Drug Type: Enzyme
Aim: Interferes with natural substances necessary for cancer cell growth. Used in patients who can no longer take asparaginase made from E. coli. and who suffer from acute lymphoblastic leukemia (ALL).
Side Effects: Nausea, vomiting, fever, hives, rash, itching, difficulty breathing or swallowing, ongoing pain that begins in the stomach area, extreme thirst, frequent urination, extreme hunger, weakness, blurred vision, headache, arm or leg swelling, shortness of breath, chest pain, unusual bleeding, yellowing of the skin or eyes, pain in the upper right part of the stomach, dark colored urine, loss of appetite, lack of energy, seizure.
Administered/Taken: Intramuscular injection.

**Blinatumomab**
Drug Type: Bispecific T-Cell Engager Antibody
Aim: Treats B-cell acute lymphoblastic leukemia (ALL) that is Philadelphia chromosome negative and is not responding to treatments by directing the body's T-cells (part of the immune system) to target and bind with the cancer cells.
Side Effects: Constipation, diarrhea, weight gain, back, joint, or muscle pain, stomach pain, difficulty falling asleep or staying asleep, swelling of the arms, hands, feet, ankles, or lower legs, pain at the injection site, chest pain, numbness or tingling in the arms, legs, hands, or feet, shortness of breath.
Administered/Taken: Intravenous injection.
Clofarabine
Drug Type: Purine Nucleoside Antimetabolite
Aim: Kills existing cancer cells and limits the growth of new cancer cells by restricting cell division in acute lymphoblastic leukemia (ALL) patients that have received at least two other treatments. Cell-cycle specific.
Side Effects: Nausea, vomiting, stomach pain, diarrhea, constipation, loss of appetite, weight loss, swelling of the inside of the mouth and nose, painful white patches in the mouth, headache, anxiety, depression, irritability, pain in the back, joints, arms, or legs, drowsiness, dry, itchy, or irritated skin, flushing, fast heartbeat, fast breathing, shortness of breath, dizziness, lightheadedness, fainting, decreased urination, sore throat, cough, fever, chills, and other signs of infection, pale skin, excessive tiredness, weakness, confusion, unusual bruising or bleeding, nosebleed, bleeding gums, blood in urine, small red or purple spots under the skin, yellowing of the skin or eyes, itching, red, warm, swollen, tender skin, uncontrollable shaking of a part of the body.
Administered/Taken: Intravenous injection.

Cyclophosphamide
Drug Type: Alkylating Agent
Aim: Stops or slows growth of cancer cells by damaging the RNA or DNA that tells the cell how to copy itself in division. Used for patients with chronic lymphocytic leukemia (CLL), chronic myelocytic leukemia (CML), acute myelocytic leukemia (AML), and acute lymphocytic leukemia (ALL). Cell-cycle nonspecific.
Side Effects: Nausea, vomiting, loss of appetite or weight, abdominal pain, diarrhea, hair loss, sores on the mouth or tongue, changes in skin color, changes in color or growth of finger or toe nail, sore throat, fever, chills, or other signs of infection, poor or slow wound healing, unusual bruising or bleeding, black, tarry stools, painful urination or red urine, rash, hives, itching, difficulty breathing or swallowing, shortness of breath, cough, swelling in the legs, ankles, or feet, chest pain, yellowing of the skin or eyes.
Administered/Taken: Intravenous, intramuscular, intraperitoneal, or intrapleural injection; tablet taken by mouth.

Cytarabine
Drug Type: Antimetabolite
Aim: Incorporated into cancer cells due to a similar structure and keeps cells from splitting. Used often with acute lymphocytic leukemia (ALL), acute and chronic myelocytic leukemia (AML), meningeal leukemia, and erythroleukemia. Cell-cycle specific.
Side Effects: Temporary low blood counts (which can result in anemia, infection, and bleeding), diarrhea, loss of appetite, skin rash and itching, flu-like symptoms, skin redness and peeling on hands and feet, temporary hair loss, eye pain and sensitivity, dizziness, headache, excessive lethargy, confusion, loss of balance, vomiting, mouth sores.
Administered/Taken: Intravenous, intramuscular, or intraventricular injection.
**Daunorubicin Hydrochloride**

**Drug Type:** Anthracycline  
**Aim:** Slows growth of cancer cells for acute lymphoblastic leukemia (ALL) patients.  
**Cell-cycle specific.**  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, diarrhea, stomach pain, hair loss, red urine, redness, pain, swelling, or burning at the site where the injection was given, rash, hives, itching, difficulty breathing or swallowing.  
**Administered/Taken:** Intravenous injection.

**Dexamethasone**

**Drug Type:** Corticosteroids  
**Aim:** Helps with swelling, vomiting, and nausea.  
**Side Effects:** Increased appetite, irritability, difficulty sleeping, swelling in ankles and feet, heartburn, muscle weakness, impaired wound healing, increased blood sugar levels, headaches, dizziness, mood swings, cataracts and bone thinning.  
**Administered/Taken:** Intravenous or intramuscular injection; tablet taken by mouth.

**Doxorubicin Hydrochloride**

**Drug Type:** Anthracycline  
**Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells.  
**Cell-cycle specific.**  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.  
**Administered/Taken:** Intravenous injection.

**Etoposide**

**Drug Type:** Podophyllotoxin Derivative  
**Aim:** Interferes with the action of topoisomerase enzymes by controlling the manipulation of the structure of DNA necessary for replication. Used with high-risk patients who have acute lymphoblastic leukemia (ALL) or acute myeloid leukemia (AML). Cell-cycle specific.  
**Side Effects:** Swelling, pain, redness, or burning at the injection site, nausea, vomiting, sores in the mouth and throat, stomach pain, diarrhea, constipation, loss of appetite or weight, unusual tiredness or weakness, pale skin, fainting, dizziness, hair loss, pain, burning, or tingling in the hands or feet, eye pain, rash, hives, itching, difficulty breathing or swallowing, fast, irregular, or pounding heartbeat, seizures, yellowing of the skin or eyes.  
**Administered/Taken:** Intravenous injection.
**Idarubicin Hydrochloride**

**Drug Type:** Anthracycline  
**Aim:** Inhibits DNA replication in cancerous cells and ultimately interferes with RNA and protein synthesis in patients with acute myeloid leukemia (AML). Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, diarrhea, sores in the mouth and throat, stomach pain, headache, joint pain, hair loss, rash, redness and blisters on the palms and soles, seizures, hives, dizziness, fainting, pale skin, difficulty urinating, yellowing of the skin or eyes.  
**Administered/Taken:** Intravenous injection.

**Imatinib**

**Drug Type:** Kinase Inhibitor  
**Aim:** Blocks the activity of tyrosine kinase, an enzyme that causes cell multiplication. Used to stop Philadelphia chromosome positive (Ph+), acute lymphoblastic leukemia (ALL), and Philadelphia chromosome positive chronic myeloid leukemia (Ph+ CML).  
**Side Effects:** Temporary low blood counts (which can result in anemia, infection, and bleeding), nausea and vomiting, swelling, muscle cramps, bone pain, diarrhea, Hemorrhage, skin rash, fever, headache, fatigue, joint pain, indigestion, abdominal pain, cough, shortness of breath, poor appetite, constipation, night sweats, nose bleeds, weakness, loss of fertility.  
**Administered/Taken:** Tablet taken by mouth with a large glass of water, after a meal.

**Mercaptopurine**

**Drug Type:** Purine Antagonist  
**Aim:** Blocks DNA synthesis and interconversions of cancerous cells in patients with acute lymphoblastic leukemia (ALL). Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, darkening of the skin, hair loss, rash, pale skin, weakness, shortness of breath, sore throat, fever, chills, or other signs of infection, swelling in the legs, ankles, or feet, unusual bruising or bleeding, yellowing of the skin or eyes, loss of appetite, diarrhea, swelling of the stomach area, pain in the upper right part of the stomach.  
**Administered/Taken:** Tablet taken by mouth, at the same time every day on an empty stomach.

**Methotrexate**

**Drug Type:** Antimetabolite  
**Aim:** Counteracts and competes with folic acid in cancer cells, resulting in folic acid deficiency in the cells and causing their death in patients with meningeal leukemia and acute lymphoblastic leukemia (ALL). Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.  
**Administered/Taken:** Intrathecal injection.
Nelarabine
*Drug Type:* Antimetabolite
*Side Effects:* Nausea, vomiting, diarrhea, constipation, loss of appetite, stomach pain or swelling, sores on the mouth or tongue, headache, dizziness, insomnia, depression, pain in arms, legs, back, or muscles, swelling of the hands, arms, feet, ankles, or lower legs, blurred vision, pale skin, shortness of breath, fast heartbeat, chest pain, cough, wheezing, unusual bleeding or bruising, nosebleeds, small red or purple dots on the skin, fever, sore throat, chills, or other signs of infection, extreme thirst, decreased urination, sunken eyes, dry mouth and skin.
*Administered/Taken:* Intravenous injection.

Pegaspargase
*Drug Type:* Enzyme
*Aim:* Blocks protein synthesis and tumor cell proliferation, keeping cells from multiplying in patients with acute lymphoblastic leukemia (ALL).
*Side Effects:* Nausea, vomiting, diarrhea, fever, tiredness, dizziness, hives, skin rash, itching, hoarseness, difficulty breathing or swallowing, headache, swelling of the face, arms, or legs, fainting, chest pain, ongoing pain that begins in the stomach area, but may spread to the back, frequent urination, increased thirst.
*Administered/Taken:* Intramuscular or intravenous injection.

Prednisone
*Drug Type:* Corticosteroid
*Aim:* Causes cancerous white blood cells to die and can prevent white blood cells from going to inflammatory areas of the body. Used in patients with acute lymphoblastic leukemia (ALL) and chronic lymphocytic leukemia (CLL).
*Side Effects:* Irritability, increased appetite, insomnia, swelling in ankles and feet, nausea, heartburn, muscle weakness, impaired wound healing, increased blood sugar levels, headaches, dizziness, mood swings, cataracts, bone thinning.
*Administered/Taken:* Tablet or liquid taken by mouth with food, juice, or soft fluids.

Teniposide
*Drug Type:* Podophyllotoxin Derivative
*Aim:* Interferes with the action of topoisomerase enzymes by controlling the manipulation of the structure of DNA necessary for replication in patients with acute lymphocytic leukemia (ALL), especially if the cancer returns after a short remission. Cell-cycle specific.
*Side Effects:* Nausea, vomiting, sores in the mouth or tongue, diarrhea, hair loss, blurred vision, pale skin, excessive tiredness, headache, confusion, pain, numbness, burning, or tingling in the hands or feet, slow or irregular heartbeat.
*Administered/Taken:* Intravenous injection.
**Thioguanine**

**Drug Type:** Purine Analog  
**Aim:** Inhibits DNA development and RNA syntheses, resulting in cell death in patients with acute myeloid leukemia (AML). Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, loss of appetite or weight, sores in the mouth and throat, headache, unusual tiredness or weakness, unusual bleeding or bruising, yellowing of the skin or eyes, flu-like symptoms, swelling of the stomach area, stomach pain (particularly in the right part of the stomach), swelling of the face, arms, hands, feet, ankles or lower legs, bloody vomit, black, tarry or bloody stools, fever, sore throat, ongoing cough and congestion, or other signs of infection, shortness of breath, lightheadedness.  
**Administered/Taken:** Tablet taken by mouth.

**Vincristine Sulfate**

**Drug Type:** Vinca Alkaloid  
**Aim:** Inhibits the microtubule structures within the cell, which aid in cell division and replication, preventing the cancer from growing in patients with acute lymphoblastic leukemia (ALL). Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite or weight, stomach pain, diarrhea, headache, hair loss, hives, rash, itching, difficulty breathing or swallowing, constipation, increased or decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, unusual bleeding or bruising, unusual tiredness or weakness, pain, numbness, burning, or tingling in the hands or feet, difficulty walking or unsteady walking, muscle or joint pain, sudden changes in vision, including loss of vision, hearing loss, dizziness, loss of the ability to move muscles and to feel a part of the body, hoarseness or loss of ability to speak loudly, seizures, jaw pain, fever, sore throat, chills, or other signs of infection.  
**Administered/Taken:** Intravenous injection.

**BONE:**

**Dactinomycin**

**Drug Type:** Antitumor Antibiotics  
**Aim:** Damages the RNA or DNA that tells the cell how to divide during several stages of the cell cycle. Cell-cycle specific.  
**Side Effects:** Vomiting, stomach pain, diarrhea, hair loss, hives, rash, difficulty breathing or swallowing, nausea, extreme tiredness, unusual bleeding or bruising, sores in the mouth and throat, lack of energy, loss of appetite, pain in the upper right part of the stomach, yellowing of the skin or eyes, fever, sore throat, ongoing cough and congestion, or other signs of infection, unusual bleeding or bruising, black and tarry stools, red blood in stools.  
**Administered/Taken:** Intravenous injection.

**Denosumab**

**Drug Type:** Rank Ligand Inhibitors  
**Aim:** Reduces fractures from certain types of cancer that began in another part of the body but has spread to the bones in areas that cannot be treated surgically. Decreases
bone breakdown and increases bone strength and density.  
**Side Effects:** Red, dry, or itchy skin, oozing or crusty blisters on skin, peeling skin, back pain, pain in your arms, muscle or joint pain, nausea, diarrhea, headache, runny nose, sore throat, muscle stiffness, twitching, cramps, or spasms, numbness or tingling in your fingers, toes, or around your mouth, hives, rash, itching, difficulty breathing or swallowing, swelling of the face, throat, tongue, or lips, dizziness, fainting, blurred vision, fever or chills, tiredness, redness, tenderness, swelling or warmth of area of skin, ear drainage or severe pain, frequent or urgent need to urinate, burning feeling when you urinate, pain, numbness, swelling, or drainage from mouth, teeth, or jaw, slow healing of the mouth or jaw, severe abdominal pain, ongoing pain that begins in the stomach area, but may spread to the back, fast heart rate.  
**Administered/Taken:** Subcutaneous injection.

**Doxorubicin Hydrochloride**  
**Drug Type:** Anthracycline  
**Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells. Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.  
**Administered/Taken:** Intravenous injection.

**KIDNEY:**  
**Everolimus**  
**Drug Type:** Kinase Inhibitor  
**Aim:** Treats patients with subependymal giant cell astrocytoma (SEGA) who are not eligible for curative surgical resection.  
**Side Effects:** Low red blood cell count, increased blood cholesterol level, increased creatinine, mouth sores, low phosphorus levels, weakness, infection, diarrhea, cough, and less commonly; rash, low blood count, nausea, vomiting, increased liver enzymes, swelling, poor appetite, shortness of breath, fever, fatigue, headache, nosebleeds, itching, lung problems, dry skin.  
**Administered/Taken:** Tablet taken by mouth, either swallowed or dissolved in water. Take at the same time each day, may be taken with or without food.
**HODGKIN LYMPHOMA:**

**Cyclophosphamide**

**Drug Type:** Alkylating Agent  
**Aim:** An anti-cancer chemotherapy drug used to treat Hodgkin’s Lymphoma, non-Hodgkin’s Lymphoma, Burkitt’s lymphoma, and other non-lymphocytic conditions such as leukemia, neuroblastoma and breast cancer. Cell-cycle non-specific.  
**Side Effects:** Nausea, vomiting, loss of appetite or weight, abdominal pain, diarrhea, hair loss, sores on the mouth or tongue, changes in skin color, changes in color or growth of finger or toe nail, sore throat, fever, chills, or other signs of infection, poor or slow wound healing, unusual bruising or bleeding, black, tarry stools, painful urination or red urine, rash, hives, itching, difficulty breathing or swallowing, shortness of breath, cough, swelling in the legs, ankles, or feet, chest pain, yellowing of the skin or eyes.  
**Administered/Taken:** Intravenous (IV) infusion and by mouth.

**Dacarbazine**

**Drug Type:** Purine Analog  
**Aim:** Stops cell growth during resting phase. Cell-cycle non-specific.  
**Side Effects:** Nausea, vomiting, loss of appetite, diarrhea, sores in the mouth and throat, hair loss, feeling of burning or tingling on the face, flushing, flu-like symptoms, redness, pain, swelling, or burning at the site where the injection was given, hives, skin rash, itching, difficulty breathing or swallowing, fever, muscle aches, and general feeling of pain and tiredness.  
**Administered/Taken:** Intravenous injection.

**Doxorubicin Hydrochloride**

**Drug Type:** Anthracycline  
**Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells. Cell-cycle specific.  
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.  
**Administered/Taken:** Intravenous injection.

**Lomustine**

**Drug Type:** Alkylating Agent  
**Aim:** Stops growth of cancer cells by damaging DNA and RNA and is a unique chemotherapy because it can pass through the blood-brain barrier. Cell-cycle non-specific.  
**Side Effects:** Nausea, vomiting, loss of appetite, sores in the mouth and throat, unusual tiredness or weakness, pale skin, fainting, hair loss, unsteady walk, slurred speech, difficulty breathing, shortness of breath, dry cough, chest pain, wheezing, decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, yellowing of eyes and skin, confusion, sudden change or loss of vision.
Administered/Taken: Tablet taken by mouth. Taken with fluids on an empty stomach. No food or drink for 2 hours after to decrease incidence of nausea.

**Procarbazine**

Drug Type: Alkylating Agent

**Aim:** Treats advanced forms of Hodgkin’s lymphoma. Cell-cycle non-specific.

**Side Effects:** Low white blood cell count, low platelet count, nausea, vomiting, poor appetite, hair loss, mouth sores, diarrhea, constipation, flu-like symptoms, central neurotoxicity, hypersensitivity, loss of fertility.

Administered/Taken: Tablet taken by mouth.

**BRAIN:**

**Everolimus**

Drug Type: Kinase Inhibitor

**Aim:** Used to treat subependymal giant cell astrocytoma (SEGA) by stopping cells from reproducing and reducing blood supply to cancer cells.

**Side Effects:** Diarrhea, constipation, change in ability to taste food, weight loss, dry mouth, weakness, headache, difficulty falling asleep or staying asleep, nosebleed, dry skin, acne, problems with nails, hair loss, pain in the arms, legs, back or joints, muscle cramps, missed or irregular menstrual periods, heavy menstrual bleeding, difficulty getting or keeping an erection, anxiety, aggression or other changes in behavior, hives, itching, swelling of the hands, feet, arms, legs, eyes, face, mouth, lips, tongue, or throat, hoarseness, difficulty breathing or swallowing, wheezing, flushing, chest pain, extreme thirst or hunger, unusual bleeding or bruising, pale skin, fast or irregular heartbeat, dizziness, seizures.

Administered/Taken: Tablet taken by mouth, either swallowed or dissolved in water. Take at the same time each day, may be taken with or without food.

**Lomustine**

Drug Type: Alkylating Agent

**Aim:** Stops growth of cancer cells by damaging DNA and RNA and is a unique chemotherapy because it can pass through the blood-brain barrier. Cell-cycle non-specific.

**Side Effects:** Nausea, vomiting, loss of appetite, sores in the mouth and throat, unusual tiredness or weakness, pale skin, fainting, hair loss, unsteady walk, slurred speech, difficulty breathing, shortness of breath, dry cough, chest pain, wheezing, decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, yellowing of eyes and skin, confusion, sudden change or loss of vision.

Administered/Taken: Tablet taken by mouth. Taken with fluids on an empty stomach. No food or drink for 2 hours after to decrease incidence of nausea.

**NEUROBLASTOMA:**

**Cyclophosphamide**

Drug Type: Alkylating Agent

**Aim:** Slows growth of cancer cells by interfering with DNA replication.

**Side Effects:** Nausea, vomiting, loss of appetite or weight, abdominal pain, diarrhea, hair
loss, sores on the mouth or tongue, changes in skin color, changes in color or growth of
finger or toe nail, sore throat, fever, chills, or other signs of infection, poor or slow wound
healing, unusual bruising or bleeding, black, tarry stools, painful urination or red urine,
rash, hives, itching, difficulty breathing or swallowing, shortness of breath, cough, swelling
in the legs, ankles, or feet, chest pain, yellowing of the skin or eyes.

**Administered/Taken:** Intravenous, intramuscular, intraperitoneal, or intrapleural injection.

**Dacarbazine**
**Drug Type:** Purine Analog
**Aim:** Stops cell growth during resting phase. Cell-cycle nonspecific.
**Side Effects:** Nausea, vomiting, loss of appetite, diarrhea, sores in the mouth and throat,
hair loss, feeling of burning or tingling on the face, flushing, flu-like symptoms, redness,
pain, swelling, or burning at the site where the injection was given, hives, skin rash, itching,
difficulty breathing or swallowing, fever, muscle aches, and general feeling of pain and
tiredness.

**Administered/Taken:** Intravenous injection.

**Dinutuximab**
**Drug Type:** Monoclonal Antibody
**Aim:** Used to treat high-risk neuroblastoma by killing cancer cells.
**Side Effects:** Vomiting, diarrhea, nausea, decreased appetite, weight gain, fever, chills,
and other signs of infection, blurred vision, changes in vision, sensitivity to light, drooping
eyelids, seizures, muscle cramps, rapid heartbeat, fatigue, blood in urine, unusual bleeding
or bruising, vomit that is bloody or looks like coffee grounds, stool that contains bright
red blood or is black and tarry, pale skin, swelling of the hands, feet, ankles, or lower legs,
shortness of breath, fainting, dizziness or lightheadedness.

**Administered/Taken:** Intravenous injection.

**Doxorubicin Hydrochloride**
**Drug Type:** Anthracycline
**Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells.
Cell-cycle specific.
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight
loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness,
dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery,
or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration
of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.

**Administered/Taken:** Intravenous injection.

**Vincristine Sulfate**
**Drug Type:** Vinca Alkaloid
**Aim:** Interferes with the formation of tumor cells in metaphase, preventing the cancer from
growing. Cell-cycle specific.
**Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite or weight,
stomach pain, diarrhea, headache, hair loss, hives, rash, itching, difficulty breathing or swallowing, constipation, increased or decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, unusual bleeding or bruising, unusual tiredness or weakness, pain, numbness, burning, or tingling in the hands or feet, difficulty walking or unsteady walking, muscle or joint pain, sudden changes in vision (including loss of vision), hearing loss, dizziness, loss of the ability to move muscles and to feel a part of the body, hoarseness or loss of ability to speak loudly, seizures, jaw pain, fever, sore throat, chills, or other signs of infection.

Administered/Taken: Intravenous injection.

**WILMS TUMOR:**

**Dactinomycin**

Drug Type: Antitumor Antibiotic

Aim: Damages DNA when cancer cells are dividing. Cell-cycle specific.

Side Effects: Vomiting, stomach pain, diarrhea, hair loss, hives, rash, difficulty breathing or swallowing, nausea, extreme tiredness, unusual bleeding or bruising, sores in the mouth and throat, lack of energy, loss of appetite, pain in the upper right part of the stomach, yellowing of the skin or eyes, fever, sore throat, ongoing cough and congestion, or other signs of infection, unusual bleeding or bruising, black and tarry stools, red blood in stools.

Administered/Taken: Intravenous injection.

**Doxorubicin Hydrochloride**

Drug Type: Anthracycline


Side Effects: Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.

Administered/Taken: Intravenous injection.

**Vincristine Sulfate**

Drug Type: Vinca Alkaloid

Aim: Interferes with the formation of tumor cells in metaphase, preventing the cancer from growing. Cell-cycle specific.

Side Effects: Nausea, vomiting, sores in the mouth and throat, loss of appetite or weight, stomach pain, diarrhea, headache, hair loss, hives, rash, itching, difficulty breathing or swallowing, constipation, increased or decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, unusual bleeding or bruising, unusual tiredness or weakness, pain, numbness, burning, or tingling in the hands or feet, difficulty walking or unsteady walking, muscle or joint pain, sudden changes in vision, including loss of vision, hearing loss, dizziness, loss of the ability to move muscles and to feel a part of the body, hoarseness or loss of ability to speak loudly, seizures, jaw pain, fever, sore throat, chills, or other signs of infection.

Administered/Taken: Intravenous injection.
**Rhabdomyosarcoma:**

**Dactinomycin**

*Drug Type:* Antitumor Antibiotic  
*Aim:* Damages DNA when cancer cells are dividing. Cell-cycle specific.  
*Side Effects:* Vomiting, stomach pain, diarrhea, hair loss, hives, rash, difficulty breathing or swallowing, nausea, extreme tiredness, unusual bleeding or bruising, sores in the mouth and throat, lack of energy, loss of appetite, pain in the upper right part of the stomach, yellowing of the skin or eyes, fever, sore throat, ongoing cough and congestion, or other signs of infection, unusual bleeding or bruising, black and tarry stools, red blood in stools.  
*Administered/Taken:* Intravenous injection.

**Vincristine Sulfate**

*Drug Type:* Vinca Alkaloid  
*Aim:* Interferes with the formation of tumor cells in metaphase, preventing the cancer from growing. Cell-cycle specific.  
*Side Effects:* Nausea, vomiting, sores in the mouth and throat, loss of appetite or weight, stomach pain, diarrhea, headache, hair loss, hives, rash, itching, difficulty breathing or swallowing, constipation, increased or decreased urination, swelling of the face, arms, hands, feet, ankles, or lower legs, unusual bleeding or bruising, unusual tiredness or weakness, pain, numbness, burning, or tingling in the hands or feet, difficulty walking or unsteady walking, muscle or joint pain, sudden changes in vision, including loss of vision, hearing loss, dizziness, loss of the ability to move muscles and to feel a part of the body, hoarseness or loss of ability to speak loudly, seizures, jaw pain, fever, sore throat, chills, or other signs of infection.  
*Administered/Taken:* Intravenous injection.

**Retinoblastoma:**

**Cyclophosphamide**

*Drug Type:* Alkylating Agent  
*Aim:* Slows growth of cancer cells by interfering with DNA replication.  
*Side Effects:* Nausea, vomiting, loss of appetite or weight, abdominal pain, diarrhea, hair loss, sores on the mouth or tongue, changes in skin color, changes in color or growth of finger or toe nail, sore throat, fever, chills, or other signs of infection, poor or slow wound healing, unusual bruising or bleeding, black, tarry stools, painful urination or red urine, rash, hives, itching, difficulty breathing or swallowing, shortness of breath, cough, swelling in the legs, ankles, or feet, chest pain, yellowing of the skin or eyes.  
*Administered/Taken:* Intravenous, intramuscular, intraperitoneal, or intrapleural injection.

**Melanoma:**

**Dacarbazine**

*Drug Type:* Purine Analog  
*Aim:* Stops cell growth during resting phase. Cell-cycle non-specific  
*Side Effects:* Nausea, vomiting, loss of appetite, diarrhea, sores in the mouth and throat, hair loss, feeling of burning or tingling on the face, flushing, flu-like symptoms, redness,
pain, swelling, or burning at the site where the injection was given, hives, skin rash, itching, difficulty breathing or swallowing, fever, muscle aches, and general feeling of pain and tiredness.

Administered/Taken: Intravenous injection.

**GERM CELL TUMORS:**

**Cyclophosphamide**

- **Drug Type:** Alkylating Agent
- **Aim:** Slows growth of cancer cells by interfering with DNA replication.
- **Side Effects:** Nausea, vomiting, loss of appetite or weight, abdominal pain, diarrhea, hair loss, sores on the mouth or tongue, changes in skin color, changes in color or growth of finger or toe nail, sore throat, fever, chills, or other signs of infection, poor or slow wound healing, unusual bruising or bleeding, black, tarry stools, painful urination or red urine, rash, hives, itching, difficulty breathing or swallowing, shortness of breath, cough, swelling in the legs, ankles, or feet, chest pain, yellowing of the skin or eyes.

Administered/Taken: Intravenous, intramuscular, intraperitoneal, or intrapleural injection.

**THYROID:**

**Doxorubicin Hydrochloride**

- **Drug Type:** Anthracycline
- **Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells.
- **Cell-cycle specific.**
- **Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.

Administered/Taken: Intravenous injection.

**SOFT TISSUE SARCOMA:**

**Doxorubicin Hydrochloride**

- **Drug Type:** Anthracycline
- **Aim:** Prevents DNA replication and ultimately inhibits protein synthesis of cancer cells.
- **Cell-cycle specific.**
- **Side Effects:** Nausea, vomiting, sores in the mouth and throat, loss of appetite (and weight loss), weight gain, stomach pain, diarrhea, increased thirst, unusual tiredness or weakness, dizziness, hair loss, separation of fingernail or toenail from the nail bed, itchy, red, watery, or irritated eyes, eye pain, pain, burning, or tingling in the hands or feet, red discoloration of urine, hives, skin rash, itching, difficulty breathing or swallowing, seizures.

Administered/Taken: Intravenous injection.

**Dactinomycin**

- **Drug Type:** Antitumor Antibiotics
- **Aim:** Damages the RNA or DNA that tells the cell how to divide during several stages of the cell cycle. **Cell-cycle specific.**
Side Effects: Vomiting, stomach pain, diarrhea, hair loss, hives, rash, difficulty breathing or swallowing, nausea, extreme tiredness, unusual bleeding or bruising, sores in the mouth and throat, lack of energy, loss of appetite, pain in the upper right part of the stomach, yellowing of the skin or eyes, fever, sore throat, ongoing cough and congestion, or other signs of infection, unusual bleeding or bruising, black and tarry stools, red blood in stools. Administered/Taken: Intravenous injection.

SYMPTOM MANAGEMENT

Suggestions

Every person’s experience with cancer and the various forms of treatment are unique to that individual. While one patient may experience one side effect, it does not guarantee that another patient will have the exact same experience. The same is true for pain management. One patient may have great results in using liquid aloe to help curb or eliminate mouth sores while another patient could use liquid aloe multiple times a day and not experience any relief. This is why it is so important to be open to trying multiple methods of symptom management in order to find just the right fit for you.

Below are some alternative suggestions, from various nurses, doctors, and families. Please remember to always consult your doctor and share any new treatment methods or routines you are implementing with them.

Consult your health care provider about these methods:

- Massage
- Acupuncture
- Tai Chi, Yoga, etc.
- Integrative approach
- Mind-body therapies
- Nutraceuticals and medicinal food
- The biochemistry of botanical medicine
- Practical approaches to creating and expanding a holistic practice
To accomplish great things, we must not only act, but also dream, not only plan, but also believe.”
– Anatole France

When facing a cancer diagnosis, your child’s doctor may provide several treatment options, including clinical trials.

What is Clinical Research?
According to the National Cancer Institute (NCI), clinical research is the study of people, data, or biological samples to better understand health and disease. Clinical trials are essential for the discovery, prevention, diagnosis and treatment of cancer. Clinical trials not only test new treatments for cancer, they also help determine the best use of existing treatments.

Two Types
1. Observational Studies: Used to gather information through observing people to see how specific characteristics change overtime.
2. Clinical Trial: Tests new treatments for a specific disease and allows researchers to better understand how a disease develops over time.

Different Types of Clinical Trials
- Treatment: This is the most common type of clinical trial. Treatment trials test all new treatments, including vaccines, drugs, new approaches to surgery, or combinations of different treatments.
- Prevention: These trials are for individuals who do not have cancer, but have a high risk of a cancer diagnosis.
- Screening: Looks for new ways of detecting cancerous cells in earlier stages so treatment can begin sooner. This could be done using a blood sample or a piece of tissue from your child’s tumor.
- Supportive and Palliative: These trials are done in order to improve your child’s quality of life by helping with pain management or other sicknesses that may arise from their cancer.

Different Phases of Clinical Trials
- Early Phase (Phase I) Trials: From Laboratory to Clinic
  o Test promising new agents in a small number of patients (usually around 20 to 80).
  o Used to determine if the treatment is safe and what the most effective dose of that drug is.
Often incorporate the standard of care therapy with the addition of another form of treatment.

**Phase II and Phase III Trials: Does the Treatment Work?**
- These trials are often the standard treatment when treating pediatric cancers.
- While safety is still a concern during these phases, determining how effective the drug is, is the main focus.
- Phase III trials are often randomized. A randomized trial randomly assigns a participant to either the standard treatment for their cancer or to the new treatment being studied to determine if one is better than the other.

**Reasons for Participating in a Clinical Trial**
- Obtain access to new drugs.
- Previous cancer treatments did not work or are no longer working.
- No other treatment options available.
- Help researchers learn more about your child’s cancer.
- Help future generations of children diagnosed with cancer.

**What to Expect**
- Taking part in a clinical trial is 100% voluntary, participation in a trial is not required for treatment of your child’s cancer.
- Before joining a clinical trial, the trial will be explained to you by a medical team. This explanation will include any risks or side effects that may be associated with the treatment, how long the trial will last, and what to expect at study visits. You will be given the opportunity to ask questions at any time during the study explanation and/or during the treatment period. Possible questions to ask before participating in a clinical trial:
  - How will this affect everyday life for my child and family?
  - How will I know if the treatment is helping my child’s cancer?
  - What happens if the treatment doesn’t help my child’s cancer?
  - Where will trial visits take place and with who?

**Costs Associated with Participating in a Clinical Trial**
- Trial participants and their insurance company are financially responsible for charges that are considered part of their routine care since they would be receiving these services even if they weren’t participating in a trial.
- Any service provided that is specifically required for research purposes and is not considered part of routine care, will not be your responsibility.

**How the National Pediatric Cancer Foundation is Supporting Cutting-Edge Clinical Research**
The NPCF funds the Sunshine Project, which is an innovative collaboration with one goal: to bring together the nation’s top doctors and researchers to fast-track less toxic, more targeted treatments and increase the survival rate for children battling cancer. By capitalizing on the strengths of researchers from a variety of scientific fields, the NPCF has
been able to streamline the process of protocol development in the hopes of delivering more personalized medicine to children with cancer.

Through the Sunshine Project, the NPCF has launched five Phase I clinical trials in just eight years, an incredibly short time in the medical world. New drugs and drug combinations have been, and continue to be, tested in these clinical trials and hold great promise for children who have not experienced positive results under the standard protocol treatment.

**Sunshine Project Affiliate Hospitals:**
1. Children’s Hospital Colorado, Aurora, CO
2. Children’s Hospital Los Angeles, Los Angeles, CA
3. Children’s National, Washington, DC
4. Connecticut Children’s Medical Center, Hartford, CT
5. Dana–Farber Cancer Institute, Boston, MA
6. Johns Hopkins All Children’s Hospital, St. Petersburg, FL
7. Johns Hopkins Medicine, Baltimore, MD
8. Levine Children’s Hospital, Charlotte, NC
9. Moffitt Cancer Center, Tampa, FL
10. Nationwide Children’s Hospital, Columbus, OH
11. Nemours Children’s Hospital, Orlando, FL
12. Nemours Children’s Specialty Care, Jacksonville, FL
13. Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE
14. Primary Children’s Hospital, Salt Lake City, UT
15. The Children’s Hospital at Montefiore, Bronx, NY
16. UF Health Shands Children’s Hospital, Gainesville, FL
17. University of Kentucky Markey Cancer Center, Lexington, KY
18. University of Miami Sylvester Comprehensive Cancer Center, Miami, FL
19. University of North Carolina Medical Center, Chapel Hill, NC
20. University of Texas MD Anderson Cancer Center, Houston, TX
21. UT Southwestern Medical Center, Dallas, TX
22. Vanderbilt-Ingram Cancer Center, Nashville, TN

**Additional Resources:**
- **National Cancer Institute**  
  Cancer.gov/about-cancer
- **ClinicalTrials.gov**  
  Clinicaltrials.gov
- **Children’s Oncology Group**  
  Childrensoncologygroup.org
STORIES OF HOPE

Ann:
I would tell other parents whose children are newly diagnosed...

• There are so many moving parts. Take it a day at a time – things change quickly, so don’t worry about next week. Stay in the present, thinking about today and the next day. It’s much easier on you and your family.

• Do your early learning with your medical staff – they will walk you through the information you need. Refrain from Google at the beginning. There is so much information out there, much of which is scary, overwhelming, and not applicable to your circumstances (but you don’t know that yet). As you get more familiar with your child’s disease, then you can do additional research that will be helpful, but in the beginning, too much information can be paralyzing and overwhelming.

• Say YES when people offer to help. Don’t be afraid to be specific with your needs – “Thank you, we don’t need meals right now, but we do need someone to transport our other children to their after-school activities.”

To help with overall treatment and feeling better, we added chiropractic care and massage therapy to our regimen, and this helped tremendously. We would get our son adjusted after a course of chemo, and it helped with body aches, headaches and overall wellness. He slept better and seemed to recover more readily after an adjustment. I would recommend gentle chiropractic care, as well as someone who treats children.

Advice I would give to another parent going through a similar experience would be that some of our greatest support came from our son’s school. Engage the administration and teachers early on, and let them know what your child needs emotionally and academically. Your child’s classmates can offer care and support in a way only other kids can. Ask your child life specialist if they can provide a Monkey in My Chair (MonkeyInMyChair.org). The monkey sits at your child’s desk to hold their place until they can return. We gave our monkey a name, and the school put him in a uniform. He came with a bag that we used to send school work back and forth, along with notes from his classmates and teachers. It was a great way for the kids to have empathy for their friend and for our son to feel engaged in daily activities.

William:
If I could give advice to another child that was diagnosed with cancer it would be to find things or activities to distract or redirect you from what’s going on. I watched every season of The Brady Bunch, Alf, and many other funny shows. It takes up time and helps you to escape while having chemo or staying in the hospital.
Caroline:

If there is one thing I could tell parents, whose children are newly diagnosed, I would say keep notes of not only what you needed to learn, what you did learn and most importantly what went well. Documenting your success and every victory along the way can put you in the mindset of finding what is going right instead of focusing on the overwhelming feeling of all the things that are going wrong. It is much more palliative to look back on your notes in years to come and smile remembering all of the victories along the way.

Advice I would give to another parent going through a similar experience would be to be as present during this time as possible. I believe that learning as much as you can during this process can be very powerful and can somehow make you as the parent feel as though you can make a difference. Feeling helpless is awful, so empowering yourself with as much knowledge about what medicines, therapies and counts your child has can help in the process of making decisions for your child.

To help increase Jackson’s platelet count (which was extremely low due to the chemo), we made sure that he was eating kale or spinach daily. These vegetables did not interfere with any medications he was taking, and his platelet count was always a little higher when he included these in his diet (even if it was disguised in a smoothie!) The other natural remedy we added to our daily routine was having Jackson drink a shot glass of aloe juice every morning. We heard that this can sometimes help eliminate or decrease the potential for mucositis, and for Jackson it really made a difference. He had only one case of mild mucositis and never got it again. We understand that these results may not work for everyone, but it sure helped us during treatment.

Now that our child has completed treatment, we continue to help other families by involving ourselves in activities that Jackson is comfortable doing. He enjoys visiting kids in the hospital and putting together snack bags for the parents and children. He remembers these gifts fondly and enjoys bringing these to families. We also participate in many other functions with local organizations that are working hard to raise money and awareness for pediatric cancer. We believe in paying back and forward.

Jackson:

To pass the time in the hospital, there are many things we would do. My mom would schedule visitors to come and see us because this helped pass the time. Sometimes the visitors came during lunch or dinner and would bring me something I was hungry for. Other times, I would have friends come up to play video games, race remote control cars, play Nerf Guns and even have ice cream sundaes in the hospital room. When it was me and my mom or dad in the hospital we would watch movies, read, do painting activities, make special gifts for the nurses and sometimes pull pranks. My mom’s friend would always bring things to the hospital that had a connection with a National Day. For example, on National Rubber Ducky Day, we had enough different ducks to pass out to the nurses. On National Mustache Day, I wore a mustache all day long and it made everyone around me laugh. There were some days I was too sick or tired to have visitors, but on the days I felt good, it was always nice to do something a little different than the day before.
Tab 4
What now?

A LOOK INSIDE

• Notes From a Nurse
• Things to Talk to Your Children About
• Care for Childhood Cancer Survivors
• Navigating School During Cancer and Beyond
• Questions to Ask Your Health Care Team
• Stories of Hope
As a Pediatric Oncology Nurse, I work very closely with the families of patients. When patients are not in the hospital or clinic getting their chemo or radiation, I encourage families to make memories and have some fun. Here are the most common questions I come across with the families I have worked with. If you are curious or concerned about an activity, don’t hesitate to ask your child’s nurse or health care provider.

Nurse Sarah
Q: Can my child go to school?
A: Yes, at various times they will be able to attend school. At moments during therapy when their counts are really low or when there is an illness going through the school, it is best not to send them. In addition, certain chemotherapy protocols allot for more time in between chemotherapy that make it easier for a child to attend school. Other protocols have a more compressed chemotherapy regimen making it much more difficult to attend school.

Q: Can my child play with other children?
A: Yes, keeping a couple general rules in mind. Be sure to ask if the other child/children have been, or currently are, sick or with fever within the past 72 hours. Have they recently been around someone else who was sick in the past 72 hours? Make sure hand hygiene is strictly followed with everyone. Don’t be afraid to ask everyone who comes over to wash their hands, or use hand sanitizer, upon arrival.

Q: Can my child go out in public without wearing a mask?
A: Yes, with the exception of a bone marrow transplant patient. Good hand hygiene is your strongest defense against viruses and illness. It is strongly suggested to stay away from crowded indoor facilities, such as movie theaters, especially when blood counts are low. If you are out and notice someone who appears to be sick, do your best to avoid that person and the area they are in.

Q: Can my child swim in freshwater such as lakes, ponds and rivers?
A: It is highly recommended to limit exposure to these bodies of water because there can be parasites and bacteria that live in these types of water. Many of which may have no harm to a healthy individual, but to someone who is immunocompromised, it can be harmful. The general rule of thumb is if the body of water is “nonmoving” you should avoid it at all costs. Moving bodies of water tend to be safer but can still present the risk of bacteria.

Q: Can my child go to public pools?
A: The short answer is NO. There is no way to know how well the pools are kept clean, and when you have multiple people in and out of a pool at any given time, the risk of contaminated water is very high. You never know how many people urinate in a pool, and there is no way to know if there is enough chlorine in the pool to kill off any bacteria. It is best to only swim in a private pool of a your own or a close friend that you know keeps their pool clean.

Q: Can my child go to the beach?
A: Yes but keeping in mind that at various times there can be viruses in the water that should be avoided. It is recommended that time spent in the ocean is limited as well. Also, it is imperative that your child wear sunscreen and that it is reapplied multiple times while being exposed to the sun. Children going through chemotherapy are extremely sensitive to the sun and can develop a sunburn much quicker, and more severe, than others.

Q: Can we have pets in our home, and if so, what kind?
A: Yes, pets are allowed in the home. The types of pets should be restricted to cats, dogs and fish. Rodents (hamsters, guinea pigs, etc.), birds, and reptiles (lizards, snakes, etc.) should not be in the home as they can carry many parasites and bacteria in their feces. With cats, the litter box should be kept clean and in an area of the home that is away from a return air duct or where a child may come into contact with it.
Q: Can my child ride roller coasters with a medi-port?
   A: Yes, but keeping in mind that certain roller coasters may cause damage to the port. Roller coasters that have an over the head safety bar should be avoided if they will be on or near the port as the jolting around can cause harm to the port. It is also a strict rule that if the child’s platelet count is below 50, they are not to go on a roller coaster as they are at an increased risk for bleeding.

Q: Can my child fly on a plane while on chemotherapy?
   A: Essentially, yes. However, if your child’s ANC is low (below 500), it would be strongly advised not to fly during that time as the risk for infection is high. The air on a plane circulates, and you cannot be sure what your child will be exposed to on the plane. If you wish, you may have your child wear a mask, but to be truly effective, you would have to change it frequently during the flight.

Q: Can my child be around someone who just had vaccines, e.g. a sibling?
   A: Yes, with the exception of the live flu-mist vaccine that is given nasally. You cannot contract anything from a vaccine that another person received.

Q: Are there certain diseases my child should not be around?
   A: Yes, all of them. You should avoid exposing your child to any communicable disease at all costs as they will be much more susceptible to having complications from them and being hospitalized. Should you learn that a child whom your child was recently interacting with develops a communicable disease, contact your oncologist immediately.

Q: Are there certain foods that my child should or shouldn’t eat during chemotherapy?
   A: In general, no. There are certain times that some patients may be receiving an oral chemotherapy agent that should not be administered with milk products as it may decrease the absorption of the chemotherapy. It is recommended that children eat a well-balanced diet. They may also take a multivitamin as long as it is discussed with your oncologist first. No supplement or vitamin should be given to your child without first consulting your oncologist. There may be some supplements that can interfere with, or decrease the effectiveness of, chemotherapy agents.
THINGS TO TALK TO YOUR
Children About
(WITH AND/ OR WITHOUT CANCER)

• Talk to your child about cancer and explain how together you will overcome this big obstacle in their life.

• Inform your child and your friends and family about what they’re going through.

• Do not lie to your child. Lying only makes things worse. No matter your child’s age, they need to know.

• Tell your child about the treatment they will be undergoing.

• Explain where your child will be staying.

• Talk to your child’s friends’ parents about what is happening. This lets them explain to their child(ren), in their own way, why their friend has not been at school, practice, etc.

• Talk to their siblings and explain what their sibling is going through so they are informed as opposed to being stuck in the dark.

• Be there for your child. This is one of the hardest battles your child will face in their life, and they need your support.

• Inform your child that cancer is not contagious, so no one gave it to them, and they cannot give it to anyone else.

• Have your neighbors and friends talk to their children about what your child is going through and how they need their support.

• Consult your kids on how their diet is going to change and of the foods they should and should not eat based on their condition.

• Talk to your child about the treatment side effects they might be experiencing or will experience in the near future.

• Stay strong. Everyone knows this is a tough time, but if you stay strong chances are that your child will too.

• Don’t jump to conclusions. Stay in the know and take things one step at a time.

• Be the best parent you can be, and treat your child as if they are no different. Although they are going through a tough time, they still want to be a kid.

• Let your kid be a kid. Kids may not understand what is happening so don’t throw it all on them. Instead, let them continue to smile and be joyful. Still, do not lie, but only bring up important topics if asked by your child or told they need to know.

• Allow parents to talk to their child(ren) about what is happening. No matter your opinions as a friend/neighbor/teammate, it’s a parent’s job to inform their child, and they can do so as they please.

• If money is a problem, and you are unable to pay for treatments, don’t be afraid to ask for help. Not only does your child need support, but you may too - so please don’t be afraid to ask for support.

• Finally, make sure to tell your child every day that you love them. Through this part of a child’s life, they are under a lot of pressure and need love and support from all the people in their life.

• If you need assistance like financial, housing, food and/or other needs, it is best to consult with your assigned social worker.
While the completion of your child’s cancer treatment is something to celebrate, it may also bring new challenges. You may worry that the cancer will return. Your child may struggle getting used to new routines. Some families enter this new phase feeling stronger, whereas others are more fragile. Many families are surprised by anxious feelings that arise during this long-awaited time when they expected to feel only relief. Instead of this being a time to go back to life as it used to be, it may be a time of continued adjustment as you leave the security of the people on your child’s health care team. Some said the transition to life after treatment took longer and was more challenging than they thought it would be.

Follow-Up Care After Cancer Treatment

It is both reassuring and essential that your child receives follow-up care from specialists after completing cancer treatment. Get a written copy of your child’s treatment summary and survivorship care plan. Ask for recommendations to hospitals that offer the type of follow-up or survivorship care that your child needs.

Treatment Summary

The treatment summary includes both diagnostic and treatment information, such as:
- Type of cancer, severity (stage, grade, or risk group), date of diagnosis, and pathology report.
- Type(s) of treatment received, including the names and doses of all medications, as well as the total amounts and sites of any radiation therapy received.
- Treatment dates.
- Key reports and scans, such as CT scans and MRIs.
- Side effects and/or complications experienced during treatment.
- Supportive care received (also called palliative care)—such as counseling or physical therapy.
- If your child was in a clinical trial, the identifying number and title of the clinical trial.
- Names and contact information of key people on your child’s health care team.

Survivorship Care Plan

A survivorship care plan (also called a follow-up care plan) is developed for each child. Survivorship care plans are based on the type of cancer and treatment your child received. For example, some children may need to return for visits each month for the first year after they have completed treatment. Others may not need to return as often. Here is the type of information that’s included in follow-up care plans for children who have been treated for cancer, as outlined in the Institute of Medicine’s fact sheet:
- Exams and tests/procedures to check for the recurrence or metastasis of cancer and a schedule of when they are needed.
- Care and support to manage any long-term side effects and check for late effects.
- Psychosocial support or counseling and referrals, as needed.
- Referrals for legal aid or financial support, as needed.
- Referrals to and coordination with specialists such as cardiologists, education specialists, endocrinologists, physical therapists, and psychologists and to appropriate treatments, clinical studies, and rehabilitation specialists.

Recommendations for healthy behaviors, such as advice regarding nutrition and physical exercise. Family-based care, education, and outreach to your child and family.
Follow-Up Care Clinics/Survivorship Clinics
Places that specialize in follow-up care for children who have been treated for cancer are called follow-up care clinics or survivorship clinics. At these clinics, your child will see specialists (for example, in cardiology, endocrinology, fertility, nutrition, psychology, and/or pulmonology) who will monitor your child's health. These clinics are usually found within hospitals.

If the hospital where your child was treated does not have such a clinic, ask your child's doctor to recommend one. You can also refer to the Children's Oncology Group which has Late Effects Directory of Services that can help you find a hospital that offers services for late effects of treatment for children's cancer.

Long-Term and Late Effects
While it may take a while for your child to get used to their new schedule, it's important to check with your child's doctor for new problems or side effects that don't seem to get better after treatment. Although many side effects go away once treatment has ended, long-term side effects, such as fatigue, may take some time to go away. Other side effects, called late effects, may not occur until months or even years after treatment.

Whether or not your child may have late effects of treatment depends on the type of cancer your child had and how it was treated, as well as personal factors, such as:
Cancer-related factors like the type of cancer, where it was in the body, and how it affected tissues and organs.
Treatment-related factors such as the type and dose of treatment(s) or the type of surgery.
Patient-related factors such as your child's gender, age at diagnosis, length of time since diagnosis/treatment, personal and family health history, and health habits.

Types of Late Effects
Late effects may be physical, emotional, or cognitive. Knowing what symptoms to be aware of and when they may occur can help you plan for the needs of your child. Not knowing what to expect can cause anxiety for some parents. However, for other parents, knowing about late effects that may or may not happen to their child in the future can be overwhelming. Many parents find it helpful to ask their child's doctor what to focus on at each step of their child's recovery.

Physical Late Effects
Physical late effects involve changes to organs, tissues, and/or body functions. They may affect your child's growth and development. Some children who have been treated for cancer have many physical late effects, whereas others have relatively few. As you talk with your child's doctor to learn what to expect, you can also learn more about treatments that may increase the risk of physical late effects in Late Effects of Treatment for Childhood Cancer.

Emotional Late Effects
Emotional late effects include changes to your child's mood, feelings, and actions. Many children are very resilient after cancer treatment. Others experience social and/or emotional problems. If your child is not sleeping well and no longer enjoys activities that they once did, it is important to talk with your child's doctor about having your child evaluated for depression.

Some children develop post-traumatic stress disorder (PTSD). This anxiety disorder arises in reaction to physical injury or severe mental or emotional distress. Symptoms of PTSD may include having flashbacks about diagnosis or treatment, avoiding places that are reminders of the experience, and being fearful, irritable, unable to sleep, or having difficulty concentrating. Ask your child's health care team to suggest resources for mental health support in your area.

Cognitive Late Effects
Cognitive late effects include changes in your child's ability to memorize, learn, and think. These types of late effects are more likely to occur in children who've had certain cancers such as brain and spinal cord
tumors, head and neck cancers, and some types of leukemia, such as ALL. Treatments such as radiation therapy to the head and certain types of chemotherapy also increase the risk of cognitive late effects. These late effects are more likely in children who were very young during treatment, who received very high doses of treatment, and whose treatment lasted a long time.

Children with cognitive late effects may have a more difficult time:
- Memorizing or remembering.
- Learning - handwriting, spelling, reading, vocabulary, and/or math may be particularly challenging.
- Thinking including concentrating, completing work on time, doing work that involves multiple steps, problem solving, and planning.

As you talk with your child’s doctor, here are some questions to consider:

**About treatment**
- Who should we talk with to get a comprehensive record of treatment(s) and medications that our child received during treatment?

**About practical steps to take at home**
- What health problems in our child should we be aware of?
- Who should I contact if health problems occur?
- Does my child need to continue taking any medicine(s)? If so, for how long?
- What types of activities may help my child? Are any activities not recommended?
- What vaccines should my child receive? When should they be given?

**About follow-up care (plan and schedule)**
- Who should I talk with to get a follow-up care plan and schedule for my child?
- Which medical experts should my child see for follow-up care?
- What tests will be done during follow-up care visits? How often and for what reason?
- Where should my child go for follow-up care visits?
- What is the schedule for these visits?

**About possible long-term and/or late side effects**
- Is my child at increased risk of having long-term side effects? If so, which ones, and how can they be managed?
- Is my child at increased risk of developing late effects later in life? If so, which ones and how likely are these to occur? How long after treatment might they occur?
- What types of specialists should my child see to manage these effects?

**About support and coping**
- What survivor support groups are available for my child? For our family?
- What are the benefits to my child of receiving professional counseling? Is this something you recommend for my child? Why or why not?

Learn more about care for pediatric cancer survivors at cancer.gov/about-cancer/coping/survivorship/child-care
Importance of Education During Diagnosis
Keeping your child academically engaged during this difficult time is not only a good idea but sometimes necessary. Staying academically involved and motivated can help your child feel a sense of normalcy, can be a break from the new routine of treatment, and can help your child stay on track with their current grade level.

School is an important aspect in any child’s life but especially during diagnosis and treatment. While doctors and nurses encourage parents to keep their children physically in school for as long as they can, too often appointments, procedures and the start of chemotherapy derails the plan of attending school on a regular basis. There are still ways for children to continue school even if they are not physically present.

- Attend school when they can and/or feel good enough to be there. Some kids decide to go to school for an hour or two in the morning when they are feeling the best. Any amount of time is helpful for the child academically and socially and, in return, helps the other children around them become more empathetic to what your child is going through.
- Use technology to keep up with classes and classmates while in the hospital or at home. As long as the teacher(s) approves of participating in a live lesson, then your child is not only learning but also feels a sense of connection to their classmates and school, which can be a moral boost for your child.
- Attend after school or extracurricular events. Even if this requires your child to wear a mask to be around a large group of people (during times of weakened immune system), it is important for them to be involved and a part of what is happening in their school community.

Hospital/Homebound Schooling
Hospital/Homebound schooling allows a child to engage in school around their schedule of hospital visits. As stated above, it is very important for children going through cancer treatment to stay on top of school as much as possible. Once you’ve decided that hospital homebound is right for your child, you will need to get the proper paperwork from the hospital. The paperwork will need to be filled out by your child’s primary oncologist. Also, you will need to contact the school and speak with the ESE Liaison. The ESE Liaison at your school will start the proper paperwork for your child to participate in the Hospital/Homebound Program. Do not worry if during this paperwork time there are days of “unexcused absences” piling up. Once all of the paperwork is complete, the unexcused absences will be changed to excused absences. Here are the basics of Hospital/Homebound from a parent’s perspective of their son’s cancer journey.

- Keep track of all paperwork, phone calls, time of call when you’re talking to the ESE liaison, hospital social worker, and oncologist regarding paperwork being submitted for the program. Through this program, your child will receive a temporary Individual Education Plan (I.E.P.). This will give you and your child legal coverage to protect them while in the program.
- When in Hospital/Homebound the child is not allowed to attend school or school activities even if they feel well enough to attend.
- A tutor from the school will be assigned to your child and will visit up to three hours per week (or what your school system provides.) The tutor will come to the home and instruct your child on the core classes (i.e. math, reading, science, history). My son was fortunate enough that this volunteer tutor was also licensed in Spanish so he was able to continue learning Spanish.
- The tutor may leave work with your child to complete while they’re in the hospital or at home.
recovering. Don’t push your child on days they aren’t up to learning. They will eventually feel better and catch up with missed work.

- The teacher will typically only focus on larger aspects of learning in each of the core subjects. Your child will not be responsible for every single assignment that is assigned while in school. Also, this should not count against their grade.
- Once your child is off treatment, you will meet with the school again to end the I.E.P.
- Most importantly, always be the advocate for your child. If your “something-is-not-right-o-meter” is going off, listen to it, and advocate for your child. Most schools go out of their way to help children and families through this process, but always listen to your gut and speak up when necessary.

**How Federal Laws Can Help Your Child**

If your child experiences side effects during treatment, the school system needs to be aware of these changes. No matter how big or small the changes, there are Civil Rights Laws in place to help your child best navigate school. Make an appointment to speak to your child’s teacher(s) and a school counselor so that, as a team, you can determine what accommodations your child will need to best succeed in school.

Two of the most common laws that can help children diagnosed with cancer are Individuals with Disabilities Education Act (IDEA) and The Rehabilitation Act of 1973, Section 504. IDEA covers children ages 3 to 22. A child must meet federal criteria in one of thirteen categories to qualify for special education or related services. Children with cancer often qualify under the “Other Health Impairment” category. Children who meet criteria for IDEA will receive an Individual Education Plan (or I.E.P) which is a legal contract that specifies what services the school will provide.

The Rehabilitation Act of 1973, Section 504 is often referred to as a 504 Plan. This plan helps to protect people with disabilities and offers accommodations to best serve the student to help them reach their highest academic potential. A 504 Plan addresses the need for access that can be provided to the student as support. Some of these accommodations include, but are not not limited to: small group instruction, fewer assignments graded, use of elevator, rest breaks, textbooks to be kept at home, early dismissal from classes, optional headwear (hats, caps, etc.), snacks, water, etc.
When my child was first diagnosed with cancer, it was the worst day of our lives. We couldn’t believe what was happening. We didn’t understand why it was happening to our daughter and to us. I felt all kinds of different emotions. I felt guilty, mad, angry, and I started questioning myself. Maybe I missed something. I felt helpless. It was really, really hard.

A time during my child’s treatment when I used my intuition was when our daughter had an allergic reaction to one of the chemo medicines, and they had to stop it. But it was a medicine that was very important as part of her treatment. Dad did his research and found another medicine that could work so we discussed with her doctors. They were all on board to help us get the medicine, and she was able to have the complete protocol.

If there is one thing I could tell parents, whose children are newly diagnosed I would say to trust God and know that He will bring you through it.

We found a lot of laughter or happiness during our time in the hospital when we played board games with the whole family. Told stories about our childhood; we got to know each other more.

Something I learned about myself during my child’s treatment was how to trust God. My faith grew stronger. I learned that God is always in control, and you have to rest knowing that He’s got you!

Advice I would give to another parent going through a similar experience would be that you have to stop asking yourself WHY and start asking “What for?” There is always something to learn from each experience.
The first time I had to get blood products I felt nervous because I wasn’t sure how it would feel. It was weird to see a bag of blood next to me, but it did help me feel better later.

When I first started chemo or radiation, I was nervous because I didn’t know what it was going to make me feel like.

To pass the time in the hospital, my family and I would play board games and tell stories.

Talking to my classmates and friends about my cancer was weird because not a lot of people knew how to react, but when you figure out how to say it, it is easier.

If I could give advice to another child that was diagnosed with cancer it would be to stay positive! Everything happens for a reason and every experience teaches you something. Also, find new things to do to keep you busy!

I continue to support other children and families going through treatment by donating to NPCF and continuing to make my care packages.

Communicating with others about my child’s diagnosis has been difficult. One thing that I learned the hard way is who your real friends are and who the people you can always count on are. People don’t know how to react, and sometimes the questions that they ask are very weird and annoying.

To help with overall treatment and feeling better, for nausea we got our daughter some acupressure bracelets that helped her a lot. We also used essential oils for the smells. As far as food, to help with her counts, she tried to eat beans, spinach and red meat. She also had and still has a sound machine in her room that helped her relax and sleep better.

Now that our child has completed treatment, we continue to help other families. My daughter came up with an idea for a fundraiser at her school for Pediatric Cancer, and we collected money to donate to the National Pediatric Cancer Foundation. She also wanted to make Care Packages for the kids in the hospital that included the things that helped her during treatment. She has done this for 2 years, and she is planning to continue doing it.

Natalie Santiago
15 years old / In remission from Hodgkin’s Lymphoma

The nurses and doctors helped me understand the situation and helped me with whatever they could.
When our son was first diagnosed, it was one of the most devastating things that we have ever experienced. It was as if our whole world just stopped. We remember having more questions than answers. One thing that was helpful to us was to have a notebook where we wrote all of our questions to ask the doctors when they came in to see our child. Also, we wrote down all of the names of the various people and their role because it was very concerning when someone would come in and say we need to take your child to X-ray, or for a CAT scan, etc. During those first few weeks everything was a blur as to what our next steps were. At All Children’s, we had a social worker who was very helpful because she was able to answer many of the millions of questions we had pertaining to insurance.

If there is one thing I could tell parents, whose children are newly diagnosed, I would say that you are your child’s voice, and don’t be afraid to use it! This is a role that we had to use frequently during our son’s care. As parents you know your child, and being their advocate when they can’t advocate for themselves is critical. In our case, our son was only 11 months old and could not speak. In our experience, being a vocal advocate for your child is welcomed and appreciated. We were able to develop an understanding and a relationship with his caregiver where we felt like a valuable member of his care team.

Something that really frustrated me was that as newly diagnosed parents, when doctors came in to speak to us, they were not always speaking in terms we could understand. This was a problem because we would ask numerous follow-up or clarifying questions, and it seemed as though they were annoyed at repeating themselves. Sometimes I felt they were talking above our heads.

We found a lot of laughter or happiness during our time in the hospital when we had our immediate family come and visit and shared a meal. These were some of our fondest memories as a family. Eating dinner and being able to laugh and sometimes cry with our loved ones is something that gave us the greatest joy. Another memory that brought us happiness is when it was a holiday and the nurses would dress up and we would do a parade around the hospital. This was very exciting time for our son but also very uplifting to us as parents because we could see all the kids happy and smiling, and that would give us great joy.

Advice I would give to another parent going through a similar experience would be to talk to your spouse about your true feelings. If you are scared, hurting, angry, etc. This was a strength for us because we were able to talk openly with each other daily about what we were feeling and support each other. Also, we would like to share with other parents, if you have other children, DON’T forget about them! They may look like they are fine, but they may have some questions or anxieties about their sibling they want to express. My boys loved to visit their brother and always wanted to know how he was doing. Lastly, seek out an organization that offers support for families. These organizations are a wealth of information on counseling and support groups, information on new treatments and events that support families.
Tab 5

Resources

A LOOK INSIDE

• Diet

• Managing Costs and Medical Information

• Coping With Emotions and Stress
Helping your children find the right balance of what they are willing to eat and what is good for them can be a challenge. Now, when you factor in chemotherapy, which can change the way things taste, it can feel like a monumental task. Keep in mind that while we want our children to eat a healthy variety of nutrient dense foods, sometimes just getting them to eat anything is what is needed. Solid foods and fluids are an important factor in helping clear the body of these treatments. So, if your child is a picky eater and only wants to eat one thing during the entire treatment, don’t stress about it. However, if they are willing to try some different foods, jump on the opportunity to incorporate some healthy variety.

Remember to always consult your child’s nutritionist so that you are aware of any foods to avoid during treatment.

**Things to know when changing your child’s diet**

- See a dietitian who knows your child’s exact condition and what they need to be eating throughout the day.
- Most diets for a child battling cancer have a base of fruits and vegetables used to help the patient stay healthy while battling this disease.
- Most diets also recommend lower fat intake, leaner choices, and refraining from animal meats. For example, instead of a steak choose a salad with a tiny bit of dressing. Dressing happens to be one of the fattiest things in the world, and although it is healthy to have a salad, it isn’t healthy to have a salad loaded with dressing.
- No raw fish or shellfish.
- Avoid foods and drinks like candy, soda, fried foods, mayonnaise, salad dressing, and butter.

**Examples of foods that may be integrated into your child’s diet:**

<table>
<thead>
<tr>
<th>Whole Grain Foods</th>
<th>Fruits</th>
<th>Proteins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clif and Luna Bars</td>
<td>Strawberries</td>
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Understand The Cost
Before treatments start, make sure you are aware of all the costs and whether or not your insurance covers it.

Understanding Your Health Insurance
It is totally normal not to have a great understanding of your health insurance, but it is important, especially when dealing with this situation. The first step is calling your health insurance to explain to them what is happening; include key details. For example, mention the type of treatments, drugs, and tests that are administered to your child to find out whether your insurance covers the treatment plan or not.

Be sure to ask about co-pays, deductibles, and other costs to ensure you know when money is due and when it is not. Be sure to ask how and when to make payments. By asking this you will know whether the insurance directly pays for your child’s treatments or if you pay and are reimbursed after. Explain the Explanation of Benefit papers so your insurance knows what you paid for. If you would prefer to speak to the same person every time you call, you can request a case manager.

Save Money On Pain Medicine
Thus far, several dollars have been spent on treatment plans and more but now you have to pay for pain medication. So what are the most affordable options?

• Ask your doctor about the generic options of medicine. Generic brand medicine usually costs less, but be sure to ask about the form of drug. Pills may cost less than other forms of medicine.
• Find out about discount drug programs.
• Some organizations have special programs to help pay for prescribed drugs. Speak with your social worker for more details.

Track Key Medical Information
Staying organized is really important when it comes to keeping track of medical documents, prescriptions, etc. When keeping track of medical information, here are a few key documents that must be recorded:
• Dates of medical visits.
• Tests and procedures received.
• Results of all procedures.
• Treatment dates.
• Side effects and symptoms with dates experienced.
• Medicine prescribed.
• Other complementary care received.
When your child is diagnosed with cancer, you, as the parent or caregiver go through so many emotions it’s hard to begin listing them all. Sadly, your child and any other children in your family are also going through a vast range of emotions. Taking care of yourself and your mental state is equally as important as the treatment your child is receiving.

While it may only be scratching the surface, we have put together some suggestions of ways you can begin to help your children and yourself cope with these emotions. Please remember that your child’s doctor, the hospital social worker and palliative care team members are always available for you to talk with. These professionals have a wealth of knowledge and are there for you...just ask.

**Suggestions for How to Help Your Child Cope with their Emotions**

**Changes in Feelings**
Although over time many children with cancer cope well, your child may feel anxious, sad, stressed, scared, or become withdrawn from time to time. Talk with your child about what she is feeling and help them find ways to cope. You and your child can also meet with a social worker, child life specialist, or psychologist about feelings that don’t have easy solutions or seem to be getting worse over time. Try these tips to help your child cope with difficult emotions:

- **Find ways to distract or entertain your child**
  Playing video games or watching movies can help your child relax. Integrative medicine practices such as muscle relaxation, guided imagery, and biofeedback may also help.

- **Stay calm and sometimes hide your feelings**
  Your child can feel your emotions. If you often feel sad or anxious, talk with your child’s health care team and your doctor about the best way to manage these emotions. However, if you often hide your emotions, your child may also hide their feelings from you.

- **Get help if you see signs of depression in your child**
  It is normal for your child to feel down or sad sometimes, but if these feelings last for too long and happen on most days, they may be a sign of depression. Talk with the doctor about emotional changes you notice in your child.

**Suggestions for How to Help Siblings Cope with their Emotions**
As a parent, you want to be there for all your children, but this can be hard when one of your children is being treated for cancer. You may notice that your other children are having a difficult time but are not sure of what to do. These suggestions have helped others:

- **Listen to and talk with your children**
  Set aside some time every day, even if it is just a few minutes, to spend with your other children. Ask how they are feeling, even if you do not have an easy solution. It’s still important to connect with them and to listen to them.

- **Keep them informed and involved**
  Talk with your other children about their sibling’s cancer and tell them what to expect during treatment. If possible, find ways to include them in visits to the hospital. If you are far from home, connect through Facetime, texts and calls frequently.
• Keep things as normal as you can
  Arrange to keep your other children involved in school-related events and other activities that are important to them. Ask key people in your family’s life to give the siblings extra support. Most people want to help and will appreciate being asked.

Suggestions for How to Help the Parent Cope with their Emotions
Make Time to Renew Your Mind and Body
It can be tempting to put your own needs on hold and focus solely on your child. But it is important to take time for yourself, so you have the energy to care for your child. Here are tips to get you started:

• Fill waiting time
  Pick a few activities that you enjoy and can do in your child’s room, such as playing a game, reading a book or magazine, writing, journaling, or listening to music.

• Find ways to relax and lower stress
  Some parents try something new, such as a yoga or deep-breathing class at the hospital. Other people are refreshed by being outdoors, even for short periods of time. Whatever the method or place, find one that brings peace to you.

• Make time for friends and loved ones
  Being with friends and family can refill your tank and reenergize you more than you can imagine. Allowing yourself time to step away from the stress and anxiety of the diagnosis is necessary and helpful.

• Stay physically active to sleep better and stay calm
  While it is hard to find time to add exercise into your routine between home and hospital – any amount of time spent on purposefully moving your body can help reduce stress and improve your sleep.
Beth:

When my child was first diagnosed, we were given so much information (verbally, physically via handouts, and website information). It would have been helpful for someone to have given us a binder that had tabs to organize everything. Even to have a list of questions that we may want to ask and places to write the answers. Also, suggestions on what to expect or a guide to use. Every diagnosis is different, but a general book of info would have helped; Almost like the “What to Expect When You’re Expecting” Books...

A time during my child’s treatment that I used my intuition was any time our daughter ran a fever or something medically came up that wasn’t on the list of things to look out for...(unexpected rash, getting hurt, exposure to others with illness.)

If there is one thing I could tell parents, whose children are newly diagnosed, I would say that you are your child’s advocate. What the doctor says isn’t law. Ask questions, ask what alternatives are available, and look for second opinions if you have any questions about what is in the treatment plan.

Something that really frustrated me was the guilt I felt thinking the reason that our daughter had cancer was because of something I did wrong.

We found a lot of laughter or happiness during our time in the hospital when we were not getting poked or prodded...just having fun watching a movie, or watching a magic show that was happening in the lobby, or enjoying a bowl of ice cream.

Something I learned about myself during my child’s treatment was that I am stronger than I think I am and so is my child.
Advice I would give to another parent going through a similar experience would be to take everything moment-to-moment and day-by-day. Things change, plans change, treatments change, the way your child responds changes. Live in the moment and don’t worry about what will happen tomorrow or next week or at the end of treatment. Never compare your child’s journey to another’s. Just like the way they grow and develop, the way their bodies react to a treatment is different for each and every child.

Communicating with others about my child’s diagnosis has been easy for us. We have very supportive friends and family. We used an online tool called CaringBridge. This helped us to deliver information in a way that others could read on their time and not get inundated with emails. It also helped us not have to send multiple emails or phone multiple people.

To help leg neuropathy we added physical therapy driven games to our regimen, and this helped strengthen our daughter’s leg muscles faster.

Now that our child has completed treatment, we continue to help other families by spreading awareness and helping to raise money for clinical trials by speaking at NPCF events. Our daughter speaks about her personal experience. She is very passionate about helping other children in treatment and helping find a cure.

Lauren:

When I was told I had cancer I was really young, so I just knew that I had a booboo in my belly and had to take medicine to get rid of it. My mom and dad told me that the medicine would make my hair fall out.

The nurses and doctors helped me understand what was going to happen every time I needed a shot, or take medicine, or have a scan. They would explain it to me so I would not be scared.

Getting an MRI, CAT Scan or X-Ray made me feel scared at first, but because I was young and had to stay still, they gave me special medicine to make me sleep. It helped because then I did not remember anything. The X-rays are just like taking a big picture; they do not hurt at all. The machines are big, loud, and scary, but none of them hurt.

The first time I had to get blood products, I got very hot and itchy. I even got a rash. The nurse gave me medicine that made the itches go away, but it made me very sleepy. That is okay, because it is better than being itchy.

Some of the thoughts or concerns I had were...How long will I have to do this? Will my hair grow back? Why did I get cancer?
When I first started chemo or radiation I had to stay in the hospital. I hated having them “access my port”. This is when they put the needle in the port so you can get the medicine you need. My mom put a special cream on my port that stayed there a long time. This helped to make it so I would not feel the needle. We had a special way we did this. I always had skittles to eat because the flush (water to clear the port) made a terrible taste in my mouth. It helped to eat skittles when they flushed my port. I would also sit on the bed on my mom’s lap and squeeze her hand as tight as I could. The radiation gave me a tummy ache. I could not eat, so they put a tube in my nose when I was sleeping. My mom would hook it up to a machine that would help feed me when I could not swallow food on my own. It did not hurt. I would watch TV, play on the computer, or color while it did this.

To pass the time in the hospital, my family and I would play lots of games, color, watch movies, and play with other kids when I was feeling okay.

Talking to my classmates and friends about my cancer was hard because they did not understand why I looked different. They did not know how to treat me at first. But once they saw me a few times after I lost my hair and realized I was the same kid as before, it was okay. I had a “Monkey in My Chair” that would sit in my seat when I was in the hospital. This helped the kids remember me and not forget me when I wasn’t there. The teacher was really nice and gave my parents my work for me to do. She also helped welcome me back to class. I would tell the kids what happened to me in the hospital. They would ask a lot of questions. It kind of made me feel special.

If I could give advice to another child that was diagnosed with cancer it would be that if you are hurting, tell someone. It is okay to cry, because it can be scary. It doesn’t always hurt and staying in the hospital can be fun sometimes. If you have a question, make sure you ask. Sometimes it helps if you understand it better.

I continue to support other children and families going through treatment by talking at different NPCF events. I want to help raise money to give other kids the medicine they need. I hope to do this enough that they will someday find a cure so no more children have to go through this.
**Tania:**

When my child was first diagnosed, I was devastated and blamed myself. I kept trying to figure out what I had done wrong... Was it the X-ray or medicines I had before I knew I was pregnant with her? Or maybe it was the candy I allowed her to eat? I know better now, but at the time those thoughts were constantly in my mind.

A time during my child’s treatment when I used my intuition was...I could usually tell when her counts were low... there are no visible signs; it was just usually a feeling I had.

If there is one thing I could tell parents, whose children are newly diagnosed, I would say to be patient. The days are long but the years are quick.

Something that really frustrated me was the amount of hospital stays because of unexpected fevers.

We found a lot of laughter or happiness during our time in the hospital when we had family sleepovers when she got admitted over weekends or holidays complete with makeovers, movies, and board games. The sleep wasn't great, but the memories I will cherish forever.

Something I learned about myself during my child’s treatment was that I’m really good at making what should have been lonely days in a hospital room into days my daughter still talks about with happiness. Thanks to Pinterest, the dollar store, and nurses with a lot of patience for our shenanigans.

Advice I would give to another parent going through a similar experience would be to take advice from other parents who have gone through this. Ignore advice from well-meaning friends they found on the internet... especially if it involves a “cure” for cancer.

Take time for yourself! If you are happy, it will be easier to take care of your child.

Communicating with others about my child’s diagnosis has been a bit hard. Start a Facebook page or group for family and friends. With treatments, setbacks or good news, it can be hard to remember who you’ve updated and who hasn’t heard yet. Being able to post what was going on made my life so much less stressful.

To help with overall treatment and feeling better, we added Coca Cola (Coke) to help cover up the taste of almost any medicine.

Now that our child has completed treatment, we continue to help other families by sharing our story and encouraging families we’ve met along the way who are still going through treatment. My daughter also enjoyed raising money for and buying blankets to donate to the hospital.
Kayleigh:

When I was told I had cancer I didn’t know what that meant, and when I found out I was very scared.

The nurses and doctors helped me get better and learn to swallow pills.

Getting an MRI, CAT Scan or X-Ray made me feel...I thought they were fun.

The first time I had to get blood products I felt really scared, but it made me feel a lot better.

Some of the thoughts or concerns I had were that I wouldn’t be able to dance anymore, but I did get to dance even if sometimes it was by myself in a hospital room.

When I first started chemo or radiation, I didn’t realize how tired and sick it would make me feel.

To pass the time in the hospital, my family and I would play games and watch movies. I got a glitter tattoo kit that I would bring to the hospital every time I went and would give everybody that came to visit tattoos including all my nurses.

Talking to my classmates and friends about my cancer was scary because they usually thought it was contagious.

If I could give advice to another child that was diagnosed with cancer it would be to be brave and learn to swallow your pills. They taste better than the liquid.

I continue to support other children and families going through treatment by keeping in touch with them and offering help and advice.
William (Trey) Carlson is headed into his senior year at H. B. Plant High School and has been involved with NPCF since he was going into his freshman year of high school. Along with the help of Preslie Price, he was able to write this toolkit and do something that he loves, helping people be better and realize new paths.

Caroline Brasfield is a Parenting Coach, Curriculum Specialist, and Educator in Pinellas County, Florida. Her son Jackson was diagnosed with Osteosarcoma, a solid bone tumor, in 2014 at age 9. Caroline, Jackson and their family are passionate about raising funds and awareness for pediatric cancer, connecting with other pediatric cancer families around the country and volunteering with NPCF.

Shari Feinberg is a pediatric hematology-oncology nurse practitioner in NYC. She has been in the field for almost 30 years, working in both inpatient and outpatient settings. Her primary area of expertise is pediatric solid tumors.

Sarah Haines, RN, BSN, CPN, has been a nurse for 6 years, all of which has been working as a pediatric oncology nurse. Since beginning her career in pediatric oncology she has developed a passion for advocacy and awareness. For several years she has been working closely with the NPCF as a liaison to help connect families for events.

Dana Levin is a 15-year survivor of Hodgkin’s Lymphoma. After having cancer, she discovered her passion for a career in nursing. She is a Nurse Practitioner with experience in adult oncology. Because of research that was done many years ago to improve the cure rate of her disease, she is living a full life with her husband and one-year-old daughter.

Amanda McNary is the loving mom of two amazing children. Ethan was diagnosed with Osteosarcoma in October of 2016. Treatment for him was successful and he has been in remission for two years. Ethan is now going into his junior year of high school and his sister, Josie, is a freshman this year. Amanda is a teacher and now has even more empathy and insight into the varying difficulties that children go through. Ethan’s cancer journey taught her the patience, kindness, and understanding that she now utilizes every day.

Preslie Price is headed into her senior year at H. B. Plant High School and joined the NPCF team while headed into her sophomore year of high school. She was inspired to write this toolkit with Trey Carlson after her mother’s breast cancer diagnosis. She has found her passion for volunteering and making a difference through the NPCF.

Tiffany Smith, MS is the Project Manager of the NPCF’s Sunshine Project at Moffitt Cancer Center in Tampa, FL. Tiffany has over 15 years of professional experience working in an oncology setting, with the last five of those years being in pediatrics. In 2019, Tiffany was awarded NPCF’s Heart of Gold Award for her dedication to NPCF’s cause of finding more targeted and less toxic treatments for children with cancer. Tiffany lives in St. Petersburg, FL with her two dogs, Ollie and Bitsy, and her cat, Moe.