THE NCCS NEUROBLASTOMA HANDBOOK

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# The NCCS Neuroblastoma Handbook

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Sarah McWhorter is the mother and primary caregiver to a neuroblastoma survivor. She brings her passion for pediatric cancer and mentoring heart to this NCCS handbook. Her son, Aiden, was diagnosed with Stage 4 High Risk Neuroblastoma in 2019 at the age of one. After the successful completion of the standard Children’s Oncology Group protocol for high risk neuroblastoma, Aiden relapsed in June of 2020. He is currently pursuing treatment at the Memorial Sloan Kettering Cancer Center and is now NED and looking forward to survivorship. When Sarah is not in treatment or enjoying travels of the world, she works as an ASL interpreter for the Deaf community in Indianapolis, IN.

Mariah Forster Olson was diagnosed with neuroblastoma in 1980 at the age of one, with a tumor growing out of her spine, wrapping around a portion of her heart, and occupying almost the entire right side of her chest. At that time, there were very few treatment options, and Mariah had them all – multiple surgeries, many radiation treatments, and two years of a new chemotherapy clinical trial, including cyclophosphamide, doxorubicin, and vincristine, which are still being used today! Outdated therapeutics and the location of her tumor have left Mariah with a number of complex medical conditions and late effects that greatly impact her life, but she strives to focus on hope, optimism, and positivity. Mariah is the Director of Survivor, Family, and Resource Services for NCCS, and she also serves on the NCCS Board and is the co-administrator of the “Neuroblastoma Family Support Group” on Facebook. Mariah also represents NCCS in the Coalition Against Childhood Cancer (CAC2), where she is the survivorship interest group liaison and the co-lead of the Leadership Transition Planning Team, and she also serves on the Board of Directors and on the Executive Committee. Mariah’s work truly fulfills her and gives her a sense of purpose, and she truly hopes to help others and provide hope, understanding, support, and encouragement. Mariah lives in La Crosse, Wisconsin with her husband, Troy, and their Siamese cat. In her spare time, Mariah volunteers for several additional nonprofit cancer organizations, is writing a book about her life, and plays the oboe professionally.
More than 15,000 children are diagnosed with one of the 16 different types of childhood cancer in the United States every year, making it the leading cause of death by disease among children. Neuroblastoma is one of the 16 types of childhood cancer that consists of a solid tumor that develops from nerve cells. It is the most common cancer diagnosed in infants, and 90% of neuroblastoma cases are diagnosed in children under five years old. Although neuroblastoma makes up 8% of all childhood cancer cases, it accounts for 15% of all childhood cancer-related deaths.

At the age of three, Michael Sexton courageously battled neuroblastoma for nine months, but his fight tragically ended in 1994. After Michael died, his parents, James and Dori Sexton, were shocked to learn that there were no major organizations funding significant research to promote a frontline treatment or a cure for neuroblastoma. In honor of Michael and other children who had died from neuroblastoma, the Neuroblastoma Children’s Cancer Society (NCCS) was formed and became a 501(c)(3) in 1994 in Hoffman Estates, Illinois.

The mission of the Neuroblastoma Children’s Cancer Society is to cure neuroblastoma and its related childhood cancers, as well as to improve the quality of life for patients, survivors, and their families. We accomplish this by raising funds to support researchers investigating the causes, treatments, and cures for neuroblastoma and related cancers. Other vital components to our mission are generating public awareness and providing support, resources, and assistance to the neuroblastoma community. Finally, we advocate for government research funding and associated public policies for all types of childhood cancers.

The Neuroblastoma Children’s Cancer Society is composed entirely of volunteers, and there are no paid staff or employees. Each person that volunteers for NCCS has been directly impacted by neuroblastoma, and we are patients, families and caregivers, survivors, and bereaved family members. Thus, each volunteer is highly invested in fulfilling the mission and goals of our organization.

The Neuroblastoma Children’s Cancer Society gives the majority of our donations to research because childhood cancers are vastly and consistently underfunded, so it falls to private organizations to fill in the funding gaps to pay for this desperately needed research. We need better, less toxic treatments to treat all types of neuroblastoma and related childhood cancers, and to decrease the number and severity of late effects for neuroblastoma survivors. In addition, although the survival rates for high-risk neuroblastoma have increased in the last few decades, we want to see this number continue to
increase. There are also no standard treatments for relapsed neuroblastoma; rather each child receives individualized treatments and are often entered into clinical trials. Again, these clinical trials cost money, but this research is absolutely imperative if we are to treat and improve the survival rates of high-risk and relapsed neuroblastoma patients, who are primarily young children.

Between 1994, when NCCS originated, and 2020, we have donated more than $2 million to neuroblastoma research and we have formed partnerships with various hospitals, including the Children’s Hospital of Los Angeles and the Children’s Hospital of Philadelphia. The majority of our research funding, however, has been donated to the University of Chicago for various neuroblastoma research grants and projects. For example, NCCS has supported research grants for the Interactive International Neuroblastoma Information Network (IININ), the Neuroblastoma Virtual Tumor Bank, the International Neuroblastoma Risk Group (INRG) Classification System, New Approaches to Neuroblastoma Therapy (NANT) Clinical Trials, the Pediatric Cancer Data Commons (PCDC), and many others.

Various types of support and services are absolutely crucial for childhood cancer patients, families, and survivors, and we want them to know that NCCS is there for them in many different ways. For example, we offer a variety of resources and educational components because when a family is immersed in childhood cancer, they are incredibly overwhelmed because there is so much information to process in a short amount of time. Knowledge and education are very important when understanding what is happening with the diagnosis, treatment, and survival of neuroblastoma, so we want to make things a little easier by providing information all in one place. That way, they do not have to search for information on their own, and it is all housed in one area for families to refer to when needed. We also believe it is important to provide various types of support networks and assistance of neuroblastoma patients, families, and survivors, and we provide this through: our private Facebook group; our Facebook, Twitter, and Instagram pages; our website; and our membership in the Coalition Against Childhood Cancer. As more patients and families face neuroblastoma or a related childhood cancer diagnosis, and as others move toward survivorship, we want those in our community to be aware of NCCS so that we can help even more patients, survivors, and their families.

The list below contains a more complete picture of NCCS’ programs and services:

- Raising money and receiving donations for childhood cancer research are absolutely critical to the mission of NCCS, and aside from private gifts, we actively accomplish this through:
  - Annual fundraisers
  - Annual races
  - Facebook Birthday Fundraisers, Giving Tuesday, and other Facebook fundraisers
- “Neuroblastoma Family Support Group,” a private Facebook group for parents/caregivers, family members, patients, and survivors to share their stories, advice, questions, support, and anything else related to neuroblastoma. This page acts as a support group for members of our community, and it provides psychosocial support for patients, survivors, and their family members. (https://www.facebook.com/groups/neuroblastomasupport/). This group contains thousands of members, and also offers: a weekly discussion topic; a file containing neuroblastoma topics and corresponding resources information; and past posts categorized by topic, so that members can easily search by subject matter for relevant information and advice. A public page on Facebook, “The Neuroblastoma Children’s Cancer Society” (https://www.facebook.com/NeuroblastomaChildrensCancerSociety/), featuring stories, data, facts and statistics, and events about neuroblastoma and related childhood cancers.
- Social media accounts on Twitter (@Fight2CureKids) and Instagram (@neuroblastomacancer).
- Distributing toys, games, and crafting projects to various children’s hospitals throughout the year, including the “Have A Heart” program during Valentine’s Day.
- Membership in the Coalition Against Childhood Cancer (CAC2), which is an organization that “advances a variety of childhood cancer causes by unifying the childhood cancer community through broad-based coordinated action and collaboration that leverages the strengths and expertise of its individual members and minimizes duplication of effort.” One of our NCCS Directors and the Program Director for this grant is also on the Board of Directors for CAC2, and she leads their Survivorship Interest Group.
- Our Website (https://www.neuroblastomacancer.org/) – We received a grant for a grant program that began in November 2020 and ends in January 2022 to assist us in creating and launching our new website. The new website contains resources that were carried over and updated from our old website, as well as new, valuable resources and information for patients, families, and survivors of neuroblastoma. These include:
  - Two new NCCS Handbooks, one aimed at current neuroblastoma patients and one aimed at neuroblastoma survivors. The handbooks contain a wealth of information about neuroblastoma, ranging from diagnosis and treatment to survivorship and bereavement.
  - A forum for visitors to submit stories or questions.
  - Our Wall of Fame, featuring members of NCCS and their fight against neuroblastoma.
  - Various ways to advocate for childhood cancer legislation and funding.
  - A database of survivorship issues and accompanying information, research, and resources.
  - Link to the Hope Portal, which is a comprehensive database that provides patients, parents, and survivors with organizations from around the country that can provide assistance, as well as resources and information. This wealth of resources is courtesy of the Coalition Against Childhood Cancer.
  - Featured books and other resources about neuroblastoma.
  - A list of ways that members and volunteers can help NCCS in the fight against neuroblastoma and related childhood cancers.

REFERENCES

General Information About Neuroblastoma

Neuroblastoma is a disease in which malignant (cancer) cells form in neuroblasts (immature nerve tissue) in the adrenal glands, neck, chest, or spinal cord.

Neuroblastoma often begins in the nerve tissue of the adrenal glands. There are two adrenal glands, one on top of each kidney in the back of the upper abdomen. The adrenal glands make important hormones that help control heart rate, blood pressure, blood sugar, and the way the body reacts to stress. Neuroblastoma may also begin in nerve tissue in the neck, chest, abdomen, or pelvis.

Neuroblastoma may be found in the adrenal glands and paraspinal nerve tissue from the neck to the pelvis.

Neuroblastoma most often begins in infancy. It is usually diagnosed between the first month of life and age five years. It is found when the tumor begins to grow and cause signs or symptoms. Sometimes it forms before birth and is found during an ultrasound of the baby.

By the time cancer is diagnosed, it has usually metastasized (spread). Neuroblastoma spreads most often to the lymph nodes, bones, bone marrow, liver, and skin in infants and children. Adolescents may also have metastasis to the lungs and brain.
Signs and symptoms of neuroblastoma include a lump in the abdomen, neck, or chest or bone pain.

The most common signs and symptoms of neuroblastoma are caused by the tumor pressing on nearby tissues as it grows or by cancer spreading to the bone. These and other signs and symptoms may be caused by neuroblastoma or by other conditions.

Check with your child’s doctor if your child has any of the following:

- Lump in the abdomen, neck, or chest.
- Bone pain.
- Swollen stomach and trouble breathing (in infants).
- Bulging eyes.
- Dark circles around the eyes ("black eyes").
- Painless, bluish lumps under the skin (in infants).
- Weakness or paralysis (loss of ability to move a body part).

Less common signs and symptoms of neuroblastoma include the following:

- Fever.
- Shortness of breath.
- Feeling tired.
- Easy bruising or bleeding.
- Petechiae (flat, pinpoint spots under the skin caused by bleeding).
- High blood pressure.
- Severe watery diarrhea.
- Horner syndrome (droopy eyelid, smaller pupil, and less sweating on one side of the face).
- Jerky muscle movements.
- Uncontrolled eye movements.

Tests that examine many different body tissues and fluids are used to diagnose neuroblastoma.

The following tests and procedures may be used to diagnose neuroblastoma:

- **Physical exam and health history**: An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient’s health habits and past illnesses and treatments will also be taken.
- **Neurological exam**: A series of questions and tests to check the brain, spinal cord, and nerve function. The exam checks a person’s mental status, coordination, ability to walk normally, and how well the muscles, senses, and reflexes work. This may also be called a neuro exam or a neurologic exam.
- **Urine catecholamine studies**: A test in which a urine sample is checked to measure the amount of certain substances, vanillylmandelic acid (VMA) and homovanillic acid (HVA), that are made when catecholamines break down and are released into the urine. A higher than normal amount of VMA or HVA can be a sign of neuroblastoma.
- **Blood chemistry studies**: A test in which a blood sample is checked to measure the amounts of certain substances released into the blood by organs and tissues in the body. A higher or lower than normal amount of a substance can be a sign of disease.
- **MIBG scan**: A procedure used to find neuroendocrine tumors, such as neuroblastoma. A very small amount of a substance called radioactive MIBG is injected into a vein and travels through the bloodstream. Neuroendocrine tumor cells take up the radioactive MIBG and are detected by a scanner. Scans may be taken
over 1-3 days. An iodine solution may be given before or during the test to keep the thyroid gland from absorbing too much of the MIBG. This test is also used to find out how well the tumor is responding to treatment. MIBG is used in high doses to treat neuroblastoma.

- **CT scan (CAT scan):** A procedure that makes a series of detailed pictures of areas inside the body, taken from different angles. The pictures are made by a computer linked to an x-ray machine. A dye may be injected into a vein or swallowed to help the organs or tissues show up more clearly. This procedure is also called computed tomography, computerized tomography, or computerized axial tomography. The child lies on a table that slides through the CT scanner, which takes x-ray pictures of the inside of the abdomen.

- **MRI (magnetic resonance imaging) with gadolinium:** A procedure that uses a magnet, radio waves, and a computer to make a series of detailed pictures of areas inside the body. A substance called gadolinium is injected into a vein. The gadolinium collects around the cancer cells so they show up brighter in the picture. This procedure is also called nuclear magnetic resonance imaging (NMRI).

- **PET scan (positron emission tomography scan):** A procedure to find malignant tumor cells in the body. A small amount of radioactive glucose (sugar) is injected into a vein. The PET scanner rotates around the body and makes a picture of where glucose is being used in the body. Malignant tumor cells show up brighter in the picture because they are more active and take up more glucose than normal cells do.

- **X-ray of the chest or bone:** An x-ray is a type of energy beam that can go through the body and onto film, making a picture of areas inside the body.

- **Ultrasound exam:** A procedure in which high-energy sound waves (ultrasound) are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissues called a sonogram. The picture can be printed to be looked at later. An ultrasound exam is not done if a CT/MRI has been done.

**A biopsy is done to diagnose neuroblastoma.**

Cells and tissues are removed during a biopsy so they can be viewed under a microscope by a pathologist to check for signs of cancer. The way the biopsy is done depends on where the tumor is in the body. Sometimes the whole tumor is removed at the same time the biopsy is done.

The following tests may be done on the tissue that is removed:

- **Cytogenetic analysis:** A laboratory test in which the chromosomes of cells in a sample of tissue are counted and checked for any changes, such as broken, missing, rearranged, or extra chromosomes. Changes in certain chromosomes may be a sign of cancer. Cytogenetic analysis is used to help diagnose cancer, plan treatment, or find out how well treatment is working.

- **Light microscopy:** A laboratory test in which cells in a sample of tissue are viewed under regular and high-powered microscopes to look for certain changes in the cells.

- **Immunohistochemistry:** A laboratory test that uses antibodies to check for certain antigens (markers) in a sample of a patient’s tissue. The antibodies are usually linked to an enzyme or a fluorescent dye. After the antibodies bind to a specific antigen in the tissue sample, the enzyme or dye is activated, and the antigen can then be seen under a microscope. This type of test is used to help diagnose cancer and to help tell one type of cancer from another type of cancer.

- **MYCN amplification study:** A laboratory study in which tumor or bone marrow cells are checked for the level of MYCN. MYCN is important for cell growth. A higher level of MYCN (more than 10 copies of the gene) is called MYCN amplification. Neuroblastoma with MYCN amplification is more likely to spread in the body and less likely to respond to treatment.

Children up to 6 months old may not need a biopsy or surgery to remove the tumor because the tumor may disappear without treatment.
Certain factors affect prognosis (chance of recovery) and treatment options.

The prognosis and treatment options depend on the following:
- Age at the time of diagnosis.
- Tumor histology (the shape, function, and structure of the tumor cells).
- The child's risk group.
- Whether there are certain changes in the genes.
- Where in the body the tumor started.
- The stage of the cancer.
- How the tumor responds to treatment.
- How much time passed between diagnosis and when the cancer recurred (for recurrent cancer).

Prognosis and treatment options for neuroblastoma are also affected by tumor biology, which includes the following:
- The patterns of the tumor cells.
- How different the tumor cells are from normal cells.
- How fast the tumor cells are growing.
- Whether the tumor shows MYCN amplification.
- Whether the tumor has changes in the ALK gene.

The tumor biology is said to be favorable or unfavorable, depending on these factors. A child with favorable tumor biology has a better chance of recovery.

In some children up to 6 months old, neuroblastoma may disappear without treatment. This is called spontaneous regression. The child is closely watched for signs or symptoms of neuroblastoma. If signs or symptoms occur, treatment may be needed.

Stages of Neuroblastoma

The following tests and procedures also may be used to determine the stage:
- **Bone marrow aspiration and biopsy:** The removal of bone marrow, blood, and a small piece of bone by inserting a hollow needle into the hipbone or breastbone. A pathologist views the bone marrow, blood, and bone under a microscope to look for signs of cancer.
- **Lymph node biopsy:** The removal of all or part of a lymph node. A pathologist views the lymph node tissue under a microscope to check for cancer cells. One of the following types of biopsies may be done:
  - **Excisional biopsy:** The removal of an entire lymph node.
  - **Incisional biopsy:** The removal of part of a lymph node.
  - **Core biopsy:** The removal of tissue from a lymph node using a wide needle.
  - **Fine-needle aspiration (FNA) biopsy:** The removal of tissue or fluid from a lymph node using a thin needle.

Cancer may spread from where it began to other parts of the body.

When cancer spreads to another part of the body, it is called metastasis. Cancer cells break away from where they began (the primary tumor) and travel through the lymph system or blood.
- **Lymph system:** The cancer gets into the lymph system, travels through the lymph vessels, and forms a tumor (metastatic tumor) in another part of the body.
- **Blood:** The cancer gets into the blood, travels through the blood vessels, and forms a tumor (metastatic tumor) in another part of the body.
The metastatic tumor is the same type of cancer as the primary tumor. For example, if neuroblastoma spreads to the liver, the cancer cells in the liver are actually neuroblastoma cells. The disease is metastatic neuroblastoma, not liver cancer.

**The following stages are used for neuroblastoma:**

**Stage 1**

In stage 1, the cancer is in only one area and all of the cancer that can be seen is completely removed during surgery.

**Stage 2**

Stage 2 is divided into stages 2A and 2B.

- **Stage 2A:** The cancer is in only one area and all of the cancer that can be seen is not completely removed during surgery.
- **Stage 2B:** The cancer is in only one area and all of the cancer that can be seen may or may not be completely removed during surgery. Cancer cells are found in the lymph nodes near the tumor.

**Stage 3**

In stage 3, one of the following is true:

- the cancer cannot be completely removed during surgery and has spread from one side of the body to the other side and may also have spread to nearby lymph nodes; or
- the cancer is on one side of the body and has spread to lymph nodes on the other side of the body; or
- the cancer is in the middle of the body and has spread to tissues or lymph nodes on both sides of the body, and the cancer cannot be removed by surgery.

**Stage 4**

Stage 4 is divided into stages 4 and 4S.

- In stage 4, the cancer has spread to distant lymph nodes or to other parts of the body.
- In stage 4S, the child is younger than 12 months, and:
  - the cancer has spread to the skin, liver, and/or bone marrow; or
  - the cancer is in only one area and all of the cancer that can be seen may or may not be completely removed during surgery; or
  - cancer cells may be found in the lymph nodes near the tumor.

**Treatment of neuroblastoma is based on risk groups.**

For many types of cancer, stages are used to plan treatment. For neuroblastoma, treatment depends on the patient's risk group. The stage of neuroblastoma is one factor used to determine risk group. Other factors are age, tumor histology, and tumor biology.

There are three risk groups: low risk, intermediate risk, and high risk.

- Low-risk and intermediate-risk neuroblastoma have a good chance of being cured.
- High-risk neuroblastoma may be hard to cure.
Sometimes neuroblastoma does not respond to treatment or comes back after treatment.

Refractory neuroblastoma is a tumor that does not respond to treatment.

Recurrent neuroblastoma is cancer that has recurred (come back) after it has been treated. The tumor may come back in the site where it began or in the central nervous system.

**Treatment Options Overview**

There are different types of treatment for patients with neuroblastoma.

Different types of treatment are available for patients with neuroblastoma. Some treatments are standard (the currently used treatment), and some are being tested in clinical trials. A treatment clinical trial is a research study meant to help improve current treatments or obtain information on new treatments for patients with cancer. When clinical trials show that a new treatment is better than the standard treatment, the new treatment may become the standard treatment.
Because cancer in children is rare, taking part in a clinical trial should be considered. Some clinical trials are open only to patients who have not started treatment.

**Children with neuroblastoma should have their treatment planned by a team of doctors who are experts in treating childhood cancer, especially neuroblastoma.**

Treatment will be overseen by a pediatric oncologist, a doctor who specializes in treating children with cancer. The pediatric oncologist works with other pediatric health care providers who are experts in treating children with neuroblastoma and who specialize in certain areas of medicine. These may include the following specialists:

- Pediatric surgeon.
- Pediatric radiation oncologist.
- Endocrinologist.
- Neurologist.
- Pediatric neuropathologist.
- Neuroradiologist.
- Pediatrician.
- Pediatric nurse specialist.
- Social worker.
- Child life professional.
- Psychologist.

**Seven types of standard treatment are used:**

**Observation:** Observation is closely monitoring a patient's condition without giving any treatment until signs or symptoms appear or change.

**Surgery:** Surgery is used to treat neuroblastoma that has not spread to other parts of the body. As much of the tumor as is safely possible is removed. Lymph nodes are also removed and checked for signs of cancer.

If the tumor cannot be removed, a biopsy may be done instead.

**Radiation therapy:** Radiation therapy is a cancer treatment that uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing. External radiation therapy uses a machine outside the body to send radiation toward the area of the body with cancer.

**Iodine 131-MIBG therapy:** Iodine 131-MIBG therapy is a treatment with radioactive iodine. The radioactive iodine is given through an intravenous (IV) line and enters the bloodstream which carries radiation directly to tumor cells. Radioactive iodine collects in neuroblastoma cells and kills them with the radiation that is given off. Iodine 131-MIBG therapy is sometimes used to treat high-risk neuroblastoma that comes back after initial treatment.

**Chemotherapy:** Chemotherapy is a cancer treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. When chemotherapy is taken by
mouth or injected into a vein or muscle, the drugs enter the bloodstream and can reach cancer cells throughout the body (systemic chemotherapy).

The use of two or more anticancer drugs is called combination chemotherapy.

**High-dose chemotherapy and radiation therapy with stem cell rescue:** High-dose chemotherapy and radiation therapy are given to kill any cancer cells that may regrow and cause the cancer to come back. Healthy cells, including blood-forming cells, are also destroyed by the cancer treatment. Stem cell rescue is a treatment to replace the blood-forming cells. Stem cells (immature blood cells) are removed from the blood or bone marrow of the patient and are frozen and stored. After the patient completes chemotherapy and radiation therapy, the stored stem cells are thawed and given back to the patient through an infusion. These reinfused stem cells grow into (and restore) the body's blood cells.

**Maintenance therapy** is given after high-dose chemotherapy and radiation therapy with stem cell rescue for 6 months and includes the following treatments:

- **Isotretinoin:** A vitamin-like drug that slows the cancer's ability to make more cancer cells and changes how these cells look and act. This drug is taken by mouth.
- **Dinutuximab:** A type of monoclonal antibody therapy that uses an antibody made in the laboratory from a single type of immune system cell. Dinutuximab identifies and attaches to a substance, called GD2, on the surface of neuroblastoma cells. Once dinutuximab attaches to the GD2, a signal is sent to the immune system that a foreign substance has been found and needs to be killed. Then the body's immune system kills the neuroblastoma cell. Dinutuximab is given by infusion. It is a type of targeted therapy.
- **Granulocyte-macrophage colony-stimulating factor (GM-CSF):** A cytokine that helps make more immune system cells, especially granulocytes and macrophages (white blood cells), which can attack and kill cancer cells.
- **Interleukin-2 (IL-2):** A type of immunotherapy that boosts the growth and activity of many immune cells, especially lymphocytes (a type of white blood cell). Lymphocytes can attack and kill cancer cells.

**Targeted therapy:** Targeted therapy is a type of treatment that uses drugs or other substances to identify and attack specific cancer cells. Targeted therapies usually cause less harm to normal cells than chemotherapy or radiation therapy do. There are different types of targeted therapies:

- **Monoclonal antibody therapy:** Monoclonal antibodies are immune system proteins made in the laboratory to treat many diseases, including cancer. As a cancer treatment, these antibodies can attach to a specific target on cancer cells or other cells that may help cancer cells grow. The antibodies are able to then kill the cancer cells, block their growth, or keep them from spreading. Monoclonal antibodies are given by infusion. They may be used alone or to carry drugs, toxins, or radioactive material directly to cancer cells. **Pembrolizumab** and **dinutuximab** are monoclonal antibodies being studied to treat neuroblastoma that has come back after treatment or has not responded to treatment. How do monoclonal antibodies work to treat cancer? This video shows how monoclonal antibodies, such as trastuzumab, pembrolizumab, and rituximab, block molecules cancer cells need to grow, flag cancer cells for destruction by the body’s immune system, or deliver harmful substances to cancer cells.
- **Tyrosine kinase inhibitor therapy:** These targeted therapy drugs block signals needed for tumors to grow. **Crizotinib** is a tyrosine kinase inhibitor used to treat neuroblastoma that has come back after treatment. **AZD1775** and **lorlatinib** are tyrosine kinase inhibitors being studied to treat neuroblastoma that has come back after treatment or has not responded to treatment.
● Histone deacetylase inhibitor therapy: This treatment causes a chemical change that stops cancer cells from growing and dividing. Vorinostat is a type of histone deacetylase inhibitor being studied to treat neuroblastoma that has come back after treatment or has not responded to treatment.

● Ornithine decarboxylase inhibitor therapy: This treatment slows the growth and division of cancer cells. Eflornithine is a type of ornithine decarboxylase inhibitor being studied to treat neuroblastoma that has come back after treatment or has not responded to treatment.

New types of treatment are being tested in clinical trials.

This summary section describes treatments that are being studied in clinical trials. It may not mention every new treatment being studied. Information about clinical trials is available from the NCI website.

Immunotherapy

Immunotherapy is a treatment that uses the patient’s immune system to fight cancer. Substances made by the body or made in a laboratory are used to boost, direct, or restore the body’s natural defenses against cancer. This cancer treatment is a type of biologic therapy.

● CAR T-cell therapy: The patient's T cells (a type of immune system cell) are changed so that they will attack certain proteins on the surface of cancer cells. T cells are taken from the patient and special receptors are added to their surface in the laboratory. The changed cells are called chimeric antigen receptor (CAR) T cells. The CAR T cells are grown in the laboratory and given to the patient by infusion. The CAR T cells multiply in the patient's blood and attack cancer cells...CAR T-cell therapy is being studied to treat neuroblastoma that has come back after treatment or has not responded to treatment.

Patients may want to think about taking part in a clinical trial.

For some patients, taking part in a clinical trial may be the best treatment choice. Clinical trials are part of the cancer research process. Clinical trials are done to find out if new cancer treatments are safe and effective or better than the standard treatment.

Many of today's standard treatments for cancer are based on earlier clinical trials. Patients who take part in a clinical trial may receive the standard treatment or be among the first to receive a new treatment. Patients who take part in clinical trials also help improve the way cancer will be treated in the future. Even when clinical trials do not lead to effective new treatments, they often answer important questions and help move research forward.

Patients can enter clinical trials before, during, or after starting their cancer treatment.

Some clinical trials only include patients who have not yet received treatment. Other trials test treatments for patients whose cancer has not gotten better. There are also clinical trials that test new ways to stop cancer from recurring (coming back) or reduce the side effects of cancer treatment. Clinical trials are taking place in many parts of the country. Information about clinical trials supported by NCI can be found on NCI's clinical trials search webpage. Clinical trials supported by other organizations can be found on the ClinicalTrials.gov website.
Follow-up tests may be needed.

Some of the tests that were done to diagnose the cancer or to find out the stage of the cancer may be repeated. Some tests will be repeated in order to see how well the treatment is working. Decisions about whether to continue, change, or stop treatment may be based on the results of these tests. Some of the tests will continue to be done from time to time after treatment has ended. The results of these tests can show if your child's condition has changed or if the cancer has recurred (come back). These tests are sometimes called follow-up tests or check-ups.

Follow-up tests for patients with neuroblastoma include the following:
- Urine catecholamine studies.
- MIBG scan.

Treatment of Low-Risk Neuroblastoma

For information about the treatments listed below, see the Treatment Option Overview section.

Treatment of newly diagnosed low-risk neuroblastoma may include the following:
- Surgery followed by observation.
- Chemotherapy and surgery, for children with symptoms or children whose tumor has continued to grow and cannot be removed by surgery.
- Chemotherapy, for certain patients.
- Observation alone for infants younger than 6 months who have small adrenal tumors or for infants who do not have signs or symptoms of neuroblastoma.
- Radiation therapy to treat tumors that are causing serious problems and do not respond quickly to chemotherapy or surgery.
- A clinical trial of treatment based on the tumor's response to treatment and tumor biology.

Use our clinical trial search to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. General information about clinical trials is also available.

Treatment of Intermediate-Risk Neuroblastoma

For information about the treatments listed below, see the Treatment Option Overview section.

Treatment of newly diagnosed intermediate-risk neuroblastoma may include the following:
- Chemotherapy for children with symptoms or to shrink a tumor that cannot be removed by surgery. Surgery may be done after chemotherapy.
- Surgery alone for infants.
- Observation alone for infants.
- Radiation therapy to treat tumors that have continued to grow during treatment with chemotherapy or tumors that cannot be removed by surgery and have continued to grow after treatment with chemotherapy.
- A clinical trial of treatment based on the tumor's response to treatment and tumor biology.

Use our clinical trial search to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. General information about clinical trials is also available.

Treatment of High-Risk Neuroblastoma

For information about the treatments listed below, see the Treatment Option Overview section.
Treatment of newly diagnosed high-risk neuroblastoma may include the following:

- A regimen of the following treatments:
  - Combination chemotherapy.
  - Surgery.
  - Two courses of high-dose combination chemotherapy followed by stem cell rescue.
  - Radiation therapy.
  - Monoclonal antibody therapy (dinutuximab) with interleukin-2 (IL-2), granulocyte-macrophage colony-stimulating factor (GM-CSF), and isotretinoin.
- A clinical trial of iodine 131-MIBG therapy or targeted therapy (crizotinib) and other treatments.
- A clinical trial of monoclonal antibody therapy (dinutuximab), GM-CSF, and combination chemotherapy.

Use our clinical trial search to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. General information about clinical trials is also available.

**Treatment of Stage 4S Neuroblastoma**

For information about the treatments listed below, see the Treatment Option Overview section. There is no standard treatment for newly diagnosed stage 4S neuroblastoma but treatment options include the following:

- Observation and supportive care for children who have favorable tumor biology and do not have signs or symptoms.
- Chemotherapy, for children who have signs or symptoms, for very young infants, or for children with unfavorable tumor biology.
- Radiation therapy for children with neuroblastoma that has spread to the liver.
- A clinical trial of treatment based on the tumor's response to treatment and tumor biology.

Use our clinical trial search to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. General information about clinical trials is also available.

**Chemotherapy Medications**

There are many different types of chemotherapy medications and combinations of medications that are given to treat neuroblastoma patients. Current, updated information on specific chemotherapy medications can be found at the resource below.

**A to Z List of Cancer Medications**


Use the A to Z lists to find consumer-friendly information about drugs for cancer and conditions related to cancer. This list is in alphabetical order by generic name and brand name. You can also find also find additional information, including the drugs approved for specific types of cancers in children, at: **Drugs Approved for Childhood Cancer** - [https://www.cancer.gov/about-cancer/treatment/drugs/childhood-cancer-fda-approved-drug](https://www.cancer.gov/about-cancer/treatment/drugs/childhood-cancer-fda-approved-drug)
Immunotherapy to Treat Cancer

Immunotherapy is a type of cancer treatment that helps your immune system fight cancer. The immune system helps your body fight infections and other diseases. It is made up of white blood cells and organs and tissues of the lymph system. Immunotherapy is a type of biological therapy. Biological therapy is a type of treatment that uses substances made from living organisms to treat cancer.

How does immunotherapy work against cancer?

Learn about nonspecific immune stimulation, T-cell transfer therapy, and immune checkpoint inhibitors, which are 3 types of immunotherapy used to treat cancer.

As part of its normal function, the immune system detects and destroys abnormal cells and most likely prevents or curbs the growth of many cancers. For instance, immune cells are sometimes found in and around tumors. These cells, called tumor-infiltrating lymphocytes or TILs, are a sign that the immune system is responding to the tumor. People whose tumors contain TILs often do better than people whose tumors don’t contain them.

Even though the immune system can prevent or slow cancer growth, cancer cells have ways to avoid destruction by the immune system. For example, cancer cells may:

- Have genetic changes that make them less visible to the immune system.
- Have proteins on their surface that turn off immune cells.
- Change the normal cells around the tumor so they interfere with how the immune system responds to the cancer cells.

Immunotherapy helps the immune system to better act against cancer.

What are the types of immunotherapy?

Several types of immunotherapy are used to treat cancer. These include:

- **Immune checkpoint inhibitors**, which are drugs that block immune checkpoints. These checkpoints are a normal part of the immune system and keep immune responses from being too strong. By blocking them, these drugs allow immune cells to respond more strongly to cancer.

- **T-cell transfer therapy**, which is a treatment that boosts the natural ability of your T cells to fight cancer. In this treatment, immune cells are taken from your tumor. Those that are most active against your cancer are selected or changed in the lab to better attack your cancer cells, grown in large batches, and put back into your body through a needle in a vein. T-cell transfer therapy may also be called adoptive cell therapy, adoptive immunotherapy, or immune cell therapy.

- **Monoclonal antibodies**, which are immune system proteins created in the lab that are designed to bind to specific targets on cancer cells. Some monoclonal antibodies mark cancer cells so that they will be better seen and destroyed by the immune system. Such monoclonal antibodies are a type of immunotherapy. Monoclonal antibodies may also be called therapeutic antibodies.

- **Treatment vaccines**, which work against cancer by boosting your immune system’s response to cancer cells. Treatment vaccines are different from the ones that help prevent disease.

- **Immune system modulators**, which enhance the body’s immune response against cancer. Some of these agents affect specific parts of the immune system, whereas others affect the immune system in a more general way.
What are the side effects of immunotherapy?
Immunotherapy can cause side effects, many of which happen when the immune system that has been revved-up to act against the cancer also acts against healthy cells and tissues in your body. Learn more about immunotherapy side effects.

How is immunotherapy given?
Different forms of immunotherapy may be given in different ways. These include:

- **Intravenous (IV)**
  The immunotherapy goes directly into a vein.

- **Oral**
  The immunotherapy comes in pills or capsules that you swallow.

- **Topical**
  The immunotherapy comes in a cream that you rub onto your skin. This type of immunotherapy can be used for very early skin cancer.

- **Intravesical**
  The immunotherapy goes directly into the bladder.

Where do you go for immunotherapy?
You may receive immunotherapy in a doctor’s office, clinic, or outpatient unit in a hospital. Outpatient means you do not spend the night in the hospital.

How often do you receive immunotherapy?
How often and how long you receive immunotherapy depends on:

- Your type of cancer and how advanced it is
- The type of immunotherapy you get
- How your body reacts to treatment

You may have treatment every day, week, or month. Some types of immunotherapy given in cycles. A cycle is a period of treatment followed by a period of rest. The rest period gives your body a chance to recover, respond to the immunotherapy, and build new healthy cells.

How can you tell if immunotherapy is working?
You will see your doctor often. He or she will give you physical exams and ask you how you feel. You will have medical tests, such as blood tests and different types of scans. These tests will measure the size of your tumor and look for changes in your blood work.
New Approaches to Neuroblastoma Therapy (NANT)

https://www.nant.org/

“Established in 2000, NANT is the only clinical trials consortium in North America focused solely on developing new treatments and biomarkers for relapsed/refractory high-risk neuroblastoma through early phase (1/2) clinical trials.”

High-risk neuroblastoma remains a challenge, despite improvements seen with intensive chemotherapy, isotretinoin, and immunotherapy. Further advances require increased understanding of the fundamental biology and genetics of neuroblastoma, and more individualized precision therapies.

NANT has established collaborations with laboratory investigators who study biologic pathways and genetic changes that may cause tumor resistance. NANT clinical investigators provide the clinical expertise to translate these lab findings into novel therapeutic trials conducted by an international consortium of experienced pediatric oncology centers. NANT trials provide the necessary safety and preliminary response data to inform (inter)national trials that will test the impact of NANT therapies on improving patient outcome. NANT integrates the input of families fighting neuroblastoma via our Parent Advisory Committee.”
GENERAL SIDE EFFECTS OF CANCER TREATMENT

**All of the information in this section has been adapted from the National Cancer Institute, and it is available in its entirety at:** [https://www.cancer.gov/about-cancer/treatment/side-effects](https://www.cancer.gov/about-cancer/treatment/side-effects)

Cancer treatments and cancer can cause side effects. Side effects are problems that occur when treatment affects healthy tissues or organs. Speak up about any problems you have. Your health care team can treat and/or talk with you about ways to reduce these side effects, so you feel better. Keep in mind that side effects vary from person to person, even among people receiving the same type of cancer treatment.

Anemia and Cancer Treatment


Anemia is a condition that can make you feel very tired, short of breath, and lightheaded. Other signs of anemia may include feeling dizzy or faint, headaches, a fast heartbeat, and/or pale skin. Cancer treatments, such as chemotherapy and radiation therapy, as well as cancers that affect the bone marrow, can cause anemia. When you are anemic, your body does not have enough red blood cells. Red blood cells are the cells that carry oxygen from the lungs throughout your body to help it work properly. You will have blood tests to check for anemia. Treatment for anemia is also based on your symptoms and on what is causing the anemia.

Ways to Manage Anemia

Here are some steps you can take if you have fatigue caused by anemia:

- **Save your energy and ask for help.** Choose the most important things to do each day. When people offer to help, let them do so. They can take you to the doctor, make meals, or do other things you are too tired to do.
- **Balance rest with activity.** Take short naps during the day, but keep in mind that too much bed rest can make you feel weak. You may feel better if you take short walks or exercise a little every day.
- **Eat and drink well.** Talk with your doctor, nurse, or a registered dietitian to learn what foods and drinks are best for you. You may need to eat foods that are high in protein or iron.
Cancer treatments may lower your appetite or change the way food tastes or smells. Side effects such as mouth and throat problems, or nausea and vomiting can also make eating difficult. Cancer-related fatigue can also lower your appetite.

Talk with your health care team if you are not hungry or if you find it difficult to eat. Don’t wait until you feel weak, have lost too much weight, or are dehydrated, to talk with your doctor or nurse. It’s important to eat well, especially during treatment for cancer.

**Appetite Loss and Cancer Treatment**

https://www.cancer.gov/about-cancer/treatment/side-effects/appetite-loss

Cancer treatments may lower your appetite or change the way food tastes or smells. Side effects such as mouth and throat problems, or nausea and vomiting can also make eating difficult. Cancer-related fatigue can also lower your appetite.

Talk with your health care team if you are not hungry or if you find it difficult to eat. Don’t wait until you feel weak, have lost too much weight, or are dehydrated, to talk with your doctor or nurse. It’s important to eat well, especially during treatment for cancer.

**Ways to Manage Appetite Loss**

Take these steps to get the nutrition you need to stay strong during treatment:

- **Drink plenty of liquids.** Drinking plenty of liquids is important, especially if you have less of an appetite. Losing fluid can lead to dehydration, a dangerous condition. You may become weak or dizzy and have dark yellow urine if you are not drinking enough liquids.

- **Choose healthy and high-nutrient foods.** Eat a little, even if you are not hungry. It may help to have five or six small meals throughout the day instead of three large meals. Most people need to eat a variety of nutrient-dense foods that are high in protein and calories. Learn ways to add calories and protein to your diet in our Eating Hints booklet.

- **Be active.** Being active can actually increase your appetite. Your appetite may increase when you take a short walk each day.

NCI's Nutrition in Cancer Care PDQ® summary has more information on the causes and management of nutritional problems that occur in cancer patients - https://www.cancer.gov/about-cancer/treatment/side-effects/appetite-loss/nutrition-pdq

**Bleeding and Bruising (Thrombocytopenia) and Cancer Treatment**


Some cancer treatments, such as chemotherapy and targeted therapy, can increase your risk of bleeding and bruising. These treatments can lower the number of platelets in the blood. Platelets are the cells that help your blood to clot and stop bleeding. When your platelet count is low, you may bruise or bleed a lot or very easily and have tiny purple or red spots on your skin. This condition is called thrombocytopenia. It is important to tell your doctor or nurse if you notice any of these changes.

Call your doctor or nurse if you have more serious problems, such as:
- Bleeding that doesn’t stop after a few minutes; bleeding from your mouth, nose, or when you vomit; bleeding from your vagina when you are not having your period (menstruation); urine that is red or pink; stools that are black or bloody; or bleeding during your period that is heavier or lasts longer than normal.
- Head or vision changes such as bad headaches or changes in how well you see, or if you feel confused or very sleepy.

**Ways to Manage Bleeding and Bruising**

Steps to take if you are at increased risk of bleeding and bruising:

- **Avoid certain medicines.** Many over-the-counter medicines contain aspirin or ibuprofen, which can increase your risk of bleeding. When in doubt, be sure to check the label. Get a list of medicines and products from your health care team that you should avoid taking. You may also be advised to limit or avoid alcohol if your platelet count is low.
- **Take extra care to prevent bleeding.** Brush your teeth gently, with a very soft toothbrush. Wear shoes, even when you are inside. Be extra careful when using sharp objects. Use an electric shaver, not a razor. Use lotion and a lip balm to prevent dry, chapped skin and lips. Tell your doctor or nurse if you are constipated or notice bleeding from your rectum.
- **Care for bleeding or bruising.** If you start to bleed, press down firmly on the area with a clean cloth. Keep pressing until the bleeding stops. If you bruise, put ice on the area.

**Constipation and Cancer Treatment**

[https://www.cancer.gov/about-cancer/treatment/side-effects/constipation](https://www.cancer.gov/about-cancer/treatment/side-effects/constipation)

Constipation is when you have infrequent bowel movements and stool that may be hard, dry, and difficult to pass. You may also have stomach cramps, bloating, and nausea when you are constipated. Cancer treatments such as chemotherapy can cause constipation. Certain medicines (such as pain medicines), changes in diet, not drinking enough fluids, and being less active may also cause constipation.

There are steps you can take to prevent constipation. It is easier to prevent constipation than to treat its complications which may include fecal impaction or bowel obstruction.

**Ways to Prevent or Treat Constipation**

Take these steps to prevent or treat constipation:

- **Eat high-fiber foods.** Adding bran to foods such as cereals or smoothies is an easy way to get more fiber in your diet. Ask your health care team how many grams of fiber you should have each day. If you have had an intestinal obstruction or intestinal surgery, you should not eat a high-fiber diet.
- **Drink plenty of liquids.** Most people need to drink at least 8 cups of liquid each day. You may need more based on your treatment, medications you are taking, or other health factors. Drinking warm or hot liquids may also help.
- **Try to be active every day.** Ask your health care team about exercises that you can do. Most people can do light exercise, even in a bed or chair. Other people choose to walk or ride an exercise bike for 15 to 30 minutes each day.
- **Learn about medicine.** Use only medicines and treatments for constipation that are prescribed by your doctor, since some may lead to bleeding, infection, or other harmful side effects in people being treated for cancer. Keep a record of your bowel movements to share with your doctor or nurse.
Delirium and Cancer Treatment

https://www.cancer.gov/about-cancer/treatment/side-effects/delirium

Delirium is a confused mental state that includes changes in awareness, thinking, judgment, sleeping patterns, as well as behavior. Although delirium can happen at the end of life, many episodes of delirium are caused by medicine or dehydration and are reversible. The symptoms of delirium usually occur suddenly (within hours or days) over a short period of time and may come and go. Although delirium may be mistaken for depression or dementia, these conditions are different and have different treatments.

Types of Delirium

The three main types of delirium include:

- **Hypoactive delirium:** The patient seems sleepy, tired, or depressed
- **Hyperactive delirium:** The patient is restless, anxious, or suddenly agitated and uncooperative
- **Mixed delirium:** The patient changes back and forth between hypoactive delirium and hyperactive delirium

Causes of Delirium

Your health care team will work to find out what is causing delirium, so that it can be treated. Causes of delirium may include:

- advanced cancer
- older age
- brain tumors
- dehydration
- infection
- taking certain medicines, such as high doses of opioids
- withdrawal from or stopping certain medicines

Early monitoring of someone with these risk factors for delirium may prevent it or allow it to be treated more quickly.

Changes caused by delirium can be upsetting for family members and dangerous to the person with cancer, especially if judgment is affected. People with delirium may be more likely to fall, unable to control their bladder and/or bowels, and more likely to become dehydrated. Their confused state may make it difficult to talk with others about their needs and make decisions about care. Family members may need to be more involved in decision-making.

Ways to Treat Delirium in People with Cancer

Steps that can be taken to treat symptoms related to delirium include:

- **Treat the causes of delirium:** If medicines are causing delirium, then reducing the dose or stopping them may treat delirium. If conditions such as dehydration, poor nutrition, and infections are causing the delirium, then treating these may help.
● **Control surroundings:** If the symptoms of delirium are mild, it may help to keep the room quiet and well lit, with a clock or calendar and familiar possessions. Having family members around and keeping the same caregivers, as much as possible, may also help.

● **Consider medicines:** Medicines are sometimes given to treat the symptoms of delirium. However, these medicines have serious side effects and patients receiving them require careful observation by a doctor.

● **Sometimes sedation may help:** After discussion with family members, sedation is sometimes used for delirium at the end of life, if it does not get better with other treatments. The doctor will discuss the decisions involved in using sedation to treat delirium with the family.

NCI's PDQ® summary on Delirium provides more information on the condition, including risk factors, diagnosis, treatment, and supportive care approaches for family and health care providers - https://www.cancer.gov/about-cancer/treatment/side-effects/memory/delirium-pdq

### Diarrhea and Cancer Treatment

https://www.cancer.gov/about-cancer/treatment/side-effects/diarrhea

Diarrhea means having bowel movements that are soft, loose, or watery more often than normal. If diarrhea is severe or lasts a long time, the body does not absorb enough water and nutrients. This can cause you to become dehydrated or malnourished. Cancer treatments, or the cancer itself, may cause diarrhea or make it worse. Some medicines, infections, and stress can also cause diarrhea. Tell your health care team if you have diarrhea.

Diarrhea that leads to dehydration (the loss of too much fluid from the body) and low levels of salt and potassium (important minerals needed by the body) can be life threatening. Call your health care team if you feel dizzy or light headed, have dark yellow urine or are not urinating, or have a fever of 100.5 °F (38 °C) or higher.

### Ways to Manage Diarrhea

You may be advised to take steps to prevent complications from diarrhea:

- **Drink plenty of fluid each day.** Most people need to drink 8 to 12 cups of fluid each day. Ask your doctor or nurse how much fluid you should drink each day. For severe diarrhea, only clear liquids or IV (intravenous) fluids may be advised for a short period.

- **Eat small meals that are easy on your stomach.** Eat six to eight small meals throughout the day, instead of three large meals. Foods high in potassium and sodium (minerals you lose when you have diarrhea) are good food choices, for most people. Limit or avoid foods and drinks that can make your diarrhea worse.

- **Check before taking medicine.** Check with your doctor or nurse before taking medicine for diarrhea. Your doctor will prescribe the correct medicine for you.

- **Keep your anal area clean and dry.** Try using warm water and wipes to stay clean. It may help to take warm, shallow baths. These are called sitz baths.


### Edema (Swelling) and Cancer Treatment

Edema, a condition in which fluid builds up in your body’s tissues, may be caused by some types of chemotherapy, certain cancers, and conditions not related to cancer.

Signs of edema may include:
- swelling in your feet, ankles, and legs
- swelling in your hands and arms
- swelling in your face or abdomen
- skin that is puffy, shiny, or looks slightly dented after being pressed
- shortness of breath, a cough, or irregular heartbeat

Tell your health care team if you notice swelling. Your doctor or nurse will determine what is causing your symptoms, advise you on steps to take, and may prescribe medicine.

Some problems related to edema are serious. Call your doctor or nurse if you feel short of breath, have a heartbeat that seems different or is not regular, have sudden swelling or swelling that is getting worse or is moving up your arms or legs, you gain weight quickly, or you don’t urinate at all or urinate only a little.

**Ways to Prevent or Lessen Edema**

Steps you can take to prevent or lessen edema-related swelling include:
- **Get comfortable.** Wear loose clothing and shoes that are not too tight. When you sit or lie down, raise your feet with a stool or pillows. Avoid crossing your legs when you sit. Talk with your health care team about wearing special stockings, sleeves, or gloves that help with circulation if your swelling is severe.
- **Exercise.** Moving the part of your body with edema can help. Your doctor may give you specific exercises, including walking, to improve circulation. However, you may be advised not to stand or walk too much at one time.
- **Limit salt (sodium) in your diet.** Avoid foods such as chips, bacon, ham, and canned soup. Check food labels for the sodium content. Don’t add salt or soy sauce to your food.
- **Take your medicine.** If your doctor prescribes a medicine called a diuretic, take it exactly as instructed. The medicine will help move the extra fluid and salt out of your body.

**Fatigue and Cancer Treatment**

https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue

Managing fatigue is an important part of your cancer treatment plan. Taking short walks and getting light exercise can actually increase most people’s energy level.

Fatigue is a common side effect of many cancer treatments, including chemotherapy, immunotherapy, radiation therapy, bone marrow transplant, and surgery. Conditions such as anemia, as well as pain, medications, and emotions, can also cause or worsen fatigue. People often describe cancer-related fatigue as feeling extremely tired, weak, heavy, run down, and having no energy. Resting does not always help with cancer-related fatigue. Cancer-related fatigue is one of the most difficult side effects for many people to cope with.

Tell your health care team if you feel extremely tired and are not able to do your normal activities or are very tired even after resting or sleeping. There are many causes of fatigue. Keeping track of your levels of energy throughout the day will help your doctor to assess your fatigue. Write down how fatigue affects your daily activities and what makes the fatigue better or worse.
Ways to Manage Fatigue

You may be advised to take these and other steps to feel better:

- **Make a plan that balances rest and activity.** Choose activities that are relaxing for you. Many people choose to listen to music, read, meditate, practice guided imagery, or spend time with people they enjoy. Relaxing can help you save your energy and lower stress. Light exercise may also be advised by your doctor to give you more energy and help you feel better.

- **Plan time to rest.** If you are tired, take short naps of less than 1 hour during the day. However, too much sleep during the day can make it difficult to sleep at night. Choose the activities that are most important to you and do them when you have the most energy. Ask for help with important tasks such as making meals or driving.

- **Eat and drink well.** Meet with a registered dietitian to learn about foods and drinks that can increase your level of energy. Foods high in protein and calories will help you keep up your strength. Some people find it easier to eat many small meals throughout the day instead of three big meals. Stay well hydrated. Limit your intake of caffeine and alcohol.

- **Meet with a specialist.** It may help to meet with a counselor, psychologist, or psychiatrist. These experts help people to cope with difficult thoughts and feelings. Lowering stress may give you more energy. Since pain that is not controlled can also be a major source of fatigue, it may help to meet with a pain or palliative care specialist.

NCI's Fatigue PDQ® summary has more information on how fatigue is assessed and treated - [https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq](https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq)

Fertility Issues in Boys and Men with Cancer


Many cancer treatments can affect a boy’s or a man’s fertility. Most likely, your doctor will talk with you about whether or not cancer treatment may lower fertility or cause infertility. However, not all doctors bring up this topic. Sometimes you, a family member, or parents of a child being treated for cancer may need to initiate this conversation. Whether or not your fertility is affected depends on factors such as:

- your baseline fertility
- your age at the time of treatment
- the type of cancer and treatment(s)
- the amount (dose) of treatment
- the length (duration) of treatment
- the amount of time that has passed since treatment
- other personal health factors

It’s important to learn how the recommended cancer treatment may affect fertility before starting treatment if at all possible. Consider asking questions such as:

- Could treatment increase the risk of, or cause, infertility?
- Are there other recommended cancer treatments that might not cause fertility problems?
- Which fertility preservation options would you advise for me?
- What fertility preservation options are available at this hospital? At a fertility clinic?
- Would you recommend a fertility specialist (such as a reproductive endocrinologist) that I could talk with to learn more?
- Is condom use advised, based on the treatment I’m receiving?
● Is birth control also recommended?
● What are the chances that my fertility will return after treatment?
Learn more about managing and coping with side effects related to Sexual Health Issues in Men.

Cancer Treatments May Affect Your Fertility

Cancer treatments are important for your future health, but they may harm reproductive organs and glands that control fertility. Changes to your fertility may be temporary or permanent. Talk with your healthcare team to learn what to expect based on your treatment(s):

● Chemotherapy (especially alkylating drugs) can damage sperm in men and sperm-forming cells (germ cells) in young boys.
● Hormone therapy (also called endocrine therapy) can decrease the production of sperm.
● Radiation therapy to the reproductive organs as well as radiation near the abdomen, pelvis, or spine may lower sperm counts and testosterone levels, causing infertility. Radiation may also destroy sperm cells and the stem cells that make sperm. Radiation therapy to the brain can damage the pituitary gland and decrease the production of testosterone and sperm. For some types of cancers, the testicles can be protected from radiation through a procedure called testicular shielding.
● Surgery for cancers of the reproductive organs and for pelvic cancers (such as bladder, colon, prostate, and rectal cancer) can damage these organs and/or nearby nerves or lymph nodes in the pelvis, leading to infertility.
● Stem cell transplants such as bone marrow transplants and peripheral blood stem cell transplants, involve receiving high doses of chemotherapy and/or radiation. These treatments can damage sperm and sperm-forming cells.
● Other treatments: Talk with your doctor to learn whether or not other types of treatment, such as immunotherapy and targeted cancer therapy, may affect your fertility.

Emotional Considerations and Support for Fertility Issues

For some men, infertility can be one of the most difficult and upsetting long-term effects of cancer treatment. Although it might feel overwhelming to think about your fertility right now, most people benefit from having talked with their doctor (or their child’s doctor, when a child is being treated for cancer) about how treatment may affect their fertility and learning about options to preserve their fertility.

Although most people want to have children at some point in their life, families can come together in many ways. For extra support during this time, reach out to your health care team with questions or concerns, as well as to professionally led support groups. If you are the parent of a young boy or teen with cancer, this video of fertility options for young male cancer patients Exit Disclaimer from the Children's Hospital of Philadelphia may help you talk with your son and his doctor.

Fertility Preservation Options for Boys and Men

Men and boys with cancer have options to preserve their fertility. These procedures may be available at the hospital where you are receiving cancer treatment or at a fertility preservation clinic. Talk with your doctor about the best option(s) for you based on your age, the type of cancer you have, and the specific treatment(s) you will be receiving. The success rate, financial cost, and availability of these procedures varies.
Sperm banking (also called semen cryopreservation) is the most common and easy option for young men of reproductive age who would like to have children one day. Samples of semen are collected and checked under a microscope in the laboratory. The sperm are then frozen and stored (banked) for the future. Sperm can be frozen for an indefinite amount of time.

Testicular shielding (also called gonadal shielding) is a procedure in which a protective cover is placed on the outside of the body to shield the testicles from scatter radiation to the pelvis when other parts of the body are being treated with radiation.

Testicular sperm extraction (TESE) is a procedure for males who are not able to produce a semen sample. Sperm is collected through a medical procedure and frozen for future use.

Testicular tissue freezing (also called testicular tissue cryopreservation) is still considered an experimental procedure at most hospitals. For boys who have not gone through puberty and are at high risk of infertility, this procedure may be an option.

If you choose to take steps to preserve your fertility, your doctor and a fertility specialist will work together to develop a treatment plan that includes fertility preservation procedures whenever possible.

Finding More Information, Support, and Clinical Trials

These organizations also have information about fertility-preservation options for people with cancer:

- Oncofertility Consortium
  Learn more about fertility preservation options, connect with a patient navigator, and find additional online and community resources
- LIVESTRONG Fertility
  Understand your fertility risks and options, and get access to fertility preservation discounts.
- National Institute of Child Health and Human Development (NICHD)
  Learn about fertility and infertility related clinical trials.
- The Children’s Hospital of Philadelphia
  Information for parents of a child with cancer includes this video of fertility options for young male cancer patients.
- American Society for Reproductive Medicine
  Find reproductive medical information and educational videos.

Fertility Issues in Girls and Women with Cancer

https://www.cancer.gov/about-cancer/treatment/side-effects/fertility-women

Many cancer treatments can affect a girl’s or woman’s fertility. Most likely, your doctor will talk with you about whether or not cancer treatment may increase the risk of, or cause, infertility. However, not all doctors bring up this topic. Sometimes you, a family member, or parents of a child being treated for cancer may need to initiate this conversation.

Whether or not fertility is affected depends on factors such as:

- your baseline fertility
- your age at the time of treatment
- the type of cancer and treatment(s)
- the amount (dose) of treatment
- the length (duration) of treatment
- the amount of time that has passed since cancer treatment
- other personal health factors
It’s important to learn how the recommended cancer treatment may affect fertility before starting treatment, whenever possible. Consider asking questions such as:

- Could treatment increase the risk of, or cause, infertility? Could treatment make it difficult to become pregnant or carry a pregnancy in the future?
- Are there other recommended cancer treatments that might not cause fertility problems?
- Which fertility option(s) would you advise for me?
- What fertility preservation options are available at this hospital? At a fertility clinic?
- Would you recommend a fertility specialist (such as a reproductive endocrinologist) who I could talk with to learn more?
- Is condom use advised, based on the treatment I’m receiving?
- Is birth control recommended?
- After treatment, what are the chances that my fertility will return? How long might it take for my fertility to return?

Learn more about managing and coping with side effects related to Sexual Health Issues in Women.

### Cancer Treatments May Affect Your Fertility

Cancer treatments are important for your future health, but they may harm reproductive organs and glands that control fertility. Changes to your fertility may be temporary or permanent. Talk with your health care team to learn what to expect, based on your treatment(s):

- **Chemotherapy** (especially alkylating agents) can affect the ovaries, causing them to stop releasing eggs and estrogen. This is called primary ovarian insufficiency (POI). Sometimes POI is temporary and your menstrual periods and fertility return after treatment. Other times, damage to your ovaries is permanent and fertility doesn’t return. You may have hot flashes, night sweats, irritability, vaginal dryness, and irregular or no menstrual periods. Chemotherapy can also lower the number of healthy eggs in the ovaries. Women who are closer to the age of natural menopause may have a greater risk of infertility. The National Institute for Child Health and Human Development (NICHD) has more information about primary ovarian insufficiency.

- **Radiation therapy** to or near the abdomen, pelvis, or spine can harm nearby reproductive organs. Some organs, such as the ovaries, can often be protected by ovarian shielding or by oophoropexy—a procedure that surgically moves the ovaries away from the radiation area. Radiation therapy to the brain can also harm the pituitary gland. This gland is important because it sends signals to the ovaries to make hormones such as estrogen that are needed for ovulation. The amount of radiation given and the part of your body being treated both play a role in whether or not fertility is affected.

- **Surgery** for cancers of the reproductive system and for cancers in the pelvis region can harm nearby reproductive tissues and cause scarring, which can affect your fertility. The size and location of the tumor are important factors in whether or not fertility is affected.

- **Hormone therapy** (also called endocrine therapy) used to treat cancer can disrupt the menstrual cycle, which may affect your fertility. Side effects depend on the specific hormones used and may include hot flashes, night sweats, and vaginal dryness.

- **Bone marrow transplants, peripheral blood stem cell transplants, and other stem cell transplants** involve receiving high doses of chemotherapy and/or radiation. These treatments can damage the ovaries and may cause infertility.

- **Other treatments:** Talk with your doctor to learn whether or not other types of treatment such as immunotherapy and targeted cancer therapy may affect your fertility.
Emotional Considerations and Support for Fertility Issues

For some women, infertility can be one of the most difficult and upsetting long-term effects of cancer treatment. While it might feel overwhelming to think about your fertility right now, most people benefit from having talked with their doctor (or their child’s doctor, when a child is being treated for cancer) about how treatment may affect their fertility and about options to preserve fertility. Although most people want to have children at some point in their life, families can come together in many ways. For extra support during this time, reach out to your health care team with questions or concerns, as well as to professionally led support groups.

If you are the parent of a young girl or teen with cancer, this video of fertility options for young female cancer patients, from the Children's Hospital of Philadelphia, may help you talk with your daughter and her doctor.

Fertility Preservation Options for Girls and Women

Women and girls with cancer have options to preserve their fertility. These procedures may be available at the hospital where you are receiving cancer treatment or at a fertility preservation clinic. Talk with your doctor about the best option(s) for you based on your age, the type of cancer you have, and the specific treatment(s) you will be receiving. The success rate, financial cost, and availability of these procedures varies.

- **Egg freezing** (also called egg or oocyte cryopreservation) is a procedure in which eggs are removed from the ovary and frozen. Later the eggs can be thawed, fertilized with sperm in the lab to form embryos, and placed in a woman’s uterus. Egg freezing is a newer procedure than embryo freezing.
- **Embryo freezing** (also called embryo banking or embryo cryopreservation) is a procedure in which eggs are removed from the ovary. They are then fertilized with sperm in the lab to form embryos and frozen for future use.
- **Ovarian shielding** (also called gonadal shielding) is a procedure in which a protective cover is placed on the outside of the body, over the ovaries and other parts of the reproductive system, to shield them from scatter radiation.
- **Ovarian tissue freezing** (also called ovarian tissue cryopreservation) is still considered an experimental procedure, for young girls who haven’t gone through puberty and don’t have mature eggs. It involves surgically removing part or all of an ovary and then freezing the ovarian tissue, which contains eggs. Later, the tissue is thawed and placed back in a woman. Although pregnancies have occurred as a result of this procedure, it’s only an option for some types of cancer.
- **Ovarian transposition** (also called oophoropexy) is an operation to move the ovaries away from the part of the body receiving radiation. This procedure may be done during surgery to remove the cancer or through laparoscopic surgery.
- **Radical trachelectomy** (also called radical cervicectomy) is surgery used to treat women with early-stage cervical cancer who would like to have children. This operation removes the cervix, nearby lymph nodes, and the upper part of the vagina. The uterus is then attached to the remaining part of the vagina, with a special band that serves as the cervix.
- **Treatment with gonadotropin-releasing hormone agonist** (also called GnRHa), a substance that causes the ovaries to stop making estrogen and progesterone. Research is ongoing to assess the effectiveness of giving GnRHa to protect the ovaries.

If you choose to take steps to preserve your fertility, your doctor and a fertility specialist will work together to develop a treatment plan that includes fertility preservation, whenever possible.
Finding More Information, Support, and Clinical Trials

These organizations also have information about fertility-preservation options for people with cancer:

- **Oncofertility Consortium**
  Learn more about fertility preservation options, connect with a patient navigator and search a database of providers.

- **LIVESTRONG Fertility**
  Understand your fertility risks and options, and get access to fertility preservation discounts.

- **National Institute of Child Health and Human Development (NICHD)**
  Learn about fertility and infertility related clinical trials.

- **The Children’s Hospital of Philadelphia**
  Information for parents who have a child with cancer includes this video on fertility options for young female cancer patients.

- **American Society for Reproductive Medicine**
  Reproductive medical information as well as educational videos.

Flu-Like Symptoms Caused by Cancer Treatments


Flu-like symptoms (also called flu-like syndrome) are a group of related side effects that may be caused by cancer treatments, such as chemotherapy and immunotherapy. If flu-like symptoms are severe, you may be advised to seek immediate medical attention. Some people who receive higher doses of treatment, or more than one treatment at a time, may have more severe flu-like symptoms.

**Talk with your doctor so you know what flu-like symptoms to expect, based on your cancer treatment.**

- Some types of chemotherapy can cause flu-like symptoms within a few hours after treatment. These symptoms generally last for 2 to 3 days.
- Some types of immunotherapy increase your body’s natural immune response, which can cause mild to severe flu-like symptoms. These symptoms often peak shortly after treatment and become less severe over time. Immunotherapy treatments such as CAR T-cell therapy and some monoclonal antibodies may cause cytokine release syndrome (CRS), a condition that can lead to severe flu-like symptoms as well as a rash, rapid heartbeat, low blood pressure, and trouble breathing. Doctors may refer to severe cases of CRS as a cytokine storm.

Ask Your Health Care Team about Flu-Like Symptoms

- What signs and symptoms might I have, based on the type of cancer treatment I am receiving?
- Which flu-like symptoms should I call you about? Which can be managed at home?

Make note of flu-like symptoms you should call your health care team about:

- **Appetite loss**
- **Body aches (muscle or joint aches)**
- **Chills**
- **Diarrhea**
- **Fatigue; lack of energy**
- **Fever of 100.5°F (38°C) or higher**
- **Headache**
- **Nausea and/or vomiting**
Ways to Manage Flu-Like Symptoms during Cancer Treatment

Keep in mind that when these symptoms occur in people receiving immunotherapy they may be diagnosed, managed, and treated differently than when they are caused by other cancer treatments. When your doctor recommends self care, here are steps you can take to feel better:

- **Appetite loss**: Drink water and other fluids advised by your health care team to stay hydrated. Drinking fluids is especially important if you are not eating much. It may be easier to eat small meals, and to eat more often. Choose foods that are high in calories and protein to give your body strength. Learn more about how to manage appetite loss.
- **Chills**: Chills are your body’s way of increasing your temperature. Ask your health care team what steps you should take if you have chills. Your health care team may advise you not to pile on blankets, since this can cause your temperature to rise even higher. When chills are severe, doctors may prescribe medicine.
- **Diarrhea**: Drink plenty of water to replace fluids you lose when you have diarrhea. Water and other fluids will help prevent dehydration, which may cause you to feel weak, dizzy, and disoriented. Your doctor may prescribe an over-the-counter diarrhea medicine. If you are receiving immunotherapy, diagnostic tests may be advised to rule out gastritis, a more serious medical condition. Learn more about how to manage diarrhea.
- **Fatigue**: Balance periods of rest with periods of activity. Choose the time of the day when you have the most energy to do an activity or to exercise. Regular exercise can help you to keep up your strength and stamina during treatment. Learn more about how to manage fatigue.
- **Fever**: Your body loses fluids when you have a fever, so it’s important to drink water to prevent dehydration. You may want to rest and put an ice pack on your forehead. Sometimes taking medicine to lower a fever can mask a more serious problem. For this reason, you may be advised to call your doctor before taking medicine to lower a fever.
- **Headache and/or body aches**: Use ice packs or place a cold washcloth on your forehead to get relief. If advised by your doctor, take over-the-counter pain relievers such as acetaminophen, ibuprofen, or aspirin.
- **Nausea and vomiting**: Try to take small sips of water, fruit juices, ginger ale, tea, and/or sports drinks, if recommended, throughout the day. Learn more about how to manage nausea and vomiting.

If these symptoms last or become severe, your doctor may advise diagnostic tests to identify what is causing these problems and determine how best to treat them.

Hair Loss (Alopecia) and Cancer Treatment

https://www.cancer.gov/about-cancer/treatment/side-effects/hair-loss

Some types of chemotherapy cause the hair on your head and other parts of your body to fall out. Radiation therapy can also cause hair loss on the part of the body that is being treated. Hair loss is called alopecia. Talk with your health care team to learn if the cancer treatment you will be receiving causes hair loss. Your doctor or nurse will share strategies that have help others, including those listed below.

Ways to Manage Hair Loss

Talk with your health care team about ways to manage before and after hair loss:

- **Treat your hair gently**. You may want to use a hairbrush with soft bristles or a wide-tooth comb. Do not use hair dryers, irons, or products such as gels or clips that may hurt your scalp. Wash your hair with a mild shampoo. Wash it less often and be very gentle. Pat it dry with a soft towel.
- **You have choices.** Some people choose to cut their hair short to make it easier to deal with when it starts to fall out. Others choose to shave their head. If you choose to shave your head, use an electric shaver so you won’t cut yourself. If you plan to buy a wig, get one while you still have hair so you can match it to the color of your hair. If you find wigs to be itchy and hot, try wearing a comfortable scarf or turban.
- **Protect and care for your scalp.** Use sunscreen or wear a hat when you are outside. Choose a comfortable scarf or hat that you enjoy and that keeps your head warm. If your scalp itches or feels tender, using lotions and conditioners can help it feel better.
- **Talk about your feelings.** Many people feel angry, depressed, or embarrassed about hair loss. It can help to share these feelings with someone who understands. Some people find it helpful to talk with other people who have lost their hair during cancer treatment. Talking openly and honestly with your children and close family members can also help you all. Tell them that you expect to lose your hair during treatment.

**Ways to Care for Your Hair When It Grows Back**

- **Be gentle.** When your hair starts to grow back, you will want to be gentle with it. Avoid too much brushing, curling, and blow-drying. You may not want to wash your hair as frequently.
- **After chemotherapy.** Hair often grows back in 2 to 3 months after treatment has ended. Your hair will be very fine when it starts to grow back. Sometimes your new hair can be curlier or straighter—or even a different color. In time, it may go back to how it was before treatment.
- **After radiation therapy.** Hair often grows back in 3 to 6 months after treatment has ended. If you received a very high dose of radiation your hair may grow back thinner or not at all on the part of your body that received radiation.

**Infection and Neutropenia during Cancer Treatment**


An infection is the invasion and growth of germs in the body, such as bacteria, viruses, yeast, or other fungi. An infection can begin anywhere in the body, may spread throughout the body, and can cause one or more of these signs:

- fever of 100.5 °F (38 °C) or higher or chills
- cough or sore throat
- diarrhea
- ear pain, headache or sinus pain, or a stiff or sore neck
- skin rash
- sores or white coating in your mouth or on your tongue
- swelling or redness, especially where a catheter enters your body
- urine that is bloody or cloudy, or pain when you urinate

Call your health care team if you have signs of an infection. Infections during cancer treatment can be life threatening and require urgent medical attention. Be sure to talk with your doctor or nurse before taking medicine—even aspirin, acetaminophen (such as Tylenol®), or ibuprofen (such as Advil®) for a fever. These medicines can lower a fever but may also mask or hide signs of a more serious problem. Some types of cancer and treatments such as chemotherapy may increase your risk of infection. This is because they lower the number of white blood cells, the cells that help your body to fight infection. During chemotherapy, there will be times in your treatment cycle when the number of white blood cells (called neutrophils) is particularly low and you are at increased risk of infection. Stress, poor nutrition, and not enough sleep can also weaken the immune system, making infection more likely.
You will have blood tests to check for neutropenia (a condition in which there is a low number of neutrophils). Medicine may sometimes be given to help prevent infection or to increase the number of white blood cells.

**Ways to Prevent Infection**

Your health care team will talk with you about these and other ways to prevent infection:

- **Wash your hands often and well.** Use soap and warm water to wash your hands well, especially before eating. Have people around you wash their hands well too.
- **Stay extra clean.** If you have a catheter, keep the area around it clean and dry. Clean your teeth well and check your mouth for sores or other signs of an infection each day. If you get a scrape or cut, clean it well. Let your doctor or nurse know if your bottom is sore or bleeds, as this could increase your risk of infection.
- **Avoid germs.** Stay away from people who are sick or have a cold. Avoid crowds and people who have just had a live vaccine, such as one for chicken pox, polio, or measles. Follow food safety guidelines; make sure the meat, fish, and eggs you eat are well cooked. Keep hot foods hot and cold foods cold. You may be advised to eat only fruits and vegetables that can be peeled, or to wash all raw fruits and vegetables very well.

**Memory or Concentration Problems and Cancer Treatment**

https://www.cancer.gov/about-cancer/treatment/side-effects/memory

Whether you have memory or concentration problems (sometimes described as a mental fog or chemo brain) depends on the type of treatment you receive, your age, and other health-related factors. Cancer treatments such as chemotherapy may cause difficulty with thinking, concentrating, or remembering things. So can some types of radiation therapy to the brain and immunotherapy. These cognitive problems may start during or after cancer treatment. Some people notice very small changes, such as a bit more difficulty remembering things, whereas others have much greater memory or concentration problems. Your doctor will assess your symptoms and advise you about ways to manage or treat these problems. Treating conditions such as poor nutrition, anxiety, depression, fatigue, and insomnia may also help.

**Ways to Manage Memory or Concentration Problems**

It’s important for you or a family member to tell your health care team if you have difficulty remembering things, thinking, or concentrating. Here are some steps you can take to manage minor memory or concentration problems:

- **Plan your day.** Do things that need the most concentration at the time of day when you feel best. Get extra rest and plenty of sleep at night. If you need to rest during the day, short naps of less than 1 hour are best. Long naps can make it more difficult to sleep at night. Keep a daily routine.
- **Exercise your body and mind.** Exercise can help to decrease stress and help you to feel more alert. Exercise releases endorphins, also known as "feel-good chemicals," which give people a feeling of well-being. Ask what light physical exercises may be helpful for you. Mind–body practices such as meditation or mental exercises such as puzzles or games also help some people.
- **Get help to remember things.** Write down and keep a list handy of important information. Use a daily planner, recorder, or other electronic device to help you remember important activities. Make a list of important names and phone numbers. Keep it in one place so it’s easy to find.

# Mouth and Throat Problems during Cancer Treatment

https://www.cancer.gov/about-cancer/treatment/side-effects/mouth-throat

Cancer treatments may cause mouth, throat, and dental problems. **Radiation therapy** to the head and neck may harm the salivary glands and tissues in your mouth and/or make it hard to chew and swallow safely. Some types of chemotherapy and immunotherapy can also harm cells in your mouth, throat, and lips. Drugs used to treat cancer and certain bone problems may also cause oral problems.

Mouth and throat problems may include:
- changes in taste (**dysgeusia**) or smell
- dry mouth (**xerostomia**)
- infections and mouth sores
- pain or swelling in your mouth (**oral mucositis**)
- sensitivity to hot or cold foods
- swallowing problems (**dysphagia**)
- tooth decay (**cavities**)

Mouth problems are more serious if they interfere with eating and drinking because they can lead to **dehydration** and/or **malnutrition**. It’s important to call your doctor or nurse if you have pain in your mouth, lips, or throat that makes it difficult to eat, drink, or sleep or if you have a **fever** of 100.5 °F (38 °C) or higher.

## Ways to Prevent Mouth and Dental Problems

Your doctor or nurse may advise you to take these and other steps:
- **Get a dental check-up before starting treatment.** Before you start treatment, visit your dentist for a cleaning and check-up. Tell the dentist about your cancer treatment and try to get any dental work completed before starting treatment.
- **Check and clean your mouth daily.** Check your mouth every day for sores or white spots. Tell your doctor or nurse as soon as you notice any changes, such as pain or sensitivity. Rinse your mouth throughout the day with a solution of warm water, baking soda, and salt. Ask your nurse to write down the mouth rinse recipe that is recommended for you. Gently brush your teeth, gums, and tongue after each meal and before going to bed at night. Use a very soft toothbrush or cotton swabs. If you are at risk of bleeding, ask if you should floss.

## Ways to Manage Mouth Problems and Changes in Taste

Your health care team may suggest that you take these and other steps to manage these problems:
- **For a sore mouth or throat:** Choose foods that are soft, wet, and easy to swallow. Soften dry foods with gravy, sauce, or other liquids. Use a blender to make milkshakes or blend your food to make it easier to swallow. Ask about pain medicine, such as lozenges or sprays that numb your mouth and make eating less painful. Avoid foods and drinks that can irritate your mouth; foods that are crunchy, salty, spicy, or sugary; and alcoholic drinks. Don’t smoke or use **tobacco** products.
● **For a dry mouth:** Drink plenty of liquids because a dry mouth can increase the risk of tooth decay and mouth infections. Keep water handy and sip it often to keep your mouth wet. Suck on ice chips or sugar-free hard candy, have frozen desserts, or chew sugar-free gum. Use a lip balm. Ask about medicines such as saliva substitutes that can coat, protect, and moisten your mouth and throat. Acupuncture may also help with dry mouth.

● **For changes to your sense of taste:** Foods may seem to have no taste or may not taste the way they used to or food may not have much taste at all. Radiation therapy may cause a change in sweet, sour, bitter, and salty tastes. Chemotherapy drugs may cause an unpleasant chemical or metallic taste in your mouth. If you have taste changes it may help to try different foods to find ones that taste best to you. Trying cold foods may also help. Here are some more tips to consider:
  - If food tastes bland, marinate foods to improve their flavor or add spices to foods.
  - If red meat tastes strange, switch to other high-protein foods such as chicken, eggs, fish, peanut butter, turkey, beans, or dairy products.
  - If foods taste salty, bitter, or acidic, try sweetening them.
  - If foods taste metallic, switch to plastic utensils and non-metal cooking dishes.
  - If you have a bad taste in your mouth, try sugar-free lemon drops, gum, or mints.

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**Mucositis – Additional Resources**

Helping mucositis - [https://www.healiosproducts.com/](https://www.healiosproducts.com/)


“Managing Mucositis in Children” - [https://www.chop.edu/conditions-diseases/managing-mucositis-children](https://www.chop.edu/conditions-diseases/managing-mucositis-children)


“Mucositis” - [https://www.hse.ie/eng/health/az/M/Mucositis/Preventing-mucositis.html](https://www.hse.ie/eng/health/az/M/Mucositis/Preventing-mucositis.html)

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**Nausea and Vomiting in People with Cancer**


Nausea is when you feel sick to your stomach, as if you are going to throw up. Vomiting is when you throw up. There are different types of nausea and vomiting caused by cancer treatment, including anticipatory, acute, and delayed nausea and vomiting. Controlling nausea and vomiting will help you to feel better and prevent more serious problems such as malnutrition and dehydration. Your doctor or nurse will work to figure out what is causing your symptoms. Medicines called anti-nausea drugs or antiemetics are effective in preventing or reducing many types of nausea and vomiting. The medicine is taken at specific times to prevent and/or control symptoms of nausea and vomiting. Listed below are some practical steps that your doctor or nurse may talk with you about, to help you feel better.
Ways to Manage Nausea and Vomiting

You may be advised to take these steps to feel better:

- **Take anti-nausea medicine.** Talk with your doctor or nurse to learn when to take your medicine. Most people need to take an anti-nausea medicine even on days when they feel well. Tell your doctor or nurse if the medicine doesn’t help. There are different kinds of medicine and one may work better than another for you.
- **Drink plenty of water and fluids.** Drinking will help to prevent dehydration, a serious problem that happens when your body loses too much fluid and you are not drinking enough. Try to sip on water, fruit juices, ginger ale, tea, and/or sports drinks throughout the day.
- **Avoid certain foods.** Don’t eat greasy, fried, sweet, or spicy foods if you feel sick after eating them. If the smell of food bothers you, ask others to make your food. Try cold foods that do not have strong smells, or let food cool down before you eat it.
- **Try these tips on treatment days.** Some people find that it helps to eat a small snack before treatment. Others avoid eating or drinking right before or after treatment because it makes them feel sick. After treatment, wait at least 1 hour before you eat or drink.
- **Learn about complementary medicine practices that may help.** Acupuncture relieves nausea and/or vomiting caused by chemotherapy in some people. Deep breathing, guided imagery, hypnosis, and other relaxation techniques (such as listening to music, reading a book, or meditating) also help some people.

Nerve Problems (Peripheral Neuropathy) and Cancer Treatment

https://www.cancer.gov/about-cancer/treatment/side-effects/nerve-problems

Some cancer treatments cause peripheral neuropathy, a result of damage to the peripheral nerves. These nerves carry information from the brain to other parts of the body. Side effects depend on which peripheral nerves (sensory, motor, or autonomic) are affected.

**Damage to sensory nerves (nerves that help you feel pain, heat, cold, and pressure) can cause:**
- tingling, numbness, or a pins-and-needles feeling in your feet and hands that may spread to your legs and arms
- inability to feel a hot or cold sensation, such as a hot stove
- inability to feel pain, such as from a cut or sore on your foot

**Damage to motor nerves (nerves that help your muscles to move) can cause:**
- weak or achy muscles. You may lose your balance or trip easily. It may also be difficult to button shirts or open jars.
- muscles that twitch and cramp or muscle wasting (if you don’t use your muscles regularly).
- swallowing or breathing difficulties (if your chest or throat muscles are affected)

**Damage to autonomic nerves (nerves that control functions such as blood pressure, digestion, heart rate, temperature, and urination) can cause:**
- digestive changes such as constipation or diarrhea
- dizzy or faint feeling, due to low blood pressure
- sexual problems; men may be unable to get an erection and women may not reach orgasm
- sweating problems (either too much or too little sweating)
- urination problems, such as leaking urine or difficulty emptying your bladder
If you start to notice any of the problems listed above, talk with your doctor or nurse. Getting these problems diagnosed and treated early is the best way to control them, prevent further damage, and to reduce pain and other complications.

Ways to Prevent or Manage Problems Related to Nerve Changes

You may be advised to take these steps:

- **Prevent falls.** Have someone help you prevent falls around the house. Move rugs out of your path so you will not trip on them. Put rails on the walls and in the bathroom, so you can hold on to them and balance yourself. Put bath mats in the shower or tub. Wear sturdy shoes with soft soles. Get up slowly after sitting or lying down, especially if you feel dizzy.
- **Take extra care in the kitchen and shower.** Use potholders in the kitchen to protect your hands from burns. Be careful when handling knives or sharp objects. Ask someone to check the water temperature, to make sure it’s not too hot.
- **Protect your hands and feet.** Wear shoes, both inside and outside. Check your arms, legs, and feet for cuts or scratches every day. When it’s cold, wear warm clothes to protect your hands and feet.
- **Ask for help and slow down.** Let people help you with difficult tasks. Slow down and give yourself more time to do things.
- **Ask about pain medicine and integrative medicine practices.** You may be prescribed pain medicine. Sometimes practices such as acupuncture, massage, physical therapy, yoga, and others may also be advised to lower pain. Talk with your health care team to learn what is advised for you.
RESOURCES & SUPPORT

General Resources and Information

- “Children’s Neuroblastoma Cancer Foundation (CNCF)”
  - “Newly Diagnosed Neuroblastoma Patients” - http://www.cncfhope.org/Newly_Diagnosed
- “Genetics and Rare Diseases Information Center: Neuroblastoma” - https://rarediseases.info.nih.gov/diseases/7185/neuroblastoma

Common Terminology

- NED (no evidence of disease)
- NEAD (no evidence of active disease)
- Refractory (disease doesn’t respond well to treatment, often refers to chemo)
- Progression (disease grows while on treatment)
- Relapse (disease reoccurs after being NED)
- Chemo resistant (disease doesn’t respond to chemo)
Overview of Treatment/Timeline of Events

Low Risk- Standard COG Protocol
- Tumor Resection- several weeks
- Watch and wait +/- Chemo- approximately 6 months

Intermediate- Standard COG Protocol- approximately 6+ months
- 4+ Rounds of Chemotherapy (every three weeks)
- Tumor Resection and recovery (several weeks)
- 2+ Rounds of Chemotherapy (every three weeks)

High Risk- Standard COG Protocol- approximately 18 months
- Biopsy/Diagnosis (several weeks)
- Chemotherapy (5+ months)
- Primary Tumor resection and recovery (several weeks)
- Double stem cell transplants and recovery (2-4+ months)
- Radiation- (several weeks)
- Immunotherapy (5+ months)
* MIBG therapy/ Chemo-Immunotherapy per trial or refractory disease*

**Memorial Sloan Kettering Cancer Center in New York City does provide an alternate protocol that does NOT include Stem Cell Transplants. See more information on Sloan’s protocols here- https://www.mskcc.org/pediatrics/cancer-care/types/neuroblastoma/treatment**

Continuing treatment options for High Risk- things to note...
“Vaccine”- New York-
Trial Information- https://clinicaltrials.gov/ct2/show/NCT00911560
- You can no longer do vaccine and DFMO in sequence.
- Required extra scans and additional testing, most can be done remote
- Trial itself doesn’t cost anything, but consult and scans are still billable
- 7 painful shots given over the course of one year, and must be done in New York City. The first 3 shots occur in the first three weeks. Oral medicine to be taken at home, 14 days on then 14 days off.
- No published studies on first remission COG kids.
- Side effects/long term effects are largely unknown
- Available for 1st remission and relapse remission.
- $35 a night for the Ronald McDonald House

“DFMO”- Charlotte, North Carolina
Trial Information- https://clinicaltrials.gov/ct2/show/NCT02395666
Published data- https://beatab.org/dfmopaper/?fbclid=IwAR1ITb0rT2m6MA0sAsFi0sW1cZM_7tnTEvXVse5hgTBHzSjjd50fLx0vCQ
- If you do DFMO, you cannot go back to do the vaccine at a later date.
- Required to start between 28 days and 60 days of last immunotherapy/ clean scan
- Required scans and additional lab testing, most can be done remote
- Trial itself doesn’t cost anything, but consult and scans are still billable
- Pills to be taken daily at home over two years, can be crushed
-Common side effect is hearing loss, yet hearing does return post treatment
-Has published studies that demonstrated 2yr outcomes
-Few side effects that could impose the quality of the child's life.
-This drug has been used in children previously (treating African Sleeping Sickness) with no poor long-term effects
-Available for 1st remission and relapse remission.

Controversies and Hot Topics
-Stem Cell Transplant vs. Sloan Protocol: Stem Cell Transplants are included in the COG protocol as they are the standard of care. This therapy has been used for years and significantly raised survival rates, which was an exciting technology prior to the addition of immunotherapy. SCT are used for those with minimal disease or currently No Evidence of Disease. The majority of transplants are relatively uneventful, but some have had devastating complications, including death. Notable complications include permanent organ damage or increased toxicity to the body, thus limiting therapy options in cases of relapse. The Sloan Protocol removes SCT from their protocol based on data from Europe, which has indicated no changes in survival outcomes when comparing kids who received SCT to those who opted out. It is notable that the European frontline therapy is different from the Children’s Oncology Group, however, which could play a factor in outcomes. Since the addition of immunotherapy, Sloan views the SCT as an outdated therapy and unnecessary exposure to toxicity. There have been no side-by-side studies comparing the current COG protocol to the Sloan protocol. Thus, the effectiveness of Stem Cell Transplants is yet to be determined. In making a decision for their child, parents weigh the benefits of treating the cancer with all possible treatment options to avoid a relapse. They also have to weigh treating a complex mutated disease vs. reducing toxicity to the body, while maintaining current survival outcomes.

-Proton vs. Photon Radiation
-Proton therapy is a newer radiation approach that spares healthy tissue, while treating the tumor bed. Radiation is released at a planned location and does not exit the body, thus sparing healthy tissue surrounding the tumor bed. This technology is more expensive and is not available at every hospital, thus the possibility of needing to travel for treatment.

-Photon Radiation is standard in COG protocol. It is the standard of care, thus has been used for many years. Radiation beams are targeted at the tumor bed, and go through healthy tissue to reach its destination. The therapy is not as targeted and has a scattering effect, reducing the chance of the edges of the site missing treatment. This treatment is more cost effective and readily available at most hospitals, thus less travel.

-HMA and VMA Validity
- A test in which a urine sample is checked to measure the amount of certain substances, vanillylmandelic acid (VMA) and homovanillic acid (HVA), that are made when catecholamines break down and are released into the urine. A higher than normal amount of VMA or HVA can be a sign of neuroblastoma. However, these same markers can be triggered by diet leading up to the urine sample. Caffeine, bananas, chocolate, and other foods and drugs can cause false positives and undue hardship to concerned parents and physicians. Thus, some physicians opt to not use this test in their evaluation. (https://www.labpedia.net/urine-analysis-part-24-urine-for-vma-vanillylmandelic-acid-catecholamines-24-hours-urine-neuroblastoma/)
Leading Neuroblastoma Research Hospitals for Second Opinions:
- Memorial Sloan Kettering - New York
- Levine Children’s Hospital- North Carolina
- Children’s Hospital of Philadelphia - Pennsylvania
- St. Jude - Tennessee
- Dana Farber Cancer Institute – Massachusetts

Facebook Pages/ Group Recommendations:
- Neuroblastoma Family Support Group
- Neuroblastoma Children’s Cancer Society
- Sloan Kettering Neuroblastoma Families
- Momcology: Neuroblastoma
- Neuroblastoma Survivors
- Neuroblastoma Survivors – Transitioning Youth & Young Adults
- Neuroblastoma Network (for survivors and/or their families)
- European Neuroblastoma Support Group
- Neuroblastoma Children’s Cancer Network for All Parents (UK)
- Neuroblastoma Angels

Notable Neuroblastoma Family Support and Research Organizations:
- Neuroblastoma Children’s Cancer Society - https://www.neuroblastomacancer.org/
- Band of Parents- https://www.bandofparents.org/
- Beat Childhood Cancer (formerly Beat NB) - https://beatcc.org/foundation/
- End Kids Cancer - https://www.endkidscancer.org/

Conferences and Events:
- Annual CNCF Parent Conference- excellent source of information and support for High Risk patients.
  Low and intermediate risk may not benefit from this conference as much. http://www.cnchope.org/CNCF_Parent_Education_Conference
  Past conferences and speakers available at: http://www.cnchope.org/CNCF_Conference_Videos
- Neuroblastoma Parent Global Symposium - https://www.nbparentsymposium.com/

Diagnosis Week – What You Need Right Now, Record Keeping

Welcome! We are so sorry that you are in this situation, but we are glad that you found this handbook. The Neuroblastoma Children’s Cancer Society, our Facebook group, and our social media pages, as well as our website and this handbook are here to offer you information about neuroblastoma and beyond. Each volunteer for NCCS has been associated with neuroblastoma in some way, whether we are parents of survivors, bereaved parents, or survivors, we have been right where you are: numb with fear of a new diagnosis, an unknown future, decision fatigue, caregiver burnout, etc. We are here to tell you, as daunting as it is… You WILL get through this. Day by day, sometimes hour by hour, and sometimes minute by minute. Cancer: “We can’t go over it, We can’t go under it. We can’t go around it, we have to go through it!”..... And through it we will. Hand and hand with you <3
Resource for Newly Diagnosed Families

“To the Mom Who is About to Hear, It’s Cancer” -  https://summerofsilence.com/2020/01/16/to-the-mom-who-is-about-to-hear-its-cancer/

Resources to Help Your Child Understand Cancer


"How a Child Understands Cancer"

"Helping Your Child Understand a Cancer Diagnosis"
https://medlineplus.gov/ency/patientinstructions/000844.htm

"If Your Child is Diagnosed with Cancer" - https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-diagnosis.html

**United Therapeutics has created some wonderful resources for neuroblastoma patients and their caregivers. Skivolo is a curious red panda who has been diagnosed with neuroblastoma and has many questions about it. There are several books available for download at: www.neuroblastoma-info.com

“The Big Adventures of Little Skivolo” - Questions (and Answers) for Young People Facing Neuroblastoma)

“The Next Big Adventure of Little Skivolo” – Helping Young People Understand Antibody Therapy
“Little Skivolo’s Big Book of Fun” – An Activity and Coloring Book for Young People in the Hospital

Your 1st Week-

What Do You Need Right Now?
-A support system, reach out for help! Help will come from the strangest places - long lost high school friends, old church buddies, your cousin’s best friends, co-workers. People are willing to help, just ask! Also, check Facebook for support groups with your specific diagnosis!
-Gift cards- gas, grocery, date nights, amazon, food delivery- people will ask how they can help you… tell them this!!!
-Calendar for scheduling of appointments
-A nice journal- jot down all your questions, and take notes when you speak with the doctor
-Hand Sanitizers- large bottles at home entrances, regular sized bottles throughout main living spaces, and mini size for diaper bag/ travel
-Disinfectant wipes
-Multiple Thermometers to always be able to check for fevers
-Car seat protectors- there may be vomit
-A “go bag” to rush to the hospital at a moment's notice, see below.

Hospital Go Bag – Necessities

Child
-Favorite sippy cup/ bottle
-Snacks

-Pajamas
-Stuffed Animal(s), Favorite toys
- Lovey/Blanket/ fun sheets/ pillow  
- Bibs  
**Caregiver/Older kids**  
- Clothes and back up clothes- there will be vomit  
- Pajamas  
- Underwear  
- Socks  
- in room shoes/slippers  
- Laundry basket for clothes transportation to and from, as well as to hold dirty laundry  
- Comfy pillow and blanket  
- white noise fan/machine/app  
- Driver’s License  
- Insurance card  
- Credit/Debit Cards  
- Cash/Coins  

-Socks  

*Generally available at the hospital, don’t need to pack!*  
- Diapers  
- Wipes  
- Sippy Cups  
- High chair  
- Play mat  
- Butt paste  
- Snacks/ Drinks  
- craft activities  
- snack menu  

**Optional- Making the Hospital Feel Like Home**  
- Window markers for decorating windows  
- Easily cleanable toys  
- Decorations/Photos and “Command Strips” to hang them  
- Personal blankets and pillows  
- Sterilite plastic three drawer bin - easy to fill and carry to and from the hospital, keeping everything organized  
- over the door shoe holder to hold crafting supplies, little toys, etc.  
- comfy towels  
- roll up foam mattress  
- facial cleansing cloths  
- coffee mug/coffee  
- scissors  

-Sheets/slipper  
- Medical Records  
- Feminine Hygiene Products  
- Toothbrush  
- Lotion  
- Shampoo  
- Conditioner  
- Deodorant  
- dry shampoo  
- Razor  
- Tylenol  
- Sleeping mask and ear plugs-there will be loud and annoying beeps allllll night long  

*Any necessities you forgot, the hospital can give you! No worries!*  
- Diapers  
- Wipes  
- Sippy Cups  
- High chair  
- Play mat  
- Butt paste  
- Snacks/ Drinks  
- craft activities  
- snack menu  

-in room alarm sounds silenced  
- Child masks- grab them at the hospital to keep them from putting their dirty hands in their mouth which is where most germs are transferred. No need to buy them!  
- Vomit bags- grab them from the hospital  
- Air humidifier  
- music therapy activity box  

- plates/ bowls  
- calendar  
- nail clippers/file  
- “Command Hooks”  
- favorite snacks  
- oil diffuser/scent plug-ins  
- Extension cord/power strip  
- Phone/tablet/laptop chargers  
- Alexa/HDMI cord/Roku/Gaming Systems etc.  
- Headphones for parents and kids  
- Nice water bottle  
- Saran wrap/baggies for leftovers  
- Food/leftovers/snacks/coffee or k cup  

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Services to use
-Shipt- if you’re child is a picky eater for a time, deliver what they are willing to eat
-Food options- See if your hospital provides a Ronald McDonald house where you can eat for free. Otherwise, you can order food from the cafeteria to be delivered to the room, bring food from home, or order delivery: Uber Eats, DoorDash, GrubHub, Eat Street, Chinese, Pizza, Jimmy Johns etc.
-Amazon Prime (no shipping costs) - maybe order special toys for extra hard days, but you can also order yourself anything that you need or want while you are at the hospital and if you are unable to leave

General Tips for Communicating with Healthcare Professionals
"Getting the Most Out of Your Doctor Appointment" - https://familydoctor.org/tips-for-talking-to-your-doctor/

"How to Talk So Your Doctor Will Listen" - https://health.usnews.com/health-care/patient-advice/articles/how-to-talk-so-your-doctor-will-listen
“Neuroblastoma – Childhood: Questions to Ask the Health Care Team” - https://www.cancer.net/cancer-types/neuroblastoma-childhood/questions-ask-doctor


"Talking with Your Doctor" - https://medlineplus.gov/talkingwithyourdoctor.html

Record Keeping

-Download the app MediSafe- easily set reminders and alarms with all these new medications you have to keep track of
-Decide how you will share information with your family and friends. Consider how public or private you want to be with your journey.
-Create a Facebook page or an account at https://www.caringbridge.org
-Crowd funding- Use https://helpinghandsawo.org/ for your fundraising. Other sites like PayPal, and GoFundMe will have service fees and take a percentage of your donations. HHAWO is a funding page only for pediatric cancers, and is provided for free to families
-Track everything on paper or on a Google Doc that can be shared with spouse, alternate caregivers, etc. Also, will help to share information with doctors out of network of your base hospital.

Recommended information to track:
-Date
-Purpose of Visit
-Treatment
-Physician
-Location
-Contact information for care providers
- Updated med list
- List of questions for the doctor

**NOTE:** Please see our Record Keeping Templates on the next four pages for examples on keeping important records.

**Importance of Keeping Personal Medical Records** –

“Keeping a Personal Medical Record” - [https://www.cancer.net/blog/2016-08/3-steps-building-personal-medical-record](https://www.cancer.net/blog/2016-08/3-steps-building-personal-medical-record)

“Medline Plus – Personal Health Record” - [https://medlineplus.gov/personalhealthrecords.html](https://medlineplus.gov/personalhealthrecords.html)

“Managing Your Care” – medical forms, medical bills and health insurance, mobile applications, etc. [https://www.cancer.net/navigating-cancer-care/managing-your-care](https://www.cancer.net/navigating-cancer-care/managing-your-care)


“Keeping Copies of Important Medical Records” - [https://www.cancer.org/content/dam/CRC/PDF/Public/8396.00.pdf](https://www.cancer.org/content/dam/CRC/PDF/Public/8396.00.pdf) (There are several resources and links within this document that may also be helpful!)

“3 Steps to Building a Personal Medical Record” - [http://www.cancer.net/blog/2016-08/3-steps-building-personal-medical-record](http://www.cancer.net/blog/2016-08/3-steps-building-personal-medical-record)

“Personal Record-Keeping for Cancer Patients” - [http://www.mesothelioma-aid.org/records.htm](http://www.mesothelioma-aid.org/records.htm) (Although this is a mesothelioma website, this particular resource is for any type of cancer patient and there is a wealth of information about Personal Health Records.)

# Record Keeping - Templates

For Medical Records

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Safe and Healthy Living
What your Home Needs to be Safe and Healthy - https://www.hud.gov/sites/documents/CONSUMERS_EDHH.PDF?fbclid=IwAR02qT4TZ762ClCjMaGYw7iBTty6prTpshak1Wp1wCH_44PpXWb4XrkZG1o

Caregiving During Treatment – Preparing the Home, Protecting a Weakened Immune System, Cleaning the Home Safely, Hygiene and Personal Care
https://www.lls.org/support/caregiver-support/caregiving-during-treatment

Preparing Your Family and Home for Chemotherapy - https://www.webmd.com/cancer/preparing-your-home-for-chemotherapy#1

Preparing Family Members to Care for the Patient at Home - https://www.oncologynurseadvisor.com/home/hot-topics/communication/preparing-family-members-to-care-for-the-patient-at-home/


Your First Month – Apps, Fundraising, Resources, and Tips
You’re Killin’ It!
Isn’t time a funny thing.. this past month has gone by so fast, and yet it feels so slow. It’s like groundhog day with the oncologist making their daily rounds and your hospital days tend to run together as one big blur. In hindsight, we can tell you that these horrid weeks won’t always be so fresh in your mind. It’s funny how your brain protects itself from trauma... Give yourself grace and time, everything will become more settled soon. All the newness of the last month is becoming more of a routine and you are killin’ it! You are about a quarter of the way done with your degree as a mom-oncologist! (Don’t we wish that were a real thing?!) You are asking all the right questions, and you are doing all the right things! Keep on keeping on, fighters!

Getting Your Bearings
-2 binders- Medical Records/ Financial Records
-Three-hole punch for organization (There are small ones that you can purchase at the dollar stores, or you can purchase a slightly larger, sturdier one at Walmart or a similar store.)
-Call your insurance and see what your deductible and maximum out-of-pocket payment will be.
-Contact your hospital's Financial Navigator/Social Worker to get signed up for Medicaid Medicaid Waivers, Social Security Disability, and other programs to help you financially.
-Get family pictures done—great for memories of what your child looked like before hair loss.
-Speaking of hair loss, it is going to start coming out by the handful, which can be heart breaking with every strand. Shaving allows you to take control of that experience in one fell swoop!
-Get to know your hospital—where to park, eat, sleep, etc.
-Find your Ronald McDonald house for free meals and free lodging for you and your family, if needed!
Useful Apps
-MediSafe - tracks and alerts medicine dosages
-Create a Facebook page for your child - this app allows you to manage this with ease.
-Countdown - track how many days since diagnosis, or since being cancer free, etc.
-iCANcerer - journey tracking app
-Google Resources
  -Google Calendar- create calendars and share across multiple devices for doctors appointments, caregiving, etc.
  -Google Sheets- for personal tracking of medical records
  -Google Drive- storage space for documents and photos
-Grocery - Walmart grocery pick-up so you don’t have to expose your kids to germs. Or, your local grocery story or other large grocery chains may have grocery pick-up availability.
-Amazon - online shopping and home delivery
-Waze - live interactive maps with ability to tell you what time you need to leave for an appointment
-Minimalist - create tasks and chores lists that need to be completed, can be shared across multiple devices.
-Your hospital patient portal - access detailed medical records, and communicate with your physician
-Credit Karma - tracks credit score if medical bills/ bills are past due and sent to collection
- Uber Eats, DoorDash, GrubHub, Eat Street, etc. - food delivery services
-Quik - great for memory video photo editing/highlight reels.
-Pic Stitch- for photo collages, great for before and after comparison photos.

Tried and True Fundraising Ideas
T-Shirts - https://www.bonfire.com/sell-online/

Wristbands - https://wristbandcreation.com/

Car Magnets - https://www.orientaltrading.com/personalized-awareness-ribbon-car-magnets-a2-13704774.filt?categoryid=90000%20201969&rd=Childhood%20cancer&fbclid=IwAR2adKfaPOCxtcoKXrkEMexO6scjtzKcSug01qBXpOFIml6gnWDDoLi7xNDI

43 Fundraising Ideas for Cancer Treatment - https://blog.fundly.com/fundraising-ideas-for-cancer/?fbclid=IwAR2yblyhwMIvM26G8R7ldHasqNgxXmE-V_6CVPCqIUWnHXQZCHZowyVR7zQQ


Miscellaneous Resources

Organizing Help/ Volunteers - https://mycancercircle.lotsahelpinghands.com/demo/
Tips From Fellow Cancer Parents

Check out this Parent to Parent Handbook Sample from Cincinnati Children’s

Don’t worry about offending other people when you are making a decision that’s in your child’s best interest. People will judge, criticize, they will be offended, they will pretend they know what you’re going through in order to support their own criticisms. However, only YOU know what’s best for your child & you should NEVER allow someone to make you feel bad or second guess your choices. You will lose friends who you thought were some of your best friends. But you will also make new friends. People will stop calling after the newness of the diagnosis wears off. Those who are true friends may not understand your reasoning behind your decisions, however they will accept your decisions with no questions asked, no judgment passed, and they will be the ones still checking on you guys 5 or 6+ months down the road.”

Do not be afraid to tell people “no” or to put a “no visitors” policy in place. According to Sarah McWhorter, who helped create this handbook and is the mother to a son with Stage IV High Risk Neuroblastoma: We are almost 6 months into Stage IV High Risk and I have had exactly one hospital stay due to fever. We have had zero setbacks in treatment because of that. I was ALWAYS the one worried prior to diagnosis about offending someone if I had to tell them no, often resulting in allowing myself to go against my better judgment, all because I didn’t want to hurt someone’s feelings or upset them. For my son’s sake, I had to step up to become his voice for him. I will tell people, ‘No, you cannot stop by.’ ‘No, I cannot let you in my house today because my son’s ANC is too low…even though you showed up with gifts for him.’ ‘No, he can’t have visitors at the hospital today because he was throwing up all night and visitors can sometimes be overwhelming and exhausting (for both him and I).’ ‘No, we can’t come for holiday dinner because you have 12 people at your house that day and that’s 12 different people who could expose him to something.’ While I am not encouraging rudeness at all, again, those who also want the best for your child like you do will understand.

Do not, do not, do not allow a diagnosis to undo all the parenting you have done up to this point. According to Sarah: When your child beats cancer, you want the same child you had before diagnosis, although no child will ever come out of treatment the same child they were at the beginning, you don’t want to lose everything you instilled in them up to that point and allow them to get away with everything simply because they are sick. Stick to your same old routines and rules as much as possible. I am very strict with my 3-year old still, enforcing manners, proper behaviors, respect, and following the rules. Sure, I cut him more slack than I did prior to his diagnosis because sometimes he is just flat-out tired and he needs me to just hug him when he begins to cry after being told to pick up his toys or being told no, instead of just telling him to go sit in time-out until he can listen. Even toddlers have emotional days and need us to stop and assess why they might be feeling a certain way and sometimes a hug or cuddle is all they really need. However, they will also still test you in normal toddler behavior ways, and those are the times to continue to parent in the same ways you had previously. If a scale is rolled into my son’s room and he decides he doesn’t want to get on it, nurses and even his dad will decide to try to negotiate with him. I simply walk up, pick him up off the bed, set him down in front of the scale and tell him it’s time to get weighed and I know he doesn’t want to, but he has to and he can go back in his bed in a minute when they get his weight. Even children with cancer need structure.”
Make a game out of everything you possibly can. According to Sarah: My son hates having to wear his mask when being accessed or de-accessed, so I started making a game out of it where we have to guess what silly face the other one is making behind the mask. I also bought him a custom Minion mask off Etsy for about $8.00 that he will wear with no problem because that’s HIS mask. We also play “Good news/Bad news” a lot. When he doesn’t want to do something or I am about to tell him something he doesn’t want to hear, I will say, “I have some good news & I have some bad news. The bad news is you have to take your oral medicine tonight. The good news is once you take it, we can watch a kid’s show before we turn off the light.” Padding the bad with the good helps him focus on the good in order to get past the bad.

Explain things to them on their level. According to Sarah: If I told my 3-year old he was going to lay on a big machine for an x-ray or MRI, he would have no clue what I was talking about, possibly leading to fear or anxiety of the unknown. Instead I tell him, “Today the doctors are going to use their x-ray vision to look at your belly. Their x-ray vision only works when you lay on their special table, though, so we have to go to where it is and you need to hold very still for them.” Everything is new to them as it is to us parents but unfortunately, while we (sometimes) understand what is going to happen, the younger ones don’t and that can lead to anxiety and fear of nothing more than the unknown, and not just the test or scan itself.

You will learn your child’s “puke face” & become a ninja who can catch it in a basin better than some MLB catchers can catch a ball! There is also something called “chemo poop” that will leave your nose burning and you will be wondering how your small child was able to accomplish such an odor from their tiny body. It is recommended to put a trashcan right outside your nearest door if your child is still in diapers to “catch and release” as quickly as possible to contain this unique smell without further spread of it through your house. You will find out that you have strength that you did not know you had and that you did not know existed. You will be strong for your child, because NOT being strong is NOT an option.

I am so sorry to hear your child and your family all have to go through what can sometimes only be described as “a living hell”. However, even on the darkest days, always find something to be grateful for…even if it’s just that your feet hit the floor that morning because if you let the negatives reign, this can take over you and can be completely overwhelming. And it’s ok to have a really big, really ugly cry whenever you need to, but always remember to pick yourself back up after and wipe off your tears.

Last Minute Tips
-Get second opinion. A third, or fourth opinion if needed. Get many as you need, they are only a phone call away and are generally free! Ask your oncologist who the leading researchers are in the field; get them on the phone!
-Stay off of Google; Google doesn’t know your child. Google will only make you worry more.
-Take Facebook advice with a grain of salt. People tend to overshare the negative things in life, this is no different online. Always talk with your oncologist if you have any concerns.
Inspirational Resources


siblings and family support
Support for Families when a Child has Cancer - https://www.cancer.gov/about-cancer/coping/caregiver-support/parents


All-Star Siblings - https://www.stillbrave.org/all-star-siblings/

Just for Sibs - https://www.acco.org/for-siblings/

Helping the Siblings of the Child with Cancer (CancerCare) - https://media.cancercare.org/publications/original/50-fs_siblings.pdf


For Parents, Caregivers and Professionals: Helping Brothers and Sisters of Children Living with Cancer (CancerCare Podcast) - https://www.cancercare.org/connect_workshops/96-cancer_siblings_2009-05-14


“Considering the Needs of Pediatric Cancer Patients' Siblings” -

“Siblings' Experiences with Childhood Cancer: A Different Way of Being in the Family” -

“Effects on Siblings of a Child with Cancer” -

“How Others Can Help
-Blood drive
-Yard work
-House cleaner
-Journey page
-Menu planning
-Getting IN the hospital and OUT with all the stuff
-Having someone on call to drop off last-minute items and foods a child will finally eat
-School buddy

-Meal trains
-Grocery pick-up and delivery
-Prescription pick-up and delivery
-Rides to appointments
-Social shield from family/friend comments
-Social confidant
-Accompany/sitting buddy during appointment
-Childhood cancer advocate for change

How to Support the Parents of a Child with Cancer - https://www.childrens.com/health-wellness/how-to-support-parents-of-a-cancer-patient


Making the Most of Clinic Visits

- Schedule an early morning appointment in the day to avoid doctors running behind, and also good if you have to come in fasting
- Prep them a few days out to remind them of appointment
- Make exciting after clinic plans - ice cream, lunch, shopping, museums, parks, etc.
- Call and double check appointment details. Do you need to be fasting, do you need labs prior, where to check in at, schedule of the day, where to park
- Consider staying at the Ronald McDonald House if you have a long drive
- Use the Waze app to tell you what time you need to leave to be there on time
- Pack the car the night before:
  - Phone charger
  - Ipad/phone
  - Wagon/ stroller
  - Blankets
  - Snacks/ drinks
  - Updated medicine list
- Lay out clothes
- Get a good night’s sleep
- Stop for a special breakfast

Doctor Appointments - Getting the most out of them, questions to ask, etc.

"Getting the Most Out of Your Doctor Appointment" - https://familydoctor.org/tips-for-talking-to-your-doctor/

"How to Talk So Your Doctor Will Listen" - https://health.usnews.com/health-care/patient-advice/articles/how-to-talk-so-your-doctor-will-listen

"Neuroblastoma - Childhood: Questions to Ask the Health Care Team" - https://www.cancer.net/cancer-types/neuroblastoma-childhood/questions-ask-health-care-team


"Talking with Your Doctor" - https://medlineplus.gov/talkingwithyourdoctor.html
Hospital Hacks
- Turn your bed sideways against the wall to have more space.
- Request a high chair or play mat, as needed.
- Pack command strips to be able to make more space to hang things as needed.
- Pack your clothes in a laundry basket, then when you get to the hospital you have a place to put your dirty clothes.
- Or pack all your hospital things in a Sterilite plastic drawer system to keep organized in the hospital.
- Buy laundry detergent pods to make packing detergent not so heavy or messy.
- Buy an over the door shoe organizer so you can stock it with crafts and toys with ease, and keep the room uncluttered.
- Request extra pillows to place on the couch, then use a fitted sheet to keep them all tucked into place for a more comfortable sleep.
- Ask if your hospital has a snack menu, the snacks can be ordered with no limits!
- Order extra nutrition drinks per tray to save for home.
- Once the kiddo is asleep for the night, grab a cab or a scooter and hit downtown! Enjoy a late-night date with your partner!

Surviving Lab Draws and Port Access
- EMLA/numbing cream or spray
- Holding a squeeze ball/toy
- Games on a phone
- Videos/ music on iPad
- Child life specialist
- Counting down
- Candy/ gum
- Rewards/ special treat afterwards
- Prep/explanation for the child prior
- Therapy dog/pet videos
- Deep breathing
- Goal setting – For example: Getting a dog at the end of treatment, thus everything you do is one step closer to getting a dog
- Light-up toys
- Involving the child in the process/decision-making
- Making up creative songs about the process
- “Helping” - pushing tubes into the draw line

Helpful Products
Ipad Floor Stand- for dressing changes
https://smile.amazon.com/dp/B07XR9NCWX/ref=cm_sw_r_cp_awdb_t1_Q5nRDdSBJDXF6

IV Pole/Wrist Connector
https://www.amazon.com/gp/product/B01N2G22HB/ref=ox_sc_act_title_1?smid=A2JLJ411H0Z3IU&psc=1
Vog Mask for Mold and Fungi Protection  
https://www.amazon.com/Vogmask-Friends-VMCV-Small/dp/B07NX4V7KN?fbclid=IwAR3fEU9UsUgzxq3PC4q4TSNX6XWZ59XcM6ByuHSaauYBANuSYYve2S0SehY&th=1

Wagon for hospital transport  

To keep your Central Line tubes out of the way  
https://www.carealine.com

Keeping Access Sites Dry  
http://www.aqua-guard.com/

Numbing Products for Port/IV Access  
https://www.amazon.com/Ebanel-Painkilling-Anesthetic-Hemorrhoid-Discomfort/dp/B019D7MQMK/ref=sr_1_1?crid=CSN8HX897J95&keywords=numbing+cream&qid=1566758959&s=gateway&sprefix=numbing+c%2Caps%2C160&sr=8-1

Adhesive remover for dressing changes  
https://www.amazon.com/SENSI-CARE-Sting-Adhesive-Releaser-Spray/dp/B00HFCHIGK/ref=sr_1_16?keywords=brave+adhesive+remover&qid=1567639267&s= gateway&sr=8-16

iPad Carrying Case  
https://smile.amazon.com/gp/aw/d/B07YD5RGZ3?psc=1&ref=ppx_pop_mob_b_asin_title

OTHER TIPS:
- Ask pharmacy for extra syringes with every medicine, stock up!
- The little circle around the syringes from the pharmacy goes in the top of the medicine bottle as a stopper, and you can easily insert the syringe for a mess free draw
- At the end of treatment, donate your medical supplies to a local non-profit or to a medical mission overseas
- Use the app MediSafe to set medicine alarms, and help keep your med list up to date

**Working While Caregiving**

Excerpts below from the article, “Employer Best Practices for Workers with Caregiving Responsibilities”:  

**Below are ways you and your employer can work together in caregiving for your child.**
Be aware of your rights. Those include federal employment statutes and regulations, including the Americans with Disabilities Act of 1990, as amended; the Equal Pay Act of 1963, as amended; the Pregnancy Discrimination Act; Title VII of the Civil Rights Act of 1964, as amended; the Family and Medical Leave Act (FMLA); the Employee Retirement Income Security Act (ERISA), 42 U.S.C. §1983, and Executive Order 13152.

Be aware of the common stereotypes or biases about caregivers that may result in unlawful conduct, including:

- assuming that female workers’ caretaking responsibilities will interfere with their ability to succeed in a fast-paced environment;
- assuming that female workers who work part-time or take advantage of flexible work arrangements are less committed to their jobs than full-time employees;
- assuming that male workers do not, or should not, have significant caregiving responsibilities;
- assuming that female workers prefer, or should prefer, to spend time with their families rather than time at work;
- assuming that female workers who are caregivers are less capable than other workers;
- assuming that pregnant workers are less reliable than other workers.

Examples of prohibited conduct related to workers’ caregiving responsibilities, such as:

- asking female applicants and employees, but not male applicants and employees, about their child care responsibilities;
- making stereotypical comments about pregnant workers or female caregivers;
- treating female workers without caregiving responsibilities more favorably than female caregivers;
- steering women with caregiving responsibilities to less prestigious or lower-paid positions;
- treating women of color who have caregiving responsibilities differently than other workers with caregiving responsibilities due to gender, race and/or national origin-based stereotypes;
- treating male workers with caregiving responsibilities more, or less, favorably than female workers with caregiving responsibilities;
- denying male workers’, but not female workers’, requests for leave related to caregiving responsibilities; and
- providing reasonable accommodations for temporary medical conditions but not for pregnancy.

Prohibit retaliation against individuals who report discrimination or harassment based on caregiving responsibilities or who provide information related to such complaints.

Identify an office or person that staff may contact if they have questions or need to file a complaint related to caregiver discrimination.

Ensure that managers at all levels are aware of, and comply with, the organization’s work-life policies. In particular, front-line supervisors, middle management and other managers who regularly interact with employees or who are responsible for assignments, leave approval, schedules, promotions
and other employment terms, conditions and benefits should be familiar with the organization’s work-life policies and supportive of employees who take advantage of available programs.

**Report complaints of caregiver discrimination efficiently and effectively.** Investigate complaints promptly and thoroughly. Take corrective action and implement corrective and preventive measures as necessary to resolve the situation and prevent problems from arising in the future.

**The employer should protect against retaliation.** They are to provide clear and credible assurances that if employees make complaints or provide information related to complaints about unfair treatment of caregivers, the employer will protect them from retaliation. They are to ensure that these anti-retaliation measures are enforced.

**Recruitment, Hiring, and Promotion**

- **They are to focus on the applicant’s qualifications** for the job in question. They are not allowed to ask questions about the applicant’s or employee’s children, plans to start a family, pregnancy, or other caregiving-related issues during interviews or performance reviews.
- **Ensure that job openings, acting positions, and promotions are communicated** to all eligible employees regardless of caregiving responsibilities.
  - They cannot assume that certain employees (for example, mothers of young children or single parents) will not be interested in positions that require significant travel or working long or unusual hours.
- **Ensure that employment decisions are well-documented and transparent** (to the extent feasible).
  - To prevent misunderstandings, clearly explain the reasoning behind employment decisions to relevant parties.
  - Retain records relevant to decisions about hiring, promotion, performance, pay, leave, benefits, awards, and other employment decisions for at least the length of time required by statute.

**Terms, Conditions, and Privileges of Employment**

- **Monitor compensation practices and performance appraisal systems** for patterns of potential discrimination against caregivers. They should ensure that performance appraisals are based on employees’ actual job performance and not on stereotypes about caregivers.
- **Review workplace policies that may limit your schedule flexibility**, such as fixed hours of work and mandatory overtime, to ensure your accommodation.
- **Request flexible work arrangements** that allow them to balance work and personal responsibilities. Create customized flexible work arrangements that meet the specific needs of the employee and employer. Ask that managers do not discourage employees from requesting flexible work arrangements or penalize employees who make such requests. Flexible work arrangements may include:
  - **General Flexible Options:**
    - **Flextime Programs.** Flextime policies generally permit employees to vary their work day start and stop times within a certain range, such as allowing an
employee to arrive at work at any time between 8:00 and 9:30 a.m. and then work for 8 hours.

- **Flexible Week Opportunities.** Flexible week opportunities may include compressed work weeks, such as a workweek consisting of four ten-hour work days.

- **Telecommuting, Work-at-Home, or Flexplace Programs.** These options enable employees to work from home or alternate office locations.
  
  o **Reduced-time options** – These options permit employees to work part-time while juggling other responsibilities, such as caregiving. Reduced-time options include:
    
    - **Part-time work opportunities.** Part-time workers should receive proportionate wages and benefits compared with full-time workers. Similarly, part-time workers should receive proportionate credit for relevant experience needed to qualify for promotions, training programs, or other employment opportunities.
    
    - **Job sharing.** Job sharing programs permit two employees to share one full-time position. In general, employees participating in job sharing programs receive a proportionate share of the salary and benefits.

- **If overtime is required, ask to make it as family-friendly as possible.** Determine whether a voluntary, rather than mandatory, overtime system would meet the needs of the organization. If not, ask to schedule overtime in advance so you can arrange for child care, elder care, or other caregiving responsibilities.

- **Ask to reassign job duties that employees are unable to perform** because of pregnancy or other caregiving responsibilities.

- **Negotiate reasonable personal or sick leave to allow employees to engage in caregiving** even if not required to do so by the Family and Medical Leave Act of 1993 (FMLA). Permit employees to use sick leave to care for family members who are ill and/or to handle medical emergencies involving family members.

  o Engage in dialogue with employer to determine the amount of leave that is appropriate and acceptable based on their workload, upcoming deadlines and personal circumstances.

  o Ensure that leave policies are available to male and female employees on an equal basis. Train managers to ensure that both male and female employees are aware of leave policies and are not implicitly or explicitly discouraged from requesting leave.

  - To the extent feasible, permit employees to take leave with little notice in case of an emergency and to use leave in short increments, rather than full days or weeks. Caregiving issues may arise suddenly and unexpectedly, and may be resolved in a relatively short amount of time.

  - With appropriate communication procedures and leave policies in place, these situations may be addressed with minimal inconvenience or cost to the employer.

- **Ask for employee schedules as early as possible** for positions that have changing work schedules so that you can arrange in advance for child care or address other personal responsibilities, thereby enabling them to more readily fulfill work responsibilities.

- **Ask for support, resources, and/or referral services** that offer caregiver-related information to employees. Such services may include an Employee Assistance Program, referral services for local child care centers or assisted living facilities, adoption assistance services, parenting education classes, college financing classes, or a toll-free caregiver hotline that provides guidance and advice to employees who have work-life balance questions or concerns.
Mental Health

Resources and Readings for Parents/Caregivers


“Parents Who Have a Child with Cancer” - https://www.cancer.gov/about-cancer/coping/caregiver-support/parents

• There are links on this page to look at the effects of childhood cancer on the child with cancer, the parents/caregivers, siblings, and other close family and friends, as well as other information on how to talk to the children, both siblings and the child that is sick.

"Support for Families When a Child has Cancer" - https://www.cancer.gov/about-cancer/coping/caregiver-support/parents


“Children with Chronic Conditions” - http://www.med.umich.edu/yourchild/topics/chronic.htm

Center for Pediatric Traumatic Stress (CPTS): Coronavirus: Helping my child cope. Here is the link: https://healthcaretoolbox.org/tools-and-resources/14-health-care-toolbox/tools-and-resources/602-covid19-children-and-families.html. It is a tip sheet from CPTS, and includes examples you can use at home, specifically tips for parents of children with existing health concerns. Lots of professional resources and links are also included for children, teens and caregivers.

Fact. Did you know that divorce rates for childhood cancer families can be up to 8 times greater than average? Also, did you know that it is impossible to care for another if you don’t take care of yourself? Do yourself a favor and GET HELP FOR YOUR FAMILY. Even if you seem to be coping, well most of these services are FREE to your family while on treatment so take advantage now! Take the time and learn to manage the stress and trauma of childhood cancer! My husband and I attend marriage therapy, and my husband actually loves it so much that he does individual therapy too. Please don’t wait any longer, get help!

Find a trauma specialized therapist here: https://www.psychologytoday.com/us/therapists/trauma-and-ptsd

**Resources on Post-Traumatic Stress Disorder**

“Childhood Cancer and Post-Traumatic Stress Disorder” - http://www.huffingtonpost.co.uk/anne-speckhard/childhood-cancer-ptsd_b_5194292.html


**Additional Readings**

For Parents & Adults

- *Care for Children and Adolescents with Cancer: Questions and Answers*. National Cancer Institute. Available at: or call 1-800-332-8615.

Books for Teens and Children
Although these books are intended for children, it is helpful when an adult reads with and helps the child reflect about what different parts of the book mean to the child.
- The Amazing Hannah, Look at Everything I Can Do! by Amy Klett. Candlelighters Childhood Cancer Foundation, 2002. For ages 1 to 6. (Also available in Spanish.)
- Courageous Calla & The Clinical Trial, by Arya Singh. 2020. Self-Published. The author of this book has Spinal Muscular Atrophy and participated in clinical trials throughout her life. The book was written because the author feels that “knowledge is an incredible source of power and comfort” and she “hopes this book can help many more kids born a little different.” It explains the basics of a clinical trial so that children and their families can understand the process better.
- Going to the Hospital, by Fred Rogers. Paperstar Book, 1997. For children 4 to 8.
- Me and My Marrow, by Karen Crowe. Published by Fujisawa Healthcare, 1999. You can buy it as a book, but it's also available online at: https://www.bridges4kids.org/Disabilities/meandmymarrow.pdf. For teens.
- Oncology, Stupology...I Want to go Home! by Marilyn K. Hershey. Butterfly Press, 1999. For ages 8 to 12. (Also available in Spanish.)

**Support Groups/Counseling**

Call for help- the Caregiver Action Network


**American Psychosocial Oncology Society**

Offers a toll-free hotline for cancer patients and advocacy organizations to obtain referrals for local counseling and support services throughout the United States. The referral program aims to connect patients or patient advocacy organizations to psychiatrists, psychologists, nurses, and social workers skilled in the management of cancer-related distress. The helpline voice-mail is monitored three times each business day. An APOS member will call within two business days to assist with a referral. Also offers an [online directory](https://www.asos.org).

**Online Communities**

Online communities let you create a personal profile where you share information about yourself for others to view. You choose whom to invite or allow access to your profile. Online communities offer several benefits for people with cancer, such as:

- Making it easier to stay in touch with family and friends
- Connecting you with others in a similar situation
- Helping people find support no matter where they live
- Giving people who don't like face-to-face groups another option to connect with others

In an online community, you can post a picture or video of yourself and share updates with people in your network whenever you choose. You are free to decide how much information you are comfortable sharing with others. Several sites offer privacy settings and tools, which let you control who can view your profile and what they can see or read. When creating a profile, learn about the privacy settings and options the site offers. This will help you find out how your information is used and how it can be accessed. Learning about such features may help you feel more comfortable when sharing your profile.

Sharing stories with other people in an online community could be a way for you to learn about treatment options and other concerns, such as side effects. While sharing these experiences is helpful, keep in mind that only your doctor can give you the best advice for your type of cancer and situation. And remember that your experience with side effects may be different from others.
If you have thought about joining an online community, here are some organizations that offer communities that can be personalized or communities for different types of cancer:

4th Angel Mentoring Program provides free, one-on-one, confidential telephone support for people with cancer and their caregivers. Trained mentors who are cancer survivors or have been a caregiver to a person with cancer offer support and guidance during a difficult time. [https://4thangel.ccf.org/](https://4thangel.ccf.org/)

Cancer Support Community is an international nonprofit dedicated to providing support, education, and hope to people affected by cancer. They provide support services through a network of professionally-led community-based centers, hospitals, community oncology practices, and online. [https://www.cancersupportcommunity.org/](https://www.cancersupportcommunity.org/)

Find a Local Support Community with the “Cancer Support Community Wellness Programs” – [https://www.cancersupportcommunity.org/find-location-near-you#tab2](https://www.cancersupportcommunity.org/find-location-near-you#tab2)

CaringBridge helps you create a free, private, and secure web page, communicate updates in a patient care journal, share pictures, and coordinate help. [https://www.caringbridge.org/](https://www.caringbridge.org/)

Friend for Life Cancer Support Network is a network of cancer survivors and caregivers who provide compassionate, one-on-one support to others diagnosed with cancer and to their loved ones. [https://www.friend4life.org/](https://www.friend4life.org/)

Inspire features groups for people with cancer and their caregivers. You can also join groups for other health conditions besides cancer. Once you join a group, you can post questions and comments on discussion boards and connect with other group members. Help other members and give encouragement by responding to their stories and questions. Several patient advocate organizations feature support communities on Inspire. [https://www.inspire.com/](https://www.inspire.com/)

Know Cancer is dedicated to connecting, educating, and empowering all people affected by the many forms of cancer. It offers an online community that provides social and professional support to patients and their loved ones. [https://www.knowcancer.com/](https://www.knowcancer.com/)

Lotsa Helping Hands helps you coordinate caregiving tasks among family members and friends. Simply fill in requests for help on a group calendar for visitors to sign up to help. For example, post the dates and times that a ride is needed to and from treatment or mark a time when help is needed with grocery shopping. Use message boards to stay up to date and try their mobile application that helps you connect. They also provide support to members and coordinators of the My Cancer Circle communities. [https://lotsahelpinghands.com/](https://lotsahelpinghands.com/) and [https://mycancercircle.lotsahelpinghands.com/caregiving/home/](https://mycancercircle.lotsahelpinghands.com/caregiving/home/)

MyLifeLine.org is a part of the Cancer Support Community. It provides free websites for people with cancer and caregivers to keep family and friends updated. Sharing a web page helps reduce the number of times you have to repeat similar conversations to people concerned about you. A calendar on the site helps you keep track of doctor and treatment visits and other important appointments. Plus, you can post requests for help, such as rides to appointments, babysitting, or donations. [https://www.mylifeline.org/](https://www.mylifeline.org/)
Navigating Cancer is a free website specifically for people with cancer and their supporters, offering tools and cancer resources that empower patients to take control of their health and partner more closely with their physicians, support network, and other like patients.  https://www.navigatingcare.com/patient/

Smart Patients is an online community where patients and families affected by a variety of illnesses can learn from each other about treatments, challenges, and how it all fits into the context of their experience.  https://www.smartpatients.com/

**Many patient advocate organizations offer online support services, such as discussion forums and chat rooms. Look for disease-specific patient advocacy organizations for information on what resources or online support services they offer.  https://www.cancer.net/coping-with-cancer/finding-support-and-information/cancer-specific-resources

National Support Organizations

Cancer Care, Inc - http://www.cancercare.org
A national, nonprofit organization that provides referrals, one-on-one counseling, specialized support groups, and educational programs.

Center for Attitudinal Healing - http://healingcenter.org
A nonprofit nonsectarian group that sponsors local and national workshops for children with catastrophic or life-threatening diseases and their siblings. It promotes the use of the arts in a loving, supportive program to help children ages six to sixteen share their feelings about their situation. It has published several excellent books.

A national nonprofit Jewish organization that provides support service programs to children and their families in crisis, including medical referrals, support groups, visit to hospitalized and housebound children, financial aid, transportation, a kosher camp for kids with cancer, and more.

Child Life Council - http://www.childlife.org
Promotes the well-being of children and families in healthcare settings by supporting the development and practice of the child life professionals with training conferences, publications, and information.

Famous Phone Friends - http://famousfonefriends.org
Links children who are confined to the hospital or home due to injury or illness with entertainers and athletes by telephone. Obtain a referral from a physician nurse, hospital volunteer, or treatment center social worker.

Advocates for children affected by childhood cancer and their families by providing financial assistance, education, and emotional support.

Songs of Love Foundation - http://www.sonsoflove.org
A nonprofit organization that has a volunteer group of more than 200 artists who produce personalized musical portraits for children and teens with chronic or life-threatening diseases.
Legal Assistance

American Bar Association - https://www.americanbar.org/

National directory of pro bono programs

Law Help - https://www.lawhelp.org/

LawHelp helps those with low- and moderate-incomes find free legal aid programs in their communities, and answers to questions about their legal rights. Able to search by zip code for legal assistance for many different issues.

National Cancer Legal Services Network - http://www.nclsn.org/
Free legal services programs assist with insurance disputes, public benefits, housing, employment issues, future care and custody planning, immigration, and advance directives.

Cancer Care - https://www.cancercare.org/tagged/legal_assistance
CancerCare provides information, resources and support to help people coping with cancer manage legal concerns, including insurance and workplace issues.

As the number of cancer survivors in the U.S. continues to grow, there is an increasing need for resources and support to help them get back to everyday life and work after diagnosis and treatment.

Articles on Legal Issues:


“Legal Assistance, Cancer, Patients, Information, Resources” - http://www.cancercare.org/tagged/legal_assistance

Attending School, Accommodations, Resources, and More

School is hard! Going to school while in treatment is even harder! Let's talk about some resources that would be of help to you and your family.

Attending School During Treatment

- Homebound instruction may be provided by the public school without an additional cost. The school district might arrange for a teacher to work with your child at home if they have to be out of school for longer periods of time, but are not in the hospital. Some children with cancer might go to school during some parts of treatment and then receive homebound instruction or hospital
instruction during other parts of their treatment. Check out this organization that helps the class and the student form a closer bond. [http://www.monkeyinmychair.org/](http://www.monkeyinmychair.org/)

- **Attending a hospital or clinic-based school.** When a child will have to be in the hospital for a long time, they might be able to have teachers from their school district or from the hospital school come and teach. In-hospital schooling can also work well for children who do not feel well enough to have more than one hour of instruction a day. Even one hour of school a day can still give the children the feeling of connection to what children without cancer do every day.

- **Attending school during treatment.** Some children can go to school during treatment, depending on their treatment schedule, how they feel, and infection risk. Ask the cancer care team when during treatment your child can go to school. Some children enjoy seeing friends when they feel well and can go for small blocks of time during the school day. There may be times when they cannot go because of how they are feeling, treatment schedules, or other factors.

- **Additional support services called 504 plans or Individualized Education Plans (IEP).** These may be part of how the school, your cancer care team, and your family work together to help your child participate in school during their treatment and after. The teacher that works for the hospital or the social worker on the cancer care team can help you understand how these services work for children with cancer.

**These therapies and services could include...**

- Speech and Audiology
- Psychological
- Physical and Occupational
- Social Work
- Counseling
- Orientation/ mobility services
- Interpreting
- Nursing/ medical services
- One on one aides
- Transportation
- Technologies- computers, FM/AM systems etc.

**Two Organizations Offering Additional Assistance**

- Able Differently - [https://www.able-differently.org/](https://www.able-differently.org/). Offers resources and information “Able-differently promotes a self-help model that serves school and younger age children and their families with special health care needs, who have not had success with typical forms of intervention. We support parents solving problems themselves with participation in family centered community partnerships such as with schools, medical homes and mental health systems. Families can then focus on building positive child-family, and cultural-community exchanges in responsive and contingent ways that fosters new opportunities and achievements.

A team encourages multiple views of the problem drawing on existing strengths and resources. We believe this community self-help model will assist families accessing services earlier and finding proactive solutions.
Your Taking Steps to Satisfy Your Child’s Special Needs
We are convinced that parents can gather a few people together to problem solve, to improve adaptive functioning and enhanced quality of life for their child and family. You may already have concerns with one or more of these conditions and now wonder what you should do.

• Attention Deficit/Hyperactive Disorders
• Autism Spectrum
• Chronic medical and physical challenges
• Emotional and behavioral conditions
• Learning and developmental disabilities
• Complex stress affecting attachment behaviors

  o “Wrightslaw” - https://www.wrightslaw.com/
    - Mission: providing accurate, reliable information about special education law and advocacy.
    - Provides:
      ● Advocate Newsletter
      ● Training Program
      ● Books and Training
      ● Advocacy Library
      ● Law Library
      ● Books, Training Downloads, DVDs, Websites
      ● Resources and Directories
      ● Blog
    - Topics (from their website):

      Advocacy
      ADD/ADHD
      Allergy/Anaphylaxis
      American Indian
      Assistive Technology
      Autism Spectrum
      Behavior & Discipline
      Bullying
      College/Continuing Ed
      Damages
      Discrimination
      Due Process
      Early Intervention (Part C)
      Eligibility
      Episodic, such as Allergies, Asthma, Diabetes, Epilepsy, etc
      ESSA
      ESY
      Evaluations
      FAPE
      Flyers
      Future Planning
      Harassment
Potential Accommodations for Kids in Treatment

- For fatigue or weakness...
  - Your child may need two sets of books, one for home and one for school.
  - Ask the school principal and cancer care team about excusing your child from certain physical education activities to avoid severe fatigue during later classes.
  - You might be able to have your child take brief rest periods or shorter school days may be needed.
  - Teens may need locker assignments closer to classrooms to get to class on time.
  - Some children may need more time on tests, quizzes or reduced assignments because of fatigue.
  - Consider the option of remote learning, with the child able to stay at home and still able to video conference into class.
  - Locker located near classrooms
  - A “scribe” for long written work
  - Use of elevator
  - Permission to leave class early to walk in uncrowded hallways
  - Buddy system for visits to the school nurse’s office
  - Rest breaks

- For appetite, thirst, or using the bathroom
Dry mouth caused by treatment could mean the child needs to carry a water bottle.
Children who have bladder or bowel problems after treatment may need long-term bathroom passes so they can take care of these needs without calling attention to the problem.
Children who are having trouble gaining weight or are underweight may also need a longer lunch period and have extra snacks.
Earlier/later lunch planned around medication and meal schedules.

- **Learning Accommodations**
  - Seating at the front of the classroom
  - Copies of teacher’s notes
  - Use of a study guide
  - Extended time on tests, classroom assignments, and homework
  - Shortened or modified assignments
  - Verbal testing
  - Memory, technology, verbal, or visual aids
  - Sending a teacher/tutor to the hospital.
  - Allowing a shorter school day.
  - Use of tape-recorded textbooks and lectures
  - Use of a computer keyboard instead of handwriting
  - Use of a calculator for math
  - Extra help with math, spelling, reading, and organizational skills
  - Grades based on work completed rather than work assigned
  - Copies of classroom notes or lesson materials presented in class

- **Health/Wellness accommodations**
  - Able to keep hand sanitizer on desk
  - Personal supplies not shared with the class
  - Permission to wear a hat at school
  - Prompt phone contact with parent when another student in the classroom has a contagious illness
  - Knowledge that there will be prolonged absences due to hospital stays, doctor visits, and treatments
  - Counseling available when feeling overwhelmed or anxious regarding their illness, feel self-conscious about their appearance, especially if they've lost their hair due to chemotherapy.
  - Permission to carry water bottle and/or snacks as needed
  - Permission to use the restroom as needed

**How do I get these services?**
These services are provided through tax dollars at no cost to you. Call your school and ask to speak with the Special Education Administrator to inquire about an Individualized Education Plan (IEP) and ask about what is needed for eligibility. (Please note, an IEP is a “written document that's developed for each public school child who is eligible for special education” [https://www.greatschools.org/gk/articles/what-is-an-iep/](https://www.greatschools.org/gk/articles/what-is-an-iep/)). Throughout your IEP process, it is important to keep notes as to what people say and when. Consider communications by email for a paper trail.
Your Rights as a Parent
IEP meetings are covered under the Family Medical Leave Act, you are legally able to leave work at any time with the appropriate FMLA paperwork submitted to your HR department.

Useful Readings

Attending School During Treatment

Returning to School After Treatment

Grades K – 5

- ABCya: www.abcya.com - Reading and math games and activities for K – 6th graders. A wonderful variety of topics are covered in these games and activities. Free resource.
- Starfall: www.starfall.com - Reading and math activities for K – 3. There are some free activities in both subjects, but to access everything you would have to purchase a subscription.
- Story Online: www.storylineonline.net - Free stories online read by celebrities.
- Homeschool for Me: www.123homeschool4me.com - Free worksheets that are printable and online games for all subjects. Free resource.
- BrainPop Jr.: www.jr.brainpop.com/ - Free educational and interactive videos and games for all ages. There are games to go along with all topics and you can even create assessments.
- Scholastic: www.classroommagazines.scholastic.com/support/learnathome.html - Fun day-by-day projects to keep the brain working.
- Bedtime Math: www.bedtimemath.org - Daily math problems posted for a quick five minutes of math fun. For more information about our program or if you have any questions for our team, please call us at 317.948.4588 or visit our website at: www.rileychildrens.org/support-services/school-program, Riley School Program ©

Grades 6 – 12

- Ask Rose: www.askrose.com or 877.275.7673 – Student tutors from Rose Hulman University. Math or science help via live chat, email or phone. Hours are 7 – 10 pm.
- Crash Course: [www.youtube.com/user/crashcourse/playlists](www.youtube.com/user/crashcourse/playlists). This is a Youtube video library full of educational topics such as literature, essay writing, biology, physics, chemistry and even study tips.
- Khan Academy: [www.khanacademy.org](www.khanacademy.org) - Online instructional/tutorial videos for K – 12 for all subject areas. Free.
- Symbolab: [www.symbolab.com](www.symbolab.com) - High-level math calculator that shows step by step when getting answers.
- Mathway: [www.mathway.com/Algebra](www.mathway.com/Algebra) - Live chat for any math help needed. For fun
- Muffalo Potato: [www.muffalopotato.com](www.muffalopotato.com) - This is a fun drawing website. Children can learn to draw different pictures using only letters and numbers via fun episodes with Muffalo and John.
- Kidz Bop: [www.kidzbop.com/videos](www.kidzbop.com/videos) - Fun dancing music videos. These are also available on YouTube.
- Drawing with Mo Willems: [www.youtube.com/watch?v=RmzjCPQv3y8](www.youtube.com/watch?v=RmzjCPQv3y8) - Fun doodles with children’s book author Mo Willems.
- Google Arts & Culture: [www.artsandculture.google.com/?mod=article_inlin](www.artsandculture.google.com/?mod=article_inlin) - Virtual tours of museums and other amazing places all over the world.
- Breathing Exercises for Children: [www.kidsyogastories.com/breathing-exercises-for-kids](www.kidsyogastories.com/breathing-exercises-for-kids) - Breathing exercises to help us stay calm, relieve our stressors and focus.
- Family BINGO - [www.docs.google.com/presentation/d/1MZ_l_reKi0v1dRqTfoi0B_yavo7kg-Zr3sCC1sD8qaw/edit?ts=5e720d57#slide=id.p](www.docs.google.com/presentation/d/1MZ_l_reKi0v1dRqTfoi0B_yavo7kg-Zr3sCC1sD8qaw/edit?ts=5e720d57#slide=id.p) - A fun bingo activity for the entire family.

**Wishes, Camps, and Retreats**

**Please visit the Hope Portal ([www.hope-portal.org](www.hope-portal.org)) for additional organizations that offer free wishes, camps, and retreats.**

**Family Retreats**

Camp Sunshine - [https://www.campsunshine.org/](https://www.campsunshine.org/)

Deliver the Dream - [https://deliverthedream.org/](https://deliverthedream.org/)

Lighthouse Family Retreat - [https://www.lighthousefamilyretreat.org/](https://www.lighthousefamilyretreat.org/)

**Family Camps**

Camp Ronald McDonald - [https://rmhcs.org/camp/page/camp-application-forms](https://rmhcs.org/camp/page/camp-application-forms)
My Camp Sunshine - https://www.mycampsunshine.com/

Camps Available per State Location

Retreats, Camps, and Recreational Programs for Cancer from Needy Meds - https://www.needymeds.org/camps/aos_camps/AOS


List of Camps for Childhood Cancer Families by State from Alex’s Lemonade Stand - https://www.alexslemonade.org/childhood-cancer/for-families/summer-camps

Wish Granting Organizations

Infants and Toddlers

A Special Wish Foundation, Inc. - http://www.spwish.org/, No age restrictions

Hope Kids - https://www.hopekids.org/, No age restrictions

Children’s Wish Foundation International - https://childrenswish.org/programs/wish-fulfillment/, Under age 4 only

Search for a Wish Granting Organization by State


Notable Wish Granting Organizations

Baking Memories 4 Kids - https://www.bakingmemories4kids.com/

Bear Necessities Pediatric Cancer Foundation - https://www.bearnecessities.org/bear-hugs/

Believe in Tomorrow - https://believeintomorrow.org

Cal’s Angels - https://www.calsangels.org/

Children’s Wish Foundation - https://childrenswish.org/programs/wish-fulfillment/

The Clayton Dabney Foundation for Kids with Cancer - https://claytondabney.org/

Dream Factory - https://dreamfactoryinc.org/

The Granted Wish Foundation - https://www.grantedwish.org/

Hope Kids - https://www.hopekids.org/


Kids Wish Network - https://www.kidswishnetwork.org/

Little Wish Foundation - https://littlewishfoundation.org/

Make-A-Wish Canada - https://www.childrenswish.ca/

Make-a-Wish Foundation - https://wish.org/

The Marty Lyons Foundation - https://martylyonsfoundation.org/
Operation Liftoff - http://www.operationliftoff.org/


Sunshine Foundation - https://www.sunshinefoundation.org/

United Special Sportsman Alliance - https://childswish.org/

Wishing Well Foundation USA - http://thewishingwellwa.org/
**All of the information in this section has been adapted from the National Cancer Institute, and it is available in its entirety at:**


**Please note that a large portion of this section is also applicable to REFRACTORY neuroblastoma, as well.**

**Treatment of Recurrent Neuroblastoma**

For information about the treatments listed below, see the [Treatment Option Overview](https://www.cancer.gov/types/neuroblastoma/patient/neuroblastoma-treatment-pdq) section.

**Patients First Treated for Low-Risk Neuroblastoma**

Treatment for [recurrent neuroblastoma](https://www.cancer.gov/types/neuroblastoma/patient/neuroblastoma-treatment-pdq) that comes back in the area where the cancer first formed may include the following:

- Surgery followed by observation or chemotherapy.
- Chemotherapy that may be followed by surgery.

Treatment for recurrent neuroblastoma that comes back in other parts of the body or that has not responded to treatment may include the following:

- Observation.
- Chemotherapy.
- Surgery followed by chemotherapy.
- Treatment as for [newly diagnosed high-risk neuroblastoma](https://www.cancer.gov/types/neuroblastoma/patient/neuroblastoma-treatment-pdq), for children older than 1 year.

**Patients First Treated for Intermediate-Risk Neuroblastoma**
Treatment for recurrent neuroblastoma that comes back in the area where the cancer first formed may include the following:
- Surgery that may be followed by chemotherapy.
- Radiation therapy for children whose disease has gotten worse after chemotherapy and second-look surgery.

Treatment for recurrent neuroblastoma that comes back in other parts of the body may include the following:
- Treatment as for newly diagnosed high-risk neuroblastoma, for children older than 1 year.

Patients First Treated for High-Risk Neuroblastoma
There is no standard treatment for recurrent neuroblastoma in patients first treated for high-risk neuroblastoma. Treatment may include the following:
- Chemotherapy.
- Combination chemotherapy with monoclonal antibody therapy (dinutuximab).
- Iodine 131-MIBG therapy to relieve symptoms and improve quality of life. It may be given alone or in combination with chemotherapy.
- Targeted therapy with crizotinib or other ALK inhibitors, for patients with changes in the ALK gene. Because there is no standard treatment, patients first treated for high-risk neuroblastoma may want to consider a clinical trial. For information about clinical trials, please see the NCI website.

Patients with Recurrent CNS Neuroblastoma
Treatment for neuroblastoma that recurs (comes back) in the central nervous system (CNS; brain and spinal cord) may include the following:
- Surgery to remove the tumor in the CNS followed by radiation therapy.
- A clinical trial of a new therapy.

Treatments Being Studied for Progressive/Recurrent Neuroblastoma
Some of the treatments being studied in clinical trials for neuroblastoma that recurs (comes back) or progresses (grows, spreads, or does not respond to treatment) include the following:
- Chemotherapy and targeted therapy (dinutuximab with or without efornithine).
- Checking a sample of the patient's tumor for certain gene changes. The type of targeted therapy that will be given to the patient depends on the type of gene change.
- Targeted therapy (AZD1775) and chemotherapy.
- Targeted therapy (pembrolizumab or lorlatinib).
- Immunotherapy (CAR T-cell therapy).
- Iodine 131-MIBG therapy given alone or with other anticancer drugs.
- Iodine 131-MIBG therapy and targeted therapy (dinutuximab).

Use our clinical trial search to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. General information about clinical trials is also available.

Treatment of Recurrent Neuroblastoma (from NCI)
Tumor growth resulting from maturation should be differentiated from tumor progression by performing a biopsy and reviewing histology. Patients may have persistent maturing disease with metaiodobenzylguanidine (MIBG) uptake that does not affect outcome, particularly patients with low-risk and intermediate-risk disease.[1] An analysis of 23 paired MIBG and positron emission tomography (PET) scans in 14 patients with refractory or recurrent high-risk neuroblastoma treated with iodine I
131-MIBG (131I-MIBG) found that the MIBG scan was more sensitive than fluorine F 18-fluorodeoxyglucose (18F-FDG) PET for detecting metastatic bone lesions, although there was a trend for 18F-FDG PET to be more sensitive for soft tissue lesions.[2]

Subclonal ALK mutations or other MAPK pathway lesions may be present at diagnosis, with subsequent clonal expansion at relapse. Consequently, serial sampling of progressive tumors may lead to the identification of potentially actionable mutations.[3,4] Modern comprehensive molecular analysis comparing primary and relapsed neuroblastoma from the same patients revealed extensive clonal enrichment and several newly discovered mutations, with many tumors showing new or clonal-enriched mutations in the RAS-MAPK pathway. This was true for patients with both high-risk and low-risk tumors at diagnosis.[5,6] (Refer to the Genomic and Biologic Features of Neuroblastoma section of this summary for more information).

If neuroblastoma recurs in a child originally diagnosed with high-risk disease, the prognosis is usually poor despite additional intensive therapy.[7-10] However, it is often possible to gain many additional months of life for these patients with alternative chemotherapy regimens.[11,12] Clinical trials are appropriate for these patients and may be offered. Information about ongoing clinical trials is available from the NCI website.

Prognostic Factors for Recurrent Neuroblastoma

The International Neuroblastoma Risk Group Project performed a survival-tree analysis of clinical and biological characteristics (defined at diagnosis) associated with survival after relapse in 2,266 patients with neuroblastoma entered on large clinical trials in well-established clinical trials groups around the world.[7] The survival-tree analysis revealed the following:

- Overall survival (OS) in the entire relapsed population was 20%.
- Among patients with all stages of disease at diagnosis, MYCN amplification predicted a poorer prognosis, measured as 5-year OS.
- Among patients diagnosed with International Neuroblastoma Staging System (INSS) stage 4 without amplification, age older than 18 months and high lactate dehydrogenase (LDH) level predicted poor prognosis.
- Among patients with MYCN amplification, those diagnosed with stage 1 and stage 2 have a better prognosis than do those diagnosed with stage 3 and stage 4.
- Among patients with MYCN-nonamplified tumors who are not stage 4, patients with hyperdiploidy had a better prognosis than did patients with diploidy in those younger than 18 months, while among those older than 18 months, patients with differentiating tumors fared much better than did patients with undifferentiated and poorly differentiated tumors.

Significant prognostic factors determined at diagnosis for post relapse survival include the following:[7]

- Age.
- INSS stage.
- MYCN status.
- Time from diagnosis to first relapse.
- LDH level, ploidy, and histologic grade of tumor differentiation (to a lesser extent).

The Children’s Oncology Group (COG) experience with recurrence in patients with low-risk and intermediate-risk neuroblastoma showed that most patients can be salvaged. The COG reported a 3-year event free survival (EFS) of 88% and an OS of 96% in intermediate-risk patients and a 5-year EFS of 89% and OS of 97% in low-risk patients.[13,14] Moreover, in most patients originally diagnosed with
low-risk or intermediate-risk disease, local recurrence or recurrence in the 4S pattern may be treated successfully with observation alone, surgery alone, or with moderate-dose chemotherapy, without myeloablative therapy and stem cell transplant. Although the OS after recurrence in children presenting with high-risk neuroblastoma is generally extremely poor, patients with high-risk neuroblastoma at first relapse after complete remission or minimal residual disease (MRD) in whom relapse was a single site of soft tissue mass (a few children also had bone marrow or bone disease at relapse) had a 5-year OS of 35% in one single-institution study. All patients underwent surgical resection of the soft tissue disease. MYCN amplification and multifocal soft tissue disease were associated with a worse post progression survival.[15]

**Recurrent Neuroblastoma in Patients Initially Classified as Low Risk**

**Locoregional recurrence**

Treatment options for locoregional recurrent neuroblastoma initially classified as low risk include the following:

1. Surgery followed by observation or chemotherapy.
2. Chemotherapy that may be followed by surgery.

Patients with favorable biology and regional recurrence more than 3 months after completion of planned treatment are observed if resection of the recurrence is total or near total (≥90% resection). Those with favorable biology and a less-than-near-total resection are treated with chemotherapy.[13,14]

Infants younger than 1 year at the time of locoregional recurrence whose tumors have any unfavorable biologic properties are observed if resection is total or near total. If the resection is less than near total, these same infants are treated with chemotherapy. Chemotherapy may consist of moderate doses of carboplatin, cyclophosphamide, doxorubicin, and etoposide, or cyclophosphamide and topotecan. The cumulative dose of each agent is kept low to minimize long-term effects from the chemotherapy regimen as used in previous COG trials (COG-P9641 and COG-A3961).[13,14]

Older children with local recurrence with either unfavorable International Neuroblastoma Pathology Classification at diagnosis or MYCN gene amplification have a poor prognosis and may be treated with surgery, aggressive combination chemotherapy, or they may be offered entry into a clinical trial.

Evidence (surgery followed by observation or chemotherapy):

1. A COG study of low-risk patients with stages 1, 2A, 2B, and 4S neuroblastoma enrolled 915 patients, 800 of whom were asymptomatic and treated with surgery alone followed by observation. The other patients received chemotherapy with or without surgery.[14]
   - About 10% of patients developed progressive or recurrent tumor. Most recurrences were treated on study with surgery alone or moderate chemotherapy with or without surgery, and most patients were salvaged, as demonstrated by the EFS (89%) and OS (97%) rates at 5 years.
Metastatic recurrence or disease refractory to standard treatment

Treatment options for metastatic recurrent neuroblastoma initially classified as low risk include the following:

1. Observation.
2. Chemotherapy.
3. Surgery followed by chemotherapy.
4. High-risk therapy.

Metastatic recurrent or progressive neuroblastoma in an infant initially categorized as low risk and younger than 1 year at recurrence may be treated according to tumor biology, as defined in the previous COG trials (COG-P9641 and COG-A3961):

1. If the biology is completely favorable, metastasis is in a 4S pattern, and the recurrence or progression is within 3 months of diagnosis, the patient is observed systematically.
2. If the metastatic progression or recurrence occurs more than 3 months after diagnosis or not in a 4S pattern, then the primary tumor is resected, if possible, and chemotherapy is given.

Chemotherapy may consist of moderate doses of carboplatin, cyclophosphamide, doxorubicin, and etoposide. The cumulative dose of each agent is kept low to minimize long-term effects from the chemotherapy regimen, as used in previous COG trials (COG-P9641 and COG-A3961).

Any child initially categorized as low risk who is older than 1 year at the time of metastatic recurrent or progressive disease and whose recurrence is not in the stage 4S pattern usually has a poor prognosis and is treated as follows:

1. High-risk therapy.

Patients with metastatic recurrent neuroblastoma are treated like patients with newly diagnosed high-risk neuroblastoma. (Refer to the Treatment Options for High-Risk Neuroblastoma section of this summary for more information.)

Recurrent Neuroblastoma in Patients Initially Classified as Intermediate Risk

The COG ANBL0531 (NCT00499616) study treated patients with newly diagnosed intermediate-risk neuroblastoma with chemotherapy consisting of carboplatin, etoposide, cyclophosphamide, and doxorubicin. Retrieval therapy was included in the protocol for patients who developed progressive nonmetastatic disease within 3 years of study enrollment. Up to six cycles of cyclophosphamide and topotecan could be given to patients. Of 27 patients who received cyclophosphamide and topotecan, 18 patients remained event free, 9 patients experienced relapse, and 2 patients died. Twenty patients who experienced an inadequate initial response to eight cycles of chemotherapy were treated with cyclophosphamide and topotecan. Of those 20 patients, 9 patients achieved a very good partial response or better; however, 6 patients developed progressive disease or experienced relapse, and 1 patient died. This suggests that more aggressive therapy is needed for patients who do not achieve the defined treatment endpoint after eight cycles of chemotherapy.[16]

Among 479 patients with intermediate-risk neuroblastoma treated on the COG-A3961 clinical trial, 42 patients developed disease progression. The rate was 10% of those with favorable biology and 17% of those with unfavorable biology. Thirty patients had locoregional recurrence, 11 patients had metastatic
recurrence, and 1 patient had both types of recurrent disease. Six of the 42 patients died of disease, while 36 patients responded to therapy. Thus, most patients with intermediate-risk neuroblastoma and disease progression may be salvaged.\[13\]

**Locoregional recurrence**

Treatment options for locoregional recurrent neuroblastoma initially classified as intermediate risk include the following:
1. Surgery (complete resection).
2. Surgery (incomplete resection) followed by chemotherapy.
3. Radiation therapy. Radiation therapy is considered only for patients with disease progression after chemotherapy and second-look surgery.\[13\]

Locoregional recurrence of neuroblastoma with favorable biology that occurs more than 3 months after completion of chemotherapy may be treated surgically. If resection is less than near total, then additional chemotherapy may be given. Chemotherapy should be selected on the basis of previous chemotherapy received.\[13\]

**Metastatic recurrence**

Treatment options for metastatic recurrent neuroblastoma initially classified as intermediate risk include the following:
1. High-risk therapy.

Patients with metastatic recurrent neuroblastoma are treated like patients with newly diagnosed high-risk neuroblastoma. (Refer to the Treatment Options for High-Risk Neuroblastoma section of this summary for more information.)

**Recurrent Neuroblastoma in Patients Initially Classified as High Risk**

Any recurrence in patients initially classified as high risk signifies a very poor prognosis.\[7\] Clinical trials may be considered. Palliative care should also be considered as part of the patient's treatment plan. An analysis of several trials included 383 patients with neuroblastoma whose tumor recurred or progressed on COG modern-era early-phase trials. The 1-year progression-free survival (PFS) rate was 21%, and the 4-year PFS rate was 6%, while the OS rates were 57% at 1 year and 20% at 4 years. Less than 10% of patients experienced no subsequent recurrence or progression. \(MYCN\) amplification predicted worse PFS and OS rates.\[17\] Although the OS after recurrence in children presenting with high-risk neuroblastoma is generally extremely poor, patients with high-risk neuroblastoma at first relapse after complete remission or MRD in whom relapse was a single site of soft tissue mass (a few children also had bone marrow or bone disease at relapse) had a 5-year OS of 35% in one single-institution study.\[15\]

Treatment options for recurrent or refractory neuroblastoma in patients initially classified as high risk include the following:
1. Chemotherapy combined with immunotherapy.
   - Temozolomide, irinotecan, and dinutuximab.\[18\]
2. 131I-MIBG. 131I-MIBG alone, in combination with other therapy, or followed by stem cell rescue.
3. ALK inhibitors. Crizotinib, or other ALK inhibitors, for patients with ALK mutations.[19]
4. Chemotherapy.
   - Topotecan in combination with cyclophosphamide or etoposide.[20]
   - Temozolomide with irinotecan.
Chemotherapy combined with immunotherapy produces the best response rate and response duration of treatments for high-risk patients with disease progression.
Evidence (chemotherapy combined with immunotherapy):
1. In the ANBL1221 (NCT01767194) trial, patients in first relapse or progression were randomly assigned to receive either temozolomide/irinotecan/dinutuximab or temozolomide/irinotecan/temsirolimus.[18]
   - Of the 17 patients treated with the combination that included dinutuximab, 9 patients (53%) had an objective response, compared with 1 of 18 patients treated with the regimen that contained temsirolimus.
Evidence (131I-MIBG):
1. For children with recurrent or refractory neuroblastoma, 131I-MIBG is an effective palliative agent and may be considered alone or in combination with chemotherapy (with stem cell rescue) in a clinical research trial.[21-26]; [27,28][Level of evidence: 3iiiA]
2. A North American retrospective study of more than 200 patients treated with 131I-MIBG therapy compared children who had recurrence or progression of disease with children who had stable or persistent disease since diagnosis.[29]
   - The rate of immediate progression after 131I-MIBG therapy was lower and OS at 2 years was better (65% vs. 39%) in patients with stable, persistent disease.
3. Tandem consolidation using 131I-MIBG, vincristine, and irinotecan with autologous stem cell transplant (SCT) followed by busulfan/melphalan with autologous SCT was retrospectively reported in eight patients and resulted in three complete responses, two partial responses, and one minor response.[28]
4. Single autologous SCT with escalating dose 131I-MIBG and carboplatin/etoposide/melphalan was studied in additional patients.[30]
   - After induction chemotherapy, 27 refractory patients and 15 progressing patients were treated, resulting in four responses. Eight patients with partial response to induction were treated, resulting in three responses.
   - The 12% incidence of sinusoidal obstructive syndrome was dose limiting.
Evidence (chemotherapy):
1. The combination of irinotecan and temozolomide had a 15% response rate in one study.[31][Level of evidence: 2A]
2. A retrospective study reported on 74 patients who received 92 cycles of ifosfamide, carboplatin, and etoposide; it included 37 patients who received peripheral blood stem cell rescue after responding to this drug combination.[32]
   - Disease regressions (major and minor responses) were achieved in 14 of 17 patients (82%) with a new relapse, 13 of 26 patients (50%) with refractory neuroblastoma, and 12 of 34 patients (35%) who were treated for progressive disease during chemotherapy ($P = .005$).
Grade 3 toxicities were rare.

3. Topotecan in combination with cyclophosphamide or etoposide has been used in patients with recurrent disease who did not receive topotecan initially.\cite{33,34}; \cite{20}\[Level of evidence: 1A]

4. High-dose carboplatin, irinotecan, and/or temozolomide has been used in relapsed patients resistant or refractory to regimens containing topotecan.\cite{34}

Allogeneic transplant has a historically low success rate in recurrent or progressive neuroblastoma. In a retrospective registry study, allogeneic SCT after a previous autologous SCT appeared to offer no benefit. Disease recurrence remains the most common cause of treatment failure.\cite{35}

Clinical trials of novel therapeutic approaches, such as a vaccine designed to induce host antiganglioside antibodies that can replicate the antineoplastic activities of intravenously administered monoclonal antibodies, are currently under investigation. Patients also receive a beta-glucan treatment, which has a broad range of immunostimulatory effects and synergizes with anti-GD2/GD3 monoclonal antibodies. In a phase I study of 15 children with high-risk neuroblastoma, the therapy was tolerated without any dose-limiting toxicity.\cite{36} Long-term PFS has been reported in patients who achieve a second or later complete or very good partial remission followed by consolidation with anti-GD2 immunotherapy and isotretinoin with or without maintenance therapy. This includes patients who had previously received anti-GD2 immunotherapy and isotretinoin.\cite{37}

Recurrent Neuroblastoma in the Central Nervous System

Central nervous system (CNS) involvement, although rare at initial presentation, may occur in 5% to 10% of patients with recurrent neuroblastoma. Because upfront treatment for newly diagnosed patients does not adequately treat the CNS, the CNS has emerged as a sanctuary site leading to relapse.\cite{38,39} CNS relapses are almost always fatal, with a median time to death of 6 months.

Treatment options for recurrent neuroblastoma in the CNS include the following:

1. Surgery and radiation therapy.

Current treatment approaches generally include eradicating bulky and microscopic residual disease in the CNS and minimal residual systemic disease that may herald further relapses. Neurosurgical interventions serve to decrease edema, control hemorrhage, and remove bulky tumor before starting therapy.

Compartmental radioimmunotherapy using intrathecal radioiodinated monoclonal antibodies has been tested in patients with recurrent metastatic CNS neuroblastoma after surgery, craniospinal radiation therapy, and chemotherapy.\cite{12}

Treatment Options Under Clinical Evaluation for Recurrent or Refractory Neuroblastoma

Information about National Cancer Institute (NCI)–supported clinical trials can be found on the NCI website. For information about clinical trials sponsored by other organizations, refer to the ClinicalTrials.gov website.

The following are examples of national and/or institutional clinical trials that are currently being conducted:
• **ANBL1821 (NCT03794349)** (Irinotecan Hydrochloride, Temozolomide, and Dinutuximab With or Without Efornithine [DFMO] in Treating Patients With Relapsed or Refractory Neuroblastoma): This trial is studying the addition of DFMO to the chemo-immunotherapy backbone, which has shown promising results in patients with recurrent neuroblastoma. DFMO is an irreversible inhibitor of ODC1, which is a downstream transcriptional target of MYCN and a key enzyme in the polyamine synthesis pathway. DFMO depletes essential polyamines necessary for tumor survival.

• **APEC1621 (NCT03155620)** (Pediatric MATCH: Targeted Therapy Directed by Genetic Testing in Treating Pediatric Patients with Relapsed or Refractory Advanced Solid Tumors, Non-Hodgkin Lymphomas, or Histiocytic Disorders): NCI-COG Pediatric Molecular Analysis for Therapeutic Choice (MATCH), referred to as Pediatric MATCH, will match targeted agents with specific molecular changes identified using a next-generation sequencing targeted assay of more than 4,000 different mutations across more than 160 genes in refractory and recurrent solid tumors. Children and adolescents aged 1 to 21 years are eligible for the trial. Tumor tissue from progressive or recurrent disease must be available for molecular characterization. Patients with tumors that have molecular variants addressed by treatment arms included in the trial will be offered treatment on Pediatric MATCH. Additional information can be obtained on the NCI website and ClinicalTrials.gov website.

• **ADV1.312 (NCT02095132)** (A Phase I/II Study of AZD1775 [MK-1775] in Combination With Oral Irinotecan in Children, Adolescents, and Young Adults With Relapsed or Refractory Solid Tumors): Wee1 is a tyrosine kinase that is activated in response to DNA damage and plays a role in chemoresistance and tolerance of oncogene-induced cellular stress. The Wee1 inhibitor AZD1775 (MK-1775) was developed to overcome this checkpoint and render cells more sensitive to chemotherapy, and it may be more effective in tumors with high levels of the MYC or MYCN oncogene.

• **ADV1.621 (NCT02332668)** (A Phase I/II Study of Pembrolizumab [MK-3475] in Children With Advanced Melanoma or a PD-L1–Positive Advanced, Relapsed or Refractory Solid Tumor or Lymphoma): Part 1 of this study will find the maximum tolerated dose, confirm the dose, and find the recommended phase II dose for pembrolizumab therapy. Part 2 of the study will further evaluate the safety and efficacy at the pediatric phase II recommended dose.

• **ENC1T-01 (NCT02311621)** (A Phase I Feasibility and Safety Study of Cellular Immunotherapy for Recurrent/Refractory Neuroblastoma Using Autologous T-cells Lentivirally Transduced to Express CD171-Specific Chimeric Antigen Receptors [CAR]): Patients with recurrent or refractory neuroblastoma are resistant to conventional chemotherapy. For this reason, the investigators are attempting to use T cells obtained directly from the patient, which can be genetically modified to express a CAR. The CAR enables the T cell to recognize and kill the neuroblastoma cell through the recognition of CD171, a protein expressed on the surface of the neuroblastoma cell. This is a phase I study designed to determine the maximum tolerated dose of the CAR T cells.

• **NANT2015-02 (NCT03107988)** (Phase I Study of Lorlatinib [PF-06463922], an Oral Small Molecule Inhibitor of ALK/ROS1, for Patients With ALK-Driven Relapsed or Refractory Neuroblastoma): This is a pediatric dose-finding study of a third-generation ALK inhibitor.
Lorlatinib is sensitive to some \textit{ALK} mutations to which crizotinib is resistant. An expansion study to include more children is also being planned.

- \textbf{N2011-01 (NCT02035137)} (Randomized Phase II Pick-the-Winner Study of 131I-MIBG, 131I-MIBG With Vincristine and Irinotecan, or 131I-MIBG With Vorinostat for Resistant/Relapsed Neuroblastoma): This study will compare three treatment regimens containing MIBG, including their effects on tumor response and associated side effects, to determine whether one therapy is better than the other for people diagnosed with relapsed or persistent neuroblastoma.

- \textbf{NANT2017-01 (NCT03332667)} (MIBG With Dinutuximab): In this pediatric phase I trial, 131I-MIBG will be administered in combination with dinutuximab (a chimeric 14.18 monoclonal antibody) to neuroblastoma patients with refractory or relapsed disease. This study will utilize a traditional phase I dose escalation 3+3 design to determine a recommended phase II pediatric dose. An expansion cohort of an additional six patients may then be enrolled.

\section*{Current Clinical Trials}

Use our advanced clinical trial search to find NCI-supported cancer clinical trials that are now enrolling patients. The search can be narrowed by location of the trial, type of treatment, name of the drug, and other criteria. General information about clinical trials is also available.

\section*{ADDITIONAL READING:}

“Neuroblastoma Relapse and Secondary Cancer” - [www.cncfhope.org/Neuroblastoma_Relapse-Secondary_Cancer](http://www.cncfhope.org/Neuroblastoma_Relapse-Secondary_Cancer)

\section*{How Do Clinical Trials Work?}
**Relapse and Clinical Trials**

Available Trials-
https://clinicaltrials.gov/

“ClinicalTrials.Gov (National Institute of Health – Neuroblastoma” –

“National Cancer Institute – Treatment Clinical Trials for Neuroblastoma” -
https://www.cancer.gov/about-cancer/treatment/clinical-trials/disease/neuroblastoma/treatment


**This site not only explains a bit about clinical trials, but there is a link at the bottom that brings you to a long list of places conducting clinical trials that you can search from.

“Beat Childhood Cancer” - https://research.beatcc.org/
- “Our Clinical Trials” - https://research.beatcc.org/clinical-trials/

“CenterWatch – Neuroblastoma Clinical Trials” - https://www.centerwatch.com/clinical-trials/listings/condition/342/neuroblastoma/

**You can also go to some of the larger hospitals’ websites and view the various clinical trials that they are doing for neuroblastoma. For example:

“Memorial Sloan Kettering Cancer Center – Neuroblastoma Clinical Trials & Research” -
https://www.mskcc.org/pediatrics/cancer-care/types/neuroblastoma/clinical-trials

If you are overwhelmed with the search for a clinical trial, look into the service below from Alex’s Lemonade Stand:

Alex’s Lemonade Stand - Clinical Trial Navigator - “We will conduct relevant searches to provide a list of pediatric oncology clinical trial options within the United States for families and their care team to consider. Along the way, we are here to answer questions and identify resources to help make the process of choosing and enrolling in a clinical trial as smooth as possible.”
https://www.alexslemonade.org/childhood-cancer/for-families/clinical-trials
What to Do Before It’s Too Late

We are incredibly sorry you are here looking for support in this manner. Cherishing the last moments on earth with your beloved child is not anything anyone should ever need support in. Below are a few tips that we have gathered from other families that have been through this experience:

- Get professional family photos done as soon as possible! Ask the hospital if they have assistance programs for these special patients, or if there are organizations that offer these services in your area.
- Take lots of photos! Make sure people are taking photos of YOU with your loved one, as well.
- Photograph the little details of your child’s body – the hands, eyes, toes, etc.
- Start recording their everyday, daily life - You will miss those minor, mundane days at home.
- Have them say phrases that you would like to hear again and again when they are gone. Ex: “I love you mommy and daddy!” “You are my favorite person.” “You’re the best mommy!” “Thank you for everything you have done for me!” “Thank you for taking good care of me, mommy.” etc.
- Sing their favorite songs with them and capture the video, too!
- You can take them to Build-A-Bear and have them record a phrase and put it inside the bear. You could also put other keepsakes in there as well, maybe a hospital band, a lock of hair, their favorite blanket, etc.
- Record audio clips of a phrase that can later be turned into a visual tattoo at www.hitbywaves.com
- Take handprints and footprints, which are great to save and maybe turn into tattoos later. Also, check out Etsy because there are places where they can turn your child’s prints into beautiful art or jewelry.
- Ask them all the questions you would ever want to know - What did they want to be when they grew up? What’s their favorite memory, in general? What is their favorite memory with YOU?
- Record your child talking about himself/herself.
- Talk and read to them constantly. Although they may not be fully conscious, they can still hear the sounds of loved ones around them for a peaceful transition.
- You can get matching necklaces and have one to keep and wear, while the other is buried or cremated with your child.
- Ask your hospital if Art Therapy would be able to provide hand molds of your child.
- Create family handprints on a canvas in a heart shape.
- Have extra help at the hospital or at home to answer phone calls, door, deliveries, food, etc. so you never have to leave your child’s side. If no one is available, consider leaving a box outside where people can leave goods and food for you so you can enjoy your peace and privacy.
- If they are old enough, get their signature or have them draw a family picture of your family
- Also, if they are old enough and want to do so, ask what they want their special day to look like. What kind of celebration of life would they like?
- Ask the child what they want to do every day? Ice cream for breakfast maybe, or a day at the beach? Do everything knowing that you did everything you could to make them happy in their final days.
Resources on Caring for Terminally Ill Children

From “Stanford Children’s Health – Lucile Packard Children’s Hospital”

- “Caring for the Terminally Ill Child” -
  https://www.stanfordchildrens.org/en/topic/category?id=31140
  INCLUDES:
  - A Child's Concept of Death
  - Discussing Death with Children
  - Anticipatory Grief
  - The Dying Process
  - Grief and Bereavement
  - Physical Needs of the Dying Child
  - Psychosocial Needs of the Dying Child
  - For Parents: Important Decisions to Be Made in the Dying Process
  - Palliative Care
  - Hospice

- “Care of the Terminally Ill Child” -
  https://www.stanfordchildrens.org/en/topic/category?id=33169
  INCLUDES:
  - Anticipatory Grief
  - A Child's Concept of Death
  - For Parents: Important Decisions to Be Made in the Dying Process
  - Discussing Death with Children
  - Grief and Bereavement
  - Hospice
  - Home Page - Care of the Terminally Ill Child
  - Physical Needs of the Dying Child
  - Palliative Care
  - The Dying Process
  - Psychosocial Needs of the Dying Child
  - Topic Index - Care of the Terminally Ill Child

Caring for a Terminally Ill Child (CancerCare) - https://www.cancer.net/navigating-cancer-care/advanced-cancer/caring-terminally-ill-child
Bereavement and Burial Support and Resources

Readings

“Planning a Funeral or Memorial Service” - https://together.stjude.org/en-us/for-families/bereavement/planning-a-funeral.html


This article addresses burial costs, in general, but discusses state and federal programs, nonprofit organizations, etc., and there is a section about children.

General Financial Support and Assistance

Fairy Godmother - https://www.fairygodmotherproject.org/our-programs/#our_services

Fighting All Monsters - https://joinourfam.com/forever
“Bereavement of a child can be emotionally and financially overwhelming. The FAM Forever Program aims to provide a family with the emotional and therapeutic support, as well as the financial costs, including burial and unexpected expenses.”

Final Farewell – http://www.finalfarewell.org/
“Final Farewell provides financial assistance, advice and guidance to grieving families from all religions and backgrounds so they may provide an affordable and decent funeral for their loved child.”

Hess Cancer Foundation - http://hesscancer.org/
One of their missions is “to provide financial assistance to those families who have lost a young child to cancer and aren’t financially prepared to address funeral and burial costs.”

Raise for Rowyn - https://www.raiseforrowyn.org/
Mission – “To provide financial assistance and emotional support to families struggling with the loss of a child.”

Sarah’s Fight for Hope Foundation - https://www.sarahsfightforhope.org/
Funeral Assistance - Every parent’s worst nightmare. This is an unplanned expense which we understand too well. We compassionately assist bereaved parents with the financial expense they face in making final arrangements.

The TEARS Foundation - https://thetearsfoundation.org/
“The TEARS Foundation seeks to compassionately lift a financial burden from families who have lost a child by providing funds to assist with the cost of burial or cremation services. We also offer parents comprehensive bereavement care in the form of grief support groups and peer companions.

**Memorial Gowns**

Angel Wings Memorial Gowns - https://www.angelwingsmemorygowns.org/

**Memorial Boxes, Caskets**

The Audrey and McKenna Foundation - https://audreyandmckenna.org/ OR https://www.facebook.com/AudreyAndMcKenna/

**Donated Burial Plots**


**Bereavement Retreats**

Sarah’s Fight for Hope Foundation - https://www.sarahsfightforhope.org/
Bereavement Retreat - Grieving mothers should be able to grieve openly and honestly with their peers because while grieving for a lost child never ends, knowing that you are not alone, knowing that you can talk about your child's fight and strength can make living a little bit easier.

**Grief Support**

The Centering Corporation
7230 Maple Street
Omaha, NE 68134
(402) 553-1200
https://centering.org/shop-all/for-bereaved-parents/
Email: Danni@centeringcorp.com
Publishes a free catalog which contains an extensive listing of books, cards, and audio and videotapes on death and grieving.

Children’s Hospice International
2202 Mt. Vernon Avenue, Suite 3c
Alexandria, VA 22301
(703) 684-0330
(800) 24-CHILD
https://www.chionline.org/

“Children’s Hospice International (CHI) is a non-profit organization established in 1983 that has pioneered and promoted the idea that critically ill children should have access to hospice/palliative care along with curative care from the time their life-threatening illness has been diagnosed.”
A self-help organization that offers understanding and friendship to bereaved families through support meetings at local chapters and telephone support (they match persons with similar losses). It publishes a newsletter for parents and one for siblings, and offers a Resource Catalog with a comprehensive list of books, audio, and video materials on adult and sibling grief.

**Grief Support Organizations**

**Bo’s Place (Houston)**
Bo’s Place offers support and community through grief support services for adults, children, and families, and they also provide education and resources for those assisting people with grief. There are multiple grief support groups (contact them for schedules and locations), an Information and Referral Line (713-942-8339), and a Resource Library (https://www.bosplace.org/en/resource-library/).
https://www.bosplace.org/en/

**Compassionate Friends**
Supporting Family after a Child Dies
https://www.compassionatefriends.org/
They also have a comprehensive list of book recommendations including the books we looked at in the library - https://www.compassionatefriends.org/books/

**Dougy Center (Portland, OR)**
The mission of The Dougy Center is to provide support in a safe place where children, teens, young adults and their families grieving a death can share their experiences. The site has lots of great info for grieving kids, teens, young adults, & adults. It also includes activities and how to help those grieving, as well as a search tool for grief support programs throughout the country.
https://www.dougy.org/

**HAND - Helping After Neonatal Death (Los Gatos)**
Resources for parents, friends, and family
http://handonline.org/

**Kara (Palo Alto)**
Individual and peer support for children and teens, families, and adults. Lots of great resources including an overnight bereavement camp for kids 6-18. They serve individuals who are grieving a death as well as those managing a terminal illness (their own or another's).
https://kara-grief.org/

**Live Like Bella (Coral Gables, Florida)**
“No child or family should have to suffer alone. Live Like Bella® provides services from in-treatment support to memorial assistance. If you or a family you know needs assistance, apply today.”
https://livelikebella.org/

National Alliance for Grieving Children
“The National Alliance for Grieving Children (NAGC) is a nonprofit organization that raises awareness about the needs of children and teens who are grieving a death and provides education and resources for anyone who supports them. Through the collective voice of our members and partners we educate, advocate and raise awareness about childhood bereavement. The NAGC is a nationwide network of professionals, institutions and volunteers who promote best practices, educational programming and critical resources to facilitate the mental, emotional and physical health of grieving children and their families.”
https://childrengrieve.org/

Project Joy and Hope (Pasadena, TX)
Project Joy and Hope “strives to prevent and relieve suffering for children with life-limiting conditions and their families…” They have a program called H.O.P.E. (Helping Our Pain Ease), which is a 7-week parental bereavement class. They also have a training program for teachers to help grieving students called “Classroom Bereavement Management.” For information on these programs, call Project Joy and Hope at: 713-944-6569 or at the toll-free number 1-866-JOYHOPE. Or, you can email them at info@joyandhope.org
https://joyandhope.org/families/access-programs/

The Shared Grief Project
Shares the stories of individuals who have experienced a major loss at an early age and have gone on to live healthy, happy and successful lives.
http://sharedgrief.org/

Readings about Grieving the Loss of a Child


*Please Note: Financial advice in this chapter may or may not be relevant to everyone. Please note that we are not responsible for any actions taken as a result of reading this document.*

**Government Assistance, Insurance, Billing, and FSA and HSA**

**Getting Started**

- Create a budget for spending expectations. Now, more than ever, is the time to watch every penny to ensure your little one gets all of the treatment that they need.
- Keep a binder of all the medical bills coming in, and track which ones have been paid. Double-check what insurance was able to cover, and make sure insurance follows your deductible and maximum out-of-pocket spending for the year. You can also use a Google Doc to track all of the spending, or to create your own budget.
- Learn about how cancer impacts your finances from Triage Cancer: [https://cancerfinances.org/toolkit/#1](https://cancerfinances.org/toolkit/#1)
- An overview of the different types of health insurance plans and some general information about them, is available from the American Cancer Society: [https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/types-of-health-insurance-plans.html](https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/types-of-health-insurance-plans.html)

**Government Assistance**

- Ask your social worker if your income qualifies for Medicaid. If not, ask if you qualify for a waiver.
  Your state may have an Aged and Disabled Waiver. This will aid in:
  - Secondary insurance to avoid co-pays
  - Government-funded nursing or childcare. Parents can qualify as a paid caregiver for their child when he or she is not daycare-eligible.
  - Other services and support provided, as needed.
- Check and double-check your eligibility for state services. Ask your social worker for advocacy agencies that help you navigate the Medicaid, disability, social security, and waiver application process. [https://www.acco.org/social-security-disability/](https://www.acco.org/social-security-disability/)
- Medicaid agencies don’t often pay for services across state lines. Treatment must be medically necessary, and not available within the state.

**Additional Readings about Health Insurance, Medicare, Medicaid, Children’s Health Insurance Program (CHIP)**
"14 Secrets Every Health Insurance Company Knows (And You Should, Too!)": https://www.prevention.com/health/health-insurance-secrets

"18 Secrets Your Health Insurance Company is Keeping from You": https://www.rd.com/health/healthcare/health-insurance-secrets/

American Cancer Society:
- "If Your Health Insurance Claim is Denied" - https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/managing-your-health-insurance/if-your-health-insurance-claim-is-denied.html


Working with Your Insurance Company

- Call your insurance and enroll in their case management program to oversee all your medical needs.
- Get a copy of your insurance policy. Know what providers are in-network, and what services are covered.
- Learn what your co-pays and what your annual out-of-pocket maximum is. Record the date which you achieved your maximum out-of-pocket for the year. If bills come in with service dates AFTER the day you achieved your maximum out-of-pocket, double-check to make sure that your insurance processed it correctly. Do not pay it until you have completed further research on the bill.
- Don’t pay any bill until you have the final Explanation of Benefits (EOB) form from your insurance company. (If you’re covered under 2 plans, wait until you have an EOB from both of them.) If there is a difference between your bill and the Explanation of Benefits, call the department that sent the bill. Be persistent about this!
- Medications should fall into your maximum out-of-pocket, so do not pay for medicines after you have reached this amount.
- Know that some treatments and therapies cause long term dental damage. Dental care for cancer patients needs to be billed under medical insurance, and NOT traditional dental insurance. Most medical insurances have a clause that states they will pay for damages that gets the mouth back to a pre-diagnosis state.
**Billing**

- Just because an office accepts your insurance, DOES NOT mean they are in network. Be sure to ask the right question… “Are you in-network for my insurance?”
- Medical bills DO NOT accrue interest. Keep this in mind when paying off debt.
- Check with your hospital to see if they have any programs that might waive some of your debt. Some medical facilities also have special grants or scholarships that pay for medical debt, as well. This may require filling out additional forms, but it can be worth it to save on your bill!
- A few hospitals and other medical facilities get money from the federal government, so they can offer free or low-cost services to those who are unable to pay. This is called the Hill-Burton Program. Find what hospitals qualify here - [https://www.hrsa.gov/get-health-care/affordable/hill-burton/index.html](https://www.hrsa.gov/get-health-care/affordable/hill-burton/index.html)
- If the medical debt is substantial, it is possible that the medical facility might accept a settlement that is smaller than the amount owed if the bill is paid in full in cash. It is worth negotiating!
- Ask the doctor or facility if they can give you the same discounts that they give Medicare or even some major health insurance companies, so that you are able to pay the bill.
- In general, never pay a bill without double-checking for accuracy. Sometimes, bills are wrongly charged for being out-of-network, not a covered benefit, or for some other reason.
- Although the bill asks for payment in full, the hospital is often willing to work with you by setting up a payment plan. As long as your account remains active, the bill will not be sent to collections. Sometimes, this payment could be as little as $50 a month!
- Pay attention to notices that say the bill will soon be turned over to a collection agency. Most people want to avoid this if at all possible because it affects their credit rating and some agencies can be very aggressive in their efforts to collect.

**Preparing for the Future**

- When shopping for health insurance, reference this document to ensure that it will provide coverage for everything a cancer family needs: [http://www.cancerinsurancechecklist.org/site/wp-content/uploads/2015/10/cancer_coverage_checklist_tabloid_dk-changes-03.pdf](http://www.cancerinsurancechecklist.org/site/wp-content/uploads/2015/10/cancer_coverage_checklist_tabloid_dk-changes-03.pdf)
- Sign up for Health Savings Accounts and/or Flexible Spending Accounts during open enrollment periods. Predict what appointments will take place for the following year to decide how much money to store in these accounts, as they are “use it or lose it” at the end of the year. HSAs are tax-free money.
- For medicine cost comparison and coupons: [https://m.goodrx.com](https://m.goodrx.com)
- “Patient Advocate Foundation – [https://www.patientadvocate.org](https://www.patientadvocate.org)

  - Co-Pay Relief Program: “The PAF Co-Pay Relief Program, one of the self-contained divisions of PAF, provides direct financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments they need. This assistance helps patients afford the out-of-pocket costs for these items that their insurance companies require.”

  Call Co-Pay Relief directly at 1-866-512-3861

**FSA/HSA**

These accounts are wonderful for many families because they allow employees to directly withdraw money from their paycheck and allocate it into a savings account for qualifying daycare and medical expenses. Check with your human resources department to see what might be a good fit for your family.
It is important to note that you will need to adjust these deductions based on your child’s insurance coverage and care. For example, if your child cannot attend daycare during treatment, you may want to lower your deductions to zero for the remainder of the year. Also, if you newly qualify for Medicaid, then you may want to decrease your medical deductions as your financial liability lowers.

Here are a few additional readings about the definitions and differences between an FSA and an HSA, and some ideas on how to make a choice between the two:


“HSA vs. FSA: Differences and How to Choose” - https://www.nerdwallet.com/blog/health/employer-offers-hsa-fsa-whats-difference/

Feeding and Nutritional Supplements

- When inpatient, the maximum amount of food that can come on a meal tray is definitely more than you would expect! Save any extra, available food for your child, yourself, and family members to help defray some food costs.
- Some hospitals offer up to 4 drinks, in addition to their meal tray. Some hospitals allow Ensure shakes or juices as choices for these drinks. Use this to your advantage and stock up on those expensive drinks to bring home with you!

Taxes for Parents of Children with Special Needs


Special school instruction can include lodging, meals, transportation and other expenses. A tax deduction requires the school to focus on adaptive education for people with neurological or physical limitations.

There may also be some home modifications required by your child’s condition. For example, air conditioning construction costs might be deductible if required for respiratory illness. Accessibility remodeling is normally deductible, too. Some kinds of modifications may be only partially deductible if they also increase the value of your home.
Travel and registration costs for conferences and seminars: If your child’s doctor will write a letter explaining how the conference will help you and your child deal with his special needs, the costs may be deductible as a medical expense.

Attendant care at work: If your child has a job that requires attendant care, the portion of those costs not covered by other programs may be deductible. Of course, if your child has a job that may mean that the deduction is on his return, not on yours, depending on how much support he/she can provide with his/her own earnings.

**Social Security – SSDI and SSI**

**Social Security Administration** - [https://www.ssa.gov/](https://www.ssa.gov/), 800-772-1213

Pays retirement, disability, and survivors benefits to workers and their families and administers the Supplemental Security Income program.

- **Social Security – Disability Benefits** - [https://www.ssa.gov/benefits/disability/](https://www.ssa.gov/benefits/disability/)
- **Supplementary Security Income** - [http://www.disability-benefits-help.org/content/about-ssi](http://www.disability-benefits-help.org/content/about-ssi)


**Organizations Offering Financial Assistance and Resources**

Please visit the **Hope Portal** for many additional organizations that offer financial resources to childhood cancer families – [www.hope-portal.org](http://www.hope-portal.org) (See further details on this wonderful program at the beginning of the “Resources, Support” chapter.)

12 Oaks Activities Assistance (Now Partnered with Cal’s Angels) - [https://www.calsangels.org/12oaks/](https://www.calsangels.org/12oaks/)
12 Oaks Foundation provides grants for children ages 8-18 to help defray costs related to sports and extra-curricular activities while the family is dealing with the financial hardships of cancer treatment.

211 - [http://www.211.org/](http://www.211.org/)

**ACCO and Candlelighters** – [https://www.acco.org/local-groups/](https://www.acco.org/local-groups/) (look up locations by state)
“American Childhood Cancer Organization and Candlelighters groups can be found across the country. These groups operate under ACCO or independently, and while we strive to provide up-to-date contact information, we cannot guarantee that any contact information on this page is the most current.”


**American Financial Solutions** - [https://www.myfinancialgoals.org/](https://www.myfinancialgoals.org/)
Nonprofit credit counseling agency that offers free debt management and educational programs to help financially distressed families.

The Assistance Fund - https://tafcares.org/

B+ Foundation - https://bepositive.org/
The B+ Foundation is committed to helping families of critically ill children with financial assistance so they can focus on helping their child get well.

Cancer Care: Financial and Co-Pay Assistance - https://www.cancercare.org/financial_assistance

Cancer Financial Assistance Coalition - https://www.cancerfac.org/


Catholic Charities USA - https://www.catholiccharitiesusa.org/

Consumer Credit Counseling Foundation - http://www.cccfusa.org/contact.html

A national, nonprofit consumer credit counseling agency that provides 24-hour toll-free telephone credit counseling. Provides help with budgets, payments, and debt collection.

Dragonfly - https://dragonfly.org/

Fairy Godmother Project - http://www.fairygodmotherproject.org

Go 4 The Goal - https://www.go4thegoal.org/family-support

Good Days - https://www.mygooddays.org/

Kelly Anne Dolan Memorial Fund - https://dolanfund.org/
This organization is dedicated to the non-medical uninsured needs of families caring for terminally, critically and chronically ill dependent children through advocacy, financial assistance, education, and informational resources. Because of limited funds they are only accepting applications from social workers in the mid-Atlantic region. However, there is good information on this site and information on how to obtain a video called, “Financial Management During Crisis.”


Lifeline - https://www.lifelinesupport.org/

Medication Assistance Programs Grid for Patients (PDF File) - https://www.cancer.net/sites/cancer.net/files/assistance_programs_grid_november_2016.pdf
Medicine Assistance Tool - https://medicineassistancetool.org/

Financial assistance programs include: meals during treatment, transportation to and from treatment, long-distance telephone cards, lodging during treatment, health-insurance premiums, and medical expenses not covered by insurance.

National Transplant Assistance Fund - https://helphopelive.org/
Provides experts to help with fundraising for uninsured expenses related to BMT’s.

National Foundation for Transplants - https://transplants.org/ (including bone marrow and stem cell transplants)

Needy Meds - https://www.needymeds.org/
- Diagnosis-Based Assistance Programs for Childhood Cancer - https://www.needymeds.org/copay_diseases.taf?_function=summary&disease_eng=Childhood%20Cancer


Patient Advocate Foundation - https://www.patientadvocate.org/
A non-profit organization that is a liaison between patient and insurers, employers and creditors to resolve insurance, job discrimination or debt crises.

Patient Services, Incorporated - https://www.patientservicesinc.org/

Ped-Onc Resource Center - http://www.ped-onc.org/
This site lists organizations that may help with aspects of financial and insurance problems, airline assistance, assistance with drugs, and governmental assistance programs.

Ronald McDonald Houses - https://www.rmhc.org/
Ronald McDonald Houses provide free lodging for families of children being treated at many hospitals. This site tells a little about the history of RMD houses, a search database to find a local house, and how one can support the cause.


Rx Hope - https://www.rxhope.com/

Sparrow Foundation - https://www.sparrowfoundation.org/

Triage Cancer - https://triagecancer.org/

Grants for Higher Income Families

United Healthcare Children’s Foundation - https://www.uhccf.org/

HealthWell Foundation - https://www.healthwellfoundation.org/patients/apply/

Cancer Response Team - https://www.cancerresponseteam.org/request-service.html
RESOURCES, SUPPORT

**The Hope Portal is the best resource that we repeatedly recommend, and that you can also access via our NCCS website or visit at:** [www.hope-portal.org](http://www.hope-portal.org)! It is run by the Coalition Against Childhood Cancer (CAC2), “a membership organization (around 100 childhood cancer organizations and more than 50 individuals who care greatly about childhood cancer). We are organized around three basic pillars of interest that our members share: Research and Treatment, Family Support and Survivorship, and Awareness and Advocacy, and we work to share information with and among our members to and provide numerous opportunities for education within each pillar. We also promote coordinated action and broad based-collaboration.” The Neuroblastoma Children’s Cancer Society (NCCS) is a proud and active member of the Coalition Against Childhood Cancer!

“The Hope Portal, [www.hope-portal.org](http://www.hope-portal.org), is a searchable database that allows childhood cancer families and healthcare professionals across the country to find support faster with less effort and in a more personalized way than ever. Users can search the Hope Portal by specifying diagnosis, geographic location, and type of assistance needed. Whether families are looking for financial support, comfort items, camps opportunities, or just someone to talk to, the Hope Portal is one-stop to help meet families’ needs.”
Neuroblastoma-Specific Resources

Neuroblastoma Children's Cancer Society

Toll Free: 800-532-5162

http://www.neuroblastomacancer.org

Pediatric Brain Tumor Foundation

828-665-6891

800-253-6530

http://www.pbtfs.org

Caregiver Resources and Organizations

10 Ways to Help a Friend with Cancer - https://www.aosw.org/AOSW/media/Main-Site-Files/People%20Affected%20by%20Cancer/Documents/10WaysHelpAFriend.pdf

Caring for the Caregiver: It's a Marathon ... Not a Sprint – https://www.aosw.org/AOSW/media/Main-Site-Files/Members/Documents/CaringForTheCaregiver-Slide-Deck.pdf


The Caregiver’s Companion Program is a free program for caregivers of blood & marrow transplant patients that combines a useful toolkit with the personalized, confidential support of a caregiver coach who understands transplant and the caregiver role. When you enroll in the program, you will receive a toolkit and be paired with a trained Be The Match® coach who will work with your schedule to find a time (about once a week) that’s best for you to talk by telephone.

Caregiver Action Network - https://caregiveraction.org/, 800-896-3650

Educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

Cocktails and Chemo - https://cocktailsandchemo.org/

“...the foundation is on a mission to care for the often forgotten caregivers. It's a lonely, thankless job and helping caregivers feel supported and find others who "get it" is at the center of everything at The Cocktails & Chemo Foundation. Through care cards, social support groups and grants, Cocktails & Chemo is reaching out to caregivers, creating a soft place for them to land on the hard days.”
Lotsa Helping Hands - https://lotsahelpinghands.com/
Powers free online caring communities that provide tools to organize daily life during times of medical crisis or caregiver exhaustion. We host more than 60,000 Private Communities that are hard at work supporting caregivers across the U.S., and we've recently launched an Open Community model to connect caregivers, individuals, and families who need help with those who want to lend a helping hand.

National Alliance for Caregiving - https://www.caregiving.org/
Is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.

This is a practical guide intended to help family caregivers feel less alone and overwhelmed. It offers resources, facts, and advice about caring for a loved one, as well as the caregiver. This resource guide can be downloaded.

Momcology - https://momcology.org/
“Our mission is simple: To help empower and heal pediatric cancer families through the resource of peer support. We believe that community is much more than belonging to something, but about doing something together that makes belonging matter. Momcology remains committed to continuing to identify gaps in the pediatric cancer caregiver paradigm, and creating intuitive, responsible and impactful solutions to better serve our community with the most accessible resources available. We identify needs, and innovate new solutions through thoughtful peer-based programs and meaningful collaborations with other mission-based pediatric oncology organizations and hospital psychosocial teams. We believe connection provides the opportunity to transform pain into purpose.”


Triage Cancer - Caregiver - https://triagecancer.org/cancer-caregiving


Additional Resources


ACL's independent living programs work to support community living and independence for people with disabilities across the nation based on the belief that all people can live with dignity, make their
own choices, and participate fully in society. These programs provide tools, resources, and support for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect.

“Nancy Keene Informational Resources” - https://www.alexslemonade.org/childhood-cancer/guides
ALSF's Childhood Cancer Guides are reviewed by renowned experts in pediatric oncology and feature stories from more than 500 parents, children with cancer, and survivors of childhood cancer. Our hope is to help those following in our footsteps. These books feature:
- Clear explanations of the various types of childhood cancer
- Descriptions of state-of-the-art treatments for childhood cancers
- Emotional support for every member of the family
- Access to helpful resources
- And more!


Ped-One Resource Center - http://www.ped-onc.org/
This site lists organizations that may help with aspects of financial and insurance problems, airline assistance, assistance with drugs, and governmental assistance programs.
- “Airline Flights” - http://ped-onc.org/resources/airlineflights.html
  These organizations provide airline flights for patients that need to travel for medical reasons.
- “Cancer Kid Camps” - http://ped-onc.org/cfissues/camps.html
  “There are a multitude of local childhood cancer groups that provide support for families of childhood cancer in their area. My list (below) includes a few of the larger, national organizations as well as some that are not in the United States. The goals of these groups include support for families, advocacy for children with cancer, building childhood cancer awareness, and finding cures for childhood cancers.”
**Please Note: This page has not been modified since January 2018.
  “Important support organizations (non-profits) for childhood cancer are listed below; the comprehensive organizations are listed first, followed by ones for specific cancers or type of support.”
- “Compassionate Use of Drugs” - http://ped-onc.org/resources/compassionateuse.html
  Sites for compassionate use, compassionate access, or expanded access protocols.
- “Hats and Wigs” - http://www.ped-onc.org/resources/hatswigs.html
- “Make A Wish Organizations and List of Wish Organizations” - http://www.ped-onc.org/cfissues/maw.html
  ACOR listservs – email support lists – were very active in the 1990s through about 2005. In 2018, there are so many social media sites that email-based groups are not as popular. But several of the ACOr listservs are still very active, and if you join and need support, members will post with help.
- “Support and Advocacy Organizations” - http://www.ped-onc.org/resources/supportorg.html
  Includes: Email Lists, Social Media, Smart Patients, Face-to-Face Groups, Support for Teens and Young Adults, Do’s and Don’ts
- “Websites/Links to Internet Resources on Childhood Cancer” - http://www.ped-onc.org/choicelinks.html
  This page lists the best (IMHO) sites for childhood cancer and for cancer in general. I call it the "Ped-Onc Editor's Choice Links Page".


**General Cancer Organizations**

This list offers organizations that offer support and services for people with any type of cancer. To view groups classified by specific disease type, view Cancer.Net’s Cancer-Specific Resources list (https://www.cancer.net/coping-with-cancer/finding-support-and-information/cancer-specific-resources). Below is a list of general cancer resources and organizations that may be helpful in finding additional information, services, and support. This list is provided for informational purposes only. As always, be sure to talk with your health care team about any questions you may have about information you find.

**4th Angel Mentoring Program** - http://www.4thangel.org

866-520-3197

**Air Charity Network** - http://www.aircharitynetwork.org

877-621-7177

**American Association for Cancer Research (AACR)** - https://www.aacr.org/

215-440-9300, Toll Free: 866-423-3965

**American Cancer Society** - http://www.cancer.org

404-320-3333, Toll Free: 800-ACS-2345, TTY: 866-288-4327
Focuses on cancer research, education and advocacy: also provides patient and family services, which vary by locality. Signature patient programs offered nationwide include: teaching women undergoing cancer treatment how to use make-up to camouflage appearance-related side effects; a peer support program that connects breast cancer survivors with women who are newly diagnosed with the disease; and a peer support and educational program for men dealing with prostate cancer.

**American Childhood Cancer Organization** - [https://www.acco.org/](https://www.acco.org/)

**855-858-2226**

The American Childhood Cancer Organization (ACCO) was founded in 1970 by parents of children and adolescents diagnosed with cancer. Formerly known as Candlelighters, ACCO is the nation’s oldest and largest grassroots organization dedicated to childhood cancer. Did you know childhood cancer is the number one disease killer of children in the United States and the leading cause of death for children between the ages of 4 and 14? ACCO is determined to change these stats and make childhood cancer a national health priority by shaping policy, supporting research, raising awareness, and providing educational resources and programs to kids with cancer, survivors, and their families.

- ACCO Free Family Resource Form – Includes kits, journals, books for a variety of ages, DVD, Cozy the Port-a-Cat, coloring book, Headbands of Hope, etc. (for patients, parents, siblings, teachers) - [https://www.tfaforms.com/4699752](https://www.tfaforms.com/4699752)

**American Society for Radiation Oncology** - [https://www.astro.org/Patient-Care.aspx](https://www.astro.org/Patient-Care.aspx)

**703-502-1550 or 1-800-962-7876**

**American Society of Breast Surgeons** - [https://www.breastsurgeons.org/](https://www.breastsurgeons.org/)

**410-992-5470, 1-877-992-5470**

**Anderson Network, A Program of Volunteer Services** - http://www.mdanderson.org/andersonnetwork

**844-348-1352**

**Arab Community Center for Economic and Social Services (ACCESS)** - [https://www.accesscommunity.org/](https://www.accesscommunity.org/)

**313-842-7010**

**Association of Community Cancer Centers (ACCC)** - [https://www.accc-cancer.org/](https://www.accc-cancer.org/)

**301-984-9496**
**CancerCare** - https://www.cancercare.org/

800-813-HOPE

National nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved. Programs - including counseling, education, financial assistance and practical help - are provided by trained oncology social workers and are completely free of charge.

**Cancer in the Family Relief Fund** - http://www.cancerfamilyrelieffund.org

**Cancer Financial Assistance Coalition** - http://www.cancerfac.org

**Cancer Hope Network** - https://www.cancerhopenetwork.org/

877-HOPENET, 908-879-6518

**Cancer Care: Counseling** - https://www.cancercare.org/counseling

Call us at 800-813-HOPE (4673) to speak with an oncology social worker or email info@cancercare.org

**Cancer Information and Support Network** – https://www.cisncancer.org/

**Cancer Legal Resource Center** - http://cancerlegalresources.org/

866-843-2572

**Cancer Research Foundation** - https://www.cancerresearchfdn.org/

312-630-0055

**Cancer Research Institute** - https://www.cancerresearch.org/

800-992-2623, 212-688-7515

**Cancer Support Community** - https://www.cancersupportcommunity.org/

202-659-9709, Toll Free: 888-793-WELL (9355)

CSC is a global network offering face to face and online emotional support, education and hope for anyone affected by cancer. Through professionally led support groups, educational workshops and mind/body programs we help people learn vital skills, regain control, reduce feelings of isolation and restore hope.

- Information on Hair Loss
“It’s difficult keeping a home clean under any circumstances, but when cancer hits a household, the burden can be overwhelming. That’s when Cleaning For A Reason steps in, partnering with more than 1,200 maid services to provide free home cleaning to cancer patients. Any woman, man, or child in active cancer treatment may apply for services. Due to demand, patients are eligible to receive just one round of services through our program. Please note that our cleaning companies volunteer their services and are not compensated in any way. When matched with a cleaning company, a patient receives a total of two free home cleanings, that is one general cleaning a month for up to two months. Please note that this is not a guaranteed service. We may not have a cleaning company in a patient’s area or if we do, the company may be at capacity with the number of patients that they are already helping.”
215-789-3600


800-323-4040 x7439

Corporate Angel Network, Inc. - http://www.corpangelnetwork.org

914-328-1313, 866-328-1313

Critical Mass: The Young Adult Cancer Alliance - https://www.criticalmass.org/

Dia de La Mujer Latina - http://www.diadelamujerlatina.org

281-489-1111

Education Network to Advance Cancer Clinical Trials (ENACCT) - https://www.facebook.com/Education-Network-to-Advance-Cancer-Clinical-Trials-117943836481/

240-482-4730

Family Reach - http://familyreach.org/

973-394-1411

FDA Cancer Liaison Program - http://www.fda.gov/ForConsumers/default.htm

1-888-INFOFDA

Federation of American Societies for Experimental Biology (FASEB) - http://www.faseb.org

301-634-7000

Fertile Action - http://www.fertileaction.org

877-276-5951


502-893-0643, 866-374-3634

HairToStay - http://www.hairtostay.org

800-270-1897
**Hospice Foundation of America** - [http://www.hospicefoundation.org](http://www.hospicefoundation.org)

800-854-3402

**I'm Too Young for This! Cancer Foundation** - [http://stupidcancer.org/](http://stupidcancer.org/)

1-877-735-4673

**Imerman Angels** - [http://www.imermanangels.org](http://www.imermanangels.org)

866-IMERMAN (463-7626)

Imerman Angels partners anyone seeking cancer support with someone just like you - a 'Mentor Angel.' A Mentor Angel is a cancer survivor or caregiver who is the same age, same gender, and most importantly, who has faced the same type of cancer. Imerman Angels is absolutely free and helps anyone touched by any type of cancer, at any cancer state level, at any age, living anywhere in the world. These one-on-one relationships give a cancer fighter or caregiver the chance to ask personal questions and get support from someone who has been there before. Mentor Angels can lend support and empathy and help cancer fighters and caregivers navigate the system, determine their options, and create their own support systems. Frequently, caregivers experience feelings similar to those of the person facing cancer. Mentor Angels can relate while being sensitive to the experience and situation.

**Intercultural Cancer Council (ICC)** - [http://iccnetwork.org](http://iccnetwork.org)

**International Association for Hospice and Palliative Care (IAHPC)** - [http://www.hospicecare.com](http://www.hospicecare.com)

936-321-9846, 866-374-2472, 346-571-5919

**International Psycho-Oncology Society** - [http://www.ipos-society.org](http://www.ipos-society.org)

416-968-0260

**Jack and Jill Late Stage Cancer Foundation** - [http://jajf.org/home/](http://jajf.org/home/)

404-537-5253

**LIVESTRONG Foundation** - [http://www.livestrong.org](http://www.livestrong.org)

512-236-8820 866-236-8820

The Livestrong Foundation helps survivors and their caregivers face the challenges and changes that come after cancer. We help you understand what to expect from the cancer experiences and help you know the right questions to ask, and we provide support along the way. Visit [www.LIVESTRONG.org/CancerSupport](http://www.LIVESTRONG.org/CancerSupport) for educational resources and one-on-one support.
**Locks of Love** - http://www.locksoflove.org

561-833-7332, 1-888-896-1588

**Look Good...Feel Better (LGFB)** - http://www.lookgoodfeelbetter.org

202-331-1770, 800-395-5665

**Lotsa Helping Hands** - http://lotsahelpinghands.com/

**Lymphatic Education & Research Network** - https://lymphaticnetwork.org

516-625-9675

**Malecare** - http://www.malecare.org

212-673-4920

**Mautner Project** - http://www.mautnerproject.org


**MyLifeLine.org** - http://www.mylifeline.org

888-234-2468, ext. 0

**MyOncofertility.org** - http://www.myoncofertility.org

1-866-708-3378

**National Accreditation Program for Breast Centers** - http://www.napbc-breast.org

312-202-5185


877-986-9472

**National Association for Home Care & Hospice** - http://www.nahc.org

202-547-7424

TTY 888-232-6348, 800-292-4636


**301-435-3848, Toll Free: 800-4-CANCER, TTY: 800-332-8615**

Information specialists from the National Cancer Institute (NCI) can answer questions about cancer, help with quitting smoking, provide informational materials, and help using the NCI website. The NCI website provides comprehensive information on cancer prevention, diagnosis, treatment, statistics, research, clinical trials and news. Click here to view fact sheets addressing many different topics. Click here to view a specific fact sheet that outlines cancer-specific supportive organizations.

- [Resource information about Integrative, Complementary and Alternative Medicine (CAM) cancer treatments](https://www.aosw.org/AOSW/media/Main-Site-Files/People%20Affected%20by%20Cancer/Documents/CAMResources-(2).pdf)

**National Cancer Survivors Day Foundation** - [http://www.ncsdf.org](http://www.ncsdf.org)

**615-794-3006**


**301-519-3153, Toll Free: 888-644-6226**

**National Coalition for Cancer Survivorship** - [http://www.canceradvocacy.org](http://www.canceradvocacy.org)

**301-650-9127, Toll Free: 877-NCCS-YES (877-622-7937)**

**National Comprehensive Cancer Network** - [http://www.nccn.com](http://www.nccn.com)

**215-690-0300**

**National Family Caregivers Association** - [http://www.nfcacares.org](http://www.nfcacares.org)

**301-942-6430, Toll Free: 800-896-3650**

**National Hospice and Palliative Care Organization** - [http://www.nhpco.org](http://www.nhpco.org)

**800-646-6460**

**National LGBT Cancer Network** - [http://www.cancer-network.org](http://www.cancer-network.org)

**212-675-2633**

301-594-5983, Toll Free: 888-FIND-NLM (888-346-3656)

**National Lymphedema Network (NLN)** - [http://www.lymphnet.org](http://www.lymphnet.org)

510-809-1660, 800-541-3259

**National Organization for Rare Disorders (NORD)** - [http://www.rarediseases.org](http://www.rarediseases.org)

203-744-0100, 800-999-6673

**Native American Cancer Research** - [http://natamcancer.org](http://natamcancer.org)

303-838-9359

**Nikolas Ritschel Foundation** - [http://www.nikolasritschelfoundation.org/](http://www.nikolasritschelfoundation.org/)

**Nueva Vida, Inc.** - [http://www.nueva-vida.org](http://www.nueva-vida.org)

202-223-9100, 1-866-986-8432

**Nurse Oncology Education Program (NOEP)** - [http://www.texasnurses.org/?NOEP](http://www.texasnurses.org/?NOEP)

800-862-2022, 512-452-0645


301-402-2964

**Office of Minority Health** - [http://minorityhealth.hhs.gov](http://minorityhealth.hhs.gov)

800-444-6472

**Oley Foundation** - [http://www.oley.org](http://www.oley.org)

518-262-5079

**OncoLink** - [http://www.oncolink.org](http://www.oncolink.org)

215-349-8895

**Oncology Nursing Society (ONS)** - [http://www.ons.org](http://www.ons.org)

412-859-6100, Toll Free: 866-257-4ONS (4667)

**Partnership for Prescription Assistance** - [http://www.pparx.org](http://www.pparx.org)
888-4PPA-NOW (477-2669)

**Patient Advocate Foundation** - [http://www.patientadvocate.org](http://www.patientadvocate.org)
757-873-6668, Toll Free: 800-532-5274

**Patient AirLift Services (PALS)** - [http://www.palservices.org](http://www.palservices.org)
888-818-1231

**Patient Power** - [http://www.patientpower.info](http://www.patientpower.info)
206-232–1542 x7


**PearlPoint Cancer Support** - [https://pearlpoint.org/](https://pearlpoint.org/)
615-467-1936, 1-877-467-1936

**Prepare to Live** - [http://www.preparetolive.org](http://www.preparetolive.org)

**Prevent Cancer Foundation** - [http://www.preventcancer.org](http://www.preventcancer.org)
703-836-4412, Toll Free: 800-227-2732

**R.A. Bloch Cancer Foundation, Inc.** - [http://www.blochcancer.org](http://www.blochcancer.org)
816-854-5050, 1-800-433-0464

**Research Advocacy Network** - [http://www.researchadvocacy.org](http://www.researchadvocacy.org)
877-276-2187

**Sam Fund** - [http://www.thesamfund.org](http://www.thesamfund.org)
617-938–3484

**Self Chec** - [http://www.selfchec.org](http://www.selfchec.org)

**Society for Women's Health Research** - [http://www.womenshealthresearch.org](http://www.womenshealthresearch.org)
202-223-8224

**Society of Nuclear Medicine** - [http://www.discovermi.org](http://www.discovermi.org)
Stand By Me - http://standbymela.org/
(818) 664-4100

Stand Up 2 Cancer - http://www.standup2cancer.org

Stupid Cancer - https://stupidcancer.org/
Stupid Cancer offers a lifeline to the adolescent and young adult cancer community by connecting them to age-appropriate resources and peers who get it. Our mission is to empower adolescents and young adults affected by cancer by ending isolation and building community.

- Our resource guide below is designed to connect you with the other great organizations offering specific resources to the AYA Cancer community - https://stupidcancer.org/get-help/resources/

610-649-3034, 866-333-1213

Talk about Health - http://talkabouthealth.com
917-710-1927

Teen Cancer America - https://teencanceramerica.org
310-208-0400

Teens Living With Cancer - http://13thirty.org/welcome/
585-563-6221

The Comprehensive Cancer Center of Wake Forest University -
http://www.wakehealth.edu/Comprehensive-Cancer-Center/
Main: (336) 716-7971, Appointments: (336) 716-WAKE

The Pink Fund - https://www.pinkfund.org/
877-234-PINK (7465)

The Rapunzel Project - http://www.rapunzelproject.org
WhatNext is a free online cancer support network, developed with the participation of the American Cancer Society, that instantly connects people fighting cancer - based on their specific diagnosis - to peers and resources that can help. Cancer patients, caregivers, survivors and loved ones are asking questions and providing insight, as well as sharing their journeys and experiences as a way to help those who are newly diagnosed know what they might expect.

Additional Resources and Ideas
*Google to see if your state has discounted museum passes for Medicaid families… here’s Indiana! https://indywithkids.com/indiana-access-pass/

*Amazon Prime $5.99 a month for Medicaid Families - https://www.amazon.com/58f8026f-0658-47d0-9752-f6fa2c69b2e2/qualify
  - Instructions: https://www.amazon.com/gp/help/customer/display.html?nodeId=GXX57KYG7NVNVHXK

For Teens

American Childhood Cancer Organization (ACCO) – https://www.acco.org/for-teens/
This site includes free resources, support networks, and informational sites.

Journey/Story Telling of your Child’s Courage

Beads of Courage - http://www.beadsofcourage.org/

ACCO Hero Beads - https://www.acco.org/hero-beads/
Hospital Comforts

**Campout from Cancer** - [http://www.campoutfromcancer.com/](http://www.campoutfromcancer.com/)
“COFC is a 501c3 nonprofit organization that sends camping themed care packages for an indoor camping adventure to children who are fighting cancer.”

**Dec My Room** - [http://www.decmyroom.org/](http://www.decmyroom.org/)
“Our Vision is to enhance the lives of children who are being admitted into a hospital for a prolonged amount of time. Dec My Room Volunteers personalize the hospital room upon their arrival with items that complement the special likes and interests of the individual patient. These items are for them to enjoy during their stay and take home when they leave. Dec My Room is a unique and innovative charitable program. Our efforts help improve the attitudes of patients and their healing process. Dec My Room is funded by grants, charitable donations, and volunteers’ support.”

**Starlight** - [https://www.starlight.org/](https://www.starlight.org/)
“Innovative and inspiring programs like Starlight Virtual Reality, Starlight Hospital Wear, and Starlight Gaming bring the very best in gaming, play, and other fun experiences to our partner hospitals’ youngest patients. Regardless of the sophistication of the illness or injury, a sick kid is still a kid.”

**Connor’s Heroes** - [https://www.connorsheroes.org/family-support/](https://www.connorsheroes.org/family-support/)
“You start with a Connor’s Heroes Bag and Backpack filled with items that childhood cancer parents recommended for the hospital. Inside are gift cards, crafts, stuffed animals, and, best of all, an iPad Mini! To receive more support from Connor’s Heroes, you enroll online or complete the form in your Heroes Bag. Our Program Director will follow up on how we can best assist your family.”

**Birthday Parties**

**Icing Smiles** - [https://www.icingsmiles.org/](https://www.icingsmiles.org/)
“Icing Smiles is a nonprofit organization that provides custom celebration cakes and other treats to families impacted by the critical illness of a child. We understand that the simple things, like a birthday cake, are luxuries to a family battling illness. Our goal is to create a custom cake for the ill child, or their sibling, that provides a temporary escape from worry and creates a positive memory during a difficult time.”

**The Confetti Foundation** - [https://www.confettifoundation.org/request-a-birthday-box](https://www.confettifoundation.org/request-a-birthday-box)
“The Mission of the Confetti Foundation is to supply birthday parties to children who have to spend their birthday in a hospital, pediatric oncology clinic, or hospice facility.”

**Tomorrow Children’s Fund** - [https://www.tcfkid.org/](https://www.tcfkid.org/)
“The Tomorrows Children’s Fund was founded by a group of committed parents to help their children and others like them with cancer and serious blood disorders. With the help of friends like you, today, TCF provides a warm, healthy and loving environment for children in treatment and a full scope of services to relieve families’ emotional and financial stress. In addition to our direct financial aid programs, TCF also offers an array of activities, events, outings, special guests and parties, designed to
provide our young patients with a brighter tomorrow. All of which confirms our belief that through hope, hard work and heartfelt generosity, extraordinary things are possible.”

**The Birthday Box** - [https://www.thebirthdaybox.org/who-we-are/](https://www.thebirthdaybox.org/who-we-are/)

“The Birthday Box is a non-profit organization that provides children in need with an opportunity to blow out candles and make a birthday wish on his or her special day. An entire birthday celebration is assembled, packaged & then delivered in a recycled box. This party in a box, includes a birthday cake, candles, party plates, a birthday present and party decorations.”

**Toys and Entertainment**

**Gold Rush Cure** - [https://goldrushcure.org/pot-of-gold/](https://goldrushcure.org/pot-of-gold/)

“Gold Rush Cure works directly with the social worker and child life teams to reach kids fighting cancer at the right time in their journey. We are integrated in some of the best centers of excellence around the US, and make it easy to support kids fighting cancer.”

**Still Brave Childhood Cancer Foundation** - [https://www.stillbrave.org/renegade-backpacks/](https://www.stillbrave.org/renegade-backpacks/)

“One of our strongest projects started by our founder, Tattoo Tom, is our RENEGADE Backpack Program. Each pack provides the essentials needed to help a child feel comfortable during chemotherapy treatment. Items that may be included are a soft chenille blanket, warm hat, hand sanitizer, emesis bags, masks, stuffed animal, a journal and pen, Happily Hungry Cookbook, and many more wonderful items. The best part of the backpacks is searching through every zipper and pocket for something new. It’s kind of a Stillbrave treasure hunt! Our future goal is to have an iPAD in every backpack. We currently include an iPOD touch, but with your help, iPADs are right around the corner!”

**American Childhood Cancer Organization** - [https://www.acco.org/for-kids/](https://www.acco.org/for-kids/)

Resources Available: Books, Medical Play Kit, Comfort Kit, Cozy Cat Stuffed Animal, Cozy Care Journal, Paul and the Dragon DVD, Hero Beads

**Dragonfly** - [https://dragonfly.org/be-a-dragonfly/patients-caregivers/](https://dragonfly.org/be-a-dragonfly/patients-caregivers/)

“The fight for excellence in pediatric cancer treatment is important, but no less important is the commitment we must make to support the families that strive for fulfilling and complete lives during and after treatment. Though treatment may end, and illness may be cured or managed, the long-term effects of factors like internal group tension, familial isolation, post-traumatic stress, the anxiety of recurrence, and the emotional, physical and financial toll on the family unit often linger for years, yes years, to come. While the importance of quality healthcare is a common shared value, we must remember to offer families a holistic, uncompromising, fighting chance at well-being, which is our urgent, passionate mission.”

**Sadie Keller Foundation** - [https://sadiekellerfoundation.org/](https://sadiekellerfoundation.org/)

“Sadie knows far too well how difficult this journey is. Being sick means sacrificing a normal childhood for countless hospital stays, getting poked and prodded, and suffering through long days of chemotherapy. So, Sadie created Milestone Gifts to celebrate milestones in the treatment of other children and to encourage them to stay strong. Big milestones include the end of chemo, end of radiation, nearing remission, leaving the hospital after a long stay, or overcoming a very difficult
procedure. A big gift for a big milestone tells a child how proud we are of their fight against cancer. Sadie’s dream is to get a Milestone Gift into the hands of each child at some point during their treatment. Donations directly help this dream become a reality.”

Penpal Program

**Tyler Robinson Foundation** - [https://www.trf.org/trf-pen-pal-program/](https://www.trf.org/trf-pen-pal-program/)

Penpal Program – Collects letters, cards, drawings, and notes of encouragement from kids for kids that have pediatric cancer.

**Kisses for Kyle Foundation** - [https://kissesforkyle.org/pen-pals/](https://kissesforkyle.org/pen-pals/)

Collects letters and art work for a child facing cancer and their siblings to connect, build friendships and help them during a challenging time!

Family Photos

**Flashes of Hope** - [https://flashesofhope.org/chapters](https://flashesofhope.org/chapters)

“We honor the courage of children with cancer; capture a moment in time and fund research so they will have the chance to create a lifetime of memories.”

**Fairy Godmother Project: Photography Program** - [https://www.fairygodmotherproject.org/our-programs/#our_services](https://www.fairygodmotherproject.org/our-programs/#our_services) (scroll down the page to this section)

“Fairy Godmother Project’s Photography Program offers 2 complimentary portrait sessions to families dealing with pediatric cancer. Each session is donated by a volunteer professional photographer and can take place at an outdoor location, home, hospital, or studio (if available). Our goal is to capture the families’ moments, connections, and love for each other despite the stress and worry that comes with pediatric cancer.”


“The Gold Hope Project is a 501(c)(3) nonprofit organization that facilitates photography of fighters and survivors of childhood cancer. We help children (infant - 21 years old) diagnosed with cancer of any form. No matter the prognosis, the fight is still waged and we support you, this includes those that have won their battle with cancer.”

**Magic Hour** - [https://magichour.org/](https://magichour.org/)

“We are a national network of professional photographers who look to serve individuals and families fighting cancer. We do this by coordinating a photo session to celebrate the truly important things in life through photography. These charitable portrait sessions provide an opportunity for families to feel special and strong while they relax, smile and enjoy time with loved ones. Above all, we strive to express compassion and love as we support them, no matter the outcome of their battle.”

iPads

**Hats**

**Love Your Melon** - [https://loveyourmelon.com/pages/requestahat](https://loveyourmelon.com/pages/requestahat)

“The Request A Hat program gives friends and family the opportunity to surprise a child battling cancer with a Love Your Melon Hat. Each Love Your Melon hat is personally given or requested for someone battling cancer, with the hope that it continues to provide smiles and support during a difficult time.”

**Ellie’s Hats** - [https://ellieshats.org/](https://ellieshats.org/)

“We founded Ellie’s Hats to brighten the day of children with cancer. Since Ellie’s Hats began six years ago, we have sent nearly 2,000 packages to children with cancer across the country. We have donated over $200,000 to families and hospitals, in the form of checks, gift cards and other items which have a direct impact on the families.”

**Wigs**

**Locks of Love** - [https://locksoflove.org/](https://locksoflove.org/)

“Our mission is to return a sense of self, confidence and normalcy to children suffering from hair loss by utilizing donated ponytails to provide the highest quality hair prosthetics to financially disadvantaged children free of charge.”

**Pink Heart Funds** - [https://pinkheartfunds.org/](https://pinkheartfunds.org/)

“Launched in 2005, Pink Heart Funds is a non-profit, 501c3 charity that provides cranial prosthetics (wigs) for children and adults with hair loss disorders, including those receiving cancer treatments.”

**Wigs 4 Kids** - [https://www.wigs4kids.org/](https://www.wigs4kids.org/)

“Maggie's Wigs 4 Kids of Michigan is a local, grassroots 501©3 nonprofit organization that provides wigs and support services to children ages 3 to 18 at no charge throughout the state of Michigan.”

**Lodging and Transportation Assistance**

**Housing**

**Cancer Support Community: Airbnb Program** - [https://www.cancersupportcommunity.org/airbnb](https://www.cancersupportcommunity.org/airbnb)

“Having free, short-term housing can help ease a patient’s financial concerns, while giving them the hope and energy they need to overcome illness. That’s where the Open Homes community comes in. Hosts can provide a free and welcoming space for people to heal.”

**Healthcare Hospitality Network** - [https://www.hhnetwork.org/find-lodging#/](https://www.hhnetwork.org/find-lodging#/)

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“The Healthcare Hospitality Network, Inc. (HHN) is a nationwide professional association of nearly 200 unique, nonprofit organizations that provide lodging and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities.”


“Each Hope Lodge offers cancer patients and their caregivers a free place to stay when their best hope for effective treatment may be in another city. Not having to worry about where to stay or how to pay for lodging allows guests to focus on getting better. Hope Lodge provides a nurturing, home-like environment where guests can retreat to private rooms or connect with others. Every Hope Lodge also offers a variety of resources and information about cancer and how best to fight the disease.”

**Please Note:** You will want to check to make sure that the Hope Lodge in your location is able to host childhood cancer patients and their families, as some have been adults-only in the past.

**Joe’s House** - [https://www.joeshouse.org/](https://www.joeshouse.org/), 877-563-7468

“Joe’s House is not an actual house, but a nonprofit organization that helps cancer patients and their families find a place to stay when traveling away from home for medical treatment.”

**Ronald McDonald House Charities** - [https://www.rmhc.org/](https://www.rmhc.org/), (630-623-7048)

“Ronald McDonald House Programs are a home away from home that provide comfort, support and resources to families who travel far from home for the medical care their child needs.”

**General Assistance**

**Alex's Lemonade Stand Travel for Care Program** - [http://www.alexslemonade.org/travel-fund](http://www.alexslemonade.org/travel-fund)

“The mission of ALSF’s Travel For Care program is to ensure children battling childhood cancer have the financial assistance needed to travel to clinical trials, experimental therapeutics, or treatment innovations not currently available at their local institution.”

**Flight Assistance**

**Air Care Alliance** - [http://www.aircareall.org](http://www.aircareall.org), (888) 260-9707

**Air Charity Network** - [http://aircharitynetwork.org](http://aircharitynetwork.org), (877) 621-7177

**Along Comes Hope** - [https://alongcomeshope.com/](https://alongcomeshope.com/), (805-322-1423)

“To inspire HOPE and healing by keeping families together, when it matters the most. We also provide support through financial assistance with travel for treatment, creative emotional support programs and advocacy to promote policy changes, awareness and education.”
Angel Flight

Angel Flight Central (Illinois, Indiana, Iowa, Kansas, Nebraska, North Dakota, Minnesota, Missouri, South Dakota, Wisconsin) - [http://www.angelflightcentral.org](http://www.angelflightcentral.org)

Angel Flight Mid-Atlantic (D.C., Delaware, Kentucky, Maryland, Michigan, Ohio, Pennsylvania (shared), Virginia, West Virginia) - [http://www.angelflightmidatlantic.org](http://www.angelflightmidatlantic.org)


Angel Flight South Central (Arkansas, Louisiana, Oklahoma, New Mexico (shared), and Texas) - [http://angelflightsc.org](http://angelflightsc.org)

Angel Flight Southeast (Florida) - [http://angelflightse.org](http://angelflightse.org)


Corporate Angel Network - [http://www.corpangelnetwork.org](http://www.corpangelnetwork.org), 1 (866) 328-1313 or (914) 328-1313

Footprints Flight - [http://www.footprintsflights.org](http://www.footprintsflights.org), (303) 799-0461

Grace On Wings - [https://www.graceonwings.org/](https://www.graceonwings.org/), (877) 754-7223

Lifeline Pilots - [http://www.lifelinepilots.org](http://www.lifelinepilots.org), 1 (800) 822-7972

Mercy Flight Southeast (Alabama, Georgia, Mississippi, South Carolina) - [http://mercyflightse.org](http://mercyflightse.org)

Mercy Medical Angels - [https://www.mercymedical.org](https://www.mercymedical.org)

“The dedicated team at Mercy Medical Angels is ready to help you and your caregiver with transportation to life changing, life-saving medical care. Request Assistance for transportation on the ground with gas cards, bus or train tickets or in the air with flights flown by volunteer pilots or the commercial airlines.”

National Patient Air Travel Helpline - 800-296-1217

Operation Lift-Off Phone - [www.operationliftoff.com](http://www.operationliftoff.com), (314) 298-9770

PAL Service Organization (East Coast Only) - [http://www.palservices.org/](http://www.palservices.org/), (888) 818-1231

Southwest Airlines Medical Transportation Grant Program (2 Round Trip Vouchers) - [http://www.southwest.com/html/southwest-difference/community-involvement/charities/medical_transportation.html#charities](http://www.southwest.com/html/southwest-difference/community-involvement/charities/medical_transportation.html#charities)
Parking in New York
SEPTEMBER
AWARENESS &
ADVOCACY

September – Childhood Cancer Awareness Month
September has been dedicated as Childhood Cancer Awareness Month, in an effort to bring recognition to the children, families, and survivors affected by childhood cancer. Childhood cancer is the leading cause of death by disease among children, and awareness is important to bring in additional funding to find cures for all types of childhood cancers and better treatments so that survivors live longer and better lives. All childhood and adolescent cancers are represented by a GOLD awareness ribbon. Gold was chosen because it is a precious metal, and nothing is more precious than children.

1. Bold and Turn Your Social Media Gold!
   A. Follow Childhood Cancer Facebook pages for easily shareable content
      i. https://www.facebook.com/CoalitionAgainstChildhoodCancer
      ii. https://www.facebook.com/MakeSeptemberGold/
      iii. https://www.facebook.com/americanchildhoodcancer/
      v. https://www.facebook.com/OAFcarepackages/
   B. “I Draw Childhood Cancer” – A mom whose child was diagnosed with cancer turned to drawing to childhood cancer and the various procedures that are involved, in an effort to help her daughters and others. https://www.facebook.com/idrawchildhoodcancer/
   C. Go Gold with Photo Frames
      Instructions on How to Add a Frame to Your Facebook Profile Photo - https://www.facebook.com/help/115229555800383

2. Do Something!
   A. Get your friends to be a donor!
      i. Bone Marrow - https://bethematch.org/

3. Fundraise for Research
   A. Worthy Research Causes
      i. The Neuroblastoma Children’s Cancer Society (NCCS) gives the majority of its donations to research - https://www.neuroblastomacancer.org/ or https://www.facebook.com/NeuroblastomaChildrensCancerSociety
      ii. https://research.beatcc.org/ (Formerly Beat Neuroblastoma)
      iii. https://www.bandofparents.org/
      iv. https://www.solvingkidscancer.org/
      v. https://www.alexslemonade.org/
Facebook Fundraisers
   i. Facebook has both Birthday fundraisers and Giving Tuesday (held annually the Tuesday after Thanksgiving) to raise money for nonprofit organizations, and NCCS is one of the nonprofits that you can select! If you have any questions or need assistance setting either of these up, please feel free to contact us!
   ii. YouTube Instructions for Creating a Facebook fundraiser - https://www.youtube.com/watch?v=wGOyV368G1Y

C. Other Creative Fundraising Options
   i. Alex’s Million Mile - Running/ Walking for a cure https://www.alexslemonade.org/campaign/the-million-mile-2020
   ii. PJammin’ For Kids with Cancer - Host a pajama day at your work or school https://www.acco.org/pjammin/

4. Create and sell...
   A. Awareness ribbons to share- get them free here- https://www.facebook.com/ShowMeYourGold365
   B. T-shirts – Below are several companies that you could utilize: Bonfire - https://www.bonfire.com/sell-online/
   From the Article, “Sell Merchandise for Your Nonprofit Without Dealing with Inventory” - https://smartcausedigital.com/articles/sell-merchandise-your-nonprofit-without-dealing-inventory, Lists the Following Companies:
   Printfection - https://www.printfection.com/
   Spreadshirt - https://www.spreadshirt.com/
   Zazzle - https://www.zazzle.com/
   C. Wristbands - https://wristbandcreation.com/ (“Find a lower price and we will beat it”)
   Oriental Trading - https://www.orientaltrading.com/personalized-awareness-ribbon-car-magnets-a2-13704774.fltr?categoryId=90000%201969&rd=Childhood%20cancer&fbclid=IwAR2adKfaP0CxtcoKXrkEMexO6scjtzKcSug0IqBx0Flm6gnWDD0Li7xNDI
   Zazzle - https://www.zazzle.com/
   E. Yard Signs/Posters – Check Pinterest and Google images for many different ideas! Or, you could visit your local print shop to get a professionally printed sign, or visit the following online companies to create posters and yard signs:
   VistaPrint - https://www.vistaprint.com/
   F. Awareness Ribbons and Decorative Hangings for Mailbox, Front Door, or Yard - Check Pinterest and Google images for many different ideas and options to create your own. Or, you can visit Etsy to purchase one.

5. Get Involved with Social Policy
   1. Sign an e-petition for federal funding and research
   2. Contact, email or tweet your congressional representatives
https://www.house.gov/representatives/find-your-representative

3. Post about childhood cancer advocacy efforts on social media outlets (Twitter, Facebook, blogs, etc.)

Additional Awareness Tools and Pages
- https://rallyfoundation.org/awareness-tools/
- https://curechildhoodcancer.org/childhood-cancer-awareness-month/?gclid=Cj0KCQjw753rBRCVARIsA4e3o478O8f18pxf50p056_zbS-S4ixdkAkNePCD00O6HNXqf9iFcWLlfm8aAhBfEALw_wcB
- The Coalition Against Childhood Cancer (CAC2) puts out facts, statistics, etc. on Facebook during the month of September on their public Facebook page. However, you can access MANY different facts, statistics, etc. all in one place about childhood cancer, which are updated on a yearly basis. The Childhood Cancer Fact Library is located at: https://cac2.org/interest-groups/awareness/childhood-cancer-fact-library/

Gold Awareness Project – The Coalition Against Childhood Cancer

**Please Note: The information below has been copied from the Coalition Against Childhood Cancer’s Gold Awareness Project, available at: https://cac2.org/interest-groups/awareness/gold-awareness-project/**

“The Gold Awareness Project offers numerous creative ways to promote powerful messages and gold icons in September to increase awareness of childhood cancer. Through this project, CAC2 hopes to inspire everyone for action and engagement locally, nationally, and globally. The CAC2 Gold Awareness Project is determined to turn the world gold in September. The Gold Awareness Project offers CAC2 members and the wider community creative ways to promote gold and September and increase awareness of childhood cancer. The Gold Awareness Project Committee has brainstormed ideas that can be carried out by organizations and individuals to increase awareness of gold and September as the color and month representing childhood cancer. We hope these ideas inspire everyone and demonstrate that the possibilities are endless. If we each do our part in our areas of the country, an increase in national awareness will follow…”

- Included in this document are ideas about how to promote childhood cancer awareness month through: Individual Statements; School Involvement; Online Campaigns; Events; Community Recognition; Community Involvement; and Long-Term Asks, which require some preparation both before and after September to implement.
- Additionally, there are templates to help you ask your local and state officials to declare September as Childhood Cancer Month. Childhood Cancer Awareness Proclamations are available at: https://cac2.org/interest-groups/advocacy/september-proclamations/

Advocacy

**Children’s Cancer Cause** is a great resource at: https://www.childrenscancercause.org/

“Children’s Cancer Cause is the leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families.
Children’s Cancer Cause leads efforts to ensure that these needs and perspectives of children with cancer are integrated into the highest deliberations on health care and cancer policy at the Federal level.”
- “Children’s Cancer Cause – The Stewart Initiative for Childhood Cancer Survivors: Policy and Advocacy” (Includes resources on advocacy and updates on policies) - https://www.childhoodcancersurvivorship.org/policy

-Check out https://www.congress.gov for any childhood cancer bills, and where they are at in the legislative process. For example, the Fairness to Kids with Cancer Act of 2019, “requires the share of federal funds for cancer research that is allocated to pediatric cancer research to equal the percentage of the U.S. population under the age of 18.” https://www.congress.gov/bill/116th-congress/house-bill/4429

-The Alliance for Childhood Cancer - https://www.allianceforchildhoodcancer.org/
“We exist to provide a forum of national patient advocacy groups and medical and scientific organizations which meets regularly, shares ideas and concerns, and works collaboratively to advance research and policies to prevent cancer, and improve public education, and the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.”

-American Cancer Society Cancer Action Network (ACS CAN) - https://www.fightcancer.org/
“If we are to succeed in our mission to end suffering and death from cancer, it won't just happen in the doctor's office or research lab. This movement must start at the statehouse and in Congress. And, it will be led by volunteers - regular people whose lives have been impacted by cancer - rallying together to demand change from their elected officials. We are the organization empowering volunteers to do just that - influence change and impact the future of cancer. From gaining dramatic increases in funding for cancer research to ensuring all Americans have access to cancer care, our work is saving lives and leading to new innovative breakthroughs in how to fight this disease.”

-Congressional Childhood Cancer Caucus - https://childhoodcancer-mccaul.house.gov/
Mission Statement: “The mission of the bipartisan Childhood Cancer Caucus is to serve as a clearinghouse for information on pediatric cancer and a forum to aid Members of Congress in working together to address pediatric cancer. The Caucus will strive to raise awareness about pediatric cancer, advocate in support of measures to prevent the pain, suffering and long-term effects of childhood cancers, and work toward the goal of eliminating cancer as a threat to all children.”

-National Coalition for Cancer Survivorship - https://www.canceradvocacy.org/
- Advocacy - https://canceradvocacy.org/get-involved/


-The Childhood Cancer Fact Library from the Coalition Against Childhood Cancer - https://cac2.org/interest-groups/awareness/childhood-cancer-fact-library/
This is updated on a yearly basis, and gives information, data, and statistics on childhood cancer and survivorship. Recently, international statistics and information was added.