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Association of Pediatric Hematology/Oncology Nurses

A Handbook for Families

Rare Tumors

ONCOLOGY SERIES

Rare Tumors

A HANDBOOK FOR FAMILIES

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WHAT ARE RARE TUMORS?

Rare tumors are defined by the Rare Disease Act of 2002 as affecting fewer than 200,000 individuals in the United States; however, this does not apply to rare pediatric cancers because pediatric cancer is rare itself. In the United States, there are about 15,000 cases of childhood cancer diagnosed each year in patients younger than 20 years old, and rare tumors account for about 9% of these.

Rare tumors are most common in 15- to-19-year-olds. They arise from the epithelial tissue, which is the source of most adult cancers; because rare tumors resemble adult cancers, the treatment of these tumors in children is often the same treatment used for adults.

Information about these particular rare cancers is difficult to find. This handbook is designed to answer some of your questions and concerns. Your treatment team will provide detailed information about your child's specific type of cancer and treatment.

According to the Children's Oncology Group, the following are considered rare tumors of childhood:

- liver tumors
- germ cell tumors
- thyroid tumors
- nasopharyngeal carcinoma
- malignant melanoma
- adrenocortical carcinoma
- pleuropulmonary blastoma.

LIVER TUMORS

What Are Liver Tumors?

Liver tumors account for about 1% of all childhood cancers, and they can be benign or malignant. The *liver* is an organ located in the upper right side of the abdomen and protected by the rib cage. The most common malignant tumors are hepatoblastoma and hepatocellular carcinoma (HCC). Hepatoblastoma occurs most frequently in infants or very young children between the ages of 2 months and 3 years. HCC occurs most frequently in children ages 10–16 years.

What Are Some of the Signs and Symptoms of Liver Cancer?

Liver cancer symptoms are usually caused when the abdomen enlarges because of the tumor growth. This often happens without any other symptoms. Other symptoms that can occur include

- loss of appetite
- vomiting
- weight loss

- stomach pain
- jaundice (a rare symptom that causes yellow discoloration of the skin and whites of the eyes)
- unequal growth of one part of the body compared with the other (e.g., one leg larger than the other)
- early signs of puberty.

What Causes Liver Cancer?

The cause of liver cancer is unclear, but it is believed to develop when the liver cells grow out of control. Mistakes (mutations) may occur during growth of the liver cells, which may cause the uncontrolled growth. Alpha-fetoprotein (AFP), a protein made by growing liver cells, is often elevated (high) in children with liver tumors.

What is the Common Treatment and Outcome for Liver Cancer?

Factors that affect treatment and cure are

- Complete tumor removal—A child whose tumor can be completely removed by surgery is most likely to be cured. Chemotherapy can be given to shrink large tumors and improve the chances of completely removing the tumor by surgery later.
- Presence of pure fetal histology—After a biopsy (surgery to remove a tumor), a pathologist will examine the tumor. If the tumor is similar to fetal liver cells (also known as pure fetal histology), there is an excellent cure rate.
- Tumor stage—The earlier stages (I or II) are more easily cured. However, 70% of liver tumors are in the later stages (III or IV) when diagnosed.
- AFP production—Most liver tumors produce AFP. Children with a high rate of AFP at diagnosis who experience a rapid decrease in AFP after starting chemotherapy have a favorable cure rate. Those who have a normal or only slightly elevated AFP may require different treatment.

GERM CELL TUMORS

What are Germ Cell Tumors?

Germ cell tumors are growths that arise in young children and teens, as well as adults. They are rare and account for about 3% of all childhood cancers. The term *germ cell* refers to “giving of life” because germ cells are the specialized cells that give rise to new life: sperm and egg cells, the sex cells that are needed for human reproduction.

Germ cell tumors often occur in the sex organs, but they can appear in several different places in the body such as the

- testes (boys)
- ovaries (girls)
- abdomen and pelvis
- mediastinum (the part of the chest between the breastplate and spinal column)
- brain.

Germ cell tumors can be malignant or benign. Malignant germ cell tumors include immature teratoma, yolk sac tumor, and choriocarcinoma. They can destroy the testes and ovaries and spread to other parts of the body (metastasis). Benign germ cell tumors include several types of teratomas, which are tumors that contain hair, muscle, and bone. They can be quite large and cause problems as a result of their size.

What are Some of the Signs and Symptoms of Germ Cell Tumors?

The symptoms depend on where the germ cell tumor is growing.

- Testicular germ cell tumors (in the testes)—These are commonly a painless mass in the scrotum (the skin that holds the testes). Parents may notice the swelling in young boys. Adolescent boys, however, may not report the growth for some time because they are embarrassed about discussing problems with their sex organs.
- Ovarian and abdominal tumors—There may be abdominal pain, bloating, constipation, and an enlarged abdomen.
- Mediastinal tumors—These are located in the middle section of the chest cavity. Often there are no symptoms at first, but they cause shortness of breath and wheezing when they become large.
- Sacrococcygeal teratomas—These are located at the base of the coccyx, or tailbone. They may present as a large mass coming from the rectum and are usually seen at birth.

What Causes Germ Cell Tumors?

The causes of germ cell tumors are not known completely. It is known that the tumors occur when cells that normally are sent to the testes or ovaries in the developing fetus fail to reach their destination. Some of these tumors occur in children with extra genetic material or more than the normal number of chromosomes.

What Is the Common Treatment and Outcome for Germ Cell Tumors?

Factors that affect treatment and cure are:

- Location—Germ cell tumors of the testes have a better prognosis because they can be surgically removed. Tumors outside the testes are more difficult to treat. Mediastinal tumors often have no early symptoms and may be difficult to treat later.
- Cell characteristics—Benign teratomas have an excellent prognosis with surgical removal. Malignant germ cell tumors require surgery and chemotherapy.
- Tumor cell markers—Many tumors produce proteins that are measured in the blood to show tumor growth and treatment success. They can be used to help decide how to treat a tumor. Two examples are AFP and beta human chorionic gonadotropin (bhCG).
- Stage—A child whose tumor has spread to different parts of the body requires more treatment.
- Age at diagnosis—Patients older than 12–15 years have a poorer outcome than younger patients.

THYROID TUMORS

What Are Thyroid Tumors?

Thyroid cancers arise from the thyroid gland. The thyroid gland is located just below the Adam's apple in the front of the neck. The thyroid gland is important because it produces hormones that are necessary for many body functions and responses. Thyroid hormones regulate the body's response to hot and cold, our energy level, and our appetite and weight. Thyroid cancer is very rare, but the cure rate is nearly 95%.

There are four types of thyroid cancer based on what the cells look like under a microscope:

- papillary
- follicular
- medullary
- anaplastic.

What Are Some of the Signs and Symptoms of Thyroid Cancer?

The first and most common symptom of thyroid cancer is usually a painless lump in the neck.

What Causes Thyroid Cancer?

The causes of thyroid cancers are not completely known.

What Is the Common Treatment and Outcome for Thyroid Cancer?

Surgery is the first line of treatment for thyroid cancer, and it is very safe for children. During surgery, all or part of the thyroid gland will be removed. If all of the thyroid gland is removed, then the thyroid hormones will have to be replaced with daily medication. This medication will be necessary for the rest of the child's life. A specialist called an endocrinologist will need to supervise follow-up care and hormone-replacement medications.

Radioactive iodine will be used if the surgeon is unable to remove all of the thyroid cancer. Other treatments may be used if the cancer has spread to other locations in the body.

NASOPHARYNGEAL TUMORS

What Are Nasopharyngeal Tumors?

Nasopharyngeal tumors arise from the epithelial tissue in the nasopharyngeal (nose and throat) area. These tumors are most common in adults, and only 9% of nasopharyngeal tumors occur in children, most commonly between the ages of 15 and 19 years.

There are three main types of nasopharyngeal tumors:

- squamous cell carcinoma
- nonkeratinizing carcinoma
- undifferentiated carcinoma.

What are Some of the Signs and Symptoms of Nasopharyngeal Tumors?

The symptoms of nasopharyngeal tumors depend on the location of the tumor. Most often, painless swelling of lymph nodes in the neck is noted. Other symptoms may include:

- nasal obstruction
- nose bleeds
- jaw pain
- hearing loss
- earache
- headache
- chronic ear infections
- cranial nerve palsies (facial drooping, for example).

What Causes Nasopharyngeal Tumors?

The cause of nasopharyngeal cancer is not completely known. There seems to be a relationship between Epstein-Barr virus and some types of nasopharyngeal carcinoma.

What Is the Common Treatment and Outcome for Nasopharyngeal Tumors?

The diagnosis of nasopharyngeal tumors is made from a biopsy of the primary site or lymph node. The stage of the disease is determined to provide treatment options. Surgery can be difficult in the area of the nose and throat, and radiation therapy is often the first line of treatment for nasopharyngeal carcinoma. Chemotherapy may also be used because nasopharyngeal tumors respond well to several chemotherapy agents.

Patients with small tumors that are within the nasopharynx have a better prognosis for cure.

MALIGNANT MELANOMA

What Is Malignant Melanoma?

Melanoma is a cancer of the skin that arises from cells that give the color to our skin, hair, and eyes. While most of these cancers are located in the skin, they can occur in the eye. Melanoma is the most serious skin cancer. Only 1% of melanoma cancer occurs in people younger than 20 years old.

What Are Some of the Signs and Symptoms of Malignant Melanoma?

The symptoms and warning signs for melanoma are often referred to as the ABCDEs, which is a way to check moles on the skin:

A = Asymmetry—The two halves of the mole do not match.

B = Border irregularity—The mole's borders are irregular or fuzzy rather than sharp.

C = Color variegation—In addition to brown and black, other colors are present.

D = Diameter—The mole is bigger than the eraser on a pencil.

E = Evolving—The mole has changed in size, shape, or color.

What Causes Malignant Melanoma?

Because there are so few cases of malignant melanoma in children, very few studies for children have been done. However, children appear to have the same risk factors as adults, including having

- a relative who had melanoma
- the presence of many moles or unusual moles
- a history of skin cancer (treated with medication that decreases immune system function)
- fair skin and sun sensitivity
- a history of sunburns
- a history of excessive use of tanning beds.

Additional risk factors in children include

- the presence of melanoma at birth
- the presence of a giant mole (giant congenital nevus)
- diagnosis of xeroderma pigmentosum
- Werner's syndrome
- family history of genetic retinoblastoma
- post-bone marrow or kidney transplant
- neurocutaneous melanosis.

What Is the Common Treatment and Outcome for Malignant Melanoma?

The treatment of children with melanoma depends on its location and stage. Children are often treated with similar therapies as adults. The stage of melanoma depends on the depth of the tumor. Surgery is the first line of treatment, and a wide surgical excision is necessary. If lymph nodes are involved, chemotherapy will be used as well. Patients will require close follow-up with skin examinations every 3–6 months.

ADRENOCORTICAL CARCINOMA

What Is Adrenocortical Carcinoma?

Adrenocortical carcinoma is a rare cancer of the adrenal glands. The adrenal glands are located on top of the kidney and are important to the body's endocrine (hormonal) system. The cortex—the outer part of the

kidney—makes several hormones, including cortisol, aldosterone, estrogen, and testosterone. These hormones regulate metabolism and body characteristics such as body shape and hair growth. Adrenocortical carcinoma begins in the cortex and can be a functioning or nonfunctioning tumor. A functioning tumor produces more of one hormone.

What Are Some of the Signs and Symptoms of Adrenocortical Carcinoma?

Adrenocortical carcinoma can cause the following symptoms:

- flushed face with pudgy cheeks (moon face)
- obesity
- stunted growth
- excessive hair growth
- unusual acne
- high blood pressure
- low potassium, thirst, muscle cramps, and weakness.

What Causes Adrenocortical Carcinoma?

The cause of adrenocortical carcinoma is unknown. It is most common in children younger than 5 years. In children, this cancer is most often seen in southern Brazil. Certain hereditary conditions carry a higher risk for this cancer, including Li-Fraumeni syndrome and Carney complex.

What Is the Common Treatment and Outcome for Adrenocortical Carcinoma?

The treatment of children with adrenocortical carcinoma depends on the stage and size of the tumor. Surgical removal of the tumor is usually the main treatment. Chemotherapy or radiation therapy may be used if the cancer has spread to other areas. Hormone regulation and replacement therapy will be an important part of treatment, along with follow-up care with an endocrinologist.

PLEUROPULMONARY BLASTOMA

What Is Pleuropulmonary Blastoma?

Pleuropulmonary blastoma (PPB) is a rare type of childhood lung cancer. PPB begins in the tissues of the pleura (a thin layer of tissue that covers the lungs and lines the interior wall of the chest cavity) or in the lung tissue itself (pulmonary). There are four main types of PPB:

- Type I is made up of cysts (air pockets) with evidence that the cysts are cancerous. This usually occurs in very young children, usually around 10 months old.
- Type Ir (the “r” stands for regressing) is similar to type I but does not have cancerous cells.
- Types II and III generally occur in children ages 3–4 years. They are cancerous and require intensive chemotherapy.

What Are Some of the Signs and Symptoms of PPB?

PPB is so rare that doctors often think the symptoms are caused by a common childhood illness and may overlook the diagnosis of PPB. The two common sets of symptoms that may indicate PPB are

- sudden, strained breathing
- cough, fever, chest pain, or symptoms of pneumonia.

What Causes PPB?

The cause of PPB is not known. Most often, it develops randomly. About 40% of the children with PPB have had or have a family history of lung cysts or kidney cysts, rare ovarian tumors (Sertoli-Leydig cell tumors), leukemia, or polyps. Gene mutations are rarely found. (Mutations in the Dicer1 gene have been reported in familial cases of PPB.)

What Is the Common Treatment and Outcome for PPB?

The treatment for children with PPB will depend on the stage, where it has spread, and whether it is affecting organ function. Surgery is the main treatment for PPB, and the goal is to completely remove the tumor. If it cannot be completely removed, chemotherapy and sometimes radiation therapy are used to treat PPB.

In the following sections, tests and treatments that may be used to diagnose and treat rare cancers will be discussed to help you learn about your child's care. Your treatment team will discuss the specific tests and treatments for cancer.

WHAT IS METASTASIS?

Metastasis refers to the spread of a tumor from its primary site (original location) to other parts of the body. If a biopsy reveals cancer, more tests will be performed to see if the cancer has spread to other organs.

WHAT IS STAGING?

Understanding the staging systems used to describe rare tumors is important for you and your child. *Staging* is the process of determining the location and amount of the disease at the time of diagnosis to make recommendations for treatment. The higher the stage number, the more the disease has spread. There is no one staging system that applies to all rare tumors. Some staging systems are developed just for a particular type of cancer.

The common elements considered in most staging systems are

- site of the primary tumor
- tumor size and number of tumors
- lymph node involvement (spread of cancer into lymph nodes)
- cell type and tumor grade (how closely the cancer cells resemble normal tissue cells)
- the presence or absence of metastasis.

TUMOR NODE METASTASIS

The most common staging system is the tumor node metastasis (TNM) staging system. The TNM system is based on the extent of the tumor (T), the extent of spread to the lymph nodes (N), and the presence of distant metastasis (M). A number is added to each letter to indicate the size or extent of the primary tumor and how much the cancer has spread.

For many cancers, TNM combinations correspond to one of five stages. Criteria for stages differ for different types of cancer.

Stage 0	Carcinoma in situ (contained in original site)
Stage I, Stage II, and Stage III	Higher numbers indicate more extensive disease: larger tumor size or spread of the cancer beyond the organ in which it first developed (to nearby lymph nodes or organs adjacent to the location of the primary tumor).
Stage IV	The cancer has spread to other organ(s).

WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

To diagnose a particular rare cancer and determine the extent of your child's disease, a number of tests and procedures are necessary. To outline the best treatment possible, it is very important to identify the exact type of cancer and its presence throughout the body. Your physician will determine which tests and procedures will be required. The chart below lists the tests most commonly done for specific rare tumors.

TEST	Liver Cancer	Germ Cell Tumor	Thyroid Cancer	Nasopharyngeal Cancers	Malignant Melanoma	Adrenocortical Carcinoma	Pleuropulmonary Blastoma
Biopsy	✔	✔	✔	✔	✔	✔	✔
X ray	✔	✔	✔	✔		✔	✔
CT scan	✔	✔		✔	✔	✔	✔
Endoscopy				✔			
PET scan	✔	✔		✔	✔	✔	✔
MRI	✔	✔		✔		✔	
Bone scan				✔			✔
Ultrasound	✔	✔	✔ (neck)			✔	
Blood tests	✔	✔	✔	✔	✔	✔	✔

Biopsy

A *needle biopsy* is a diagnostic procedure in which a needle is used to obtain tissue samples from an organ, bone, lymph node, or mass. Removing tissue samples is necessary to make a diagnosis and determine what treatment should be chosen. Sometimes this is done in the operating room and sometimes in the radiology department.

Your child's comfort and anxiety levels always will be considered in planning procedures that involve needles. Tissue samples from the biopsy are sent to the pathologist, who will examine the tissue under a microscope to look for cancer cells.

X ray

A chest X ray may be necessary to determine whether the disease has spread to the lungs. A chest X ray takes a picture of the organs and bones inside the chest.

CT Scan (CAT Scan)

The computerized axial tomography (CT or CAT) scan is a computer-assisted X ray that shows very detailed pictures of areas inside the body from different angles. The procedure is painless and quick, but children must lie completely still during the scan. Some children require sedation to help them lie still. Your child may be asked not to eat or drink for several hours before the exam, and it may be necessary for him or her to drink a liquid containing a flavorless dye that makes the picture clearer. Usually a small amount of dye is injected into a vein. Generally, no side effects occur from either type of dye, although allergic reactions are possible.

MRI

Magnetic resonance imaging (MRI) is a test that gives very exact pictures of organs and tumors inside the body. Your child will lie on a table that will then move into a tube-like machine that surrounds your child with a magnetic field. The test is painless, but the machine makes a loud banging noise that may be scary for some children. Children must be able to lie completely still during the scan, and some may require sedation.

PET Scan

A positron emission tomography (PET) scan is a procedure that provides images of the body similar to MRI and CT scans, but with a big difference. MRI and CT provide very detailed images of the body that show the size and shape of organs and tumors, but PET scans show the chemical and functional changes within the body. Functional changes take place before physical changes, and as a result, the PET scan can help diagnose cancer early.

The PET scan involves three steps: injection of a radioactive material, a waiting period (30–60 minutes), and scanning by the PET machine. During the waiting period and the scanning, your child must lie still. The scanning process is painless, but some children may require sedation.

Bone Scan

During a bone scan, a small amount of radioactive material is injected into your child's vein and travels throughout his or her blood system. After 2–3 hours, a scanner takes pictures of your child's entire body as she or he lies still. The scanning process is painless, but some children may require sedation.

Ultrasound

Ultrasound uses high-frequency sound waves and their echoes to make cross-sectional images of the inside of your child's body. Clear jelly is placed over the part of the body that is being studied. A small, round handle is then placed on the jelly and moved around to get a clear picture of the tissue or organ. An ultrasound is painless and produces no radiation.

Blood Tests

Blood tests are used throughout therapy to monitor your child's response to treatment and possible side effects of therapy. Blood tests are done to monitor blood cells, body salts, and chemistries. A complete blood count (CBC) is useful in detecting a drop in the number of red blood cells (oxygen carriers), white blood cells (infection fighters), and platelets (cells that help blood clot properly). Blood chemistries such as blood urea nitrogen (BUN) and creatinine monitor changes in kidney function. Other chemistries, such as alanine aminotransferase (ALT), aspartate aminotransferase (AST), and bilirubin, may be done to assess liver function.

Blood tests for tumor markers may also be done. Tumor markers are substances that can be found in abnormal amounts in blood, urine, or tissues of some patients with cancer. Different tumor markers are found in different types of cancer. For example, the tumor markers AFP and bhCG are found in germ cell tumors and the tumor marker AFP is found in liver tumors. In adrenocortical carcinoma, hormone levels are tested. Tumor markers help with diagnosis, treatment follow-up, and in determining if the cancer has returned.

Venous Access Device (VAD)

Often, if chemotherapy is to be given, a surgeon will insert a small plastic tube called a venous access device (VAD) or line ("port") into a large blood vessel, usually under the collarbone. The VAD can be used for blood tests, medications, chemotherapy, blood products, and nutritional support when needed. You and your treatment team will decide whether your child needs a VAD. The VAD is usually left in place until treatment is finished and then is removed.

HOW ARE RARE TUMORS TREATED?

The goal of treatment for rare tumors is to cure the disease while minimizing the treatment-related side effects or adverse reactions. The most common therapies are surgery, chemotherapy, and radiation therapy.

Surgery

Surgery is one type of treatment used in the care of children with rare tumors. The role that surgery plays in the treatment depends upon the type, location, and extent of the cancer. Surgeries are classified according to the primary purpose that they serve in treatment.

Primary surgery removes all or most of the tumor at the time of diagnosis. In some cases, the tumor is too big or is in an area of the body where it cannot be safely removed. In these cases, primary surgery is done after chemotherapy or radiation therapy, which help reduce the size of the tumor.

Chemotherapy

Chemotherapy involves administering medicines that will help kill the cancer cells and prevent the cancer from spreading to new places. A variety of medications are given in combination to kill the cancer cells, but no one chemotherapy medicine can control the disease by itself. Many different chemotherapy combinations are possible. The exact combination of chemotherapy agents used depends on the stage and type of cancer and other treatment considerations. Each of the medications kills the cancer cells in a different way, which is why chemotherapy medications are usually given in combinations.

Most are given through a vein or through the VAD. Some of the medicines are taken by mouth and can be given at home. When chemotherapy is given, close monitoring of your child will be a priority. Your child's treatment team will explain the possible side effects of the specific chemotherapy medicines your child will receive.

Radiation Therapy

Radiation therapy may be used in the treatment of some rare tumors. Radiation therapy is a special kind of X-ray treatment that kills or damages rapidly growing cells like cancer cells. Radiation may be given before or after chemotherapy. If radiation therapy is necessary for your child, the radiation therapy specialist will discuss with you exactly how the radiation will be given and how long the treatments will last.

Most children experience very few side effects while they are receiving radiation therapy. Some children may be more tired or have decreased appetites, and some may experience redness or increased pigmentation of the skin at the radiation site. The side effects of radiation depend on the area of the body treated, and they usually clear up after treatment. There can be side effects that develop later, however, and the possible effects will be discussed with you in detail by your treatment team.

HOW LONG WILL MY CHILD'S THERAPY LAST?

This depends on the type and stage of your child's disease at the time of diagnosis. The length of treatment may be changed based on your child's response to the treatment.

WHAT IF THE CANCER RETURNS?

Sometimes cancer may come back (also known as a recurrence or relapse). If this happens, your child's medical team may suggest additional chemotherapy and radiation therapy.

WHAT NEW METHODS OF TREATMENT ARE AVAILABLE?

These childhood cancers are so rare, with so few children affected, that it is difficult to study them. The Children's Oncology Group (COG) includes institutions that care for virtually all children with cancer in North America. COG has established a Rare Tumor Committee to focus on these cancers and increase knowledge of the diseases and their treatments.

Most of the advances in the treatment of childhood cancer have been made through a process known as clinical trials. In clinical trials, the best known (standard) treatment for a particular cancer is compared with a new (experimental) treatment that is believed to be at least as good as and possibly better than the standard treatment.

Participation in clinical trials is voluntary. Because they involve research into new treatment plans, all risks cannot be known ahead of time, and unknown side effects may occur. However, children who participate in clinical trials can be among the first to benefit from new treatment approaches. Before making a decision about your child's participation in a clinical trial, you should discuss all the risks and benefits with your child's treatment team.

More information about clinical trials is available in the free booklet *Taking Part in Cancer Treatment Research Studies* from the National Cancer Institute. To obtain the booklet, as well as a great deal of useful information about childhood cancer, call 800.4CANCER (800.422.6237). The booklet can also be downloaded from the Patient Education Publications section of the National Cancer Institute website at **www.cancer.gov**.

WHAT ARE THE POTENTIAL LATE EFFECTS OF TREATMENT FOR RARE TUMORS?

Like all patients who have been treated with chemotherapy or radiation, survivors of rare tumors may be at risk for developing problems or side effects months or years after treatment. Children who received radiation to the chest area as part of their cancer treatment are at risk for breast and cardiac complications. Other problems may include delayed development of puberty in males, decreased fertility (ability to have children), thyroid or lung problems, increased risk of developing a second primary cancer, delayed growth and development, or bone health issues.

To help patients monitor their overall health after treatment is completed, it is important that cancer survivors seek appropriate cancer-related follow-up care. All survivors of childhood cancer should have access to cancer-related (treatment-related) follow-up care, services, and healthcare professionals knowledgeable about late effects of childhood cancer treatment. There are many survivor clinics located at cancer centers throughout the country that offer access to experts who can address a wide range of follow-up concerns.

To obtain more information on specific long-term side effects of cancer treatment, go to **www.CureSearch.org**.

HOW CAN I WORK WITH MY CHILD'S HEALTHCARE TEAM?

Because you know your child better than anyone else, the healthcare team will need your help in managing your child's disease. It is important to communicate openly. Be sure to question your child's doctor or nurse whenever there is anything you are unsure about. It helps to write down your questions when you think of them. Here are some examples of questions to ask:

- What kind of cancer does my child have?
- Has the cancer spread beyond the primary site?
- What treatment choices are available?
- What treatment do you recommend, and why?
- What risks or side effects does the recommended treatment have?
- What should we do to prepare for treatment?
- What is my child's outlook for survival?
- What are the chances of the cancer coming back?
- If my child's cancer returns, are other treatment options available?

Use this space to write down some additional questions.

ARE MY FEELINGS NORMAL? WHAT CAN I DO ABOUT THEM?

Hearing that your child has cancer can be shocking and overwhelming. At first you may not believe it, or you may hope that the diagnosis is wrong. However, the changes you see in your child and the experience of being in the hospital and beginning treatment will no doubt confirm the reality of your child's situation.

Many family members feel that they are somehow responsible for the child's disease, or they feel guilty that they were not able to detect it sooner. Remember that this disease was not caused or triggered by anything anyone did to the child, something the child ate, or anything that happened during pregnancy. It also was not triggered by the child's activity in sports. In addition to shock and guilt, you and your family probably will feel anger and sadness.

Even the youngest family members are likely to be affected. These feelings are normal, and each family member will express them in different ways and at different times. It can be very difficult to feel so many strong emotions all at once. Talking honestly with each other about feelings, reactions, and questions will help everyone in the family. It may seem difficult to talk to friends, family, or even medical staff, but expressing your feelings will help you cope with this situation. Your child will benefit if family members continue to show their caring through support and communication.

HOW CAN I HELP MY CHILD?

As a parent, you will often notice changes in your child during treatment for cancer. These changes or symptoms can make you feel even more helpless. It is important to remember that, in spite of changes on the outside, your child is still the same person on the inside. Hair loss and other changes in body appearance are temporary. They often bother the adults involved much more than the child or their siblings and friends.

All of your feelings about what your child is going through during treatment for cancer must be balanced by remembering that treatment provides an opportunity to cure the disease and to have your child go on to live a full and meaningful life.

It is important to reinforce to your child that nothing he or she did or said caused this disease. Telling your child that your angry or sad feelings are directed at the cancer, not at him or her, will help preserve honesty and closeness in your relationship. Don't hesitate to ask your child to express his or her feelings, and don't be afraid to explain what is happening and why.

In spite of the disease, your child is still developing and learning. All children—sick and well—need love, attention, discipline, limits, and the opportunity to learn new skills and try new activities. As you begin to learn about your child's new needs, it is important to remember that he or she still has all the rights of any growing, developing person.

Many patients with rare tumors are adolescents, and this requires special considerations. Do not avoid using direct terms and explanations. Children will tolerate treatment better if they understand it and are allowed to be active decision makers whenever possible. The same is true for parents.

IS MY CHILD'S DIET IMPORTANT DURING TREATMENT?

Yes. We know from research that well-nourished children tolerate therapy better and have fewer treatment delays because of illness. It may be difficult for your child to resume normal eating habits while receiving therapy, so you will need to be flexible and creative. Children's food preferences and tastes may change throughout therapy. Often, numerous small meals are easier to tolerate than three large ones.

Children usually are more interested in eating foods that they help prepare. It is important to include your child in the social activity of family meals even if full meals aren't eaten. Remember, nobody wins food fights—it is best not to force your child to eat.

Make sure that foods high in protein and carbohydrates are readily available. Multivitamins, herbs, and all other medicines should be approved by your healthcare team before you give them to your child because they may interact with the chemotherapy medications. A dietitian trained in the energy needs of children with cancer can offer you guidance. The medical staff can intervene if there is a nutritional problem.

CAN MY CHILD ATTEND SCHOOL DURING TREATMENT?

Your child's ability to attend school will depend on the intensity of the therapy and his or her response to treatment. Some children tolerate chemotherapy and radiation better than others. Your child may not be able to attend school for extended periods because of treatment or hospitalization.

However, it is important that your child keep up with his or her schoolwork. Talk to staff at your child's school about arranging services, including help from a home tutor, until he or she is able to return to school. You also should discuss school attendance with your child's doctor. Many pediatric hospitals have school programs that enable children to attend school while hospitalized.

School is important because it helps children and adolescents maintain social contact with their peers. Having time with friends will be an important part of your child's recovery and will ease the adjustment when he or she returns to school. It is important to return your child to school as soon as he or she is medically able to do so.

PROGNOSIS STATEMENT

Prognosis is a word that doctors use to describe what they believe the outcome will be for a patient, including the chances of recovery. Your child's cancer prognosis is as unique as he or she is. There are many factors that affect survival outcomes. A child's age at diagnosis, the extent of disease, genetic factors, infections, nutrition, delays in the timing of treatment, and how well your child's body can tolerate chemotherapy and radiation all play an important role in the child's long-term outcome. Because general statements about survival rates are just numbers, please talk to your medical team about your child's individual prognosis and plan of care.

ONLINE RESOURCES

Children's Oncology Group (**www.childrensoncologygroup.org**)

CureSearch (www.curesearch.org)

National Cancer Institute (www.cancer.gov)

IMPORTANT PHONE NUMBERS

NOTES

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