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Association of Pediatric Hematology/Oncology Nurses

A Handbook for Families

Ewing Sarcoma
Family of Tumors

ONCOLOGY SERIES

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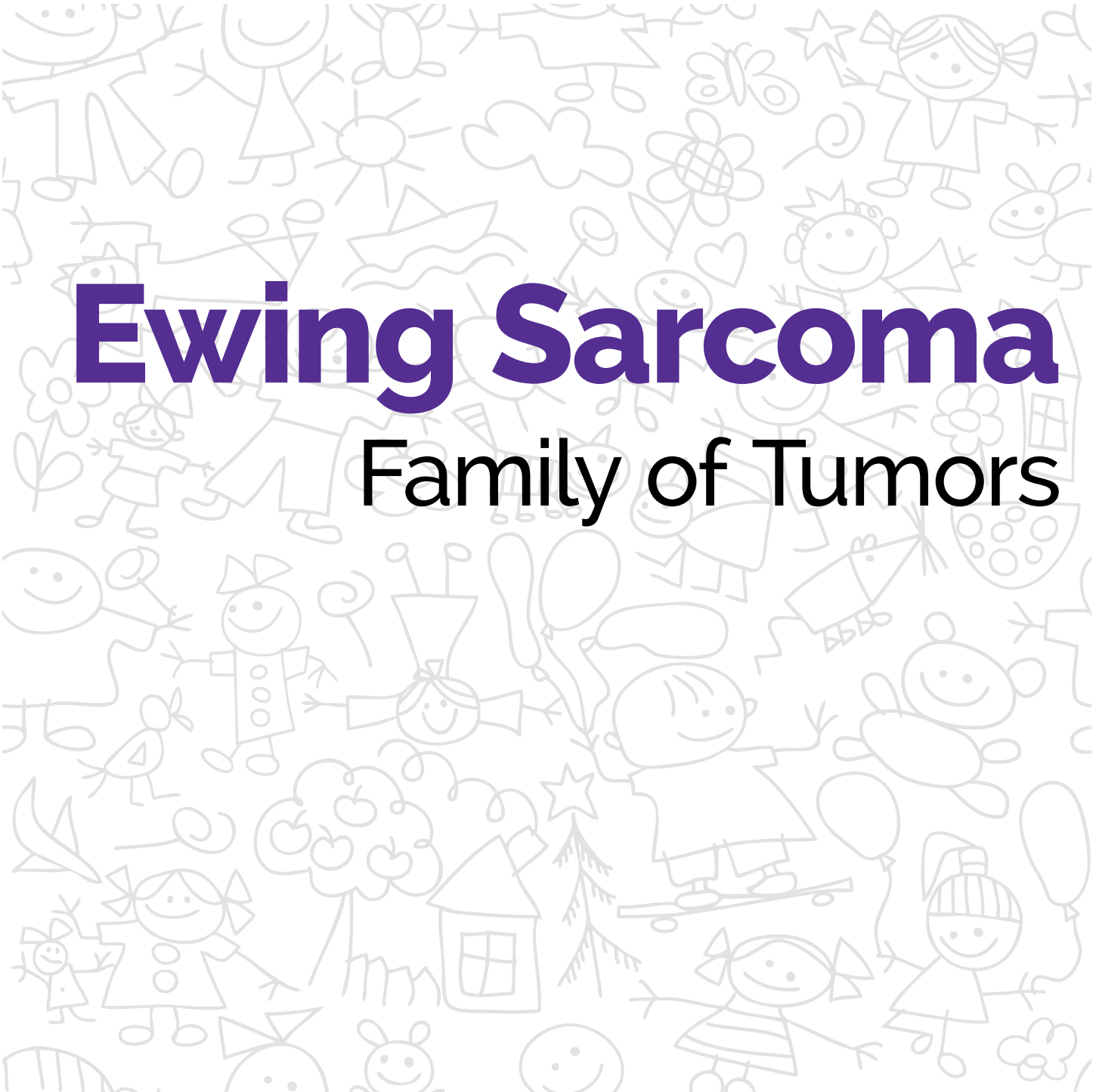

ONCOLOGY SERIES

EWING SARCOMA
A HANDBOOK FOR FAMILIES

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ABOUT THIS COVER

This cover is specially designed for your child to color and personalize. When your child finishes decorating the cover, return it to the clinic or doctor's office where you received the handbook. Your child's healthcare provider will then send it to APHON for posting on the APHON website.

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WHAT IS EWING SARCOMA?

Ewing sarcoma is a type of cancerous tumor arising from the bone or soft tissues. Ewing sarcoma belongs to a grouping of tumors called the *Ewing sarcoma family of tumors* (EFT). EFT consists of Ewing sarcoma of the bone, extraosseous Ewing sarcoma (EES), Askin tumor, primitive neuroectodermal tumor (PNET) of the bone, and PNET of the soft tissue. Under the microscope, EFT tumors appear similar, and are made up of small, round "blue" cells. These tumors are generally evaluated and treated the same way. To simplify, the term Ewing sarcoma will be used throughout this book to refer to any one of these tumors.

In 1921 Dr. James Ewing became the first to describe Ewing sarcoma. After osteosarcoma, Ewing sarcoma is the most common type of childhood bone cancer. It is usually found in the pelvic bones, the upper arm, the spine, the ribs, or one of the long bones of the leg called the femur, but it can occur in any bone in the body.

Ewing sarcoma found in the soft tissues around the bone is called *extraosseous* or *extraskeletal Ewing sarcoma* (EES). EES is most commonly found in the thigh, pelvis, spine area, chest wall, or foot.

Ewing sarcoma found in the chest wall may be referred to as an *Askin tumor*.

Peripheral PNET is the least common member of EFT. It is also a round-cell tumor, but it is made up of young nerve cells. PNET can occur in the bone or soft tissues.

WHAT ARE SOME OF THE SIGNS AND SYMPTOMS OF EWING SARCOMA?

The most common symptom of Ewing sarcoma is pain at the site of the tumor. Often the pain will wake one up from sleep. There may also be swelling or a soft mass around the affected bone or tissue. If the tumor is located in the pelvis, there could be signs of bowel or bladder disturbance. If the tumor is located in the spine, back pain, weakness in the arms or legs, or numbness is often felt. If the tumor is located in the chest wall, symptoms may include cough, shortness of breath, or chest pain. Often, a pathological fracture, which is a break that occurs without trauma, is present at diagnosis because the tumor has weakened the bone. It is important to understand that trauma did not cause the cancer. Children frequently have painful lumps as a result of normal play activities, so oftentimes Ewing sarcoma is diagnosed only after a lump has persisted for several months. Other less common symptoms of Ewing sarcoma are weight loss and fever.

WHAT CAUSES EWING SARCOMA?

We do not know what causes Ewing sarcoma. We know that Ewing sarcoma is not contagious—that is, it cannot be caught from another person. For many adult cancers, lifestyle-related risk factors play a large role. No behaviors or lifestyle habits, including those practiced during pregnancy, have been associated with the development of Ewing sarcoma. Studies of children with Ewing sarcoma have not found links to radiation, chemicals, or other environmental factors. In addition, Ewing sarcoma is not caused by too much or too little of a particular food group in your child's diet.

WHO GETS EWING SARCOMA?

Approximately 200–250 children in the United States are diagnosed with Ewing sarcoma each year. Ewing sarcoma is mostly found in adolescents 10–20 years of age. This group accounts for a little more than 1% of all childhood cancers. About 30% of all Ewing sarcomas occur in adults over the age of 20. Most patients are Caucasian, and males are affected more often than females. Ewing sarcoma is extremely rare among those of Asian or African descent.

IS EWING SARCOMA INHERITED?

There is no reason to believe that Ewing sarcoma is genetic or inherited from a family member. It is rare for more than one person in a family to have this type of tumor.

WHAT IS METASTASIS?

Metastasis refers to the spread of a tumor from its original location, or the primary site, to other parts of the body. Metastases are found in approximately 30% of patients with Ewing sarcoma at the time of their diagnosis. Half of the metastases are usually found in the lungs, and half are in other places—often other bones. Metastasis in the bone marrow (inside of the bones where blood cells are made) is less common. Some signs and symptoms of metastases include fever, pain, weight loss, and fatigue.

WHAT IS STAGING?

Staging is the process of determining the location and amount of the cancer at the time of diagnosis. Staging for Ewing sarcoma is based on the location of the tumor and whether it has spread. A tumor is staged as either localized or metastatic. A *localized tumor* is one that has not spread to another part of the body, while a metastatic tumor is one that has spread. The method of treatment proposed for your child will depend upon the stage of the disease at the time of diagnosis.

WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

To diagnose Ewing sarcoma and determine the extent of your child's disease, a number of tests and procedures are needed. A member of your child's healthcare team will take a complete history of the illness, which includes a determination of the location, duration, and intensity of any pain. A physical examination will be performed to check for a limp, limited range of motion in the joints, or any soft tissue masses or lumps. In addition, blood tests and radiographic imaging studies will be needed as described on the next page.

X RAY

A plain X ray is usually the first type of radiographic imaging your child will experience. An X ray will be done to evaluate the site where your child experiences pain or swelling. X rays may show that a tumor is present in the bone or soft tissues, and may prompt further tests. A chest X ray may also be done to determine whether the tumor has spread to the lungs. Efforts will be made to minimize your child's exposure to X rays.

MRI

Magnetic resonance imaging (MRI) is a test that gives very exact pictures of organs and tumors inside the body. MRI is used to evaluate the primary tumor site in more detail and can reveal soft tissue, nerve, and blood vessel involvement. An MRI usually takes 1–2 hours to complete. Your child must not move at all during the test. If your child is not able to lie completely still or is too young to lie still for this test, he or she may be given a sedative or anesthesia to help him or her sleep during the test.

A small amount of dye will be injected into a vein during the test, but otherwise the test is painless.

The machine makes a loud noise during the test. If your child does not receive sedation to help him or her sleep for the test, he or she should be prepared for the noise and the possibility of using ear plugs or a headset during the test. Because MRI uses a very powerful magnet, no metal is allowed near the MRI machine. Hospital staff will remind you of this prior to the test.

CAT OR CT SCAN

A *computerized axial tomography* (CAT) or *computerized tomography* (CT) scan is a computer-assisted X ray that shows pictures of internal organs and tumors. A CT of the chest is often done to look for lung metastases.

CT scans are painless, but your child must be able to lie absolutely still during the scan. Some children require sedation or anesthesia to help them lie still.

It may be necessary to have your child drink a liquid containing a flavorless dye that will help make the pictures clearer. In other cases, a small amount of dye may be injected into a vein. Generally, there are no side effects from either type of dye; however, some children may have allergic reactions to the dye.

There is some radiation exposure with this test. Your child's healthcare team will try to minimize how often it is done, but it is very helpful in diagnosing and following the stage and location of the cancer.

BONE SCAN

A bone scan may be done to determine whether the tumor has spread to any other bones. A small amount of dye is injected into a vein and allowed approximately 2 hours to distribute throughout your child's body before pictures are taken. The scanning process is painless, but your child may need sedation to prevent him or her from moving.

PET SCAN

A *positron emission tomography* (PET) scan is a diagnostic test used to detect cancer, determine tumor stage, and evaluate the effectiveness of cancer treatments. The PET scan helps evaluate whether the tumor is alive and growing or dead. Before the scan, radioactive sugar molecules are injected into your child's body through an intravenous (IV) line. Cancer cells have the ability to absorb sugar more quickly than normal cells, so they appear to light up or are bright on the PET scan. An active or alive tumor will absorb more sugar than a dead or nonactive tumor.

A PET scan often complements the information gathered from the CT, MRI, and bone scan. Your child will need to limit food and sugar intake prior to this scan.

TUMOR BIOPSY

A biopsy of the tumor helps your child's healthcare team make the diagnosis and choose the proper treatment. The biopsy is usually done through an incision made by a surgeon in the operating room while your child is under sedation or anesthesia. Some medical centers do the biopsy in the radiology department, where the biopsy sample is obtained through a needle guided into the tumor. Your child's comfort and anxiety level will always be considered in planning procedures that involve needles.

Under a microscope, the small, round blue cells of Ewing sarcoma appear the same as the cells of other childhood cancers. The pathologist will look at the tumor sample and determine the type of cancer. The pathologist uses several tests to confirm the diagnosis, which may take up to a week or more.

Cytogenetic testing is an important part of this process. Cytogenetic testing includes evaluation of the genes or chromosomes that make up a tumor cell. Frequently, chromosomes (pieces of DNA) translocate (change location) in Ewing sarcoma. In most cases, translocations occur in chromosomes 11 and 22, when a piece of chromosome 11 attaches to 22. Less often, a piece of 22 attaches to a random chromosome. Once a translocation takes place, the EWS gene on chromosome 22 starts reproducing continuously, creating many cancerous cells and eventually forming an Ewing sarcoma tumor. Finding these translocations helps differentiate between Ewing sarcoma and another childhood cancer. Special molecular testing including fluorescent in situ hybridization (FISH) and reverse transcriptase PCR (RT-PCR) can be performed on the tumor tissue to look for these specific translocations.

BLOOD TESTS

Blood tests monitor your child's blood cells, body salts, and chemistries. A complete blood count (CBC) is useful in detecting a drop in the number of red blood cells (blood cells that carry oxygen), white blood cells (blood cells that fight infection), and platelets (blood cells that assist in clotting). If the CBC results are abnormal, your child's healthcare team may be concerned about disease in the bone marrow, as all blood cells are produced in the bone marrow. Blood tests such as creatinine and blood urea nitrogen (BUN) monitor changes in kidney function. Blood tests called hepatic function panel and bilirubin detect changes in liver function. These tests are usually done at the time of diagnosis to rule out other diseases and to serve as a baseline for your child. Blood tests will then be used throughout treatment to monitor for possible side effects and your child's response to treatment.

BONE MARROW ASPIRATION AND BIOPSY

Bone marrow aspiration and biopsy determine whether tumor cells are in the bone marrow. Bone marrow aspiration involves inserting a needle into the hip bone and drawing some bone marrow into a syringe. It is usually necessary to obtain bone marrow samples from both hip bones. Another part of this test, a biopsy, involves taking a small piece of the hip bone to examine for tumor cells. This is the only way to positively determine whether tumor cells are in the bone marrow and helps your child's physician determine the stage of the disease and choose the proper treatment. Medication can be used to help your child remain still and to minimize any discomfort.

ECHOCARDIOGRAM AND ELECTROCARDIOGRAM

Echocardiogram, often referred to as a cardiac echo or simply an echo, is an ultrasound of the heart. An echocardiogram reveals the size and shape of your child's heart and also how well the heart is functioning. This serves as a baseline test because chemotherapy can weaken the heart muscle. Echocardiograms will be repeated throughout your child's treatment to monitor for any signs of heart dysfunction.

An *electrocardiogram*, or EKG, is a recording of the electrical activity of the heart. *Electrodes*, which are soft stickers connected to wires, are attached to the surface of the skin on your child's chest. Impulses from the heart are sensed through the electrodes and recorded or displayed by a machine placed next to the body. This is another way to measure how well the heart is working, and it will be repeated throughout your child's treatment.

VENOUS ACCESS DEVICE

A *venous access device* (VAD), sometimes called a central line or a port-a-cath, is a temporary or permanent IV tube that may be used during your child's therapy. This tube can be used to administer medications, chemotherapy, blood products, and nutritional support when needed. Sometimes a VAD will also be used to draw blood for testing. It is inserted by a surgeon while your child is under anesthesia. You and your child's healthcare team will decide whether your child needs a VAD.

HOW IS EWING SARCOMA TREATED?

Three types of therapy are commonly used to treat Ewing sarcoma: surgery, chemotherapy, and radiation. The type of therapy chosen depends upon the age of your child, location of the cancer, and the extent of the disease. In most cases a combination of chemotherapy, surgery, and radiation is needed. Ewing sarcoma is radiosensitive, so radiation is always a good option when there is no surgical option available. Radiation may also be needed if microscopic cells are left behind after surgery. Your child's healthcare team will talk with you about the best treatment for your child. You, your child, and the healthcare team will then make decisions about your child's treatment.

CHEMOTHERAPY

Chemotherapy involves medicines that help kill the cancer cells, shrink the tumor, and prevent cancer cells from spreading. Ewing sarcoma can spread early in your child's illness, making chemotherapy an important part of your child's treatment. Several chemotherapy medications can kill the cells that cause Ewing sarcoma, but no single chemotherapy medicine alone can control the cancer. As a result, chemotherapy medications are usually given in combinations. Each cycle of treatment usually lasts several days. It may be given in the hospital, requiring an overnight stay, or in an outpatient clinic, requiring daily visits. The entire treatment including chemotherapy, surgery, and radiation may last approximately 8–10 months.

Your child's healthcare team will discuss with you the specific chemotherapy medications your child will receive and how and when they will be given. Most medications are given through the veins or a VAD. Your child's healthcare team will also explain the possible side effects of the specific chemotherapy treatment that your child will receive.

SURGERY

It is sometimes possible to remove the entire tumor by surgery at the time of diagnosis. More commonly, Ewing sarcoma requires a combination of chemotherapy, surgery, and possibly radiation therapy. Typically treatment starts with chemotherapy. Chemotherapy may shrink the size of the tumor, which helps to decrease the risk of surgical injury to the healthy tissues surrounding the tumor. When the surgeon removes the tumor,

he or she will aim to take out the entire tumor with a small amount of healthy surrounding tissue, called the margin. This reduces the chance that the tumor will regrow in this area. Once the tumor is removed, a pathologist will look at it under a microscope to ensure that there are no tumor cells at the edge of the margin. If tumors cells are seen at the margin, it is believed that cells may have been left behind in your child's body. Radiation therapy will then be needed. Your medical team will discuss these results and decisions with you. If your child's cancer is metastatic or if tumors are in certain locations, surgery may not be an option.

RADIATION

Radiation therapy is a very precise kind of X ray treatment. Radiation may be used alone or in combination with surgery, depending on the location of the Ewing sarcoma. It is given in carefully measured amounts by radiation therapy experts. If radiation is necessary for your child, the radiation therapy doctor will discuss with you exactly how the radiation will be given and how long the treatments will last. Radiation therapy is usually given once daily, Monday through Friday, for several weeks in a row. In general, a child experiences few side effects while he or she is getting radiation therapy. Some children become more tired than usual or have decreased appetites. Other possible side effects will be discussed in detail with you and your child prior to starting therapy.

ARE THERE CONCERNS TO ADDRESS PRIOR TO INITIATING TREATMENT?

Yes. Short and long-term side effects may occur as a result of treatment. Therefore, before starting any chemotherapy, surgery, or radiation, it is important to obtain baseline information about your child's health and organ function.

Some potential long-term side effects include the following:

- Damage to the muscle of the heart—Doxorubicin is a chemotherapy agent that may cause damage to the heart muscle. It is important to obtain a baseline echocardiogram (ultrasound of the heart) to establish baseline function and to evaluate if it is safe to proceed. Your child's healthcare team should inform you about possible heart protectant medications.
- Disturbance in sexual development and adult infertility—Ifosfamide, which comes from a class of chemotherapy drugs called alkylating agents, may cause disturbance in sexual development and infertility as an adult. Boys are affected more than girls. Methods to bank female eggs or sperm should be explored when age appropriate. These methods should be reviewed with your child's healthcare team. Information concerning infertility may be found on the Fertile Hope website at www.fertilehope.org.
- Weakened bones and impaired growth—Radiation may have long-term side effects on bones exposed to radiation. Side effects include weakening and slowed or limited bone growth. This can result in differences in the lengths of the extremities, as well as altered function of the affected extremity. Your child's healthcare team will discuss with you ways to improve bone health and/or how to compensate for limitations in bone growth.
- Hardware failure and infection—If your child underwent surgery to remove the tumor from a bone, internal hardware, also called a prosthetic, was likely placed inside your child's body. Internal prosthetics will generally need to be revised in the future through surgical procedures to account for growth. Internal prosthetics also come with a lifelong potential risk of infection and hardware

failure, which require close follow-up care with your surgeon. For children undergoing amputation, external prosthetics are often used to aid in function and mobility. External prosthetics also require changes to be made for growth and other reasons.

HOW LONG WILL MY CHILD'S THERAPY LAST?

Treatment for Ewing sarcoma typically lasts about 8–10 months. Once treatment is finished, frequent monitoring with physical exam and imaging is required until at least 5 years after treatment to monitor for the return of the cancer and for any side effects of treatment. Yearly follow-ups will be needed throughout your child's life to monitor for possible late side effects from treatment, such as heart and lung problems, slowed or decreased growth and development of the bones, changes in sexual development and ability to have children, changes in intellectual ability or learning problems, and development of secondary cancers.

WHAT NEW METHODS OF TREATMENT EXIST?

Most advances in the treatment of childhood cancer have been made through processes called clinical trials. During clinical trials, the best known, standard treatment for a particular cancer is compared with a new, experimental treatment. This experimental treatment is believed to be at least as good as, and possibly better than, the standard treatment. Clinical trials allow doctors to determine whether promising new treatments are safe and effective.

Participation in clinical trials is voluntary. Because clinical trials involve research into new treatment plans, all risks and side effects cannot be known ahead of time. 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 the potential risks and benefits with your child's healthcare team.

More information about clinical trials is available in the free booklet *Taking Part in Clinical Trials: What Cancer Patients Need to Know* (National Cancer Institute Publication No. 98-4250). To obtain the booklet and other useful information about childhood cancer, call 800.4CANCER (800.422.6237). The booklet can also be downloaded from the National Cancer Institute website at www.cancer.gov/clinicaltrials/resources/taking-part-treatment-trials. You can find general information on clinical trials at www.cancer.gov/clinicaltrials/resources/what-to-know-about-trials or call the American Cancer Society at 800.ACS.2345.

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Complementary therapy refers to medicines or modalities that are used along with your recommended

treatment. There are many complementary therapies that are safe and may help relieve symptoms or side effects, ease pain, provide relaxation, and help your child enjoy life. Examples include herbal medications, massage, music, dance, acupuncture, meditation, and yoga. Consult your child's healthcare team prior to starting any of these therapies to prevent possible harmful interactions between chemotherapy and herbs.

Alternative therapies are used in the place of standard medical care. These therapies have not been tested in clinical trials, and have not been proven safe or effective. If you chose an alternative therapy method before standard care, the delay in treatment may give the tumor time to grow, lowering your child's chances of being cured.

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

Your child's care requires a team approach. As a parent, you are a major part of the team. You know your child better than anyone else, so the healthcare team will need your help and input to provide comprehensive care to you and your child. It is important to communicate openly with your child's healthcare team. Be sure to question your child's doctor or nurse about anything you are unsure about. It helps to write down your questions and to keep a treatment diary of your child's course.

HERE ARE SOME QUESTIONS YOU MIGHT WANT TO ASK:

- What kind of cancer does my child have?
- Has the cancer spread beyond the primary site?
- What is the stage of the cancer, and what does that mean?
- If we had caught this earlier, would it have made a difference?
- What treatment choices are available?
- What treatment do you recommend and why?
- What risks or side effects does the recommended treatment have?
- How do we prepare for treatment?
- Will my child survive?
- Will my child lose his or her hair?
- What are the chances that the cancer will return?

Your child's healthcare team will usually include several types of doctors: an *oncologist*, who specializes in cancer and its treatment; one or more *surgeons*, who may perform the biopsy to make the diagnosis of cancer, put in a VAD, and/or remove the tumor entirely; and a *radiation oncologist*, who specializes in treating children with radiation therapy when needed. Other members of the healthcare team include nurses, nurse practitioners, physician's assistants, psychologists, social workers, child life specialists,
dieticians, physical therapists, occupational therapists, pharmacists, home care nurses, and chaplains.

Use this space to write down some additional questions.

ARE MY FEELINGS NORMAL, AND 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 confirm the reality of your child's situation.

Many family members feel that they are somehow responsible for their child's disease. For example, you might feel guilty that you did not detect it sooner. Remember that this disease often is not noticeable until it is quite advanced, so there may have been no way to detect it in the early stages.

In addition to shock and guilt, you and your family will probably 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 at once. Talking honestly with one another about feelings, reactions, and questions will help everyone in the family. It may also help to get assistance from a counselor or psychologist. Speak with your healthcare team about the availability of a counselor at your hospital.

It may seem difficult to talk to friends, family, or even medical staff, but venting your feelings can help you cope. Remember that you and your family members can help your child by showing them you care through unconditional support and open communication.

HOW CAN I HELP MY CHILD?

As a parent, you will notice changes in your child during the treatment. These changes can make you feel even more helpless. It is essential to remember that, in spite of changes on the outside, on the inside your child is still the same person. Hair loss and other changes in body appearance are temporary. They often bother adults much more than they bother the child or the child's siblings and friends. It is important to remember that treatment provides an opportunity to cure the disease, allowing your child to have 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 the anger and sadness you feel are directed at the cancer and not at him or her will help preserve honesty and closeness in your relationship. Like you, your child will need someone with whom he or she can share feelings. 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. If you need help supporting your child or talking with your child about his or her cancer, discuss your concerns and need for support with your healthcare team.

In spite of the disease, your child is still growing 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 the new, special needs of your child, it is important to remember that he or she still has all the needs and rights of any growing, developing person. Use direct terms and explanations with your child. Children 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 due to illness.

It may be difficult for your child to resume normal eating habits during therapy, so you will need to be flexible and creative. Often numerous small meals are more tolerable 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. You need to discuss multivitamins, medicines, and herbs with your healthcare team before you give them to your child, because an interaction between them and the chemotherapy is possible. A dietitian trained in children's calorie and energy needs 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 on the 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 should also discuss school attendance with your child's healthcare team. Many pediatric hospitals have programs that enable children to attend school while they are hospitalized.

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

SUGGESTED READING

CureSearch for Children's Cancer at www.curesearch.org

National Cancer Institute. (2013). Ewing sarcoma treatment (PDQ®). Available at http://www.cancer.gov/types/bone/patient/ewing-treatment-pdq#section/all.

IMPORTANT PHONE NUMBERS

NOTES

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