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Association of Pediatric Hematology/Oncology Nurses

A Handbook for Families

Osteosarcoma

ONCOLOGY SERIES

Osteosarcoma

A HANDBOOK FOR FAMILIES

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WHAT IS OSTEOSARCOMA?

Osteosarcoma is a cancerous tumor that develops from osteoblasts (bone cells). It frequently starts in the ends of the long bones, such as the bones in the arms and legs, but it can be found in other bones as well. The most common sites are the distal femur (the thigh bone just above the knee), the proximal tibia (the shin bone just below the knee), and the proximal humerus (the arm just below the shoulder).

WHAT ARE SOME OF THE SIGNS AND SYMPTOMS OF OSTEOSARCOMA?

There may be swelling and pain in the bone over the area of the tumor. Pain may be worse with exercise or at night. A lump or bump with swelling may develop days to weeks after the onset of pain. If the tumor is in the hip or leg area, the child may limp. In some children, the first sign of the disease is a break in the affected bone. It is important to know that the break did not cause the cancer in that area. Although uncommon, loss of bowel or bladder control and back pain may be a sign of a tumor in the pelvis or the base of the spine.

WHAT CAUSES OSTEOSARCOMA?

We do not know what causes osteosarcoma. We do know, however, that there is an increased risk of developing osteosarcoma in bones that have been treated with radiation in the past. Previous treatment with chemotherapy (specifically, alkylating agents) has also been associated with an increased risk of developing osteosarcoma. We also know that osteosarcoma is not contagious and cannot be caught from another person.

Adults who have Paget's disease (a chronic bone disorder) have an increased chance of developing osteosarcoma after age 50.

WHO GETS OSTEOSARCOMA?

Despite being the most common type of bone cancer, osteosarcoma is still very rare. It occurs most often in children and young adults between 10 and 20 years of age during the adolescent growth spurt or other periods of rapid bone growth. There is no relationship between a person's height and the risk of developing osteosarcoma.

IS OSTEOSARCOMA INHERITED?

More research is needed to determine what role genetics plays in osteosarcoma. Children who have inherited retinoblastoma, Li-Fraumeni syndrome, or Rothmund-Thomson syndrome have an increased risk of developing osteosarcoma. The role of genetics continues to be studied by researchers.

WHAT IS METASTASIS?

Metastasis refers to the spread of a tumor from its original location (primary site) to other parts of the body. When osteosarcoma spreads, it usually goes to the lungs. It also can spread to other bones. About 20% of children with osteosarcoma have metastasis at the time they are diagnosed. It is important to determine whether any metastatic disease is present at diagnosis to decide on the best treatment for your child.

WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

To diagnose osteosarcoma and determine the extent of your child's disease, a number of tests and procedures are necessary, including many of the following:

Tumor Biopsy

This test is necessary to determine what type of cancer the child has. It also helps determine what treatment should be chosen. The biopsy is usually done in the operating room by a surgeon while the child is under heavy sedation or anesthesia. Some medical centers do the biopsy in the radiology department. In some cases, the biopsy sample is obtained through a needle that is guided into the tumor. In other cases, an incision is made. Your child's comfort and anxiety level will always be considered in planning procedures that involve needles.

MRI

Magnetic resonance imaging (MRI) is a test that gives very exact pictures of the muscles, nerves, blood vessels, and tumor inside the body. The child is asked to lie on a table, which is then moved into a tube-like machine that surrounds the child with a magnetic field. The test is painless, but the machine makes quite a bit of noise. The child must not move at all during the test. If your child is not able to lie completely still, a sedative may be given to make him or her sleep through the MRI. Sometimes a small amount of dye is injected into a vein. Generally, no side effects from either type of dye occur, although allergic reactions are possible.

CT Scan

The computerized tomography (CT) scan is a computer-assisted X ray that shows very precise pictures. This is used to examine the lungs for tumors. The procedure is painless, but the child must be able to lie absolutely still during the scan. Some children require sedation to help them lie still. Sometimes a small amount of dye is injected into a vein. Generally, no side effects from either type of dye occur, although allergic reactions are possible.

Bone Scan

A bone scan is done to look at all bones in the body for areas of bone where the tumor is growing. It involves injecting a small amount of isotope (radioactive marker) into a vein, allowing 2–3 hours for the isotope to distribute itself throughout the body, and then having the child lie still for the scan (pictures) to be taken of the entire body. This isotope is picked up by tumor cells so that the tumor's location in the body can be seen. The scanning process is painless, but some children need sedation to help them lie still.

X rays

Regular X rays, which may be referred to as plain films of the bones, are taken of the affected area and any other areas of concern. Efforts will be made to minimize your child's exposure to X rays.

Blood Tests

Blood tests are done to monitor the 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 (oxygen carriers), white blood cells (infection fighters), or platelets (cells that help blood clot properly). Alkaline phosphate and lactic dehydrogenase (LDH) levels may be high in the blood due to bone growth from the tumor. This blood level is high in 30%–40% of patients diagnosed with osteosarcoma. Blood chemistries such as BUN (blood urea nitrogen) and creatinine monitor changes in kidney function. Chemistries like hepatic function panel and bilirubin detect changes in liver function. All these tests are usually done at the time of diagnosis to rule out other diseases, and they are also used throughout therapy to monitor the child's response to treatment and to detect possible side effects of treatment.

Venous Access Device

A venous access device (VAD), sometimes called a central line or a port-a-cath, is a permanent intravenous (IV) tube that allows medicine to be given and blood to be removed without painful needle sticks. It can be used to administer medications, chemotherapy, blood products, and nutritional support when needed, as well as to draw blood for testing. It is inserted by a surgeon in the operating room while the child is under anesthesia. You and your child's doctor will decide whether your child needs a VAD.

HOW CAN OSTEOSARCOMA BE TREATED?

Treatment for osteosarcoma includes both chemotherapy and surgery. Radiation is not usually used to treat this type of cancer. Your child's doctor will talk with you about the best treatment for your child.

Chemotherapy

Chemotherapy involves medicines that will help kill the cancer cells, shrink the tumor, and prevent it from spreading to new places. Several chemotherapy medications are known to be effective in killing osteosarcoma cells, but no single drug can control this disease by itself. As a result, chemotherapy medications are usually given in a specially sequenced combination. Most are given through the VAD. Your child's treatment, including the possible side effects of the chemotherapy medications, will be explained in detail by your child's doctor and nurses.

Surgery

The goal of surgery is to remove all of the tumor, as well as 5 mm of healthy tissue around it. There are several types of surgery available for patients with osteosarcoma, depending upon the location and the size of the tumor, whether the nerves and blood vessels are separate from the tumor, the age of the child, and the characteristics of the tumor (in particular, whether a bone fracture has developed). Before surgery is done, a conference will be held between your family and the members of the healthcare team.

Before the operation, the surgeon will tell you what to expect during the recovery period. After some types of surgery, the child must wear a cast or splint. Some children need to stay in bed for a few days. Physical and occupational therapy will help the child recover the function of the affected area after surgery. Some children benefit from going to a rehabilitation unit where they can receive intensive therapy for a few weeks. The timing of the surgery depends on the site and extent of the tumor, but it is often done after several rounds of chemotherapy have been given to help reduce the tumor size.

HOW LONG WILL MY CHILD'S THERAPY LAST?

The chemotherapy course of treatment can last 9–12 months. Each treatment usually lasts several days and is given in the hospital or clinic. Follow-up blood tests and physical exams between chemotherapy treatments are done in an outpatient clinic.

WHAT NEW METHODS OF TREATMENT ARE THERE?

There are not many new methods of treatment for osteosarcoma today, but researchers continue to investigate the use of monoclonal antibodies and their effect on the immune system and the cancer cells. 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 to a new (experimental) treatment that 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. Many clinical trials for children with cancer in the United States are managed by the Children's Oncology Group (COG), but large cancer treatment centers may have their own clinical research studies available.

Participation in clinical trials is voluntary. On one hand, because clinical trials involve research into new treatment plans, all risks cannot be known ahead of time and unknown side effects may occur. On the other hand, children who participate in clinical trials may 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 risks and potential benefits with your child's doctor and treatment team.

More information about clinical trials is available at http://curesearch.org/Clinical-Trials.

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

Your child's care requires a team approach. Because you know your child better than anyone else, the medical staff will need your help to manage the disease. It is important to communicate openly. Be sure to question your child's doctor or nurse whenever there is anything you are not sure 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 a recurrence?

Use this space to write down any 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 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 by anything anyone did to the child, anything the child ate, or anything that happened during pregnancy. It also was not triggered by the child's participation 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 venting your feelings will help you cope with this situation. Your child will benefit if family members continue to show they care through support and communication.

HOW CAN I HELP MY CHILD?

As a parent, you will often notice changes or symptoms in your child during that can make you feel even more helpless. It is essential to remember that, in spite of changes on the outside, your child is still the same person on the inside. Hair loss and physical alterations are temporary and often bother adults more than the child or their siblings and friends. All 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.

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. Like you, your child will need someone with whom to 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.

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 your child's new requirements, remember that he or she still has all the needs and rights of any growing, developing person. Do not avoid using direct terms and explanations with your child. They will tolerate treatment better if they understand it and are allowed to be active decision makers whenever possible.

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 while receiving therapy, so you will need to be flexible and creative. The child's food preferences and tastes may change throughout therapy. Numerous small meals are often easier to tolerate than three large ones. Children usually are more interested in eating foods that they help prepare. Include your child in the social activity of family meals even if they don't eat full meals. 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 their response to treatment. Some children tolerate chemotherapy better than others. Your child may not be able to attend school for extended periods, but 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 education programs that enable children to attend school while hospitalized.

School is important because it helps children 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 for your child to return to school as soon as he or she is medically able to do so.

ONLINE RESOURCES

CureSearch www.curesearch.org

National Cancer Institute, Bone Cancer http://www.cancer.gov/cancertopics/types/bone/bone-fact-sheet

American Cancer Society http://www.cancer.org/cancer/osteosarcoma/index

IMPORTANT PHONE NUMBERS

NOTES

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