



Cancer Connections Online Monthly Forum 2007 Archive Presentation

June 2007: Pediatric Oncology Support, by Sarah Blackburn,
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For this month we will be talking about Pediatric Cancer. First we will discuss briefly what cancer is, how it is treated and subsequently, how to cope with various age groups and the supports that are out there. I look forward to answering any of your questions and hearing you feedback.

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WHAT IS CANCER?

Cancer is one name for a group of diseases. Each type of cancer has its own name, treatment, and chances of control or cure. To understand cancer, you must first understand about cells. Cells are the basic building blocks that make up all the tissues and organs in the body. Cells divide to make new cells to replace damaged or old cells. Each cell has a nucleus (command center) that tells the cell when to divide and when to die. When cancer occurs, something goes wrong in the command center. The cancer cells grow out of control. Cancer cells divide when they shouldn't and stay alive longer than they should. Cancer cells can take the place of normal cells. A solid mass of cancer cells is called a tumor.

Types of Childhood Cancer

Cancer in children can be divided into three groups.

- * Leukemias are cancers of the blood.
- * Lymphomas are cancers of the lymph system.
- * Other common types of cancer in children are of the kidney, adrenal glands, brain, muscles or bone.

Your doctor and nurse will talk with you about your child's type of cancer.

How Childhood Cancer Differs from Adult Cancer

Cancers in children occur much less often and are different than in adults. Cancer in children usually grows in different types of body tissue. The most common sites of cancer in adults are skin, breast, prostate, lung, and colon. As previously noted, for children, cancers of the blood and bone marrow, lymph tissue, brain, nervous system, muscles, kidneys, and bone are most common. Cancer in children tends to respond better than cancer in adults to treatment.



Causes of Childhood Cancer

Many parents wonder what caused their child's cancer. They may fear that something they did or did not do caused the disease. As far as we know, nothing that you or your child did caused or could have prevented the cancer. We know that cancer is not contagious. You cannot catch cancer from another person.

Scientists are working to find the causes of cancer in children. For now, we do not know the exact cause of most childhood cancers. Only a few childhood cancers are hereditary (passed on from parent to child). Most parents think about what may have caused cancer in their child. Parents may feel responsible and blame themselves even though they could not have prevented the cancer. These feelings may be upsetting, but they are normal. If you have thoughts or concerns about what may have caused your child's cancer, talk to your doctor or nurse.

HOW IS CANCER TREATED?

Several different ways are used to treat cancer. As you read earlier, cancer cells grow out of control. Each type of cancer may be treated differently, depending on what researchers have found to be the most effective treatment in killing the particular type of cancer cell. In some cases, several types of cancer treatment are given. The main types of cancer treatment are described in the following section.

Chemotherapy

Chemotherapy is medicine that stops cells from growing or causes cell death. Each type of chemotherapy stops cell growth or kills cells in a different way. When chemotherapy destroys cancer cells, healthy cells may also be damaged. Chemotherapy can be given by mouth, or into a vein, muscle, or spinal fluid. You will receive written information about the different kinds of chemotherapy medicine that your child will receive. Common side effects of most chemotherapy medicines include nausea, vomiting, low blood counts, mouth sores, and hair loss. Some side effects happen right away while some occur months to years later. The type and severity of long-term side effects depends on the type of chemotherapy that is given. For example, some chemotherapy medicines can cause learning problems while others can cause problems with fertility.

Radiation Therapy

Radiation is the use of high-energy x-rays to kill or hurt rapidly growing cells, such as cancer cells. Radiation can also damage healthy cells. Unlike chemotherapy, radiation does not cause cell damage throughout the body. Radiation only damages cells in the area of the body where the radiation is given. If your child needs to receive radiation, the radiation field (area) will be measured precisely and marked on your child's body. This process is called simulation. Side effects of radiation depend on the dose received and the area of the body that is treated. Mouth sores are a common side effect of radiation to the head or neck. If the hipbones or spine are

radiated, blood counts may become low. Sometimes side effects of radiation are not seen for months or years. For example, radiation to the head and spine can lead to decreased growth, hormone production problems and/or learning disabilities. Radiation to the pelvis can cause problems with fertility.

Surgery

Different types of surgery are used to treat cancer. Taking out the tumor may be the only treatment needed, but usually chemotherapy or radiation is also used to kill any remaining cancer cells. Most surgeries take place in the operating room under general anesthesia.

Primary surgery

Primary surgery removes all or most of the tumor at the time of diagnosis. Sometimes, due to size or the area of the body, the tumor can not be safely removed right away. In this case, chemotherapy or radiation may be given before surgery to help shrink the tumor and make it easier to remove.

Second look surgery

Second look surgery is performed after treatment with chemotherapy, radiation, or primary surgery. Surgeons are able to see how well the treatments have worked in killing the cancer cells, and may be able to remove any remaining tumor.

Supportive care surgery

Supportive care surgery is done to help your child cope with cancer treatments. Your child may need to have a central venous line (catheter) placed in a vein in the chest. The line will allow treatments to be given and blood samples taken without your child being "stuck" with a needle. If your child is not able to take food by mouth, a gastrostomy tube (G-tube) may be surgically placed into your child's stomach. The G-tube can be used to feed your child until your child can eat things by mouth.

HELPING YOUR CHILD COPE

Cancer creates many changes and challenges for children and their families. As a parent or caregiver you may be asking:

- * What does my child know about cancer?
- * How will my child feel about the treatment?
- * How can I support my child?

Children of different ages understand and react differently to cancer and its treatment. Your child's personality, normal coping style, support system, treatment plan, as well as age or developmental level will affect how your child copes with cancer. When children are faced with stress their normal behaviors may change. They often become more dependent on adults or may

act younger than their age (baby talk, wetting pants after being potty trained, etc.). Your child may not know how to handle the many feelings that have been caused by the cancer diagnosis. You are a very important part of your child's life for many different reasons. You know what your child has experienced in the past and how your child usually handles stress. You can help the health care team to understand your child. You and the health care team can work together to find new ways to help your child cope with cancer and treatment. In the following section, common responses of children of different ages to stress and cancer are described. The section also contains specific suggestions for how to help children in each age group cope.

Infant (birth - 12 months)

Infants look to their parent(s)/caregivers to meet their needs. They rely on adults for food, comfort, play, and care. Infants learn about the world around them through their senses (i.e. can sense new smells, colors, tastes) and trust in people and things that are familiar. Infants have no concept of the meaning of cancer or its implications. They do respond to the new people and the environment around them.

Issue

- How you can support your infant
- Separation from familiar people
- Be with your infant as much as possible.
- Leave a shirt with your smell on it if you need to go.
- Rock or hold your infant when in the hospital.
- Keep a familiar blanket and toys in the crib.
- Fear of strangers
- Have familiar people care for your child. Limit the number of people and voices in the room.

Development

- Let your child explore toys with hands and mouths. (Check for small pieces that may choke your infant.)
- Use gentle touch and massage to comfort your infant. Talk to and play games, like peek-a-boo, with your infant like you would at home.

Sense of safety

- Keep your infant's crib safe. Ask that any procedures be done in the treatment room.
- Wake your infant before a painful procedure.
- Continue or develop familiar feeding, bedtime, and bath time routines, like rocking, touch, singing.

Toddler (12 months - 3 years)

Toddlers are beginning to want to do more on their own. Your toddler's favorite words may be "me do" or "no." Growing toddlers need to be able to do some things by themselves to promote a sense of control. Toddlers show you how they feel in their actions because they do not have the words to describe their feelings. They have a hard time understanding how the body works. Toddlers tend to think that they make things happen. They can create their own false ideas about how they got sick and what happens to them (I hurt because I was bad).

Issues

- How you can support your toddler
- Fear of separation
- Be with your toddler as much as possible.
- When you leave, tell your toddler where you are going and when you will be back.
- When you are gone, leave something of yours, like a picture or shirt, for your toddler to keep until you return.

Fear of strangers

Have familiar people care for your toddler. Provide security objects like a blanket or stuffed animal.

Loss of control

- Let your toddler make choices whenever you can. Apple juice or orange juice?
- Do not offer a choice when no choice exists. Are you ready for your medicine?
- Give your toddler a job to do. Hold this band-aid.
- Let your toddler play and be in control of the game or activity.

Loss of normal routine

- Try to keep eating, sleeping, and bathing routines as normal as possible.
- Let your toddler play with favorite toys.

Behavior changes

- Give your toddler safe ways to express anger and other feelings. (Play-Doh, painting, building blocks)
- Tell your toddler that it is all right to feel mad or sad.
- Spend time with your child and offer reassurance.
- Set limits with your toddler and discipline when needed.

Fear of treatment

- Assure your toddler that he/she did nothing wrong.
- Keep security objects, like blankets, pacifiers, favorite toy, nearby.
- Tell your toddler what will happen just before the treatment or procedure.
- Use simple words, pictures, or books to tell them what will happen.

Preschooler (3 years - 5 years)

Preschoolers are also trying to do things on their own. They take pride in being able to do things for themselves; "I can do it." Preschoolers are learning more words to tell you what they think and feel. However, they often use their play to tell you these same things. They can see the hospital and treatment as punishment for something they did wrong. Also, they often get confused by adult words and make up reasons for the things that happen.

Issues

- How you can support your preschooler
- Magical thinking (Made up reasons for what happens)
- Tell your child what will happen a little before the treatment.
- Use of terms that your child may not understand (A CAT Scan has to do with a cat.)
- Use simple words, pictures, or books to tell your child about what will happen.

Fear of harm to their body and the unknown

Let your child play with doctor kits and safe medical supplies like a blood pressure cuff.

Loss of control

- Allow your preschooler to make choice whenever you can. Apple juice or orange juice?
- Do not offer choices when choices do not exist. Are you ready for your medicine?
- Give your preschooler a job to do. Hold the band-aid.

Loss of normal routines

Praise your child for doing things independently. Dressing, brushing teeth, feeding.

Behavior changes

- Give your preschooler time to adjust to new changes.
- Use play to help your child to show feelings.

School Age (6 years - 12 years)

School age children take pride in being able to do most things by themselves. They enjoy school because it helps them to learn and master new things. Their friends are becoming more important. School age children are able to think in terms of cause and effect and have a better sense of time. They have more words to describe their bodies, thoughts, and feelings. School age children can also understand more of how their bodies work. However, they still may have a hard time with, and be confused by, medical words.

Issues

How you can support your school-aged child

- Loss of control
- Allow your school-aged child to make choices whenever you can.
- Do not offer choices when no choices exist. Give your school-aged child a job to do.
- Let your school-aged child practice things that are new and scary.
- Let your school-aged child go to school or do school work and activities.
- Provide games, play, and activities.

Being away from friends and school

- Have your school-aged child write letters or call friends.
- Let friends visit when your school-aged child feels well enough.

Fear of harm to body and unknown

- Use simple works, pictures, or books to tell your school-aged child what will happen.
- Tell your school-aged child what will happen a few days before the treatment, if possible.
- Let your school-aged child play with safe medical supplies like a blood pressure cuff.

Teens (13 years - 18 years)

Teens are beginning to see themselves as individuals in the world. They are striving to be independent from the adults around them. As teens strive to think and act for themselves, their peers become even more important. Teens want to be like their friends and are concerned with how they are viewed by others. Illness and treatment cause teens to be different when they are trying so hard to be the same. Teens are able to see not only cause and effect, but also can see things from many points of view.

Issues

How you can support your teen

- Loss of control
- Allow your teen to make choices whenever you can.
- Loss of independence
- Let your teen be active in social and school activities.
- Involve your teen in the treatment plan by including them when talking to the team about the plan.
- Encourage your teen to do self care as much as possible. Bathing, dressing, grooming, eating.

Body image

- Give your teen chances to talk about physical and emotional changes.
- Tell your teen that having feelings about illness and treatment is all right.



- Self-esteem
- Point out things that your teen does well. Allow your teen to do things that makes him/her feel good about himself/herself.

Loss of privacy

Respect that teens may need to do some things by themselves when possible. Bathroom, phone calls, email. Offer your teen private time.

Separation from peers

- Encourage time with peers.
- Allow friends to visit or call in the hospital or home.

Concern for the future

- Answer questions openly and honestly.
- Help your teen plan for the future.
- Encourage your teen to keep doing normal things like school.

Behavior changes

- Give your teen safe ways to express feelings, especially anger.
- Physical activity, talking, writing.
- Assure your teen that all feelings are normal: Guilt, fear, sadness.

CARING FOR THE WHOLE FAMILY

Coping with Your Feelings

Since the time of your child's diagnosis, your lives have not been the same. The diagnosis of cancer brings changes to your life and the lives of the whole family. Every family is different. Each family has ways to cope with stressful experiences. Many families have told us about feeling fear, anger, depression, and guilt. All these feelings are common human emotions. You are not alone. Talking with family and friends, a member of the health care team, or another parent of a child who has cancer may be helpful. By sharing these feelings you may find it easier to cope with the changes you are experiencing.

Fear

The time of diagnosis is often the most difficult. The fear of the unknown may be overwhelming. This experience may be your child's first hospitalization. Dealing with the stress of your child adapting to a new and sometimes frightening environment may be difficult. You may also have

fears about treatment, your expenses, or how you will help your child to cope with cancer. Talking about these fears and getting them out in the open can be helpful. The health care team is here to listen to your concerns and help you.

Anger

At times you may feel very angry at what is happening. Some families are angry with God or a cruel fate for singling them out. Some are mad at the health care team for not finding an answer to what is happening with their child. You may even feel angry with your child for getting sick and turning your life upside down. Feeling angry is a normal reaction. Finding a safe outlet to let off steam may be helpful. For example, take a walk or talk with someone to let the tension out.

Guilt

Parents often feel guilty for not knowing that their child was sick. Many parents wonder if they did something to cause their child to get cancer. Siblings may also feel guilty that they are healthy. Young children often experience "magical thinking" and may feel that they caused the illness (We had a fight and I wished he would die!). Everyone in the family needs to be assured that they did not cause the cancer nor could they have done anything to prevent it.

Depression

People use depression to describe a range of emotions and behaviors. Feeling "blue" or sad is a normal reaction to the diagnosis of cancer and the treatment demands. The diagnosis may also require changes in family routine and bring feelings of social isolation. These changes and losses may produce grief reactions. You may notice symptoms of grief, such as crying spells, decreased appetite or compulsive eating, lack of interest, decreased energy, lack of concentration, poor problem solving, and physical symptoms such as tightness in the chest or headaches. With the support of family, friends, and the health care team, most parents are able to work through these emotions and use coping skills that are needed to meet care demands. Individual or family counseling allows parents a way to discover their strengths within. Sometimes parents find that their emotions are so overwhelming that they feel that they cannot cope with the demands being placed on them. When other life stressors, such as death, loss of a job, moving, marital problems, divorce, emotional problems, or substance abuse existed prior to the diagnosis, the situation may be more difficult. It may help to discuss your feelings with a trusted member of the health care team. Counseling and medications are available and may be needed.

Coping with Your Child's Illness

Some suggestions to help you cope with your child's illness include:

- * Make a special effort to find a private time to talk with your spouse or a close friend. Try to talk about things other than your sick child.
- * Try not to talk about your child in his/her presence unless he/she is included in the conversation.

- * Find ways to reduce stress. You know what would work best for you. Some people exercise, while others enjoy reading or shopping.
- * Try to take turns with your spouse or other support person when staying with your child in the hospital or coming for clinic visits. Both parents can be involved with the child's treatment. Sharing responsibilities also reduces the gap that may grow between parents when one is more involved in care than the other.
- * Ask a member of the health care team for help and support.
- * Talk to other parents of children with cancer.

Impact of the Child's Cancer on a Marriage

A chronic illness can quickly turn a family's life upside down. Parents often become exhausted trying to cope with the needs of the child and the rest of the family. Many parents try to continue to work at their jobs and keep the home routine as normal as possible. Many couples feel a strain on their relationship. Parents often say that they do not have time for each other. They may feel angry and frustrated with what has happened to their child. Three things may help prevent the breakdown of a marriage: respecting coping styles, maintaining communication, and accepting changing roles.

Respecting coping styles

Each person responds differently to stress. Some parents may withdraw, others may cry or get angry, while others may cope by gathering information. Parents need to learn and respect the different ways each has in coping with the child's illness. Try to understand where your partner is in accepting what is happening.

Maintaining communication

The key to any successful relationship is communication. The need to talk about feelings, fears, appreciation, and information is even greater during times of stress. Silence can make you feel separated from your partner. By sharing feelings and information you can stay connected and be better able to make decisions.

Accepting changing roles

The demands of illness and treatment can change the roles of family members. For example, the husband may have been the decision-maker in the family, but now the mother is making the decisions with the health care team because the husband is at work. Another example would be if the mother is used to taking care of the home, but doesn't have time because she is caring for the child in the hospital. An older sibling, other family member, or friend may have to help out more in the home. The change in roles can cause stress within a marriage or family. Some temporary role changes may be necessary to support the ill child. Some role changes may become permanent, if the changes help improve how parents or family members work together.

Impact of Cancer on Siblings

Brothers and sisters of a child with cancer may have many different feelings and responses. Often they have needs similar to their sick brother or sister. They may feel upset, scared, and unsure of what the future holds. Siblings may fear the word cancer and worry about death. Regardless of age, they will sense a change in their family life. While siblings may feel sad and worried about their sick brother or sister, they may also feel some resentment or anger. Mom and Dad are spending all of their time with or talking about the sick child. Friends and family send gifts and money. Children, especially young ones, may feel jealous. Siblings may also feel sad and cry easily. Often siblings have problems of their own, such as depression, trouble sleeping, physical complaints or problems in school.

How to help siblings

The following suggestions may be useful in helping your other children cope with their brother or sister's illness:

- * Try to spend time alone with your other children, doing things that are of interest to them.
- * Let your other children know they are still loved and important to you.
- * Talk with your other children about the diagnosis, treatment, and effect on their brother or sister. What you tell them will depend on their ages and ability to understand. Assure them that cancer is not contagious and they are not responsible for their brother or sister getting cancer.
- * Take your other children with you to the hospital to help them feel involved in the care and treatments of your sick child. Taking them to the hospital or clinic may help to decrease their fears and help to keep a feeling of closeness with their brother or sister.
- * Ask a loving friend or relative to stay in your home, rather than send your children elsewhere.
- * Allow your children to help with chores at home to help them feel needed and help you too.
- * Talk with your children's teachers. Teachers can be supportive to your children and let you know about any school-related problems.
- * Ask for help from a member of the health care team

Impact of Cancer on Grandparents

Grandparents have a variety of responses when they hear that their grandchild has cancer. Like you, they may feel shock and disbelief. Grandparents may feel guilty for living a long life. They may also feel they are responsible, thinking they in some way passed cancer through the family. Grandparents may also feel sadness, not just for their grandchild, but for their son or daughter as well. Grandparents can be a great help to you and your family. If they are still in good health and can be with you, they can relieve you in the hospital or help you at home. A grandparent may also give your other children the attention, comfort, and love that they need. Grandparents can also serve as contact persons. They can give information to other family members, so you don't have to spend as much time on the phone or emailing. Including grandparents in meetings with the health care team can help them to understand the plan of care for their grandchild.



Disciplining Your Child with Cancer

From the moment a child is diagnosed with cancer, the normal family routine is disrupted. The child becomes the center of attention of family members and friends. Often, the child receives many gifts. Although the child may feel sick, gifts and attention are still fun. Children can get use to being "special" and want the special treatment to continue. Discipline problems are most common when the special attention stops and normal activities resume. The illness itself can also interfere with discipline. Children are likely to act more immature and more dependent when they feel sick. Pain and the side effects of treatment can make any child irritable. Many medicines, like steroids, can also cause irritability. These behavior changes can make it difficult to know what is reasonable to expect of your child. Many parents feel helpless and guilty when they see their child suffer. You may feel the need to make up for the suffering by giving special privileges. These feelings are normal. However, becoming too lenient is a problem too. Children expect and need adults to give them structure. Rules and limits provide security. If a parent does not expect the child to behave or follow the same rules that were in place before the illness, the child may think the illness is worse than he/she has been told. The child may think that the condition is hopeless. Keep in mind the following guidelines when deciding on how you can provide limits for your child:

- * Set clear, consistent, and age-appropriate limits.
- * Adjust your expectations to your child's current condition. If your child is not feeling well, "please" and "thank you" may not be reasonable with every request.
- * Use praise and attention to reward good behavior.
- * Use alternatives to spanking. Try using a "time out" approach or taking away privileges.