



Psychosocial Services *An Educator's Guide*

Welcoming the Child with Cancer Back to School

 The Children's Hospital
of Philadelphia®

CANCER CENTER

c a n c e r . c h o p . e d u

Unity

I dreamed I stood in a studio
And watched two sculptors there.
The clay they used was a young child's mind.
And they fashioned it with care.
One was a teacher; the tools he used
Were books and music and art.
One a parent with a guiding hand,
And a gentle loving heart.
Day after day the teacher toiled
With touch that was deft and sure,
While the parent labored by his side,
And polished and smothered it o'er.
And when at last their task was done,
They were proud of what they had wrought.
For the things they had molded into the child
Could neither be sold nor bought.
And each agreed he would have failed
If he had worked alone.
For behind the parent stood the school,
And behind the teacher, the home.



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Introduction

The staff in the Division of Oncology at The Children's Hospital of Philadelphia realizes that educating a child with cancer can be challenging and sometimes overwhelming. The following information is intended to guide you through the experience.

At The Children's Hospital of Philadelphia, we believe in a team approach. The treatment team consists of an oncologist, primary nurse, social worker, nutritionist, psychologist, child life specialist and Hospital teacher. The team members follow the child's treatment and communicate on a regular basis with one another and the family.

The staff at The Children's Hospital of Philadelphia is available to you as a resource and for support. Together, we can facilitate the child's successful reintegration back into the classroom. From the beginning, we emphasize the need to make the child's life as normal as possible. Thus, we encourage children to return to school and to resume socializing with their peers as they had done prior to diagnosis. As educators, you play an important role on the child's team in helping the child with cancer return to school.

This book is intended to be a helpful resource in understanding more about cancer and how it may impact the child. Medical information, such as types of cancer, cancer treatments and treatment side effects, are provided. Information regarding the emotional needs of children with cancer and children in your class is also included to help you learn about the reactions these children may have to the child with cancer returning to school. School re-entry and other academic-related information is discussed to help you become more comfortable in dealing with what to expect and how you can help with the child's return to school. Finally, information for both you and the school nurse is provided, such as important contact information and steps to follow in case the child with cancer becomes ill at school.

Medical Information

Medical Diagnoses

Numerous types of cancers are common in children. It is important to realize that most common cancers seen in adults (such as breast cancer, lung cancer, skin cancer and ovarian cancer) are rarely seen in children. Childhood cancers tend to respond better to treatment, and children more easily tolerate treatment. The following is a list of some of the common cancers found in children.

Cancer: Used to describe many diseases that involve cells that grow and reproduce in an abnormal, uncontrollable manner.

Leukemia: The most common form of childhood cancer, leukemia is an abnormal number and type of white blood cell produced by the bone marrow. It is characterized by the presence of immature, malignant white blood cells, called "blasts." These blasts are produced by the bone marrow and accumulate in the blood, bone marrow and other organs. Leukemia is most often treated by chemotherapy.

Brain tumors: Collectively, these are the second most commonly occurring cancer in children. Typically, surgery, radiation therapy and/or chemotherapy treat these tumors. Size, type and location of the tumor determine overall prognosis.

Sarcomas: This type of tumor can occur throughout the body. Osteogenic sarcoma is a type of bone cancer that most frequently involves the large bones of the upper arm or leg. Ewing's sarcoma can occur in almost any bone in the body but usually occurs in the spine, ribs, or pelvis. Rhabdomyosarcoma is a tumor that arises from soft tissue and the head and neck are the most common sites.

Lymphomas: A group of malignant diseases that affect the lymph system and tissues. Hodgkin's disease is the most common of the lymphomas. It involves lymph nodes near the surface of the body. Non-Hodgkin's lymphoma tends to develop in the bowel and in the midsection of the chest.

Retinoblastoma: The disease in which a malignant tumor forms in the retina of the eye. When the tumor is very large, it is usually necessary to remove the entire eye. Radiation therapy and sometimes chemotherapy are also used as treatment options.

Neuroblastoma: A disease that develops in young nerve cells, these are tumors of the nerve tissue that involve the sympathetic nervous system. They are commonly found above the kidneys in the adrenal glands. However, they can also be found in the chest, pelvis and neck. The disease is treated with surgery, radiation and chemotherapy.

Wilm's tumor: The most common kidney cancer occurring in children. It generally occurs in young children under the age of 7, with the majority of cases in children ages 1 to 4. This cancer is highly curable.



Treatment

Cancer treatment usually involves one or all of three methods—surgery, radiation and chemotherapy. Surgery is usually performed to determine if the tumor is malignant or benign, to remove the tumor if cancer cells are found and to see if the cancer has spread to other areas of the body. Radiation therapy uses X-rays to destroy the abnormal cells in the body and is most often used with chemotherapy treatments. Chemotherapy consists of administering doses of medicines that kill cells. The chemotherapy can be administered directly into the vein, orally through pills or given as an injection into a muscle.

In some cases, to improve the child's chances of achieving full remission or cure, a bone marrow transplant may be an option. This procedure involves taking bone marrow or stem cells from oneself or a matched donor.

Every child follows an individualized treatment plan that may last for several years. Many forms of cancer will require the child to visit The Children's Hospital of Philadelphia's outpatient clinic at least once a week when the child is not hospitalized.

Side Effects of Treatment

The treatment for cancer can result in immediate and long-term complications. Some common side effects are hair loss, fatigue, nausea, vomiting, susceptibility to infection, irritability, mood swings, bruises, behavior changes, weakened muscles, sleep problems, headache, poor concentration and coordination, and weight loss or gain. Depending upon the child's treatment and cancer type, hearing loss, vision loss, partial paralysis, growth delays and heart damage may also occur.

When surgery is part of the child's protocol, the child may also have to deal with possible amputation, scars and other permanent physical changes.

A child who undergoes a bone marrow transplant will have an extended hospitalization in isolation. There are also restrictions on when the child can go back to school once he or she has been sent home from the hospital after a bone marrow transplant.

Emotional Needs

Emotional Reactions to Cancer Diagnosis

A child with a new diagnosis of cancer is likely to exhibit many different feelings, including sadness, frustration, anger, fear, guilt and confusion. It is important for teachers to realize that all these feelings are normal and that children need support in order to work through this difficult time. A child's understanding of what cancer is and how it will affect his or her life depends on his or her age and developmental level. However, regardless of their age, all children need ongoing support and reassurance that cancer has not changed who they are.

Early School-age Children (Preschool—3rd grade)

At this age, children are most distressed about the elements of treatment that are frightening, such as getting needles and procedures they will endure. They see things in a concrete, immediate context and are not able to grasp the severity of their illness.

School-age Children (4th-6th grade)

During this period, children are more able to focus on peer reactions and not being able to do all of the things other children are doing. They also tend to have a better understanding of what cancer is and how it affects their health. For example, school-age children can understand that they need to take medication to improve their health.



Adolescents (7th-12th grade)

When it comes to cancer, teens are unique. While these young people may be facing cancer, they're also confronting all the usual issues of adolescence. After cancer diagnosis, they may feel very alone and dependent on others. Feelings of sadness and depression are also common. They may realize that they will not be able to do some things that are important to them for a long time, if ever. They feel sad when they realize they are now different from their peers. Illness and treatment cause teens to be different when they are trying so hard to fit in. They think about the changes in their body that will result from cancer and its treatment, and feel depressed about how they will look and how their friends may see them. They may also feel hopeless, and fear that the treatment will not work. During this period, adolescents may also focus on the meaning of life and the cancer's effect on their identity. They may joke around about their cancer, distract from it, try to "think positively," or even rebel against parents, doctors and treatments.

Emotional Reactions to Returning to School

Children and the adults in their lives have many concerns about returning to school after extended absences for treatment and hospitalization. It is necessary to be aware

of the child's needs upon returning to school, but teachers should also be aware of the concerns of parents and themselves.

Early School-age Children (Preschool — 3rd grade)

Children at this age may tend to feel some degree of fear and anxiety about returning to school. If they have not been to school even for a short period of time since their diagnosis, they may display school phobia.

School-age Children (4th-6th grade)

These children may also display some school phobia if there has been little to no interaction with the school during diagnosis and treatment. Children at this age may begin to feel stressed and overwhelmed. Children at this age who have had little or no contact with peers since diagnosis may begin to feel depressed, anxious and have lowered self-esteem.

Questions Commonly Asked by School-age Students

Q. *Can you catch cancer like you catch a cold?*

A: No, you can't catch cancer like you catch a cold or the flu. Cancer occurs when there are sick cells inside our bodies and they can't be spread to anyone else.

Q. *Why did (student) lose his or her hair? Will it grow back?*

A: (Student) lost his or her hair because he or she needs to take special medicine to get rid of all the sick cells in their body. This medicine sometimes also gets rid of some healthy cells too, like hair cells, because it's trying to do a really good job of making (student) well again. (Student's) hair will grow back after he or she is done taking their special medicine.

Q. *Did (student) get cancer because he or she was bad? Is this punishment?*

A: No, (student) was not bad and getting cancer is nobody's fault. Sometimes the doctors know why someone gets cancer and other times they don't but they always know how to help them.

Q. *Will (student) come back to school for good?*

A: Sometimes kids with cancer come back to school for good but other times they need to return to the hospital every once in awhile to get better. We don't know for sure what (student's) schedule will be like but I know we'll all be happy to see him or her when he or she is here.

Q. *What is chemotherapy? What is radiation?*

A: Chemotherapy is a special mix of cancer fighting medicines and radiation is a special cancer fighting beam. The doctors give both of these treatments to people with cancer to help them get better.

Q. *Can you die from cancer? Will (student) die like my grandpa died?*

A: Some people do die from cancer but many, many kids get better. The doctors are very good at helping kids get better and back to being a kid.

Q. *Once cancer goes away, can it come back?*

A: Cancer can come back but that does not happen all of the time. If it does happen, (student) can go back to his or her doctor for help.

Q. *Can (student) still go to gym class with us when he or she comes back?*

A: (Student's) doctor will tell him or her if he or she is able to go back to gym class. But, even if (student) can't go to gym class now doesn't mean he or she may not be able to go later. There are lots of things that (student) will work back up to again.

Q. *What does (student) do when he or she is in the hospital?*

A: (Student) does many different things at the hospital. He or she talks to the doctors, gets treatment and

sometimes even gets to play games. Other times, (Student) is just resting and getting better. He or she can read and watch movies and play games in their room or in other parts of the hospital too.

Q. *Is (student) still our friend?*

A: (Student) is definitely still your friend. Just like you miss him or her while he or she is away, (Student) misses you too. A really great way to be a good friend to (Student) during this time is to stay in touch. When people are in the hospital, they love to hear from their friends. There are so many ways to stay in touch like email, phone call, text, video messaging or writing him or her a letter or sending them a card.

Adolescents (7th-12th grade)

Adolescents may experience a variety of emotions about returning to school. Teens may be eager to return to school both to reintegrate with peers and to gain a renewed sense of normalcy. They may have anxiety about having to go back after a long absence or perhaps having to repeat a year of school. Older kids and teens may not want to go back to school because they look different, or because their long absences may have changed their social standing with friends. If treatment has changed the way they learn, that may also be frustrating and hard to deal with. Students may or may not verbalize their concerns depending on their comfort level. Attention should be placed on addressing these concerns whether or not they are verbalized.

Adults

Parents also have emotional reactions to their child returning to school. They may worry that their child will get an infection. Parents may also worry that going to school is an additional stressor for their child at this time. They are likely to feel not only anxious and reluctant about their child going back to school, but also vulnerable and afraid for them as well.

Teachers also have reactions to having a student in their class with cancer. You may have the fear of not knowing what to expect physically of the child. You may be overwhelmed with all that is going on and be unsure of what to expect from the child academically when he or she returns to the classroom. Personally, you may have feelings of shock, worry and grief over the illness and be unsure how to handle the student's needs. It is important that you seek answers to the many questions you have so that everyone can work together. It is vital that teachers address the student's specific needs.

School Nurses

Including the school nurse in discussions is helpful as well. The nurse may be needed if the child feels ill at school or requires the administration of medications or other health services throughout the school day.

Common Peer Misconceptions and Fears

Early School-age Children (Kindergarten-3rd grade)

Children at this age may believe that cancer is a virus or a flu that you can catch like a cold. Students in the classroom may also believe their peer became sick because they did something bad (i.e. said a “bad word”). Students may also believe that cancer has changed their classmate and that he or she isn’t the same person as before. It is important to address and correct these fears and misconceptions in order to communicate accurate information to help prevent the child with cancer from being isolated from his or her peers.

School-age Children (4th-6th grade)

Students in this age group need help differentiating among diseases. It is important to review how diseases are spread. At this age, children understand that you can’t catch cancer like the flu. Students at this age are also able to understand how the child with cancer feels, and they can place themselves in that child’s position. It may be helpful to facilitate a discussion in which you ask the students about things that might help them feel better if they had cancer or if they had to be in the hospital. This can help students relate to their peer. This is a good way to learn more about students’ misconceptions. For example, children may know an elderly relative who has died of cancer and associate this experience with their peer. Teachers can help children to understand the differences between adult and childhood cancers as well as help children understand that every situation is unique.

Adolescents (7th-12th grade)

Students at this age may want to know about the scientific basis for the disease and may understand the need to treat their classmate with cancer the same as others. They may also be able to empathize with the child with cancer and want to know about the probability of getting cancer. Young people who are educated about cancer may grow up to be compassionate adults who will reach out to others in times of need. Providing straightforward, reassuring answers to children’s questions can help turn anxious classmates into supportive friends.

For the Teacher

How Teachers and The Children’s Hospital of Philadelphia School Program Can Work Together

School is an integral part of every child’s life. Children with cancer can continue to stay involved with their schoolwork through daily participation in The Children’s Hospital of Philadelphia School Program. The main goals of the School Program are to help the child maintain and develop new academic skills and to make the transition from the Hospital back to school as smooth as possible. The program also helps reduce the stresses of hospitalization by helping the child participate in the familiar and “normal” school activities.

The Hospital School Program is staffed by certified teachers. They see the children for approximately one hour each. The children are grouped together based on age and educational needs. Bedside tutoring is also available. The educational services that are available are academic assessment, direct instruction and school re-entry facilitation.

You can work with the program by sending your student’s work to the Hospital so the Hospital teachers can help keep your student on track. Determine what is most important for the student to focus upon given the limited amount of direct tutoring. Give written expectations to the Hospital program for prolonged hospitalizations, and devise a plan to reach these goals. Send textbooks and assignments to the Hospital in order to maintain consistency. It is also possible to fax tests and new assignments to the patient in the Hospital. The Hospital teachers can then monitor the patient and return the material when completed.

Communication and consistency are most important in successfully working together to help children with cancer. Do not hesitate to call the Hospital School Program with ideas and suggestions to help your student stay on track and to maintain as much normalcy as possible. Once children miss an extended amount of time away from their schools and peers, attending school in the Hospital becomes a motivating factor to get back to school. Therefore, by sending assignments and keeping the class in touch with the student, it makes a difficult time a bit easier.

Teachers and Classmates Can Help Ease the Transition Back to School

- Encourage the class to brainstorm ideas on how they can support the student who is undergoing cancer treatment. Kids tend to have great ideas.
- Call or e-mail the student while he or she is in the Hospital or at home.
- While staying in the Hospital, a student can establish an e-mail account through a free web-based company on the internet. Obtain the student's e-mail address at the Hospital and keep in touch. Have the class take turns writing to the student. Keep the student up-to-date on the happenings at school. Send virtual cards through www.chop.edu.
- Record class activities to share with the student who might appreciate seeing his or her friends at school. Things to record include birthday parties, guest speakers, special events and field trips. Maybe the class could write and perform a skit for the student.
- Make bright and cheery posters for the student to hang up in his or her hospital room.
- Remember to keep in touch throughout treatment and not just when the child is first diagnosed.
- Create a memory book for the student. For example, have each student in the class put his or her picture on a page and then write a message to the student in the Hospital. Classmates might also want to create games, such as word searches and crossword puzzles, to include in the special book.
- Organize a fundraiser to help raise money for the child's family (e.g. penny drive, button sale, dance-a-thon, bake sale, etc.).
- Design and create a quilt for the child. The quilt can then be used when the child is in the Hospital and clinic.
- Allot some time for the Hospital's education liaison social worker to talk to the class about the student's illness. The child and parents often enjoy participating in this program.
- Incorporate a lesson about cancer into health or science class. Allow the student to help prepare the lesson or personally present it if he or she is comfortable with the idea.
- Encourage the student to make a show-and-tell booklet for the class. This booklet could include pictures of the Hospital and clinic.

- Include the student in as many school activities as possible. The student might be unable to attend school for an entire day but may be able to participate in a class party or field trip.
- Remain flexible throughout treatment. Support the student and family's needs as they arise.

Preparing a Class Discussion

As the liaison between the child with cancer and the other children in the class, teachers are in an excellent position to prepare a class discussion. Here are some general guidelines to follow when preparing the class discussion that will take place either when the student is diagnosed with cancer or when the student with cancer returns to school. Ideally, the student should be present and actively participate in the class discussion. It is important to recognize that every presentation will be different depending on the type of cancer, the prognosis and the age of the child. Having the child actively participate helps the class realize that it's okay to talk about cancer. It also gives the class a direct opportunity to ask the student questions and for you, the teacher, to intervene as necessary. However, it is important to respect the patient and family's wishes about whether a class discussion should be held. Families may decide not to have a formal class discussion. Therefore, both parental and child permission is vital before planning the discussion.



Discussion of General Medical Experiences

If you hold a discussion, present a simple but factual explanation of the illness. When addressing student concerns, one useful technique is to ask “How would you feel if you had to stay in the hospital or had a serious illness?” and “What would help you feel better if you did?” This is also a time for students to ask questions and for the facilitator to clarify any misconceptions. It is important to discuss the student’s particular disease and to explain its causes. Every class discussion will be different depending on the child’s condition and unique issues.

Having the child actively participate helps the class realize that it is acceptable to talk about the condition. It also gives the class a direct opportunity to ask the student questions and for the teacher to intervene as necessary.

Presentation of Illness

Depending on the age of the students, continue with a discussion about diagnosis and what treatments the student will or did have to undergo at the Hospital. Ask the students, “What helps you get better when you are sick?” When they answer “medicine,” begin to explain chemotherapy and radiation in an age-appropriate manner.

Discussion of Side Effects

Explain what can happen when the good medicine kills the bad cells. Sometimes it can make you lose your hair, lose or gain weight, feel tired, have nausea, etc. Have the student talk about losing hair, and explain that when he or she is done with treatment it will grow back. If the student is comfortable, have him or her explain how treatment made him or her feel.

Dispelling Myths

Explain that cancer doesn’t change the student. Ask questions like, “Do you still think that [student] likes to go to the movies and eat popcorn?” The class will respond, “Yeah!” Ask the students if they think they can catch cancer if they sit next to [student] in class. Some, depending on age, may answer yes. Explain that cancer is not a virus like a cold or chicken pox—you can’t give it to one another. Reassure classmates that it does not spread like a cold or the flu.

Encourage Peer Support

Support students’ suggestions and offer advice about how to be a good friend and support [student] throughout his or her illness. Ask the class:

- “Do you think it’s hard for [student] to get all those needles and lose his or her hair?” “Yes!”
- “Do you think it’s hard to come to school when you feel tired and sick?” “Yes!”
- “Do you think kids should tease [student] because he or she has cancer and the medicine made her lose her hair? No!”
- “What will you do if other kids start teasing her?”

If a Student Dies

Coordinating with their school and crisis team, teachers can support classmates dealing with the loss of a student in the following ways:

- Develop a plan for supporting family members, especially siblings who attend the same school.
- Maintain open communication among the students who wish to talk about the death of the child. For young children, it may be necessary to have some discussion about what happens when someone dies (i.e., the body doesn’t breathe or see or feel anymore).
- Clarify any misconceptions students may have about what death is or why the child is no longer a part of the class.
- Provide healthy ways for the students to express their feelings regarding the loss of their classmate (e.g., send a card to the family, write a letter to the child, paint a picture of the child, make a scrapbook of the class and include the child who is gone, read a book about death or change).
- Provide a time and place away from classmates for those children who may need some time alone to grieve the loss in their own way.
- Continue the classroom routine as much as possible and try not to change expectations of the students. Stability will help decrease their feelings of helplessness.
- Keep listening and observing. Those students who cannot verbally express their feelings about the loss will revert to displaying nonverbal signs such as anger, frustration, acting out, anxiety, withdrawal or aggressiveness.
- Explore resources at your school, local children’s hospital or community agencies.

School Re-entry:

How The Children's Hospital of Philadelphia Can Help

School is an important part of a child's life. Disruptions to the school schedule as a result of cancer treatment can make the return to school difficult. It may be helpful to consider inviting a Children's Hospital of Philadelphia representative (usually a child life specialist or social worker) to come to the school for a short presentation about The Children's Hospital of Philadelphia and to help lead a class discussion. This individual will be able to answer questions that you are unable to answer and will be able to respond to additional questions you may have. Such a presentation can help to ease the transition back into the school environment. Parent and child permission should be obtained before any such presentation occurs.

Steps for School Re-entry

- Identify an individual from the school who knows the student and the family, and who feels comfortable intervening for the student.
- This individual should contact the primary caregiver to discuss what types of accommodations the child will need to maintain academic progress. If desired, the primary caregiver may arrange for a school conference with all of the student's teachers. Other people who would be helpful in the meeting are the school nurse, guidance counselor, school psychologist, principal and the social worker or child life specialist from The Children's Hospital of Philadelphia.
- At the conference, school personnel should ask the student's caregiver what they and their child would like shared with the student's classmates, teachers and the rest of the staff. The comfort level for disclosing information varies greatly from family to family, so it's best to ask.
- Establish an Individualized Health Plan (IHP) based on the teacher and primary caregiver's expectation from the conference. Also, consider formalizing IHP in 504 Service Plan or IEP.
- Facilitate tutoring and/or intermittent instruction when the student is unable to attend school as appropriate.
- Continually reevaluate the student's needs to determine if they are being met. Revise the IHP as necessary.
- Maintain regular communication with the primary caregiver and the Hospital School Program. Don't hesitate to call the Hospital with any questions (check with the guidance counselor — you may need a parent-signed release of information).

Academic Impacts

A child's overall ability to keep up in the classroom may be impacted in the time leading up to diagnosis and during and after treatment due to high rates of school absenteeism and side effects of treatment. During this period of time, the child may need to miss school in order to attend medical appointments. During the treatment phase, children will typically continue to miss school in order to receive treatment. Depending upon the treatment type, intensity and the response to treatment, children may need to be hospitalized.

The many side effects from cancer treatment impact learning and performance in the classroom. It is important that teachers are aware of some of the potential changes that may be seen when a child with cancer returns to school. These problems in academic functioning may occur immediately following treatment and may continue to emerge for years after treatment has finished. The following is a list of some common problems that may occur following cancer treatment.

- Problems maintaining attention
- Difficulty remembering information
- Difficulty in reading comprehension
- Difficulty with math calculations
- Difficulty in handwriting speed and accuracy
- Difficulty copying visual information (for example, transferring information from the board to paper)
- Difficulty completing tasks quickly
- Difficulty keeping pace with new material
- Difficulty with planning and organizing
- Difficulty learning and retrieving information that is novel or does not have a meaningful context
- Difficulty in problem solving
- Problems detecting social cues and keeping up in social conversations

You may need to make some changes to your classroom in order to accommodate the needs of the child with cancer upon his or her return. It is important to be aware of the possibility of these changes and to note any changes you may see throughout the school year. Many children with cancer begin to receive special services in school and may become eligible for an IEP or 504C Plan. It is critical that teachers are involved in this process as you see the child on a daily basis, and you may be called upon to make changes within your classroom to further meet the needs of the child.

If the child already has an IEP, revisions may be needed to accommodate new needs based on the child's diagnosis of cancer.

Important Medical Information for the School Nurse and Teacher

Guide for Medical Situations

The school nurse and teacher play a very important role in the medical care of the child with cancer. After all, the child with cancer has special medical needs. This information outlines the appropriate protocol to use when these medical situations arise. In addition, this knowledge can help educate others within the school because they are aware of the special needs of the child as well. If questions arise, contact the parents first because they are taught how to care for their children at home. **In addition, if you have any further questions, the Oncology Clinic triage nurse is available Monday-Friday 8:30 a.m.–5 p.m. at (215) 590-2299. Remember — Communication is KEY!**

Nosebleeds

When can they occur?

- if the child's platelet count is decreased

What do I do?

- sit the child up and tilt his or her head forward
- squeeze both sides of child's nose for 5 minutes
- if it doesn't stop, continue to hold for 10 minutes

What if the bleeding doesn't stop in 10 minutes or the child has more than two nosebleeds in one day?

- Contact the parents. The child may have to have a blood count check and possibly receive a platelet transfusion.

Note:

- It is important that the child does not blow his or her nose
- It is vital that the child does not try to remove any clot with his or her fingers
- Tilting the child's head back should be avoided because if the child swallows the blood it can cause emesis and stomach upset

Fevers

What can a fever indicate?

- infection, a serious infection or a cold

- side effect from a drug

What do I do?

- CALL THE PARENTS IMMEDIATELY
- Note: Do not give the child Tylenol unless the parent has received permission from the doctors. Aspirin and Motrin should be avoided due to risk of bleeding.

Chicken Pox and Measles (Rubella)

What are chicken pox and measles, and how do they affect the child with cancer?

- Like chicken pox, measles is a contagious disease that can cause serious infection in children with cancer.

What do I do?

- Notify parents when a classmate becomes infected with chicken pox or measles, so you can reduce the chance of serious infection to the child with cancer.

Central Venous Catheters

What are they?

- lines designed to administer long-term chemotherapy infusions, total parenteral nutrition, blood products, or antibiotics

What do they do?

- help obtain frequent blood samples and monitor central venous pressure

What types of catheters are generally used?

- Broviac
- Hickman
- Infus-a-port

How are they cared for?

- Parents are taught how to care for the Broviac or Hickman catheters. There is a sterile dressing that is changed once a week. The catheters are threaded into a vein of the chest, and the tubing can be seen outside the child's chest. Rarely, the child may discover a small leak either coming from the catheter or from the cap if it is not secure. If this happens make sure the clamp is clamped closed and speak with the parents.
- The Infus-a-port is a disk that sits under the skin on the child's chest, which is also threaded into a vein. When

the port needs to be used at the clinic it is accessed with a needle. When the treatment is done, the needle is removed.

Note:

- The child should be restricted from contact sports but can run and play as long as his or her energy level allows.

Pain and Headaches

Why might pain occur?

- result of chemotherapy, injury or cancer itself

Can I administer analgesics?

- No. Speak with the parents first. Parents will need to get advice from the doctor. Tylenol is the analgesic of choice. Do not give aspirin or Motrin, due to bleeding tendencies. Stronger analgesics may need to be prescribed for chronic or persistent pain.

Gastrointestinal Side Effects

What are some common side effects from chemotherapy and/or radiation?

- nausea
- vomiting
- constipation
- diarrhea
- mouth Sores

What should I do if these occur in school?

- Call the parent if nausea and vomiting persists (child is at risk for dehydration). The child may need to receive anti-nausea medicine and/or intravenous fluids.

Helpful Contact Numbers for the Educator

Hospital (inpatient)

The Children's Hospital of Philadelphia

Phone Number: (215) 590-5538

Treatment Center (outpatient)

Philadelphia Location: (215) 590-2299
(Oncology Clinic at Children's Hospital)

Voorhees Location: (609) 590-8552

King of Prussia Location: (610) 337-8160

Understanding the Psychosocial Support Available at The Children's Hospital of Philadelphia

Child Life Specialist: Works with children and family members to help them better cope with the healthcare experience by providing play and developmentally appropriate services, education, preparation for medical procedures and emotional support.

Clinical Psychologist: Administers tests to determine at what level a child is functioning intellectually and emotionally provides psychotherapy for patients and families and conducts research on psychological topics.

Nurse: Coordinates and plans child's care and serves as a resource for the family.

Social Worker: Helps individuals and families cope with a chronic illness and informs families about resources available within the Hospital and the community to help families deal with problems they may encounter.

Glossary of Medical Terms

Anemia: Decrease in the number of circulating red blood cells, or a condition in which the hemoglobin is less than normal. It may be caused by cancer cells in the bone marrow, radiation, or chemo.

Benign: That which is not cancerous. A benign tumor is a noncancerous growth.

Biopsy: The removal and microscopic examination of tissue from the living body for diagnosis.

Blood Count: The number of red cells, white cells and platelets in a sample of blood.

Bone Marrow: The inner, spongy tissue of bones where blood cells are made.

Bone Marrow Transplant: A portion of the patient or donor's bone marrow is withdrawn, cleansed, treated and stored. The cleansed marrow is given by transfusion.

Immunotherapy: Treating a patient by using the body's own capacity to respond immunologically.

Intravenous: Directly into a vein (blood vessel).

Indwelling Catheter: A long, silastic rubber tube with a small removable injection cap that attaches to the end of the catheter. Also called a Hickman or Broviac.

Lethargy: A feeling of sluggishness; having very little energy.

Low white count/Leukopenia: An abnormally low number of

white blood cells in the blood. White blood cells are responsible for fighting infections and providing immunity.

Malignant: That which is cancerous.

Metastasis: The transfer of disease from one part of the body to another. In cancer, the new growths are characteristic of the original tumor.

Platelet: A part of the blood that plugs up holes in blood vessels after an injury.

Prognosis: A forecast as to the probable course and outcome of the disease.

Remission: The decrease or disappearance of evidence of a disease.

Resources

Books, pamphlets, movies, articles, organizations and websites can help alleviate anxiety associated with welcoming the child with cancer back to school. After all, knowledge is power.

American Cancer Society. (1988). *Back to school: A handbook for teachers of children with cancer.*

Bain, L. (1995). *The Children's Hospital of Philadelphia: A parent's guide to childhood cancer.* Dell Publishing: New York.

Keene, N. (1997). *Childhood leukemia: A guide for families, friends, and caregivers.* O'Reilly: Cambridge.

Keene, N. (Ed.). (2003). *Educating the child with cancer: A guide for parents and teachers.* Candlelighters Childhood Cancer Foundation.

McDougal, S. (1997). *Children with cancer: Effects and educational implications.* Accessed via the following website: <http://www.acor.org/ped-onc/cfissues/backtoschool/cwc.html>

National Cancer Institute. (1993). *Young people with cancer: A handbook for parents.*

Nessim, S., & Katz, E.R. (1995). *Cancervive Teacher's Guide for Kids with Cancer.* Can be found at the following website: <http://www.cancervive.org>

Nessim, S. (1992). *Cancervive: The challenge of life after cancer.* Can be found at the following website: <http://www.cancervive.org>

Peckman, V. (1993). *Children with cancer in the classroom.* *Teaching Exceptional Children*, 27-32.

Spinelli, C.G. (2004). *Dealing with cancer in the classroom: The teacher's role and responsibilities.* *Teaching Exceptional Children*, 36(4), 14-21. [Can be accessed via the following website: <http://specialchildren.about.com/od/medicalissues/a/cancerschool.htm>]

Why Charlie Brown Why? (1990). A supplemental video for early school-age students to watch after class preparation.

Organization Contacts for Educational Materials

American Cancer Society

1599 Clifton Road, N.E.

Atlanta, GA 30329

Phone: 1-800-ACS-2345

Website: www.cancer.org

American Childhood Cancer Organization

Phone: 1-855-858-2226

Website: www.acco.org

Provides information on cognitive late effects in survivors as well as support and advocacy information. This is a self-help network for parents of children with cancer. Services include support from other families, reading materials, a quarterly newsletter for parents and professionals, and a newsletter for children.

CureSearch

Phone: 1-800-458-6223

Website: www.curesearch.org

This website provides links for parents and teachers for supporting patients of cancer and their siblings. It includes ideas about how a teacher or his/her classroom can help a child with cancer. Educators will find information on talking to a classroom about a student's cancer diagnosis.

Leukemia and Lymphoma Society

Phone: 1-800-955-4572

Website: www.lls.org

This website provides information and resources related to leukemia and lymphoma. It offers many educational materials that are helpful to patients, families and educators, such as "Learning and Living Cancer." Download this booklet here: bit.ly/LearningAndLiving

National Dissemination Center for Children with Disabilities

Phone: 1-800-695-0285

Website: www.nichcy.org

The new center serves as a central source of information on: IDEA, special education law, and research-based information on effective educational practices. The Center offers bilingual services and a team of research and information specialists who are available to talk with you and address your individual questions and concerns in English or in Spanish.

Legal Rights

Education Law Center (ELC)

Phone: 215-238-6970

Web: www.elc-pa.org/

Provides free legal assistance to parents, students, and advocates on education law matters, and advises parents of their rights to special services under the law. The center publishes a free guide for parents, "The Right to Special Education in Pennsylvania." To access the New Jersey ELC: www.edlawcenter.org

Wrightslaw

Email: webmaster@wrightslaw.com

Web: www.wrightslaw.com

Wrightslaw is an information and support website covering a wide range of special education, legal, and policy topics, and publishes materials on these topics. Additional resources include information on books, DVDs, websites, and searchable libraries.

