

Childhood Cancer and School

Children with cancer often experience disruptions in their education due to repeated hospitalizations, side effects from chemotherapy, or generally not feeling well enough to fully participate in daily school life. As their health improves and treatment allows, returning to school can be either a relief or a challenge for children with cancer.

For many children, school is a refuge from the world of hospitals and procedures—a place for fun, friendship, and learning. Because school is the defining structure of every child's daily life, returning to school signals normalcy; indeed, expectations of school attendance impart a clear and reassuring message that there is a future. Other children, especially teens, may dread returning to school because of temporary or permanent changes to their appearance or concerns that prolonged absences may have changed their social standing with their friends. Additionally, school can become a major source of frustration for children who develop learning disabilities as a result of treatment. These learning differences, if handled in an insensitive or uninformed manner, can affect a child's confidence and self-esteem. The issues of educating children with cancer are complex, but most can be managed successfully through planning and good communication.

Keeping the school informed about treatment

Communicating with the school often does not enter a parent's mind during the nightmarish days after diagnosis. Keeping the school informed, however, lays the foundation for the months or years of collaboration as the child goes through the rigors of treatment for cancer. Parents need to forge a strong alliance with the school professionals to ensure that their child, who may be emotionally and/or physically fragile, continues to be welcomed and nurtured at school.

As soon as your child is diagnosed, notify the principal in writing of the child's diagnosis and hospitalization. The next step in ensuring a good relationship is choosing an advocate to be the liaison among hospital, family, and school. The advocate will work to keep information flowing between the hospital and school, and

will help pave the way for a successful school re-entry for the sick child. Often the advocate is the hospital social worker, but it may also be a hospital or school nurse, psychologist, principal, or other motivated individual. The most important qualifications for this role are good communication skills, knowledge of educational programs and procedures, comfort in dealing with school issues, and organizational skills. It must be someone you trust to act fairly on your child's behalf.

You will need to sign a release form authorizing the school and hospital to exchange information. Schools have these forms.

The advocate should locate a contact person at the school (or hospital) and should provide frequent updates about the child's medical condition, treatment, emotional state, and tentative re-entry date. The advocate should encourage questions and address staff concerns about having a seriously ill child in school.

Keeping teacher and classmates involved

While your child is hospitalized, it is vital to his well-being to stay connected with his teacher and classmates. Children attend school not only for instruction but also to develop communication and social skills.

The teacher should be getting updates through the advocate, but the parent can help by calling the teacher periodically and bringing notes or taped messages to the classroom.

The following are suggestions for keeping the teacher and classmates involved:

- Give the teacher copies of the Candlelighters' book *Educating the Child with Cancer* and the American Cancer Society's *Back to School: A Handbook for Teachers of Children with Cancer*.
- Have the pediatric oncology nurse or social worker come to class to give a presentation about what is happening to their classmate and how he will look and feel when he returns. This should include a question-and-answer session to clear up misconceptions and allay fears. Teenagers should be involved in deciding what information should be given to classmates.

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- Send pictures of your child on treatment to the school. Some families fill photo albums with pictures that are shared with the classmates.
- Encourage classmates to keep in touch by sending notes, calling on the phone, sending class pictures, or making a banner.
- Call the American Cancer Society, (800) ACS-2345, and ask for a comprehensive list of the printed materials and outreach programs available for teachers and parents. Canadians can find information through the Canadian Cancer Society's Cancer Information Service at (888) 939-3333.

Keeping up with schoolwork

Whenever your child is able, keeping up with schoolwork should be a priority. Learning can continue despite school absences. Parents should communicate with the teacher to keep abreast of the subjects being covered in school. Often, the teacher will send assignments and materials home with siblings, or arrangements can be made for pick-up.

To help your child keep up in school, you need to request special education eligibility. Then the child can qualify for an itinerant teacher. Without an IEP or 504 plan, the child is legally entitled to nothing except what the school voluntarily provides, and this is not enforceable.

Joanne Holt, a high school Director of Special Education, suggests:

If children are having difficulty remaining interested in schoolwork due to fatigue and not feeling well, it may be useful to consider alternative learning activities. In such circumstances, a parent and child might identify an area of special interest or curiosity (e.g., dinosaurs, space, animals, nature, the Wild West, etc.). Children may find it more interesting to develop reading skills, learn math concepts, develop writing skills, and learn research and study principles in the context of a high-interest area while still learning and maintaining the concepts being introduced in school.

Play is a significant part of such activities and can often spark imaginative activities. It is important that the school be aware of and supportive of such an approach; most often they are and, in fact, may be valuable resources for ideas and activities. The goal is to encourage confidence and prepare the child for the least disruptive re-entry to school routines.

Siblings need help, too

The diagnosis of cancer catastrophically affects all members of the family. Siblings can be overlooked in the early months when the parents are spending most of their time caring for the ill child at the hospital, clinic, or in the home. Many siblings keep their feelings bottled up inside to prevent placing additional burdens on their distraught parents. Often, the place where siblings act out the most is at school. It is very common for siblings to withdraw or become disruptive in the classroom, cry easily, become frustrated, fall behind in class work, bring home failing grades, cut classes, become rebellious towards authority, or have fistfights with classmates. Siblings, like parents, are overwhelmed by feelings, and generally have fewer coping skills.

You should send a letter to the school principal of each sibling, asking the principal to alert teachers, counselors, and nurses about the cancer diagnosis in the family and ask for their help and support for the siblings.

This parent regrets not having been aware of the impact of cancer on a sibling:

Lindsey was in kindergarten when Jesse was first diagnosed. Because we heard nothing from the kindergarten teacher, we assumed that things were going well. At the end of the year, the teacher told us that Lindsey frequently spent part of each day hiding under her desk. When I asked why we had never been told, the teacher said she thought that we already had enough to worry about dealing with Jesse's illness and treatment. She was wrong to make decisions for us, but I wish we had been more attentive. Lindsey needed help.

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Remember to include the siblings' teachers in all conferences at school. If the siblings' teachers are in different schools or they have several teachers (e.g., in middle school and high school), ask the principal to send a school representative. They need to be aware of the stresses facing the family, and understand that feelings may bubble to the surface in their classroom. It is essential that parents advocate for the healthy child's emotional and educational needs as well as their sick child's.

Returning to school

Although it is normal that parents don't think about school during the early efforts to save their child's life, hospital personnel should reinforce the importance of an early return to school. Going to school helps children regain a sense of normalcy and provides a lifeline of hope for the future.

Preparation is the key to a successful re-entry to school. The parent should ask the physician or primary nurse to prepare a letter for the school staff containing the following information:

- The student's health status and its probable affect on attendance.
- Whether she will attend full or half days.
- Whether he can attend unrestricted general physical education classes, general physical education with restrictions (e.g., no running), or Adaptive Physical Education for disabled children.
- How much recess is allowed, if any.
- A description of any changes in her physical appearance (e.g., will she bring a wig?).
- Her feelings about returning to school.
- Any anticipated behavioral changes resulting from medication or treatment.
- The possible effect of medications on her academic performance.
- When any medications or other health services need to be given at school.
- A reminder to never give any medication, especially

aspirin, which can cause uncontrollable bleeding, without parental permission.

- Any special considerations such as extra snacks, rest periods, extra time to get from class to class, use of the nearest restroom (even if it's the teacher's), and the need to leave for the restroom without permission.
- Dietary restrictions, if any.
- Concerns about exposure to communicable disease.
- A list of signs and symptoms requiring parent notification—e.g., fever, nausea, pain, swelling, bruising, or nosebleeds. If parents are divorced, which parent to notify or which to notify first.
- A reminder that the teacher's job is to teach, and the parent and nurse will take care of all medical issues.

Once the faculty has a chance to read the letter, request an IEP meeting that includes faculty, administrators, the school nurse, school counselor and psychologist, and special education personnel. At this meeting, answer any questions about the information contained in the letter, pass out booklets on children with cancer in the classroom, formulate a communicable disease notification strategy (if necessary), discuss the ongoing need for appropriate discipline, and do your best to establish a rapport with the entire staff. Take this opportunity to express appreciation for the school's help and your hopes for close collaboration in the future to create a supportive climate for your child

This parent expressed gratitude both to the teacher and to school officials:

I still feel unbelievable gratitude when I think of the school principal and my daughter's kindergarten teacher that first year. The principal's eyes filled with tears when I told her what was happening, and she said, "You tell us what you need and I'll move the earth to get it for you." She hand-picked a wonderful teacher for her, made sure that a chicken pox notification plan was in place, and kept in touch with me for feedback. She recently retired, and I sent her a

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glowing letter, which I copied to the school superintendent and school board. Words can't express how wonderful they were.

The following are additional parent suggestions on how to prevent problems through preparation and communication:

- Keep the school informed and involved from the beginning. This fosters a feeling that “we’re all in this together.”
- Reassure the staff that even if the child looks frail, he really needs to be in school. This child’s school librarian responded helpfully:
- Reassure other children that your child poses no health threat to anyone. Bring the pediatric oncology nurse back into the class to talk about cancer and answer questions whenever necessary. This should also be done at the beginning of each new year to prepare the new classmates.
- Ask the school to bend some rules and policies if you think it will help your youngster. For example, wearing a hat can sometimes eliminate teasing and leaving a three-ring binder with notes, papers, tests, etc., in the classroom can prevent the need to carry a heavy backpack.
- For elementary school children, enlist the aid of the hospital advocate or school counselor to help select the teacher for the upcoming year. Although this violates the policy at some schools, it can go a long way toward preventing problems. Although you have no legal right to this, you can ask nicely to have the policy modified for your child.
- Prepare both teacher(s) and student for the upcoming year.
- Get professional help. The school counselor can talk with your child about problems with grades or classes. A mental health professional can help your child express emotions about what is happening in school and other areas in your child’s life.
- Realize that teachers and other school staff can be frightened, biased, overwhelmed, and discouraged by

a child with a life-threatening illness in their classroom. Accurate information and words of appreciation can provide much needed support.

Avoiding communicable diseases

Communicable diseases can be dangerous to immunosuppressed children. To prevent exposure, parents need to work closely with the school to develop a chicken pox, shingles, and measles outbreak plan. Check to see if your child’s school already has an organized disease notification plan. Parents need to be notified immediately if their child has been exposed to chicken pox so that the child can receive the varicella zoster immune globulin (VZIG) injection within 72 hours of exposure. Several methods are used to ensure prompt reporting of outbreaks. Some parents notify all the classmates’ parents by letter to ask for help. If the parent has a good rapport with the teacher, she can have the teacher report any cases, as in the arrangement for this child:

My daughter’s preschool was very concerned and organized about the chicken pox reporting. They noted on each child’s folder whether he or she had already contracted chicken pox. They told each parent individually about the dangers to Katy, and then frequently reminded everyone in the monthly newsletters. The parents were absolutely great, and we always had time to keep her out of school until there were no new cases. With the help of these parents, teachers, our neighbors, and friends, Katy dodged exposure for almost three years. She caught chicken pox seven months after treatment ended and had a perfectly normal case.

Other parents enlist the help of the office workers who answer the phone calls from parents of absent children, the way this child’s parents did:

We asked the two ladies in the office to write down the illness of any child in Mrs. Williams’ class. That way the teacher could check daily and call me if any of the kids in her class came down with chicken pox.

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What about preschoolers?

A large proportion of children diagnosed with cancer are preschoolers. Parents face the dilemma of continuing preschool through treatment, risking exposure to all the usual childhood viruses and diseases, or holding their child out, which denies them the opportunity for social growth and development. The decision is a purely personal one made after considering the following issues:

- Has the child already had chicken pox?
- Is the child already enrolled and comfortable in a preschool program?
- Are social needs being met by siblings and/or neighbors?
- Is preschool an option, given medical considerations?

The terminally ill child and school

In the sad event that the child's health continues to deteriorate and all possible treatments have been exhausted, it is time for the students and staff to discuss ways to be supportive during his final days. Classmates need timely information about their ill classmate, so that they can deal with his declining health and prepare for his death. The possibility of death from cancer should have been sensitively raised in the initial class presentation prior to the student's return to school, but additional information is needed if the student's health declines. The following are suggestions on how to prepare for the death of a classmate:

- The entire school staff needs to be in continuous communication with parents and hospital. They need to be reassured that death will not suddenly occur at school, that the child will either die at home or in the hospital.
- Staff needs to be aware that participation at school is vital to a sick child's well-being. They should welcome and support the child's need to attend school as long as possible.
- Staff can design flexible programs for the ill student—for example, part-time school attendance and/or part-

time home tutoring (if appropriate) for a child too weak to attend school all day.

- Staff can designate a "safe person" and "safe haven" in the school building so that the student can retreat if physically or emotionally overwhelmed.
- The hospital advocate should meet with school personnel and the student's class to answer questions about the student's health status and to address fears and misconceptions about death.
- It is helpful to provide reading materials on death and dying for the ill child's classmates, siblings' classmates, teachers, and staff.
- Extraordinary efforts should be made to keep in touch once the child can no longer attend school. Cards, banners, tapes, telephone calls, or conference calls (on the principal's speaker phone) from the entire class are good ways to share thoughts and best wishes.
- Visits to the hospital or child's home should be made, if appropriate. If the child is too sick to entertain visitors, the class could come wave at the front window and drop off cards or gifts.
- The class can send a book of jokes, a Walkman and tapes, or a basket of small gifts to the hospital.
- The class can decorate the family's front door, mailbox, and yard when the child is returning home from the hospital.

All of the above activities encourage empathy and concern in classmates, as well as help them adjust to the decline and imminent death of their friend.

When a child dies, a memorial service at school gives students a chance to grieve. School counselors or psychologists should talk to the classmates to allow them to express their feelings.

Parents appreciate receiving stories or poems about their departed child from classmates, and attending the funeral also supports the grieving family.

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This fact sheet was adapted from *Childhood Cancer: A Parent's Guide to Solid Tumor Cancers*, by Honna Janes-Hodder and Nancy Keene, © 1999 by Patient-Centered Guides. Also available is *Childhood Leukemia: A Guide for Parents, Families, and Caregivers, Second Edition*, by Nancy Keene, © 1999 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see www.patientcenters.com.