

# Helping Schools Cope With Childhood Cancer

## Current Facts and Creative Solutions



## Acknowledgements

Many have contributed to the evolution of this booklet since Anne Chambers, Ann Klinck, and David Rynard created the original version over 20 years ago.

I would like to express my gratitude to ChildCan and the Thames Valley District School Board who made the initial booklet possible. I would also like to thank my wonderful colleagues who have reviewed and helped improve the revisions of this document over the years.

The inspiration for the case studies and many of the practical ideas contained herein comes from the children I have worked with, their families, teachers, and classmates. You continue to inspire me with your courage, creativity, and compassion.

Ann Klinck, Editor

## Terms of Use

We are pleased to offer the 2011 revision as a free on-line educational resource. We invite educators, families, and health professionals to use and share this resource to help children with cancer continue their education after a cancer diagnosis.

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### **The Pediatric Cancer School Support Program Children's Hospital, London Health Sciences Centre**

The Pediatric Cancer School Support Program helps children with cancer continue with their education after a cancer diagnosis. The program supports children with cancer, their families and their school communities during their cancer journey. Support continues to be available after treatment ends to help children optimize their educational outcomes.

This program has been in existence since April 1990. We are grateful to ChildCan, who had the vision to fund this program for the first 9 years, and to the Paediatric Oncology Group of Ontario (POGO), whose ongoing leadership and advocacy led to comprehensive funding for pediatric cancer care in Ontario.



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## INTRODUCTION

School is a central part of a child's life. School encourages the learning and intellectual growth necessary for adulthood and is a major contributor to a child's socialization. With 5-year childhood cancer survival rates now approaching 80%, it is essential that the care of children with cancer include planning to address their educational needs.

A childhood cancer diagnosis is a family crisis. Initially, the family's resources and energy are directed towards addressing the child's medical needs, coping with the emotional reactions of all the family members, and making the practical arrangements needed to coordinate the child's care. However, sooner than some might expect, the child and parents will begin to wonder and worry about how the disease will affect the child's schooling.

A return to school activities can be a critical step in the rehabilitation process and should be implemented as soon as is reasonable. With very few exceptions, children with cancer can continue with their education in some way during treatment. As a future-focused activity, continuing with education can provide tangible evidence that life continues and foster hope in the child and those around him.

A child with cancer requires an educational plan that addresses physical, academic, social, and emotional needs, regardless of whether school attendance is possible, or alternative solutions are needed. Furthermore, a child's success is best fostered when the concerns of the child, siblings, parents, peers, and teachers are addressed.

But where does an educator begin? Because childhood cancer is a relatively rare occurrence, educators may find themselves facing a situation with which they have little knowledge and less experience. They will also be supporting a child and family through a difficult, life-threatening, and often unpredictable challenge. Meeting the educational needs of a child with cancer requires compassion, creativity, and flexibility.

This booklet was created as a resource for educators to help children with cancer continue their education after a cancer diagnosis. It was written with the following objectives:

- to present an overview of current information on childhood cancer and the treatment experience of the child with cancer
- to provide insight into the emotional impact of childhood cancer on the child, the family, school staff, and classmates
- to help educators provide support to the child with cancer and their family
- to give educators the knowledge and confidence to help them educate and support peers and classmates
- to provide some practical resources and case examples to help with the planning process
- and, to introduce some specific situations such as terminal illness, and the challenges of survivorship.

We hope that educators will find this resource useful as they work as a team with families and health care professionals to develop plans that optimize the child's educational opportunities during treatment and beyond.

# CHILDHOOD CANCER

## General Information

### What is cancer?

Cancer is a group of diseases characterized by abnormal, rapid and uncontrolled cell growth.

### What is the incidence of childhood cancer?

Childhood cancer is relatively rare. Less than two percent of all cases of cancer occur in childhood. Nonetheless, it is estimated that about 1 in 400 children will be diagnosed with cancer before their 18<sup>th</sup> birthday.

### What causes childhood cancer?

The causes of childhood cancer are largely unknown. Children with some genetic defects are at a higher risk for developing certain kinds of cancer and exposure to ionizing radiation is known to increase childhood cancer rates, but these factors account for only a very small percentage of cases. In the large majority of cases, there is no explanation for why a child develops cancer.

#### Childhood Cancer in School-aged Children

**Leukemias** are cancers of the blood cells which arise out of the bone marrow and account for about 40% of all childhood cancer cases. The most common of these is **Acute Lymphoblastic Leukemia (ALL)**. **Acute Myeloid Leukemia (AML)** accounts for most of the other cases.

**Central Nervous System Tumours** of the brain and spinal cord are the most common solid tumours in children. Please see **Appendix A** for more information on brain tumours.

**Lymphomas** originate from cells in the lymph nodes or other lymphatic tissues and include **Hodgkins Lymphoma** and a number of **Non-Hodgkin's Lymphomas**.

**Kidney Tumours** are more likely to occur in the first five years of life. The most common of these is the **Wilms' Tumour**.

**Rhabdomyosarcoma** is a cancer of the connective tissue that can arise from a number of different locations in the body.

**Osteosarcoma** is the most common bone tumour of childhood and often affects the long bones of the arms and leg.

**Ewings Sarcoma** is a tumour that occurs in the bone or the soft tissue. It often occurs in the pelvis or the leg bones.

**Neuroblastoma** originates in primitive nerve cells in the adrenal gland and a chain of nerves along the spine. While neuroblastoma in infancy usually has good outcomes, in older children it is more aggressive and challenging to treat.

**Other Cancers:** Children may also develop germ cell tumours which arise from reproductive cells, tumours that arise in the liver, as well as other rare forms of cancer. There are also other disorders, technically not cancer, which are treated with cancer treatment (e.g. severe aplastic anemia, multi-system Langerhans' histiocytosis).

## How is childhood cancer different from adult cancer?

With a few exceptions, childhood cancer consists of a different group of diseases which tend to affect different parts of the body than adult cancer. Childhood cancer often grows rapidly and has a more sudden onset than adult cancer. In general, childhood cancer responds more favourably to treatment.

**Perhaps most importantly, childhood cancer occurs in a developing human being. Children continue to grow physically, emotionally, socially, and cognitively during the challenges of treatment.**

## How is cancer detected and diagnosed?

Children present with various symptoms, which are dependent on the type of cancer. For example, children with leukemia may present with pallor, excessive bruising, or fever. Children with lymphoma may have swelling of the lymph nodes. Headaches, morning vomiting, seizures, weakness, or vision problems may occur when a child has a brain tumour. Children with other solid tumours may experience pain, swelling, or a loss of function in the affected area or surrounding organs.

Children will undergo a battery of tests to determine the type of cancer, and to determine the stage or risk group within that particular cancer type.

### Tests, Tests, and More Tests

**Blood Tests:** Blood tests can be used to determine the presence of leukemia cells in the blood. Blood tests also evaluate important elements within the blood which can be affected by treatment. You may hear the child or parents refer to the results of these tests as “blood counts”.

**X-Rays/CT Scans/MRI Scans/Ultrasound/PET Scans:** Various types of scans are used to “see” the internal structures of the body. Scans may assist in determining the diagnosis and the extent of the illness. Scans are repeated over the course of therapy to assess treatment response. These tests are not painful but require the child to be very still for varying lengths of time. Younger children may require sedation.

**Lumbar Puncture/Spinal Tap:** A lumbar puncture (LP) is a procedure in which a needle is inserted into the space between the vertebrae to withdraw cerebrospinal fluid (CSF) to test for the presence of cancer cells in the central nervous system. Sedation is often used.

**Bone Marrow Examination:** The bone marrow is the spongy centre of the bone and is the factory that produces the majority of cells that circulate in the blood stream. Cancer may arise in these cells or spread here from other places. A bone marrow aspiration is a test wherein a needle is inserted into the hip bone and a sample is withdrawn. In a bone marrow biopsy a special needle is used to remove a small piece of hard bone marrow tissue. The child is often sedated during these painful procedures.

**Biopsy:** A biopsy is a procedure in which a small piece of a tumour is removed so that the specific type of tumour can be identified.

## **What is the chance for cure?**

In all but a few cases, treatment is initiated with the goal to cure the cancer. Due to the improvement in cancer therapies over the last four decades, and the improved ability to manage complications, it is now estimated that about 80% of all children with cancer will survive for five years from diagnosis, and most of these will be considered cured (Ellison et al, 2009). Keep in mind however, that cure rates vary significantly depending on the type of cancer and the extent of disease.

Sometimes cancer progresses during treatment, and in other cases cancer recurs after treatment. Additional treatment is often possible, and can sometimes be successful in eliminating the cancer. However, failure to control the cancer results in progression of the disease and eventual death. Sadly, despite the many advances in treatment, cancer still represents the leading disease-related cause of death for children in the developed world.

*“If children have the ability to ignore all odds and percentages, then maybe we can all learn from them. When you think about it, what other choice is there but to hope? We have two options, medically and emotionally: give up, or Fight Like Hell.”*

Lance Armstrong

## Treatment

The treatment of cancer is a long, hard fight for the child, family, and community. Children are treated in larger medical facilities where they can receive the comprehensive, specialized care that they need, and have access to the most up-to-date treatment options. This means that many families must travel outside of their home community for some or all of their child's care.

Treating cancer is a team effort and includes a number of professionals. An effort is made to provide support to the entire family and address the many needs that arise over the course of cancer treatment and during follow-up care.

### The Treatment Team

While treatment teams vary at different centres, the list below will give you an idea of the professionals who may be involved in a child's care. It will also help you appreciate the sometimes overwhelming number of people that a family may meet over the course of treatment!

**Physicians** who specialize in the diagnosis and treatment of childhood cancer and blood disease are known as *Hematologist/Oncologists*. A *Neurosurgeon, Neurologist or Neuro-Oncologist* may be involved in the care of children with brain tumours. *Radiation Oncologists* provide radiation treatments for cancer. *Surgeons* may carry out biopsies, remove tumours or insert central lines. Other pediatric specialists may be consulted to address complications that can arise during treatment.

**Nurses** provide a wide range of services and support. Nurses provide front-line care and administer treatment to children. Nursing roles often include patient and parent education, case management to coordinate the child's care, and patient advocacy and support. Nurses may also provide in-home support and care in the child's community.

**Psychosocial Support** may be provided by a number of professionals. *Social Workers* often provide counseling to families, and help them access community resources. A *Psychologist* may provide psychological assessment, treatment, and education regarding adjustment and coping. *Child Life Workers* focus on the developmental needs of children in the treatment setting and work to reduce stress and help children understand the hospital experience, often through the use of play. Some centres even have *Art Therapists, Music Therapists, or Therapeutic Clowns* on staff. *Chaplains* are available to help address the families' spiritual needs.

**Other Health Professionals** may address the specific needs of children brought about by their disease and treatment. For example, a *Dietician* can help address the nutritional needs of children. *Physiotherapists, Speech and Language Therapists, and Occupational Therapists* may help with rehabilitation in the hospital or community. A *Neuropsychologist* may assess children to determine how disease and treatment has affected their cognitive skills and make recommendations to assist with school planning.

**School-Related Services** may be available through a formal school re-entry program. If this is not available, most treatment centres have professionals willing to consult with educators. As well, some pediatric hospitals have on-site teachers who may teach the child at the treatment centre, and who may also liaise with the child's school.

**Community Agencies** also provide support to families of children with cancer. These may include government agencies, charitable organizations, hospice organizations, camps for families coping with childhood cancer, and support groups for patients and families.



## Treatment Methods

Cancer treatments are aimed at destroying the fast-dividing cancer cells. Following diagnosis and disease assessment, most children are placed on a treatment protocol, a kind of a roadmap of their care.

The type of cancer, its location, the extent of the disease, and the child's response to treatment are some of the factors that can determine the details of a child's treatment plan. As a result, treatment can vary significantly depending on the child's illness and situation.

Some treatment plans require frequent hospitalization while others take place primarily in day-treatment clinics. Treatment protocols can range in length from several months, to several years. Finally, the frequency and intensity of treatment can vary among treatment protocols, or within a child's individual plan. On the next page you will find some examples of what a typical treatment day might be like for a child with cancer.

**Chemotherapy** agents are drugs that destroy cancer cells. Most children receive a combination of these medications. These drugs may be given by mouth, by injection, or intravenously (into a vein). Chemotherapy can also be administered into the spinal fluid during a lumbar puncture. Depending on the treatment regimen and the drugs involved, chemotherapy may require a hospital admission, be given in a day-treatment clinic, or given at home.

**Surgery** may be undertaken to totally or partially remove a tumour. When removing a tumour the surgeon must consider the tumour's size and location, and the potential for complications with removal. In some cases, treatment with chemotherapy or radiation is given prior to surgery so the tumour is easier to remove.

Surgery is an important part of treatment for bone tumours, many of which are located in the limbs. Some children may have a limb salvage surgery, a procedure in which the affected bone is removed and replaced with a prosthetic implant or bone grafts. In other cases amputation may be the best option, and the child will eventually be fitted with an artificial limb.

**Radiation** is the use of high-powered radioactive particles to destroy cancer cells. Radiation may be directed at a specific tumour or may be used as a preventative measure in areas of high risk for disease spread such as the central nervous system in the case of some patients with leukemia. Radiation therapy usually consists of brief daily treatments over a number of weeks. Sedation may be required for young children who are unable to lie still.

**Stem Cell or Bone Marrow Transplant** is used to treat children with a variety of cancers and blood diseases. Stem cells are immature blood cells that have the ability to develop into the full range of mature blood cells. These cells are found in the bone marrow, in the bloodstream, and in umbilical cord blood.

Depending on the situation, healthy stem cells are collected from the affected child, a family member (often a sibling), or unrelated donor. Donor cells must match the child's marrow. Next, intensive chemotherapy, and sometimes radiation is given to destroy any cancer cells within the patient. The healthy stem cells are then infused into the child. The child usually remains in isolation in the hospital for about four to six weeks because of a very high risk of infection and other complications. For a period of months following the transplant, the child will continue their recovery in isolation at home and require follow-up for ongoing care.

**Non-traditional Therapies** may be considered by parents, especially when conventional treatments offer little or no chance for cure. There is little research evaluating or supporting the effectiveness of these therapies for cancer treatment. Alternative practices may also be initiated to offer comfort or relieve side effects. It is important that families consult with their oncologist as some therapies may interact negatively with conventional treatment.

### **A Day in the Treatment Clinic: Ava, age 5**

- 9:00 am: Ava and her mother, Jill, arrive at the clinic after a 90 minute drive from home. They register at reception and go into the waiting room to play.
- 9:35 am: The nurse checks Ava's weight height, temperature and blood pressure. Ava receives her hospital armband. Ava has a finger poke and blood is sent to the lab. Numbing cream is put on her chest over her port and covered with a special dressing. Jill answers questions about Ava's health since her last clinic visit.
- 9:50 am: While waiting for the blood test results that determine whether she can receive her chemotherapy treatment, Ava plays with the Child Life Worker and another child. Ava starts an art project while Jill talks privately to the social worker about some financial difficulties the family is facing. After this, Ava and Jill have a snack.
- 11:50 am: Ava's blood test results come back and orders are sent to the pharmacy for chemotherapy. Ava and Jill are sent to one of the exam rooms. They read a story together while they wait.
- 12:20 pm: The oncologist examines Ava and answers some of Jill's questions.
- 12:35 pm: Ava returns to the play room to finish her art project.
- 12:45 pm: A nurse takes Ava to the treatment room. She accesses Ava's port and attaches Ava to an I.V. pole. Ava receives fluids, followed by her chemo. During this time she watches a movie and then falls asleep. Jill reviews the next treatment phase with Ava's nurse case manager. Then she calls her sister to remind her to pick up Ava's siblings from school. Ava wakes up. She plays a video game.
- 3:00 pm: Jill goes to the pharmacy to pick up some medications while Ava works on a craft. When Jill returns, they eat their lunch. They chat with another family they met at camp last summer.
- 4:20 pm: The treatments are finished. The needle is removed from Ava's port and she chooses a bandage to put on it. Ava asks if they can stop at her favourite store before heading home. They arrive home at 6:30 pm.

### **A Day on the Inpatient Unit: Joe, age 14**

- 7:30 am: Joe wakes up when his breakfast tray arrives. He slept poorly last night for many reasons: blood pressure checks, frequent urination due to the IV fluids he has received, and the baby crying in the next room. He tries to go back to sleep.
- 9:00 am: The nurse takes some blood. Joe doesn't have much appetite for his breakfast. His mom arrives at the hospital after taking his little sister to school. She brings some of his grandma's muffins for Joe. He eats a little. Joe can't sleep so he plays a video game.
- 10:30 am: "The Team" including several "doctors in training" enters the small room. They all stand around the bed and ask Joe and his mom lots of questions, some personal. He is tired of answering the same questions every day.
- 10:45 am: Joe fills out a menu for tomorrow. Nothing looks appealing to him right now. The art therapist stops by and gives Joe a project to work on. The nurse starts some more fluids running in his IV. The dietician comes in and reminds him he needs to drink lots of fluids, and talks to Joe about how to include more calories in his diet.
- 11:30 am: Joe and his mom go for a walk outside. Later, when the chemotherapy starts running he will need to stay in his room.
- 12:00 pm: Lunch arrives. Joe eats a little and tries to drink.
- 12:20pm: The chemotherapy starts running. Joe tries to sleep for a while. The nurse periodically comes into the room to take his blood pressure and adjust his IV pump.
- 1:30 pm: Joe wakes up feeling sick to his stomach and calls the nurse. She gives him some medication. He sleeps a little more and feels a little better. His mom needs to leave to take care of some things at home.
- 3:30 pm: The chemotherapy is done for today. Joe continues to receive IV fluids. Joe's teacher comes by and does some math with him. He leaves him some homework.
- 4:00 pm: Joe chats with a couple of his friends on-line.
- 5:00 pm: Supper arrives. Joe texts home to ask someone to bring him some "real food".
- 5:30 pm: Joe tries to do some homework. Fortunately he is interrupted when his dad arrives with one of Joe's friends and a pizza. The boys play video games together.
- 9:00 pm: Joe's friend leaves. He and his dad watch television for a few hours. His dad spends the night on a pull-out cot in the room.

## Making Treatment Less Painful: Central Lines

Reliable intravenous access is important for children receiving cancer treatment. In addition to chemotherapy, they may require IV access for fluids, nutrients, blood products or other medications (e.g., antibiotics). Children's veins are small, and accessing them can be difficult and painful. Early in treatment, most children have a mechanical device inserted to help make treatment easier.

An **internal central line**, sometimes called a port-a-catheter or "port" is a totally implanted device. The catheter (plastic tube) is tunneled under the skin towards the neck where it enters a large vein. The access point is visible as a small raised area on the chest, beneath the skin. A numbing cream can be put onto the skin prior to use. The port is accessed during treatment by inserting a special needle through the skin into the reservoir. The port is de-accessed (needle removed) when treatment is completed. A port requires no home maintenance when not in use.

Other children will have an **external central line** sometimes known as a Hickman or a Broviac. Part of the catheter is tunneled under the skin in the chest and travels towards the neck where it enters a main vein. The remaining part of the tubing extends down out of the body. The tubing is secured by a small cuff, just under the skin. Medications are given by accessing the valves at the end of the tubes. The area where the tube exits the body must remain clean and dry and covered with a dressing.

A **peripherally inserted central catheter** is referred to as a PIC or PICC line. A PICC is a long catheter or tube which is inserted into one of the large veins, usually in the arm near the bend of the elbow. The tube is slid into the vein until the tip sits in a large vein just above the heart. The tube outside the body has a special cap to which a drip line or syringe can be attached. The tube is clamped and the line is covered with a dressing when not in use.

After treatment ends, the central line may remain in place for a little while. The eventual removal of the central line can be a significant milestone for the child and the family.

### Central Lines at School

While not in use, internal catheters (e.g. ports) are not a major cause for concern at school. The child can usually partake in regular P.E. and recess activities except full contact sports. It can be helpful to tell the other children about the port and encourage them to play with care because it will be painful if bumped.

Although it is rare for an internal catheter to be damaged by outside trauma, it is advisable to let parents know if it is bumped in any way. Also, let parents know if the child complains of any discomfort in the area since this could indicate an infection or other problem.

External catheters and PICC lines require more caution. The site where the tube enters the body should remain dry and under a dressing. Children with external catheters may secure the tubes in some way so that the lines are less likely to interfere with play. PICC lines may be secured under a bandage. Children can participate in some physical activities at school, but modifications to physical education activities will be required so that the line will not be hit.

External catheters become very securely attached within a few weeks of insertion so it is unlikely they will become dislodged. It is also extremely unlikely that the tubes will become damaged in the course of normal school activities. Again, inform parents of any concerns.

**The preceding information is for general information only. Please consult with the child's parents or care providers for specific guidelines and precautions for the child at your school.**

## Side Effects, Complications, and Supportive Care

Cancer treatment can cause a variety of unwanted effects. These may range from easily managed medication side effects to serious complications that require hospitalization. Supportive care is treatment that prevents, controls, or relieves side effects and complications.

Many children receive care that is preventative in nature. For example, children take antibiotics to prevent infections and may use a special mouth rinse to prevent mouth sores. Children often receive anti-nausea medications to prevent or lessen the nausea and vomiting associated with treatment. Sometimes children receive injections to help the body rebuild the blood supply between treatments. Blood transfusions may also be required.

Of course not all side effects and complications are preventable, nor are they predictable. Unplanned hospitalizations to treat infections or other complications are not uncommon. Educational planning should have the flexibility to accommodate the unexpected.

### Side Effects at School

When children are well enough to go to school, it is important that teachers be aware of side effects that may impact a child's day-to-day functioning. Some more common concerns are listed below with suggestions for coping at school. **This information should not replace advice from the child's parents and health care providers.**

**Risk of Infection:** Chemotherapy treatment results in a decreased level of white blood cells which compromises the child's ability to fight infections. It is natural for parents and teachers to be anxious about the child re-entering the school community. However, the child's physician would not recommend school attendance if he or she did not feel it was safe. Furthermore, some serious infections are caused by organisms in a child's own body rather than outside sources. No amount of isolation will protect a child from these!

Children who attend school will be exposed to common viral illnesses in the school community. While most of these do not present a serious threat, there are notable exceptions, namely chickenpox. The timely reporting of chickenpox exposure allows the child with cancer to receive an injection that can prevent or lessen the impact of this illness.

The following precautions can minimize the risk of contagious illnesses for children at school:

- Encourage good hand washing for the child and classmates. The child should avoid contact with pet excreta and stale water.
- With parental consent, educate the school community about the child's situation (See **Appendix B** and **C** for related materials.)
- Let parents know when there are higher than expected levels of contagious illness in the school. They can ask their care provider whether attendance is advisable.
- Routine immunizations will need to be delayed until after treatment ends.

#### A Note about Fever

Fever is a sign of infection, and sometimes the only observable sign of infection in an immunocompromised child. If the child shows signs of a fever (flushed cheeks, warm skin, lethargy) please contact parents immediately as the child may require immediate medical attention. Some parents may provide a thermometer and request school personnel to take the child's temperature when a fever is suspected.

**Hair Loss and Thinning:** Hair loss occurs because treatment affects all fast-growing cells, including those that produce hair. Hair thinning and loss may be the first obvious sign of treatment and can be quite distressing for parents and children. Children are often fearful that they will be teased because of hair loss. Hair loss is nearly always temporary.

- Prepare classmates for hair loss.
- Alter rules around hats. Make sure all staff members are aware of the exceptions.

**Fatigue and Activity Level:** Teachers often wonder about the child's ability to participate in physical activities at school. While children are usually encouraged to participate as much as possible, fatigue is a very real effect of cancer treatment. It can be caused by a number of factors including a decreased number of red blood cells, interrupted sleep patterns due to medications, stress, and travel to and from treatments. Energy levels can be quite variable and the day-to-day ability to participate will need to be assessed with input from the child and parent. (Please refer to Other Physical Challenges below for additional factors to consider.)

- Consider a shortened school day if full days appear to be taxing.
- Encourage physical activity when the child is well enough, as tolerated.
- When needed, modify physical education classes so that the child can participate in a less active way. (e.g., walk instead of run, be a referee.) One teacher incorporated the child's physiotherapy exercises into the class warm-up for P.E. class!
- Encourage classmates to participate in "quieter" activities at recess so the child is included.
- If possible, provide an area where the child can rest when needed.
- Call parents if the child is too tired to benefit from being in the school environment.

**Bleeding:** A decrease in platelets (blood cells that help stop bleeding) will make the child more prone to bleeding and bruising.

- Report any bleeding to parents, especially unexpected bleeding of nose or gums ASAP.
- Avoid contact sports.
- When injured, a longer period of direct pressure may be needed to stop bleeding.
- Take universal precautions when cleaning and bandaging cuts or scrapes.

**Mood Changes:** Changes in mood may be related to medications (e.g., steroids), a brain tumour, an emotional reaction to diagnosis and treatment, or worry about upcoming treatment.

- Be aware of times when the child may be more irritable or sensitive.
- Inappropriate behaviour should not be excused. However, use judgment to determine consequences. As one mother said. "It's ok to be grumpy; it's not ok to be rude."
- Let parents know if the child is having a difficult day, or if concerns continue over time.

**Nausea and Vomiting:** Some chemotherapy drugs affect the stomach lining and the vomiting control centre in the brain. Vomiting may last a day or two after treatment, while nausea may persist for longer. Medications can help but may not be completely effective for all children.

- If the child is unwell, treat the child as you would any other child with nausea and vomiting. Provide a place to rest near a bathroom and call parents.

**Weight Changes/Nutritional Needs:** Some medications increase appetite. On the other hand, appetite may be decreased due to nausea or medications that affect the taste of food.

- If needed, provide opportunities to snack during class time because of food cravings.

- Allow for smaller, more frequent meals and provide encouragement to eat and drink.

**Sun Sensitivity:** Some medications increase the child's susceptibility to sunburn.

- Encourage the use of hats and sunscreen.
- Ensure shade is available during the mid-day hours.

Side effects can vary significantly from child to child. **Again, please consult with parents and health professionals to determine what side effects to expect and how best to address these at school.**

## **Other Physical Challenges**

There are a number of less common situations which merit additional accommodations, precautions, or restrictions in the school environment. For example, a child who has a limb salvage procedure or amputation of the leg will have mobility challenges. A child with a brain tumour may have sensory impairment, compromised motor functioning, or be at risk for seizures.

One commonly used chemotherapy drug can result in a complication known as peripheral neuropathy, a condition that damages the nerves that control the muscles. This may affect a number of motor skills but can have a particular affect on a child's ability to print or write.

Another commonly used steroid medication can occasionally result in a serious complication called avascular necrosis, a condition which affects the blood supply to the bones, often affecting the hip and/or leg joints. Children may be required to avoid weight-bearing activities for an extended time period.

In cases like these, it will be necessary to collaborate with professionals such as physiotherapists, occupational therapists, speech and language pathologists, or specialist teachers to determine how best to meet the child's needs at school.

# COPING WITH CHILDHOOD CANCER

*"Cancer touches us all..... somehow." (Amanda, age 13, sibling of a child with cancer)*

## Educators

For many adults, cancer is a word fraught with emotion and associated with the possibility of death. Some of us remember our parents or grandparents whispering about the unmentionable "C word". Most of us have had some experience with cancer in our own lives. However, in most cases our knowledge and experiences of cancer are related to an adult with the disease.

A cancer diagnosis during childhood seems especially cruel and unfair, and can be particularly distressing for people who have made a career of nurturing and educating our children. Educators may experience a host of emotions including sadness, fear, helplessness, guilt or anger. They may also feel relief and hope when they learn of the excellent outcomes for many children with cancer.

It is not unusual for teachers to feel apprehensive about the child's return to school. They may experience some doubt about their ability to address the child's physical needs, especially if the child is still receiving treatment. Educators may also wonder whether they can competently handle the emotional ramifications of the situation. For example, they may feel unsure about what to say to the student, the parents, and classmates. They may be uncertain how to evaluate or discipline a "sick" child.

Educators must strive to work through initial feelings of grief and anxiety, and obtain the information and support they need to approach the situation in a positive way. A teacher's attitude will play a role in the child's and their classmates' subsequent adjustment to the illness.

### **Tips for Teachers: Helping Yourself First**

- Allow yourself permission to grieve. Most adults have had cancer touch their lives before. Past experiences may be affecting your reaction.
- Gather as much information as possible. If the treatment centre has a formal school liaison service, take advantage of it. If not, with the parents' permission contact the treatment centre.
- Look for resources on childhood cancer. (See **Appendix G** for some sources.) Access school-based resources. School counselors, psychology or social work staff may be able to assist you and your students. They may also be able to connect you with colleagues who have gone through a similar experience.
- Try to develop and project a positive attitude of hope. Not only will you feel better, your optimism will be relayed to the child with cancer, classmates and others in your school community.
- If possible, visit the child in the hospital to become familiar with the child's experience.
- If you are still struggling, ask for help. Your workplace likely has resources that can assist you.



## The Family

Families have described childhood cancer treatment as an unanticipated and very difficult roller coaster ride, with peaks and valleys, unexpected turns, and a complete loss of control. Family members grieve the loss of a healthy child while experiencing the uncertainty and terror of the child's life-threatening illness. Practically, the realities of childhood cancer treatment will require significant changes to the family's daily life. For example:

- Family routines will need to be adjusted around appointments, treatments and of medication schedules.
- A parent may need to take a leave from work to support the child. Decreased income and increased expenses often result in financial strain.
- At least initially, siblings may rely on extended family or friends for care.
- The unpredictability of the child's illness can make it difficult to make plans or attend special events (e.g., vacations, a sibling's concert or sports activity).
- Couples often "divide and conquer" with one parent spending time at the treatment centre, while the other holds things together at home. Tasks routinely done by one parent may fall onto their partner. Time apart, shifting roles and different coping styles can place stress on a marriage.
- Divorced or separated parents may need to communicate and work together more often, and do so under extremely stressful circumstances.
- Lone parents may have additional challenges such as juggling the needs of other children at home, and struggling with a decrease or loss of the sole family income.

Families must navigate the difficult path from the crisis of diagnosis to the "new normal" of cancer treatment. Families are diverse and so too are the many ways that families adjust to childhood cancer diagnosis and treatment. Many factors may influence how a particular family adjusts to the new demands. Some of these include the number and ages of the children, the nature of the family's social support network, the extended family's ability to help, family coping skills and style, cultural factors, communication styles, the flexibility of parents' employers, financial resources, the parent's ability to comprehend medical language, the distance from the hospital, and the existence of other stressors.

While it is important to remember that childhood cancer affects the family as a whole, it also presents different challenges for the various family members.

## The Child with Cancer

Children's reactions to their diagnosis will be dictated to a large extent by their cognitive and emotional maturity. For this reason, reactions for different age groups are presented below.

**Preschool Children:** Very young children will not understand the seriousness of their illness, or the extent of treatment they will require. They will not understand why they need to undergo so many painful and unpleasant experiences, nor appreciate why their parents cannot protect them from these situations. The constant presence and reassurance of a parent or a significant attachment figure will help them feel safe and secure.

**Early School Years (Grades Kindergarten to 3):** Young children interpret their world on a very concrete level. They may have a basic understanding of their illness and treatment, but are unlikely to fully understand the implications of their diagnosis or the reasons for the many, often invasive, medical procedures they must endure. They will require reassurance that they did nothing to cause the illness, and that they are not being punished. It is not unusual for behaviour to regress for a time. For example, a formerly confident child may experience more difficulty separating from their parents or find comfort in previously outgrown activities or toys. Hair loss often bothers adults more than children at this stage.

**Middle School Years (Grades 4 to 6):** Children at this stage of development will have a fuller understanding of their illness but may continue to have the concerns of younger children discussed above. In addition, they will become increasingly concerned with the social implications of their illness. This may involve a greater preoccupation about hair loss, cancer and death, and the potential changes in their social status and relationships. They will be more aware and sensitive to the comments and reactions of others. They often worry about missing school and may fear they will have to repeat a grade.

**Teens (Grade 7 to 12):** Adolescence is a time when social relationships with peers are very important and teens are striving for independence and autonomy from parents. A cancer diagnosis can result in less time spent with peers, an increased dependence on parents and other adults, and the need to put plans on hold while they deal with their illness.

Older children and teenagers are extremely conscious of their physical appearance and may be especially susceptible to the fear of social rejection. They may be hesitant to have other people know about their disease because of the perceived stigma of being "different". Anxiety about returning to school is not unusual. Teens often worry about their ability to keep up with academic demands, and the fact that they may not be able to graduate with their peers. They also feel sad that they are missing out on social and extracurricular activities.

As children mature into young adults, they can more fully appreciate serious questions about their own mortality and the potential long-term implications of their disease on their future. They are also working towards developing an identity. Perhaps because of this, some teens report that they develop a different life perspective than their peers.

**Bigger Concerns:** The reactions described above are quite normal and usually resolve as the child adjusts to their situation. Less often, more extreme reactions may require intervention. Concerning reactions could include significant academic decline (not due to absenteeism or disease and treatment factors), extreme aggressive or acting out behaviour, increased anxiety, sadness or social withdrawal, and preoccupation with death. Teens may also engage in risk-taking behaviour, become non-compliant with medication, or drop out of school. Please let parents know if you have any concerns about the child. There are likely professionals at the hospital that can provide additional support to the family.

### **Tips for Teachers: Helping the Child with Cancer**

- If possible, visit or call the child in the hospital or at home. Let them know you are thinking of them.
- Children will benefit from talking with teachers, parents, or hospital personnel in preparation for the return to school. They will cope far better knowing what to expect, and how to respond. They also need a chance to express their worries and concerns and to know how these will be addressed.
- Be alert to rumours on the school yard and attempt to dispel them as soon as possible. It may be helpful to have a standard response to inquiries, with approval from the family (e.g., "He's getting excellent care and we are hopeful he will get well.").
- Work with families and hospital staff to develop an educational program that will meet the child's needs. Let the child know that you will help them continue with their education and stay connected with their friends.
- When the child returns to school designate a person who the child knows well as a "go to" person. This individual can check in with the child regularly, and be available if the student needs to let someone know they are physically or emotionally uncomfortable.
- Most children who attend school report that they just want to be treated like everyone else. As hard as it may be, try not to be overprotective. Normalize the child's school experience as much as possible, while adjusting expectations when needed.
- When the child cannot attend for longer periods of time, establish regular contact with the parents or a liaison from the treatment centre. Plan ways that classmates can maintain regular contact with the child. (See "How Classmates Can Help".)
- Encourage a supportive classroom environment. (Refer to "Classmates" section.)

## **Parents**

Parents experience a loss of control as they realize their natural instincts to protect their child are no longer enough. Treatment requires parents to entrust their child's care and future to strangers, and to watch their child endure many invasive and unpleasant procedures. In the midst of intense emotional turmoil, parents need to meet and form working relationships with a large number of care providers, learn a myriad of medical terminology, and master an extensive list of new care requirements for their child.

The day-to-day parenting of a child with a life-threatening illness presents significant challenges. Parents work hard to normalize the situation. Nonetheless, it is natural to be very protective and even indulgent at times, especially in the early stages of the illness or when the prognosis is very uncertain.

Immediately after diagnosis, many parents cannot imagine their child returning to school. However, as they adjust to the situation, most parents recognize the importance of their child continuing their education as soon as is reasonable. When a return to school is possible, apprehension is not unusual. Parents have many questions and concerns. For example:

- Will my child be more vulnerable to infection in the school setting?
- Will my child's teachers be able to manage my child's side effects and special needs?

- What if my child gets teased?
- Will they be held back a grade?
- Will my child be able to cope?
- What about the needs of my other children?

### **Tips for Teachers: Helping Parents**

- As soon as you know of a diagnosis, contact the parents and let them know you are thinking of them and the child.
- When the family is ready, provide parents with opportunities to share their questions and concerns about their child's return to school, or the alternative plans available to help their child continue with their education. Including treatment centre staff in this process may be helpful.
- Having a good plan in place to address the child's needs is the best way to reassure parents. However, let parents know that the plan will be reviewed and can be adjusted if required.
- Communicate with parents on a regular basis. Address potential problems early, and ask for their suggestions and feedback on how to best help their child. A communication book that travels with the child can be especially helpful for younger students.
- If the child is away for a time period, make an effort to find out why and let parents know of your concern. Keep parents updated on upcoming classroom and school activities.
- Let parents know that you are working hard to learn about their child's illness. For example, tell them you have read any information provided by the treatment centre.
- Let parents know how you are addressing the needs of other students.
- Keep parents informed about siblings' adjustment and any support is available at school.

## **Siblings**

Brothers and sisters of childhood cancer patients have a very difficult time as well. As parental time and attention necessarily shifts to the ill child, parents may be less available to address siblings' needs. Needs may go unnoticed, especially if siblings hide their feelings in an effort to "protect" their parents. In other cases, siblings may act out to get attention.

Changes in home routines and family roles may result in someone different managing homework and extracurricular activities. Older siblings may take on more responsibility and independence with household chores or child care at home.

At school, it is not unusual for siblings to be approached by other students who have heard rumours about the child's illness. For example, having another student ask "Is your sister going to die?" may cause further fears and distress. It is overwhelming for a sibling to be thrust into the role of family spokesperson when they may not fully understand the situation themselves!

Following is a list of common reactions of siblings. These will be mitigated by factors such as the child's age, their pre-illness functioning, and their knowledge about cancer<sup>1</sup>.

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<sup>1</sup> Adapted from *When your Brother or Sister has Cancer*. American Cancer Society, 1996

- *Worrying.* Naturally, siblings worry about their ill brother or sister. Misconceptions and a limited knowledge about cancer may add to their concern. For example, they may worry about their sibling dying, even when the prognosis is very good. Siblings' worries may increase when the child and parents are away at the treatment centre, or, when they witness their parents' anxiety.
- *Feeling sad.* It is normal for children to experience a grief reaction after a diagnosis. Children often mirror the level of sadness shown by other family members.
- *Feeling guilty.* Sometimes children think that they should have been the one to get sick, or that they in some way caused the illness. After all, how many of us have wished ill-will on a brother or sister in a fit of sibling rivalry? Guilty feelings may be more pronounced if siblings have not gotten along well in the past.
- *Feeling jealous and left out.* The child with cancer gets a lot of attention (and gifts) from family, friends, and hospital staff. Siblings may resent their parents' decreased availability and even view the child's treatment days as "special" outings. Parents may miss important events in the siblings' lives because of the needs of the ill child.
- *Missing family members.* Siblings miss the child and parents when they are away, especially if absences are extended. Siblings close in age also miss the availability of their regular playmate.
- *Feeling angry.* A childhood cancer diagnosis is not fair, and some siblings can be very angry. As treatment progresses and the cancer patient looks and acts more "healthy", brothers and sisters may resent the continued attention given to the patient.
- *Worrying that other family members might get cancer.* Even with reassurance that the likelihood that other family members will get cancer is low, children may fear for their parents or selves. Sometimes siblings will develop physical symptoms, either because they are worried, or as a way of getting attention.

All of these concerns are normal, and usually, siblings will respond to a safe and understanding environment in which to discuss their feelings. Many children find the predictable school environment comforting, and some siblings may wish to speak about their concerns with their teacher, principal or counselor. More severe reactions may require professional intervention.

#### **Tips for Teachers: Helping Siblings**

- If you teach a sibling, find out what you can about the affected child's treatment and how it will impact the family. Siblings' teachers should be included in staff education and planning.
- Be available to talk or listen should the need arise. However, keep in mind that not all children will want to discuss the situation at school.
- Provide a "safe" person and place for times when the sibling is overwhelmed or struggling.
- A special job or extra attention can go a long way to help a sibling feel appreciated.
- Siblings may feel special and involved if they are given the responsibility for delivering information from the school to their brother or sister. However, ensure this is the case.
- With the family's consent, educate the sibling's peers about the situation and discuss how they can provide support.
- It can be very helpful and reassuring for siblings to spend some time at the treatment centre with the child and parents. Accommodate occasional absences as required.
- Be aware that unfinished homework or late assignments could be the result of an unexpected complication or hospital visit. Allow flexibility when appropriate.
- Let parents know if there are concerns about the siblings' adjustment, or if a sibling appears to have any inaccurate ideas about the child's illness.

## Classmates

Each child in the classroom will have their own individual understanding of cancer. This understanding will be affected by the child's developmental level, knowledge and life experience. The word "cancer" may be linked to an unpleasant memory about the loss of a relative or adult friend, or a high-profile individual who has had cancer<sup>2</sup>.

Teachers may be hesitant to discuss the child's situation in the classroom. They may believe the information will scare the children and be uncertain how to answer the many, sometimes difficult questions that children will inevitably ask.

However it is important to remember that children will almost always learn about the situation one way or another. A clear, consistent, positive and age-appropriate message from a knowledgeable adult is invariably better than rumours heard on the school yard, or, information gleaned from the hushed conversations of adults in the community. Also, when teachers do not address the child's illness, they send the message that the child's cancer is something too terrible to mention.

In addition to providing age-appropriate information, the goal of any discussion should be to foster understanding and acceptance of the child with cancer, while acknowledging and addressing the feelings, concerns, and questions of classmates. Discussing the child's situation can help students to empathize with the ill child and siblings, and encourage them to think about ways they can help.

### Tips for Teachers: Planning a Classroom Discussion

- Get the family's permission.
- Decide what sort of presentation will best suit the needs of the children at your school. A very short, informal discussion at circle time may address the needs of young children; a formal presentation in a larger group with an "expert" visitor may be appropriate for older children, while an intimate discussion among selected peers may be best for teens.
- Obtain accurate and up-to-date information. Access resources (e.g., books, videos) to help with your presentation. See **Appendix G** for more information.
- Determine if the child with cancer would like to be present during these discussions. In some cases it may be better to talk while the child is absent so classmates do not feel inhibited to ask questions. In other cases, seeing the child is very reassuring for classmates and the child is empowered by participating.
- Decide who will benefit from a discussion. Just classmates? All the students in the child's grade? Siblings' classmates? A selected group of a teen's peers?
- Select a speaker who is comfortable discussing cancer.
- If someone other than a teacher is speaking to the class, ensure that key teachers are present and involved during the presentation. They will know the needs of the children involved in the discussion and be able to handle any situations that may arise. Most importantly, teachers will inevitably need to provide follow-up support and information to students.

Please see **Appendix D** for a sample outline of a classroom discussion and additional issues to consider.

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<sup>2</sup> In Canada many children's early knowledge of cancer comes from their school's participation in the Terry Fox Run. In addition to learning about this positive role model, this means that they may associate cancer with amputation and eventual death.

## Teens

Older children and teens are often reluctant to have their classmates know the details of their cancer diagnosis. This is more likely in the teen years when a student may have a number of classmates who they do not know very well. Of course the student's wishes and privacy must always be respected.

Teens with cancer should be given as much control as possible over any discussions at school. They may wish to decide who will be present, who will lead the discussion, and what information will be shared. For example, many teens prefer that only a smaller group of their peers receive information about their situation.

Some teens may wish to share information with their friends themselves. In these cases, it is important to let teens know that they can change their minds. For example, one initially reluctant student allowed teachers to share some basic facts about his disease when inaccurate rumours began to circulate at school and on the internet.

The friends of older children and teens are likely to be experiencing a more sophisticated grief reaction to the diagnosis and may need an opportunity to work through these feelings. If needed, find additional services for peers having especial difficulty with the situation.

Finally, keep in mind that older children and teens may rely on peers for support. Empowering teens to help their friend can be helpful for both the teen with cancer and peers.

## Keeping in Touch and Helping Out

How many adults are not sure what to do or what to say when a friend is seriously ill? When a classmate has cancer, children can learn valuable life lessons on how to support someone who is unwell. Finally, when friends reach out, the child with cancer will usually find it easier to return to school.

### **Tips for Teachers: Helping Classmates Help**

- Ask students for ideas. What would help them if they were ill? Children come up with creative ideas, and their knowledge of the child's likes and dislikes are invaluable.
- Keep in touch when the child is not at school. Send cards, make a book of jokes, make a video letter, create a class journal with daily contributions from classmates, record a special event. If longer absences are anticipated, make it part of your class routine so that communication is ongoing and regular.
- Have a simple fundraiser and buy a gift that can help pass time during waits at the hospital (e.g., books, videos, an electronic game, craft materials). One child, who was diagnosed late in the school year, received small boxes from her class containing notes, jokes, and small gifts, one for each day of summer vacation.
- Embrace technology. Some children will be able to access the internet from their rooms at the treatment centre. With an inexpensive webcam, it may be possible to arrange on-line visits. Some families or teens may create blogs for their children or set-up social networking sites. Often they are willing to allow access to the school community. (Bend the rules about on-line activities if you have to!)

### Helping Classmates Help (continued)

- Find out if it is possible to have a few friends visit the child at home or in hospital.
- Some classes have all worn hats on the day of the child's return or made their classroom a "hats on zone" for the duration of the child's hair loss. (Some classmates have gone as far as shaving their heads, or cut their hair to raise funds for a related charity.)
- Most children report that they want to be treated the same as they were before they got cancer. Encourage friends not to overwhelm their classmate with attention when they return to school.
- If the child is not well enough to participate in some activities, ask for volunteers to participate in an alternative activity with the child.

## The School Community

A childhood cancer diagnosis often affects the entire school community. We are all social creatures and news, especially bad news, travels quickly among students, their parents, and school staff. Furthermore, the school is an important gathering place, especially in smaller communities.

### Respecting Privacy

Educators will inevitably find themselves receiving questions from students and parents about the ill child. While these inquiries arise out of genuine concern and a desire to help, it is ethically and legally important to clarify with the family what information, if any, they wish to share and with whom. It may be possible to obtain information about the family's preference directly, or, with consent, indirectly, through someone at the treatment centre. With the family's approval, sharing a simple, clear, consistent and positive message can be a helpful approach.

Most families are open to some information being shared within the school community because they appreciate that people will hear the news eventually. However, the amount and type of information they wish to share varies considerably among families.

With parental consent, it is helpful to have a standard message to relay to those who ask about the child. A simple statement such as "He's getting the best treatment available and we are hopeful he will get well" or "We understand this type of cancer is very treatable and are looking forward to her return to school later in the year" can allay the concerns of students and parents and prevent speculation and rumours.

Families may be willing to have more information given to those closest to the child. A more detailed communication can serve a number of functions. For example, a detailed letter can convey a hopeful message, inform parents about any planned classroom discussion, provide guidelines about visiting, share contact information for children who can't attend school, and ask other parents to inform the office about contagious illnesses when the child returns to school. Sample letters are included in **Appendix C**.



## Practical Support

When a child is diagnosed with cancer, people feel helpless. School staff, students, and parents in the school community often feel better if they can offer assistance to the family in some way.

**Fundraising:** It is not unusual for school communities to organize fundraising activities to help the family financially. Others may want to honour the child by raising funds for a charity related to childhood cancer. <sup>3</sup> **However, it is important to make sure that families are comfortable with any planned fundraising, especially when the event involves publicity outside of the school community.** While some families are very open and appreciative of these activities, others may find the increased attention an additional source of stress, especially early in treatment.

Fundraisers may range from low key events (e.g., students pay a dollar to wear a hat to school or sell frozen treats at recess) to larger scale community events (e.g., the parent-teacher organization organizes a benefit dinner dance and silent auction.)

### Suggestions for Practical Support

People often want to do something to help the family. There are a number of practical ways that friends in the community can provide support:

- Meals can be provided for the freezer. Meals may be especially appreciated on days when the child has appointments at the hospital.
- When the family is out of town, snow removal, lawn mowing, or pet-sitting can be helpful.
- Help with siblings by driving them to extracurricular activities, providing help with homework, or providing after school care on longer clinic days.
- Provide gift cards for long distance phone calls, take out food, movie rentals, or gas.
- Parents may appreciate care packages with toiletries for times in the hospital.

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<sup>3</sup> Many jurisdictions recognize September as “Childhood Cancer Awareness Month”. Wear your gold ribbons and consider an activity at your school!

# EDUCATIONAL PLANNING

There is no one-size-fits-all approach that addresses the educational needs of children with cancer. Educational planning should include input from as many people as possible including the parents, the child, health care professionals, and educators.

Most children are able to continue with their education in some way while receiving treatment. Some children will be well enough to attend school, others will require alternative services, and others will require an approach which combines both. When making a decision, it is important to first consider the following factors:

- The demands of treatment (e.g., time at the treatment centre vs. time at home, number of appointments, distance to hospital, general health and potential side effects)
- The child's stamina, energy level and physical readiness
- The child's (and parents') psychological readiness
- The child's social needs
- The child's age and developmental level
- The child's pre-illness academic functioning and the academic demands of their school program
- The child's fondness for school, motivation, and ability to work independently
- Changes in functioning (e.g., mobility, sensory ability, motor skills, cognitive changes)
- The possible need for formal identification as a special needs student.

For children well enough to attend school, a number of additional factors need to be considered:

- The child's care needs at school (e.g., risk of infection, medication, central line, etc.)
- Potential side effects and plans for addressing them
- The physical layout and accessibility of the school (e.g., stairs vs. elevators, distance between classes, bathroom needs)
- The need for additional personnel to provide support
- Preparation for peers and school staff
- Plans for urgent situations (e.g., informing parents of fever)
- Plans to address the child's emotional needs.

## **“The best laid plans....”**

Treatment-related factors may be hard to predict, especially early after diagnosis. Furthermore, plans may need to be re-worked due to the unexpected side effects or complications that can accompany cancer treatment, or because different phases of treatment necessitate different approaches. Even from day-to-day, a different response may be required on the child's “bad days” than on their “good days”. Therefore, any plans should be considered a work in progress and educators should periodically consult with the child and parents to assess how well the plan is working, and whether adjustments are needed.

As mentioned earlier, most physicians encourage children to continue with their education whenever possible, and to attend school when they are well enough. When possible, an early return to school has many advantages: it is often easier for the child, classmates are often reassured by the child's presence, and it helps greatly to normalize the child's life.

**See Appendix E for a more comprehensive list of issues to consider when planning.**

## Case Examples

Each child with cancer will require an individualized approach to educational planning. The cases below demonstrate both the variability of needs, and the flexibility that can be required when helping a child who is battling cancer.

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*Lucas was a very strong student prior to his cancer diagnosis in 4<sup>th</sup> Grade. He misses about 5 to 8 days of school a month due to treatment demands and side-effects, with absences ranging from one to four days in length. Lucas wakes up eager to go to school. However, he tires easily and by early afternoon he usually needs a nap.*

**Solution:** Whenever possible, Lucas attends school in the mornings. His parents and teacher have agreed that the focus of his education will be on language arts and mathematics, which are taught early in the day. The teacher gives Lucas little homework, especially if she is confident he knows the material. Lucas loves art class, which occurs later in the day with a different teacher. Sometimes, after a nap at home, Lucas returns to school for this class. His art teacher also provides Lucas with art materials and projects that he can do at home. Complications part way through treatment result in a two-month period during which Lucas cannot attend school. A teacher continues to provide math and language arts instruction in the home during this time.

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*Jeremy is a Grade 1 student who has recently been diagnosed with Acute Lymphoblastic Leukemia. The first six months of his treatment include a two week admission followed by frequent outpatient visits. During some of this time, his physicians recommend against school attendance. Due to infections, he has several, week-long admissions in the hospital. The remainder of his treatment is less intense and requires him to go to the hospital one day a month.*

**Solution:** Jeremy's school board approves up to 5 hours a week of home-based instruction during the first six months of treatment. They have employed a teacher who has the flexibility to schedule her time around his health and treatment schedule. Whenever he is well enough, Jeremy attends school, often for several weeks at a time. On weeks when he is unable to attend, Jeremy receives instruction at home. He also stops by the school for brief visits with his friends at recess. When his treatment becomes less intense, Jeremy returns to school on a regular basis, missing only occasional days for treatment.

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*Early in 6<sup>th</sup> grade, Nina was diagnosed with a slow-growing brain tumour in an inoperable location. As a result of the tumour, her balance and coordination have become compromised, and she has had some changes in her vision. She travels to a treatment centre in another city for chemotherapy treatments every Tuesday, and misses an additional two to three days a month for other appointments. She is well enough to attend school most days. Nina is an average student, except for math, which she finds more difficult.*

**Solution:** A team meeting is held at the school to plan for Nina's return. Input is gathered from parents, a nurse from the hospital, a vision specialist teacher, and occupational and physical therapists. All her teachers are present. Nina is formally identified as a special needs student. Nina returns to school part-time after her diagnosis and gradually increases her time at school. She uses a walker, and a classroom aide is available to ensure her safety when ambulating or using the washroom. During gym class, the aide helps her complete work she has missed, or takes Nina and one of her friends for a walk outside.

Because Nina's attendance is usually predictable, her math teacher makes an effort to introduce new math concepts on days when Nina attends school. She has paired Nina with a helpful seatmate who is strong in math. Teachers also give Nina school work the night before her appointments, which she works on during the drive to the hospital or her long waits in the clinic. Her homeroom teacher checks in frequently with the family to ensure that Nina is not overwhelmed. She also helps Nina prioritize her homework so she can focus on the most important assignments. As the impact of Nina's motor and vision challenges becomes apparent, Nina is provided with a laptop and software to help her work more independently.

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*Krista is diagnosed with AML early in 8<sup>th</sup> grade. She is admitted to the hospital in another school district where she spends all but two days of the next three months. Krista can rarely leave her room at the hospital because of her compromised immune system. She is then transferred to a larger treatment centre for a bone marrow transplant where she spends about six weeks before returning home. During the first six months of her recovery, she is not able to attend school and has regular clinic visits at the hospital. She is a very social child who misses her friends a lot. Her parents are immigrants who highly value education and are concerned that their daughter will fall behind at school.*

**Solution:** The hospital teacher is able to provide bedside instruction 45 minutes each day while Krista is in the hospital. On "good days" he covers the math units being taught in Krista's home classroom. He also provides language arts programming through the study of some popular teen novels. On "tired days" the teacher simply reads to her during their time together. On "bad days" Krista is too unwell to do school work. When Krista returns home after her bone marrow transplant, she receives three hours a week of home-based instruction through her local school district, again with a focus on the math and language arts curriculum. The teacher is able to flex these hours and carry forward un-used hours to times when Krista is feeling well. Krista's science teacher allows Krista to view his class via webcam, thanks to a laptop provided by a charitable organization. Some of Krista's classmates form a club to help Krista. They post messages on her website every day and take turns chatting with her on-line after school. She is able to attend her Grade 8 graduation. She begins high school full time the following year. The guidance counselor and teachers are aware of her situation, and monitor her progress so that extra assistance can be offered if needed.

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## Teens: Special Challenges

Frequent absences are much harder to accommodate in secondary school. Courses are often taught over shorter time periods and several weeks of a class may include a considerable amount of course content. Teachers will need to carefully consider how they can flexibly accommodate the needs of a student with cancer while still enabling the student to meet curriculum expectations. The following factors are important when deciding what approach will work best for an older student:

- Prior academic performance
- Ability to work independently
- Requirements for graduation
- Student preference of subjects
- Student motivation
- Social needs
- Flexibility of course content
- Style and flexibility of teachers.

**On-line/Correspondence Courses:** Correspondence courses seem like a ready made solution for high school students undergoing cancer treatment. These courses can work well for some students, in some cases. Courses with flexible deadlines and on-line teacher support increase the likelihood of success. However, the emotional and physical demands of treatment may make independent study a poor option for many students. It can however, be helpful to combine the convenience of correspondence materials with the support of teacher in the home.

**Case Examples:** The students described in the two examples below have very similar medical situations. However, because other factors vary considerably, very different approaches are required to help the students achieve success.

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*Fatima is diagnosed with Hodgkin's lymphoma a few months into the first semester of her Grade 11 year. She is determined to attend school whenever possible. She is a strong, dedicated student who can work independently. She hopes to study medicine in the future. Her chemotherapy treatments allow her to attend school about two out of every three weeks. She misses additional days due to fatigue or other appointments. Her treatment lasts about 6 months.*

**Solution:** After much discussion, Fatima agrees to drop two of her 4 courses, a science credit with a lab component, and her physical education credit. She attends her English and History classes whenever possible. Teachers have arranged for missed school work to be provided ahead of time or sent home with Fatima's older sister. She keeps in touch with her teachers by e-mail to find out what she has missed, review lessons, and ask questions. She often submits her assignments on-line. When it is determined that she is keeping up well in these courses, she begins working on an on-line Civics course. This course has flexible deadlines and she is able to continue it through the second semester, along with two additional courses at school. Fatima is feeling better by the summer and takes summer school courses so that she will be able to graduate with her friends.

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*Terry is part way through his Grade 10 year when he is diagnosed with Hodgkin's lymphoma. His treatment will continue for the rest the school year. He has some pre-existing learning disabilities. He is not a highly motivated student and occasionally skips classes. However, he is a very social boy with many friends at school. He is a talented guitar player and has always been far more diligent about his music lessons than his homework. While he could potentially attend classes some of the time, he is overwhelmed with the thought of trying to keep up academically, and is unmotivated to go to school. He has trouble getting up in the morning. His parents feel unable to "push" him to do school work and have not followed through with the school to arrange for Terry to continue with his education.*

**Solution:** After confirming with Terry's nurse case manager that he is well enough, the guidance counselor follows up with the family and arranges for Terry to receive instruction in the resource room at school in the afternoon. The number of days varies each week and is determined through weekly e-mail correspondence with parents. The teacher and the resource teacher work together and break the Geography course into manageable units that accommodate Terry's learning needs, and allow him to successfully complete all of the work at school. At first, Terry is reluctant to return to school. However, he is motivated to come at lunch hour so he can spend time with his friends prior to beginning school work. Terry completes one credit this way, and is proud when he receives his best grade since beginning secondary school. He is granted an independent study music credit in recognition of his guitar lessons, and participates in the year end music concert. After his illness, he skips classes less often and is more willing to seek out extra help at school. He graduates a year behind his peers.

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## Evaluating Academic Progress

How does a teacher assign a grade to a ill child? Sometimes the child has missed too much school to adequately assess progress. Also, if academic progress is poor, school personnel are likely to be hesitant to add another burden to an already overtaxed family by assigning poor grades. However, it is important to remember that most children do survive cancer.

Many problems can be avoided if teachers clarify ahead of time with students and parents what is expected in order to receive a given grade or meet course or curriculum requirements. Also, if poor grades are anticipated, it can be helpful to meet with the family to prepare them for what is to come, and to put plans in place to make up for the shortfalls in the child's performance in the future. Ideally, education plans will include measures to address evaluation so that difficulties can be avoided.

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**Case example:** *Emma is a grade 4 student who receives home-based instruction after a diagnosis of a bone tumour. Because Emma completes only some of the curriculum requirements, the teacher is unable to evaluate Emma's progress according to the standards laid out by school authorities. Emma, previously an A student, is devastated when her report card has no grades entered and "not enough data to evaluate" written in the comment sections. She tells her mother she feels like the school work she has struggled to complete has not counted for anything!*

**Solution:** The next term the teacher creates an "unofficial" report card which gives Emma grades for the units of study and assignments she completes. She provides parents with some activities for Emily to work on during the summer vacation. Finally, she keeps a record of the curriculum components that Emily does not complete so that next year's teachers will be aware of suspected gaps in learning.

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## Difficult Decisions

Should a child repeat a grade? A child who has missed an entire year of school may find it more of a burden to have to catch up or fail subjects later on, than to be held back a year and receive extra help. On the other hand, adjusting to a new peer group may make re-entry especially challenging.

There is no rule regarding such cases. When faced with difficult decisions regarding academic placement, teachers will need to consult with parents, assess all of the factors involved and come up with a plan that addresses the child needs and monitors the child's progress. It is also important to consider that the accepted practice and policies of a school district may not always fit the individual circumstances of a child with cancer.

## **COMPLETING TREATMENT**

The end of treatment is a much anticipated event for children and parents alike. The end of procedures and unpleasant side effects is cause to celebrate. Some families mark the occasion with “no more chemo” parties. Yet, families often report ambivalent feelings during this time.

Many parents and some children find the end of treatment very anxiety-provoking. One parent said, “It’s as if my child was drowning and someone threw him a life preserver. Now we take the life preserver away and hope he can swim on his own.” While many children enjoy seeing their hospital “family” at follow-up appointments, these visits can bring up worries about possible recurrence and memories of unpleasant procedures.

Educators need to appreciate that the cancer journey is not over, and that families may require support as they transition to post-treatment life. Families must once again, find a “new normal” as the child moves from active treatment to follow-up care.

The development and implementation of a good educational plan early in treatment should help pave the way for a smooth transition to post-treatment schooling. Even so, it is recommended that educators consult with the family to plan for the child’s post-treatment education. For example, there is a good possibility that the child may require some extra help to fill in the gaps in knowledge created by absenteeism during treatment, and plans should be in place to closely monitor the child’s progress. A child who is re-entering school after a long absence may also require other interventions (e.g., an updated classroom discussion, a modified school day).

Planning should also consider the physical issues that will remain for a time after treatment. Children may take some time to regain their physical strength and stamina. Central lines may stay in place for a while. Precautions around the risk of infection will need to be kept in place while the child’s immune system continues to recover after treatment. Children may need to be re-immunized after treatment and there is a period of time before this can occur.

Consultation with parents will continue to be necessary as the child begins the gradual transition from cancer patient to cancer survivor.

### **Late Effects of Treatment**

Many children survive childhood cancer and go on to lead healthy, productive lives. However, some survivors experience lasting effects of their cancer experience. While some of these effects are immediate and obvious (e.g., an amputation, tumour-related vision loss) others may not become apparent for some time.

Depending on the treatment received, cancer survivors may be at risk for a number of “late effects”. Some examples of late effects include infertility, compromised lung or heart functioning, hearing loss, growth deficiencies, decreased bone density, learning challenges, or a higher risk of developing another cancer later in life.

Finally, as these children develop emotionally and cognitively, they may find themselves re-processing and understanding their cancer experience in a more sophisticated way. For all these reasons, there is growing recognition that childhood cancer survivors require comprehensive and ongoing monitoring and support.

### **Cognitive Late Effects at School**

A sub-set of childhood cancer survivors is at risk for developing treatment-related learning difficulties. Children treated with cranial radiation, and those who have had brain surgery or neurological complications are especially at risk. Some chemotherapy agents can also affect subsequent learning. Children who receive these treatments at a younger age seem to be particularly vulnerable. At-risk groups include those treated for brain tumours, and children treated for some leukemias and lymphomas. However, not all at-risk children go on to have learning difficulties.

What does a teacher look for? First, consult with parents and health care providers to determine if the child is actually at risk from treatment. Note that these problems often present as a gradual slowing in development over time in comparison to peers, rather than as a sudden loss of pre-existing skills. As a result, problems may not become apparent until after treatment ends. Finally other factors (i.e., increased absenteeism) may be contributing to academic challenges.

Ongoing monitoring of academic progress is essential for children at risk for learning difficulties so that prompt identification and remediation of learning problems can occur. Research has found that these children may experience difficulty in a number of areas including executive functions (initiating tasks, planning, organizing, multi-tasking), attention and memory, learning new concepts, visual-motor processing, and performing under time pressure.

In many cases, a neuropsychological or psycho-educational assessment will be extremely useful in assisting with program planning. Assessments can sometimes be arranged at the child's treatment facility for children at risk. In many cases, children with a high risk of learning problems may routinely receive assessments as part of their follow-up care.

As with any child, other factors such as prior learning ability, parental involvement, and the timely implementation of appropriate educational supports will help determine a child's academic outcome.

Other lasting effects of treatment may need to be considered in a child's educational programming:

- Sensory loss (e.g., hearing loss due to certain chemotherapy drugs, vision loss due to a brain tumour)
- Physical Limitations (e.g., compromised balance or motor skills due to a brain tumour or treatment complications, restrictions on high impact activities for a child with an artificial joint)
- Other Needs: (e.g., kidney protection during gym class for a child with only one kidney.)

New developments in cancer therapies aim to lessen adverse effects, but risk-free treatment is not yet a reality. Until that time, childhood cancer survivors will continue to require careful monitoring and assessment, ideally in specialized follow-up clinics. Educators who work with childhood cancer survivors must appreciate that the end of treatment does not always mean an end to the challenges that these children face.



# SPECIAL CHALLENGES

## Disease Progression and Recurrence

Sometimes a child's disease does not respond to the initial treatment, and the cancer continues to progress. In these cases, the child's treatment plan will be revised. Treatment often intensifies and with that comes a greater risk of side effects and complications. When the disease progresses during treatment, outcomes are poorer than initially predicted. If all further treatment fails, the child will receive palliative care (see below.)

In other cases a child will be well for a time following treatment and then suffer a recurrence or relapse of the disease. While the prognosis for cure is not as good the second time around, it is sometimes possible to successfully treat a recurrence, and more and more children are surviving after a second course of treatment. In other cases, continued treatment will decrease or control the disease for a time.

Disease progression or recurrence will mean a whole new set of challenges for families and school communities. New plans will need to be put in place to support the child and family.

## Terminal Illness

Although the prognosis for childhood cancer is generally hopeful, sometimes a disease cannot be controlled and is ultimately fatal. In this event, school and medical staff must be prepared to deal sensitively with the child, the family, and classmates.

When all curative treatment options have been exhausted, the child will receive **palliative care**. Palliative care is aimed at keeping the child as comfortable and pain-free as possible while attempting to maintain the quality of the child's remaining time. Children may receive chemotherapy treatments or radiation to help relieve pain and discomfort. They will likely require increased levels of pain medication and care as the disease progresses.

There may be a period of weeks or months, when the child is well enough to participate in some regular activities. Some families plan a special trip, or try to pack in as many of the child's favourite activities as possible while the child is well enough to enjoy them. This may mean the child and the siblings spend less time at school. Other families may focus on keeping routines as normal as possible for as long as possible. In these cases the child may wish to spend time in the classroom or with friends.

With home care services and portable pain control equipment, many families opt to have their child die in the home. Others may choose to have the child die in at the treatment centre or in a hospital palliative care unit or hospice setting closer to home.

## Coping at School

The school community can play an important role for the student near the end of life. Continued school attendance may be possible for a time, and important for some children. As one of the few normal activities available, it can provide relief from despair. It can be challenging for educators to facilitate the child's need to continue living, while coping with their own feelings and the reactions of the child, family, and classmates to the child's failing health.

Maintaining contact with friends can be especially important for a child in the final stages of life. Furthermore, the opportunity to show their love and support for the child can help classmates' grieving process in later days. **See Appendix F for additional information and resources.**

## **CONCLUSION**

Finding out a child has cancer is devastating for the family and those around them. However, perhaps because they have no other choice, families find the hope and courage to cope with the child's illness, and integrate the many accompanying challenges into their daily lives.

When the child is ready to continue with their education, educators must be prepared to meet the needs of the child, the family, and those in the school community. From the crisis of diagnosis, through the rigours of treatment, and hopefully, to the emergence into survivorship, these children require thoughtful, individualized planning to address their educational needs. It is our sincere hope that this publication has provided educators with information, ideas, and suggestions to help them meet the needs of the child with cancer with compassion, flexibility, and creativity.

## Appendix A: Additional Information about Brain Tumours

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A broad definition of a brain tumour is a “group of unnecessary cells growing in the brain”. Usually, brain tumours are confined to the brain or spinal cord and don’t spread to other parts of the body the ways other malignancies do.

Although brain tumours can strike at any age, childhood brain tumours are different from adult brain tumours. For example, a majority of childhood brain tumours occur in the back compartment of the brain called the posterior fossa, a location far less common in adults. Pediatric tumours also may behave differently than adult tumours, both in terms of their growth patterns and how they respond to treatment.

### Benign vs. Malignant

Brain tumours are graded depending on how abnormal the cells in the tumour look when viewed by a pathologist under a microscope. Tumours may be staged from stage 1 (lowest grade) to stage 4 (highest grade). A low-grade or benign tumour grows slowly and has cells that look fairly similar to normal brain cells. A high-grade or malignant tumour has cells that look quite abnormal and can grow quite aggressively within the brain.

The term “benign” can be somewhat confusing when discussing brain tumours. For example, a low-grade tumour may arise in an inoperable location. In this case the growth of a benign tumour could result in serious complications or even death. Furthermore, even operable low-grade tumours may have complications that cause significant disability and have serious implications for a child’s functioning at school. Finally, very occasionally, a low-grade tumour can change into a faster-growing form.

### Types of Brain Tumours

There are a number of ways to categorize and name brain tumours. Below is a description of some of the brain tumours more commonly seen in children and treated by cancer specialists. For additional information on these or other tumours, please refer to the resources listed in **Appendix G**.

**Brain Stem Gliomas** are tumours located in the very base of the brain. This part of the brain is responsible for a number of vital functions (e.g., heart rate and breathing) which makes surgical removal impossible. Tumours in this location may be low-grade, or, more-commonly in children, faster growing.

**Optic Nerve Gliomas** are located on or near the nerve that connects the eye and the brain. They are often slow-growing but can have serious implications for a child’s vision.

**Astrocytomas** arise from cells that make up the support structure of the brain. These may range from low grade to high grade and treatments will vary considerably as a result.

**Primitive Neural Ectodermal Tumours (PNET)** are believed to arise from primitive nerve cells in the brain. A PNET is a very aggressive tumour that can spread through the cerebrospinal fluid. One type of these, **Medulloblastoma**, occurs in the back of the brain or near the brain stem. Another, **Pineoblastoma** occurs in the area of the pineal gland.

**Ependymomas** arise out of the cells that line the passageways where cerebrospinal is produced and stored and most commonly occur in the ventricles of the brain (see info below).

**Crainopharyngiomas** arise in the area of the pituitary gland and the optic nerves. Tumours often have both a solid component and fluid filled component (cyst).

**Rhabdoid tumours** are very aggressive tumours that can arise in various locations in the brain.

## Treatment

Treatment decisions will depend on a number of factors including the tumour type and grade, the location of the tumour and surgical options, and whether the tumour is sensitive to chemotherapy or radiation treatments. The age of the child and the degree of tumour-related symptoms may also be considered. Surgery alone may successfully treat many low grade tumours. However, when surgery is not possible or advisable, other treatments may be considered. Children with high-grade tumours will almost always receive radiation and/or chemotherapy treatments.

### Hydrocephalus and Shunts

Cerebrospinal fluid (CSF) is the fluid that is found within and around our brain and spinal cord. This fluid is constantly produced by the body and flows through the ventricles, a system of interconnected cavities in the brain. Brain tumours sometimes cause blockages which do not allow the fluid to flow properly. Hydrocephalus occurs when excess fluid in the brain builds up in the ventricles and causes excess pressure inside the brain.

Hydrocephalus can be treated surgically. In some cases children will have a shunt placed in their brain. This device consists of a tube that drains the excess fluid from the ventricles to another part of the body where it can be reabsorbed, usually in the abdomen.

Children with shunts may need to take greater care with physical activities. Also, teachers should be aware of signs that the shunt is malfunctioning such as headaches, changes in vision or level of consciousness. **If your student has a shunt, please ask parents for specific information about precautions.**

## Complications

Sometimes, children with brain tumours may already have developed neurological deficits prior to diagnosis. For example, depending on the location of the tumour, they may have one-sided weakness, changes in gait, or changes in vision or cognitive processes.

Children may also have complications as a result of the treatment they receive. For example, a child who has surgery in the posterior fossa area of the brain may develop posterior fossa syndrome, an unusual complication which can include difficulty coordinating motor movements, decreased or absent speech, low muscle tone, and changes in vision. While these children always regain some function, many are left with residual difficulties which will have a long-term impact on their lives.

As mentioned earlier, children treated for brain tumours are at particular risk for later cognitive challenges. Furthermore, as with any brain injury, deficits in information processing may affect subsequent development. As a result, children who initially seem to be achieving well (i.e., have age-appropriate academic skills), may fail to keep pace with their peers as the demands of school increase over time. It is very important that progress be monitored closely and that strategies and supports be put into place at school to optimize the child's learning.

Many children treated for brain tumours will have access to neuropsychological assessment through their treatment centre. Assessment results will be invaluable in assisting with a child's educational planning.

## Appendix B: Informing the School Community

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When a child returns to school, parents are very anxious about their child's exposure to contagious illness. In particular, chickenpox can be quite serious for an immunocompromised child. It is almost inevitable that there will be chickenpox outbreaks at an elementary school. With parental consent, a general notice can be sent out to the school community asking for assistance. Regular reminders in a school newsletter may also be appreciated by families.

Some families may prefer not to share information so widely. If this is the case, keep in mind that the greatest risk of contagion comes from children who share a common air space for an extended period of time. This may include children in the same classroom, those riding the same bus, or classes that often work together (e.g. reading buddies).

*Dear Parents:*

*We have a child at our school who is receiving treatment for childhood cancer. She is doing well and attends school at this time.*

*Because the child's immune system is affected by the chemotherapy treatments, she is at a greater risk from contagious illness than other children. In particular, **it is important that you let us know as soon as possible if your child develops chickenpox.** Please let us know when the rash broke out.*

*As always, we ask that children be kept home from school when they are unwell. Thank you for your understanding and cooperation. Please call if you have questions or concerns.*

A more detailed letter may be appropriate for parents of the child's immediate peer group. The example below demonstrates the range of information which could be included.

*Dear Parents:*

*As some of you have heard, one of our Grade 3 students has been diagnosed with leukemia. While this is sad and serious news, you will be encouraged to learn that this is a very treatable illness. Julie's physicians are hopeful she will make a full recovery. She is not able to attend school at this time but hopes to return later this year. Of course cancer is not contagious.*

*We want to let you know that we will be discussing Julie's situation at school. Tomorrow, a representative from the Children's Hospital will speak to our Grade 3 classes. She will also spend some time with the fifth grade classmates of Julie's older brother. The children will receive age appropriate information about the illness and treatment. They will have an opportunity to ask questions and discuss how they can support their friend.*

*We know that classmates are eager to see Julie. At this time the family is adjusting to the diagnosis and Julie is not well enough to have visitors. Her parents have asked us to let you know that they will invite friends to visit when Julie is feeling better. They thank friends for the many cards, gifts, and flowers that Julie has received. There is a mailbox in the classroom where children can drop off letters and cards. You are also invited to visit Julie's website.*

*Our PTA is planning a spaghetti dinner fundraiser for the family. More information will be provided soon.*

*Thank you for your understanding and cooperation. Please call the principal if you have questions or concerns.*

## Appendix C: Alert for School Office

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# IMPORTANT

The following child has a compromised immune system due to medical treatment.

Name: \_\_\_\_\_ Grade/Teacher: \_\_\_\_\_

### Actions Required

- (1) If the child is unwell with a fever or suspected fever, please contact parents immediately.
- (2) Please let parents know as soon as possible if it is determined that the child has been exposed to chickenpox.

Determining Risk of Exposure: If a parent calls the school to report that a child has chickenpox, please ask when the rash appeared, and please note when the child was last at school.

The child named above will need immediate medical follow-up in the following circumstances:

*The child was with the infected child in the same classroom, cloakroom, or school bus, or the children were playing directly together on the playground during the following time periods:*

1. *The 48-hour period before the spots appeared.*
2. *The first five to six days after the spots appear (i.e. until the spots crust over).*

As a courtesy, please let parents know when there are chickenpox outbreaks at school, even if the child is not at immediate risk. Also, please let the parents know ASAP if there are any unusual contagious illnesses at school (e.g. measles), or higher than usual rates of serious contagious illness (e.g. influenza).

Parent's Name: \_\_\_\_\_ Phone: \_\_\_\_\_

## Appendix D: Guidelines for Classroom Discussions

Presenting information in a question and answer format can encourage class participation. This format also allows the educator to assess what the children already have heard about the situation, learn about classmates' past experiences with cancer, and gain insight into their fears, concerns, and questions. Below is a suggested outline for a classroom discussion.

Younger Children	Older Children and Teens
<b><i>What is cancer?</i></b>	
<p>Simple explanations are usually best. For example, leukemia is sick blood. A tumour is a lump that grew where it shouldn't have grown.</p>	<p>Older children will understand that the body is made of cells. Cancer cells are "wild cells" growing out of control. Emphasize that there are many types of cancer and they can be very different.</p>
<b><i>How do you get cancer?</i></b>	
<p>Stress that you can't catch cancer and no one made it happen. It doesn't happen to children very often.</p>	<p>Stress that we don't know why children get cancer and that it is a rare occurrence. Even older children may need reassurance that you can't catch cancer or wonder if something or someone caused it.</p> <p>Older children may be curious about diagnostic tests are used.</p>
<b><i>Will my friend die?</i></b>	
<p>Until about age 6, children have a limited understanding of death, unless they have had a personal experience.</p> <p>After this age, children nearly always wonder if the child could die, even if they do not ask. Tell children that you don't know what will happen, but you do know that the doctors are working hard to make the child well. The child is planning on getting better and needs everyone to hope he will get better too. Young children easily adopt a hopeful perspective.</p>	<p>Stress that childhood cancer is a <i>treatable</i> disease and most children get better. If treatment is progressing well, share this with classmates.</p> <p>It's ok to acknowledge the uncertainty of the child's outcome. However, normalize the situation by observing that we all deal with uncertainty every day. Discuss how being hopeful is more helpful than asking "what if" and how a positive attitude will help everyone, including their friend with cancer.</p>
<b><i>How do doctors treat cancer?</i></b>	
<p>Explain simply the type of treatment the child is receiving (e.g., chemotherapy is medicine that fights cancer, radiation is strong energy beams aimed at the cancer).</p> <p>This is a good opportunity to share information about a central line, and to allow the child to share their experiences if they are present. Sometimes parents will provide photos of the child at the hospital.</p>	<p>Let classmates know that cancer treatment is aimed at destroying the "wild" cells and keeping them from coming back; this is an opportunity for a science lesson.</p> <p>Describe the child's treatment. If the child is present, this is an excellent opportunity to allow them to share their experiences. Review safety around central lines.</p>

Younger Children	Older Children and Teens
<b><i>Will the child be well enough to come to school?</i></b>	
<p>Explain that cancer medicine is very strong and sometimes it does some extra things.</p> <p>Describe the side effects that children will notice (e.g., hair loss, a round face from steroids, fatigue). Stress that these are temporary.</p> <p>Let the children know if they can expect their friend back at school or if they are being taught at home or at the hospital.</p> <p>Regardless of age, it is helpful to discuss the child's decreased ability to fight germs with a focus on the prevention of the transmission of contagious illness (e.g. hand washing).</p>	<p>Cancer treatment has side effects; discuss what a side effect is and have students think of other examples of side effects (e.g., insecticides kill both good and bad insects). Explain that the chemotherapy can't tell the difference between the cancer cells and other cells in the body.</p> <p>Discuss the side effects that will be noticeable (e.g. hair loss) or that will affect the child's ability to participate in school (fatigue, compromised immune system).</p>
<b><i>How would it feel to find out you had cancer?</i></b>	
<p>Ask children for their thoughts. Encourage empathy. For example ask:</p> <p>How do you feel when you are sick?          Have you been in the hospital?          How would you feel if you lost your hair?          How would you feel if you couldn't come to school?</p>	<p>Ask students for their ideas. Make a list. Be sure they identify the following: fear, sadness, worry, anger, shock, hope. Discuss how it might feel to deal with the reactions of other people on the return to school.</p>
<b><i>How do we treat the child with cancer?</i></b>	
<p>Stress that although their friend may look a little different, he or she is still the same person. Explain that the child will just want to be treated the same as always. (Younger children tend to do this quite naturally!)</p> <p>It may be helpful to role-play the child's return so that the child is not overwhelmed by classmates' affection and excitement.</p>	<p>Ask the children how they would like to be treated after a cancer diagnosis. What would they be worried about? How would they want their friends to react? It is helpful to talk about not staring, what they might say, whether the child will want questions asked, and how being over-solicitous may not be helpful.</p> <p>Remind students that it can be hard to re-enter into a group when peer groups have been established.</p>
<b><i>How else can we help?</i></b>	
<p>Help children brain storm ways they can keep in touch with the child when she can't attend school. Structured projects are often helpful to keep the child part of the class (e.g., regular letters, group art projects).</p> <p>If the child wears a hat when she returns to school, perhaps everyone can wear a hat in your classroom.</p>	<p>Help children think of ways to keep in touch with their friend if the child can't attend (e.g., cards, letters, phone calls, emails, texts, social networks, visits if possible.)</p> <p>If rules allow, consider a webcam connection for an online visit.</p> <p>Older children may want to set up a club to keep in regular touch with the child, or to raise money for a charity or the family.</p>



Younger Children	Older Children and Teens
<b><i>How do we feel when a friend gets cancer?</i></b>	
<p>Discuss how it is normal to be sad and scared when a friend is very ill. Talk about what children can do to help themselves feel better (e.g., make a card for their friend, get a hug, talk to a parent, do something fun).</p>	<p>Acknowledge that this is a very serious situation and it is normal for friends to feel sad, worried, scared, or angry. Discuss different ways to cope when they are feeling bad, and the need to talk about their concerns.</p> <p>Help children distinguish between normal concerns and more extreme reactions that require adult help.</p>

### **Additional Issues to Consider (See also, page 19)**

***Siblings' Classmates:*** Change the focus of the discussion to address how it would feel if your brother or sister had cancer and how the children can support the sibling. Some siblings appreciate the opportunity to be the focus of attention for a change.

***Concerns about Emotional Reactions:*** Many educators are concerned that children will become highly emotional during a classroom discussion. In fact, this is seldom the case and children usually find a discussion reassuring rather than distressing. A relaxed, straight-forward, and positive approach will put every one at ease and set the tone for the discussion. However, it can be helpful to have an additional staff member available to provide support if it is required. Also, if a classmate is currently dealing with another cancer-related experience, consult with parents prior to the discussion.

***Prior Experience with Cancer:*** It is not uncommon for children to share stories about family members or friends who have had cancer, either during or after the discussion. Often, children are simply taking an opportunity to share something important that they may not otherwise have a chance to talk about. Usually children are very matter-of-fact about their experiences and a simple acknowledgement of the situation and their feelings is all that is required. However, if you have concerns about the reactions or questions of a particular child, follow up with parents.

Of course, it is always important to stress that there are many kinds of cancer, that cancer in children is different than cancer in adults, and that every cancer experience is unique.

***Opportunities for Questions:*** Older children are sometimes self-conscious about asking questions, especially if the child is present. Making a question box available for a few days before the presentation can be helpful. It is also important to provide additional opportunities for questions after children have had a chance to process the new information they have learned.

***Sharing Personal Medical Experiences:*** Younger children often like to discuss their own experiences of illness or hospitalization. At times, this can be distracting and veer the conversation away from its intended course. Consider channeling this desire into other activities (e.g., journals, an art activity, a future circle time or show and tell session).

***Adult Cancer and Health Promotion:*** Older students may identify factors that can cause adult cancer (e.g., sun exposure, smoking). It is important to stress that these factors did not cause the child's cancer. However, it can be an opportunity to stress health promotion such as sun protection, abstention from smoking, healthy diet, exercise, and regular medical check-ups.

***Unexpected Hospitalizations or Events:*** Because the course of cancer treatment is unpredictable, it may be necessary to provide occasional updates on the child's progress or situation. For example, a child who has attended school regularly may be hospitalized because of an infection. Classmates may worry unnecessarily that a hospitalization is an indication of something worse, like a recurrence, unless reassured otherwise.

## Appendix E: Considerations for Educational Planning

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The information below will help educators identify the many possible issues to consider when developing a plan to meet the needs of a child with cancer. Please note the following caveats:

- This is intended to be a comprehensive list. Not all information will apply to every child. Also, it is likely impossible (and inadvisable!) to cover all relevant issues at one time.
- As they start this process, educators will almost invariably feel like they do not have all the information they need. Childhood cancer can be uncertain and unpredictable. Plans need to be a work in progress.
- Parents are encouraged to take a “one-day-at-a-time” approach, especially in the early days of treatment. As a result, they may only be able to focus on short-range plans. Also, parents may be physically or emotionally unable to attend meetings. It is important that they be included in the process, but try to do this in a way that is unobtrusive and undemanding.

### Identifying the Participants

Ideally, planning will involve collaboration among educators, parents and professionals involved in the child’s care. A parent is always the best source of information on their child’s current needs and reactions, while a healthcare professional’s knowledge and experience allows them to know what strategies are most likely to be helpful.

It is important to include school administrators, school counsellors, resource teachers, and the teachers directly involved with the child in the planning process. It will also be helpful to include siblings’ teachers in some of the discussions. Finally, if there is reason to think that the child will need more intensive support (e.g., a child with significant physical challenges) consider including consultants from your school district or therapists who work with the child.

### Gathering Information about the Child’s Illness

What is the child’s diagnosis? What are the treatment goals?

What is the estimated length of treatment?

What type of treatment will the child receive? (e.g., chemotherapy, radiation, surgery)

What are the demands of treatment? (e.g., stays in hospital, day treatment, medications at home, or a combination; frequency/length of visits to hospital, location of treatment centre)

### Choosing an Approach to address Learning Needs

When will the child be well enough to return to school activities?

Will needs best be met by attendance at school, alternative instruction or some combination?

Will needs remain consistent throughout treatment or change over time?

What will be the academic and other goals/expectations this year? (e.g., all subjects, core subject areas, key math concepts, physical rehabilitation, socialization with peers?)

What important academic content has already been missed? Can we address this?

Does the child have any prior learning difficulties which need to be addressed in the plan?

Has the child’s disease/ treatment affected their ability to learn in any way? (e.g., brain tumour)

## **Addressing the Child's Needs when School Attendance is Possible**

### **Physical Needs:**

Are there any restrictions or limitations on physical activities? (e.g., physical education, recess)

Are there needs related to mobility, accessibility of our building, or equipment?

How is the child's energy level and stamina? How will we address fatigue? Is there a need for a graduated entry or a modified day?

Does the child have a central line? Are there any restrictions or precautions related to this?

What is the action plan if the child has a fever or is unwell or injured?

Are there any signs to watch for that might indicate the child is unwell? (e.g., signs of a fever)

What actions are needed to address the risk of infection? (e.g., monitoring exposure to chickenpox, ensuring ease of hand washing in the classroom)

Are there any dietary restrictions or needs? (e.g., need for snacks)

Are there any needs around toileting or other self-care concerns?

Are there concerns about sun sensitivity? (e.g., need to remind the child to apply sunscreen)

Are there limits to the child's ability to perform basic academic tasks? (e.g., fine motor weakness)

Are there any sensory challenges (i.e., vision or hearing loss)?

Are there any other concerns? (e.g., seizures, shunt, feeding tube)

### **Emotional Needs:**

What is the child's understanding of the illness?

What is the child's coping style? How will they be likely to respond if they are distressed?

Will the child be comfortable reporting concerns to a teacher? Who is the best "go to" person for child? Who else is available if that person is absent?

Is the child's mood affected by medication? (e.g., steroids)

How is the child feeling about the return to school? Have they been in touch with peers since diagnosis? Do the child and family want information shared with peers?

Is the child self-conscious about physical changes such as hair loss? How can we address these concerns?

Are classmates prepared for the child's return? Do they know how to be supportive?

Are plans in place to keep in touch with the child in the event of a longer absence?

### **Addressing Needs when the Child cannot attend**

What documentation is required to receive approval for home-based instruction or another alternative? Who is responsible for implementation and how long will the process take?

What physical and emotional needs should the teacher be aware of (refer to questions above)?

What time of day is the child most available to learn (i.e., feeling well, most energetic)?

How will the teacher providing alternative instruction keep in touch with teachers at the school?

Who will be responsible for evaluating the child's progress?

If correspondence courses are being used, which teacher is responsible for their oversight?

How will we encourage friends to keep in touch with the child on a regular basis? Are visitors allowed? Can the child visit the classroom?

When can the child come back to school and when will we begin to plan for the return?

### **Addressing the Needs of the Family**

Which staff member(s) will have primary contact with parents?

How will regular communication with parents take place? (e.g., communication book, regular phone contact, face-to-face)

What do siblings understand about the illness?

Are there others caring for the siblings when the child and parents are at the treatment centre?

Will it be helpful to inform siblings' peers? What are the siblings' wishes?

Will siblings miss any school due to the child's illness, and if so, how will we address this?

Who will siblings be comfortable approaching if they have concerns?

If fundraising is considered, has the family been consulted?

### **Addressing the Illness in the School Community**

What are the family's decisions about sharing information with the school community?

Assuming consent, which children will benefit from learning about the child's situation?

When should a discussion take place?

Who will lead the discussion? Who will be available to provide support if required?

What information will be shared?

Will other parents be informed before or after the discussion takes place? How?

Will information be shared with the larger school community? Is the family open to a general statement being given to in response to inquiries?

Are there any peers, classmates, or teachers who we anticipate will require additional support?

Have all relevant personnel been educated about the child's situation? (e.g., supply teachers, lunchroom supervisor, and custodian)

Do teachers know who to contact with questions and concerns? Do they know how to access the information and resources we have gathered?

### **Looking Ahead**

Who will be responsible for monitoring and evaluating our plan?

How soon will we assess?

Who can keep us updated on the child's progress if the family is unable to do so?

Are any needs anticipated in the future?

Is the child at risk for treatment-related learning difficulties?

## Appendix F: Challenges at the End of Life

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The death of a student is one of the more difficult challenges of an educator's career. Ultimately, educators closest to the child and their classmates will be required to address the day-to-day reactions of students as they anticipate and eventually grieve the loss of their classmate. Administrators need to make sure that these teachers receive the support they need.

Many school districts have teams in place to deal with unexpected tragedies. However, these teams may have less experience addressing an anticipated death. Additional information and support may be available from hospice organizations or the child's treatment centre.

### Taking the Lead from the Family

Naturally, any planned intervention at the school will respect the wishes of the child and family. It can be very difficult to speak to parents about their wishes, or to request permission to share information within the school community. It is recommended that one staff member be designated as the primary contact with the family. Ideally this should be someone the family has come to trust over the course of the child's illness. If contact with the family is difficult, parents may allow an extended family member or someone at the treatment centre to relay information to the school community on their behalf.

Occasionally, the family's wishes may not seem in sync with the perceived needs of the school community. For example, teachers may be unable to answer students' questions about a child's failing health because parents have not yet addressed the situation with the child or younger siblings. Other times, a family member may discuss the child's impending death very openly, and teachers may need to address the reactions of other students earlier than anticipated. The best plan always respects and supports the family and their wishes.

#### **Before the Death: Preparing for a difficult Journey**

- Organize a staff meeting. Encourage open communication among staff members. Invite consultants from your school system, the treatment centre, or a hospice agency to help facilitate and provide information on resources and supports.
- Determine if the child will be returning to school. If so, work with parents to develop a plan that addresses the emotional, social, physical, and ongoing learning needs of the child.
- Provide classmates with opportunities to support and show caring for their classmate.
- Assign someone to ensure that sibling needs at school are addressed before and after the death. Make sure siblings have a place to go and someone to talk to if they are upset.
- Learn as much as you can about how children understand death and how they grieve.
- Determine if and when to tell classmates that the child is dying. Respect the family's wishes and take the lead from the children. Inform other parents about any planned discussions.
- Some general information can provide a starting point for further conversation. (e.g., "Joey is very sick. The doctors are doing everything they can to help him but they might not be able to make him better.") Even in the face of this news, children will often continue to be hopeful, or not fully take in the gravity of the situation. That's ok. They will process the information as they are able.
- Keep the lines of communication open. Answer questions as honestly as you can and don't be concerned if there is no answer. If you're afraid, admit it. If you are sad, admit that too.
- Recognize that teachers are not super human. Seek support if you need it.
- Plan ahead. When the child dies, who should be called, who will tell the children? Who will be available to help at short notice? If letters home are planned, find templates ahead of time, so the task is easier later.

### **After the Death: The Journey continues**

- Tell the children simply but honestly about the death. Use clear language like “dead” and “died” and avoid euphemisms like “sleep”, “lost”, and “taken away” as these can be taken literally, especially by younger children. Be careful not to equate illness with death. Many people get sick and don’t die. Ideally, this information should be presented by someone who knows the children, in a familiar setting (e.g., own classrooms).
- Remember that even for older children, this may be their first experience with death.
- Provide a space with support staff for children to go if they are feeling overwhelmed. Often children are able to return to the classroom after a little time away to process and express their feelings. However, if a child is especially upset, you may wish to call parents and see if they would like to take their child home.
- Acknowledge the children’s feelings of sadness, anger, fear, and loneliness. It is ok to share your own feelings with the children. Provide opportunities to work through the feelings. Children may prefer to express feelings nonverbally through artwork, or write in a “memory book” about their friend. Don’t be alarmed if younger children act out their experiences through play.
- All children will grieve in their own way and at their own pace. Help children understand that everyone grieves differently and there is no “right” way to cope with something this difficult. Encourage them to respect these differences and support each other.
- Children often grieve in “spurts” and may seem quite distressed in one moment and then return happily to normal play in the next.
- Even on the day of the death, try to keep familiar classroom routines in place. Many children will need the normalcy of regular activities.
- Send a note home to announce the death and share information about any arrangements. A choice to attend a visitation or memorial service is a family decision, and parents should be encouraged to take the lead from their children. If a student wishes to attend a service and parents are unavailable to go with them, make sure there is adequate adult support available.
- Be sensitive to the needs of children and staff members who may be especially prone to grief reactions because of losses in their own lives.
- Provide children with ongoing opportunities to ask questions. Young children may ask the same questions on a number of occasions as they come to an understanding of the death. Try to ascertain what information the child is looking for and keep answers simple.
- Remember that children may lack the words to express what they are feeling. Grief may be reflected in behaviour, either acting out or withdrawing. Make parents aware of any concerns.
- Consider holding a memorial service or event at school and invite the family. Planning a memorial service for their friend can be very therapeutic for other students. The service could be “A Celebration of Life” with songs, readings and presentations, and may occur weeks after the death.
- Provide opportunities for grieving following the death. Keep an area of remembrance at the school for as long as children need it (e.g., pictures, a memory book).
- Commemorate the child’s life. For example, plant a tree, initiate fund raising in the child’s memory, or create an award or scholarship in the child’s name.

## Case Examples

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*Ryan was diagnosed with Stage IV Neuroblastoma when he was 3 years old. He underwent 1 ½ years of intensive treatment. For a time, his disease was in remission and he attended kindergarten regularly. His disease recurred part way through first grade. The Hospital-School Liaison provided the children with some information about Ryan's situation at that time. Additional treatment kept the disease from progressing and he attended school on an occasional basis. Part way through his second grade year the cancer began to grow aggressively. After an unsuccessful trial of a new chemotherapy drug, treatment was discontinued. Three weeks before summer vacation, he was admitted to the palliative care unit at the hospital because his mother could no longer manage his symptoms and care at home. Ryan was not expected to survive the summer.*

**Solution:** The hospital-school liaison, school social worker, and principal discussed the need to prepare Ryan's classmates for his death. Ryan's mother generously gave consent for them to "do whatever they felt was best" to help Ryan's friends. The principal sent a letter to the classmates' parents about the situation and a planned discussion. Parents were invited to attend if they wished. One mother chose to have her child opt out of the discussion because his grandfather had recently died. The Hospital-School Liaison told the children that Ryan was getting sicker, the doctors didn't have any more medicine to help him, and they believed he would die. Some children clearly understood their friend would die, while others remained hopeful he would get better. However, most of the conversation focused on how friends could help Ryan at this time, and how they could manage their own feelings.

The class made a letter-writing schedule and each day a letter was faxed to the hospital. His teacher visited every week. The PTA provided gift cards and care packages for the family. Before summer vacation, the principal developed a telephone tree so that staff and parents could be informed if Ryan died during the summer break. Ryan died several weeks later. The school's tragic events team was available for the first week of the next school year to provide support to friends and teachers. A month later, the class held a small memorial service for Ryan and planted a tree in his honour.

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*Annie was 14 years old when her cancer returned for the second time. There were no remaining options for treatment. Annie loved school and expressed a desire to attend as long as she was able. She continued to attend her small, faith-based high school, but over time her health deteriorated and her energy decreased.*

**Solution:** Teachers set up a bed for Annie in a small room by the school office. Annie rested each lunch hour. Some afternoons she returned to her classes, on others she chose to go home. She became more ill and required continuous pain medication. However, she still came to the school for an hour or two on most days, with a family member or home care nurse in attendance. More and more of her time was spent in the small room. Classmates took turns visiting with her, reading, listening to music, praying, or just chatting. Students had many opportunities to discuss their friend's impending death and process their feelings with the support of the school pastor. Annie's visits gradually became less frequent with the last one occurring 2 weeks prior to her death.

Annie's parents asked the school choir to sing at Annie's funeral service and several friends spoke about their friend. After her death "Annie's Room" became a place where friends could go if they were missing their friend. The following year, the school raised funds for a camp Annie had attended.

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*Steven was 10 years old when he was diagnosed with an incurable brain tumour. He had become very ill in a very short time. Radiation treatments were expected to shrink the tumour and relieve his symptoms for a while, but his parents were told the tumour would eventually progress and Steven would likely survive less than a year. They chose not to tell Steven about his prognosis because they wanted his last months to be as worry-free as possible.*

*At first, Steven's parents were hesitant to send him to school. However, as he began to feel better Steven's persistent requests that he attend school, his physician's encouragement, and their wish to have Steven live a "normal life" caused them to reconsider. His parents were initially opposed to any information being shared with other children at the school because they were concerned that Steven or his five-year-old sister might learn about his prognosis.*

**Solution:** After some discussion with the hospital psychologist Steven's parents agreed it would be helpful for the teacher to share some limited information with the children, namely to address the obvious physical changes and side effects that were evident from the treatment. The psychologist consulted with the teacher by phone and helped her find the words to address the students' needs for information, while respecting the family's wishes. The teacher also impressed upon the students the need to respect Steven's privacy and minimize gossip outside the classroom.

Steven attended school half days but stayed in for recess at his parents' request. Friends took turns staying inside with him, usually playing on the computer together. He was well enough to attend school for about five months.

When Steven became too ill to attend, classmates sent him cards, letters, jokes, and a video of the school play. When children began to ask the inevitable questions, staff merely confirmed that Steven was quite ill and re-focussed the children's energy on finding ways they could show their love and support of Steven. Teachers found it difficult when they could not answer questions directly, but, out of respect for the family and the younger sibling, they did not share any more information with the students.

The school social worker provided an in-service to help teachers prepare for Steven's death and make a plan to address children's needs when the news came. They also discussed how they could support Steven's little sister. The social worker and her colleagues provided support and follow-up to staff and students when Steven died. Six weeks after Steven's death, the students presented a memorial service for their classmate. They sang his favourite song and shared a list of all of their favorite memories of their friend. Although the family did not feel ready to attend the service, they later donated all of Steven's books to the classroom. Each classmate was invited to take a book home at the end of the year.

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## Appendix G: Additional Resources and Support

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### Information about Childhood Cancer and Treatment

Brain Tumour Foundation of Canada (2007). *Patient resource manual: Pediatric version*. Available at [www.braintumour.ca](http://www.braintumour.ca) (also available in French)

Janes-Hodder, H. & Keene, N. (2002), *Childhood Cancer: A Parents Guide to Solid Tumours*, O'Reilly Media.

Keene, N. (2010). *Childhood Leukemia: A Guide for Families, Friends and Caregivers*. O'Reilly Media.

Keene N., Hobbie, W., and Ruccione, K. (2006). *Childhood Cancer Survivors: A Practical Guide to your Future*. O'Reilly Media.

[www.curesearch.org](http://www.curesearch.org)

<http://www.macmillan.org.uk>

[www.abta.org](http://www.abta.org)

### Resources for Teachers

Keene, N. (Ed.) (2003). *Educating the Child with Cancer*. Candlelighters Childhood Cancer Foundation.

Nessim, S. and Katz, E.R. (2000). *Cancervive Teacher's Guide for Kids with Cancer*. Cancervive.

Leukemia and Lymphoma Society. *The Trish Green Back to School Program for Children with Cancer*. Info at [www.lls.org](http://www.lls.org).

[www.childhoodcancer.ca/educatorsguide](http://www.childhoodcancer.ca/educatorsguide) (lots of information and practical information)

<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/> (information on supporting kids with illness at school)

### Resources for Children

American Cancer Society. *Jacob has Cancer and his Friends want to Help*. (colouring book).

Barton, Denise (2008). *'C' is for Cancer*. For more info e-mail [DeniseBarton@telus.net](mailto:DeniseBarton@telus.net).

Dodd, M. (2004). *Oliver's Story*, Candlelighters Childhood Cancer Foundation.

Hershey, M.K. (1999). *Oncology is Stupology...I want to go Home*. Butterfly Press.

Klett, A. (2002). *The Amazing Hannah*. Candlelighters Childhood Cancer Foundation.

Krishner, T. (1992). *Kathy's Hats*. Morton Grove, Illinois: Albert Whitman's Co.

Martin, K. (2005). *H is for Hair Fairy*. Trafford Publishing.

Sanford, D. (1992). *No Longer Afraid*. Multnomah Press.

Schultz, C.M. (1990). *Why, Charlie Brown, Why?* New York, Topper Books (video also available from [www.lls.org](http://www.lls.org) and at [www.youtube.com](http://www.youtube.com))

Ulberg, K. (2000). *Stevie's New Blood*. Oncology Nursing Society.

Zammit, M. (2005). *A Friend in Hope*. Brain Tumour Foundation of Canada.

[www.teenslivingwithcancer.org](http://www.teenslivingwithcancer.org)

[www.cancerkids.com](http://www.cancerkids.com)

## Resources about Death and Grief

Dyregrov, A. (2008). *Grief in Children: A Guide for Adults*. Jessica Kingsley Publishers.

Mellonie, B. and Ingpen, B. (1983). *Lifetimes: The Beautiful Way to Explain Death to Children*. Bantam Books.

Wolfelt, A.D. (2004). *A Child's View of Grief*. Companion Press.

Stickney, D. (2004). *Water Bugs and Dragonflies*. Pilgrim Press.

Fox, M. (1994). *Tough Boris*. Sandpiper.

Hanson, Warren (1997). *The Next Place*. Walmand House Press.

Mills, J.C. (2003). *Gentle Willow: A Story for Children about Dying*. Magination Press.

Peen, Audrey. (2009). *Chester Raccoon and the Acorn full of Memories*. Tanglewood Press.

[www.centering.org](http://www.centering.org)

[www.compassionbooks.com](http://www.compassionbooks.com)

[www.dougy.org](http://www.dougy.org)

## Helpful Organizations: Information and Support

American Brain Tumour Association :  
[www.abta.org](http://www.abta.org)

Canadian Cancer Society  
[www.cancer.ca](http://www.cancer.ca)

American Cancer Society  
[www.cancer.org](http://www.cancer.org)

ChildCan (Southwestern Ontario)  
[www.childcan.on.ca](http://www.childcan.on.ca)

Brain Tumour Foundation of Canada  
[www.braintumour.ca](http://www.braintumour.ca)

Leukemia and Lymphoma Society/  
Leukemia and Lymphoma Society of  
Canada  
[www.lls.org](http://www.lls.org)

Candlelighters Childhood Cancer  
Foundation  
[www.candlelighters.org](http://www.candlelighters.org)

National Brain Tumour Society  
[www.braintumour.org](http://www.braintumour.org)

Childhood Cancer Canada Foundation  
[www.childhoodcancer.ca](http://www.childhoodcancer.ca)

Paediatric Oncology Group of Ontario  
[www.pogo.ca](http://www.pogo.ca)

Caring Bridge (websites for families)  
[www.caringbridge.org](http://www.caringbridge.org)

SuperSibs (support for siblings)  
[www.supersibs.org](http://www.supersibs.org)

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Katz, E.R. & Ingle-Nelson, M.J. (1988). School and the seriously ill child. In B. Martin (Editor), *Pediatric Hospice Care: What Helps*. Los Angeles, California: Children's Hospital of Los Angeles.

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<http://www.macmillan.org.uk>