Children with Cancer:
A Guide for Educators

Second Edition

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO

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A Guide for Educators

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

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Acknowledgments

This booklet was developed by POGO Pediatric Interlink Community Cancer Nurses, a nursing program that provides supportive care for pediatric oncology patients across Ontario. As part of their role, POGO Interlink Nurses work collaboratively with educators and families to support children to maintain their connection with school throughout their cancer journeys.

At present, 10 POGO Interlink Nurses (nine full-time equivalent positions) serve well-defined geographic areas across Ontario and are cross appointed at service delivery sites, including:

- Children's Hospital of Eastern Ontario (Ottawa)
- Children's Hospital, London Health Sciences Centre
- Health Sciences North (Sudbury)
- McMaster Children's Hospital, Hamilton Health Sciences
- The Hospital for Sick Children (Toronto)

To learn more about how POGO Interlink Nurses work with families whose children have cancer, please speak to your POGO Interlink Nurse or contact the POGO Interlink Team Leader. Contact details can be found on the POGO website, www.pogo.ca.

POGO gratefully acknowledges the many contributions of health care professionals, teachers and parents who have assisted with the development of this booklet.

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About POGO

The Pediatric Oncology Group of Ontario (POGO) is a collaboration of dedicated specialty programs and health care professionals who care for children with malignant disease, committed to delivering the right care at the right time and in the right place for children with cancer and their families. POGO has done this work since 1983 in partnership with the five specialty pediatric oncology programs in Ontario:

- The Hospital for Sick Children (Toronto)
- McMaster Children's Hospital, Hamilton Health Sciences
- Children's Hospital, London Health Sciences Centre
- Kingston General Hospital
- Children's Hospital of Eastern Ontario (Ottawa)

The organization has built a reputation for recommendations based on solid information, scientific evidence and extensive clinical experience, and has provided advice, leadership and provincial coordination for pediatric cancer care and control as principal advisor to the Ontario Ministry of Health and Long-Term Care (MOHLTC). A growing number of partners contribute to POGO's work, including community hospitals and community services, families of children who have cancer and survivors of a malignancy during childhood, corporate and private benefactors and volunteers.

Through health care innovation, survivor care, financial assistance for families, policy development, education, population surveillance and research POGO has created a highly integrated and seamless pediatric cancer system that supports children and families throughout the spectrum of illness, recovery and survivorship.

POGO Programs and Services

POGO Provincial Pediatric Oncology Satellite Clinics provide care in seven designated community hospitals, closer to families' homes—reducing the burdens of being away from home over a lengthy and intense course of illness, and decompressing service demand in diagnosing hospitals.

POGO's Pediatric Oncology Financial Assistance Program (POFAP) reimburses families for some of the out-of-pocket costs they incur when a child undergoes cancer treatment. In addition to costs associated with travel, accommodations and babysitting, one parent often has to give up work to care for the ill child. This can consume approximately one-third of a family's after-tax income, adding significant financial stress during a difficult time.

POGO AfterCare Clinics monitor and promote the health of childhood cancer survivors who may face late effects of their disease and treatment. These clinics also collect data relevant to care and long-term health outcomes, facilitating research that will improve the care of future generations of patients. Over 2,000 survivors are currently cared for by seven POGO AfterCare Clinics located across Ontario.

POGO's Successful Academic and Vocational Transition Initiative (SAVTI) aims to promote the integration of childhood cancer survivors as they transition into post-secondary education or workplaces. SAVTI offers counselling, assistance and support to survivors experiencing cognitive late-effects of the cancer and its treatment.

KEYS to Succeed is POGO's newest pilot innovation program for young survivors of childhood cancer. It will evaluate ways of supporting young survivors with cognitive challenges through the elementary school years.

POGO Resources

Can I Catch Cancer? is a compilation of some of kids' most frequently asked questions, with answers provided by POGO Interlink Nurses. Download the PDF at www.pogo.ca.

The POGO Resource Guide is the first resource guide for families of children with cancer, facilitating access to psychosocial, educational, financial, respite, palliative care and other services. It is a valuable directory for professionals and families, accessible online at www.pogo.ca.

POGO's *Money Matters* Booklet and related brochures are practical guides to financial programs and benefits. Developed as a resource for professional care providers and families, the booklet identifies many sources of assistance available to ease the financial burdens of families of children with malignant disease. It is available to families from their health care team, specifically their social worker or POGO Interlink Nurse and it can be downloaded at www.pogo.ca.

Ways to Help POGO

When a child is diagnosed with cancer, it affects the whole family. Often one parent needs to give up work to take care of the ill child and the family is left financially unstable. POGO helps to ease this financial burden by reimbursing families for out-of-pocket costs associated with treatment—costs such as accommodation during treatment in distant specialty centres, childcare for siblings who are left at home and meals while at the hospital. This financial support is just one of the ways POGO makes a tangible difference to a family with a child in cancer treatment.

Children and schools can make a difference too!

POGO works with schools to create meaningful activities that help promote community service, build awareness about cancer during childhood, and raise funds to support kids with cancer and their families. Contact POGO's Development Office today at 1.855.FOR.POGO (1.855.367.7646) or 416.592.1232 to engage the students at your school and support kids with cancer.

Introduction

This booklet has been created to support the education of children and adolescents with cancer. It acknowledges the importance of schooling and the challenges of educating children undergoing cancer treatment. It contains general information about childhood cancers and practical strategies for the educators and administrators who strive to support them through the cancer journey.

Childhood Cancer & Treatment

Understanding Cancer in Children

What is Cancer?

Cancer is an uncontrolled growth of abnormal cells. There are many types of cancer, usually classified either by the kind of cell from which the cancer originated or by the part of the body from where the abnormal cell originated.

How is Childhood Cancer Different from Adult Cancer?

Cancer in children is uncommon when compared with adults. Childhood cancers account for <1% of all cancers.

The types of cancer that affect children are different than those in adults. The most common cancers in children are leukemia (a cancer of the blood) and brain tumours. The most common cancers in adults are prostate, breast, lung and colorectal. These are extremely rare in children.

In general, childhood cancers are more responsive to therapy and overall cure rates are much higher. Approximately 75-80% of all children diagnosed with cancer are cured of their disease.

As a result of high cure rates and their younger age, children are at greater risk for developing long-term side effects following cancer therapy and must be monitored on an ongoing basis.

What Causes Childhood Cancer?

The origins of childhood cancer are generally unknown. Currently there is no clear understanding of either inherited or environmental causes in most childhood cancers.

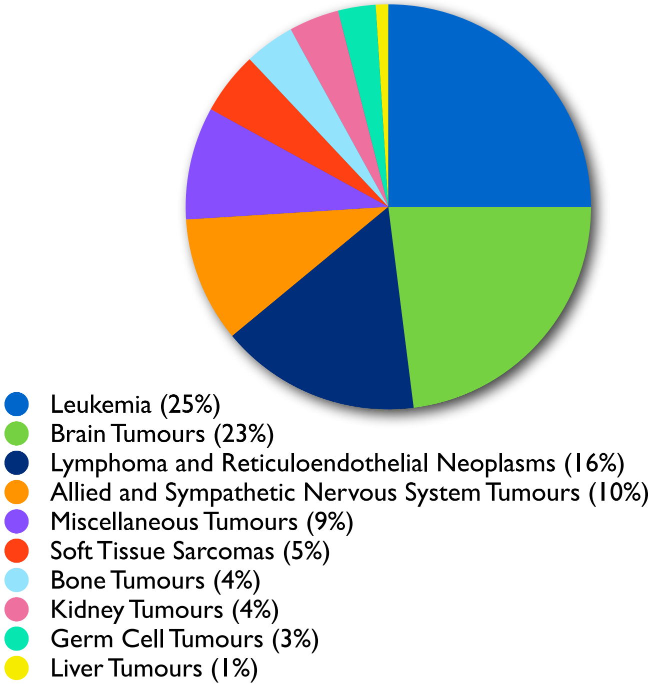
How Many Children are Diagnosed with Cancer?

The five-year annual average of new pediatric cancer diagnoses in Ontario from 2008 – 2012 was 545. (Source: POGONIS, May 2013, Pediatric Oncology Group of Ontario.)

The overall survival at five years for children age 0-14 in Ontario from 2000 – 2004 was 80%. (Source: POGONIS Reports, November 2010, Pediatric Oncology Group of Ontario.)

Distribution of New Cases of Pediatric Cancers Diagnosed in Ontario at the Five Pediatric Tertiary Centres from 2008 – 2012

(Source of data: POGONIS, May 2013, POGO)



Common Types of Cancer in Children

Tynan Studio

Cancers are generally divided into three broad categories: leukemias and lymphomas, brain tumours and solid tumours.

Leukemias and Lymphomas

Leukemia is cancer of the blood cells and accounts for 30% of all childhood cancers. Children with leukemia may present with symptoms of fatigue, fever and bruising. The most common type of leukemia is acute lymphoblastic leukemia (ALL) which accounts for 80% of the cases. This disease is most common in young children (peak age at diagnosis is four years). The treatment for ALL lasts from 2.5 – 3 years. The prognosis is generally very favourable with more than 85% of children being cured of their disease. The other common type of leukemia in children is acute myeloid leukemia (AML) accounting for 20% of the cases. The treatment for AML is shorter, lasting 4 – 6 months but is very intensive with almost all of therapy requiring the child to stay continuously in the hospital and sometimes requiring a bone marrow transplant. The outcome for children with AML is less favourable with only 50% of children being cured.

Lymphomas are cancers that originate in the immune cells often presenting as enlarged lymph nodes. Lymphomas are divided into two groups, Hodgkin's and non-Hodgkin's lymphoma. Combined, they account for approximately 12% of childhood cancers. Hodgkin's disease is the most common form of lymphoma and is the most common type of cancer in teenagers. Treatment varies by the type of lymphoma and involves chemotherapy and sometimes radiation with varied duration from several months to several years. The prognosis for children with lymphoma is generally very good.

Brain Tumours

Brain tumours are a group of different types of cancers of the brain and are the second most common cancer in children. Symptoms may include headaches, nausea and vomiting, changes in vision, clumsiness and loss of balance. Treatment varies depending on the nature and location of the tumour. It may involve a combination of surgery, chemotherapy, very high dose chemotherapy with hematopoietic (blood cells) stem cell rescue and radiation. The length of treatment varies and the overall survival also varies widely depending on the type of brain tumour. A portion of survivors of childhood brain tumours will have significant long-term effects.

Solid Tumours

Solid tumours are a varied group of tumours arising from any group of tissues other than the blood, immune cells or brain. Solid tumours start in the organ of origin and can metastasize (spread) to other parts of the body. The treatment for solid tumours varies by the type but often includes chemotherapy, surgery and radiation therapy. The duration of treatment varies but is often between six months and one year. The prognosis for children with solid tumours depends on the tumour type and the amount of spread (or stage).

Bone Tumours such as Ewing's sarcoma and osteosarcoma account for about 6% of tumours. Pain and swelling are common symptoms and can be confused with injuries. These tumours are more common in teenagers.

Rhabdomyosarcoma is cancer of muscle. It may present as a lump and accounts for about 6% of childhood cancers. It affects children of all ages.

Neuroblastoma is a tumour of nerve cells outside the brain, most often occurring in the adrenal gland (which sits on top the kidney). It accounts for about 5% of childhood cancers and is very uncommon in older children. Symptoms vary depending on the size and location of the tumour.

Kidney Tumours account for about 10% of childhood cancers. The most common form is called Wilms tumour. They commonly present as a large lump in the abdomen and are much more common in young children.

Retinoblastoma is the most common eye tumour in children. It is most common in infants. Most cases involve one eye but some children who have specific genetic defects can have disease in both eyes.

Other Cancers include liver tumours, germ cell tumours (such as ovarian and testicular cancers) and other rare cancers.

Common Tests

Children receiving treatment for cancers undergo many tests. Some tests are done to establish the diagnosis (such as tumour biopsy). Other tests are done to evaluate where the cancer is located in the body (staging). Ongoing testing throughout cancer treatment helps to determine if cancer therapy is effective and to monitor for the side effects of treatment.

Blood Tests

There are many different types of blood tests, but the most common test in the oncology department is the CBC (complete blood count). The CBC measures the number of blood cells in the child's body, specifically, white blood cells, red blood cells (haemoglobin) and platelets (tiny cells that help the blood clot). Families may refer to their child being "neutropenic," which means that the child's infection-fighting white blood cells are low.

Bone Marrow Aspirate

Bone marrow is the soft spongy material that is found within the centre of most large bones in the body. This is where blood cells are made, such as red blood cells, white blood cells and platelets. An aspirate removes a sample of the liquid bone marrow. This test is done to confirm a diagnosis of leukemia or to rule out or confirm bone marrow involvement with other cancers.

Lumbar Puncture

A lumbar puncture (also known as a spinal tap) is a test used to look at the cerebrospinal fluid (CSF is fluid that surrounds the brain and spinal cord). A needle is inserted into the spinal canal and samples of cerebrospinal fluid are taken for diagnosis. Chemotherapy can also be given into the spinal canal via lumbar puncture.

CT/CAT Scan (Computerized Axial Tomography)

CT scanning uses special x-ray equipment in combination with sophisticated computers to produce multiple images or pictures of the inside of the body. They are often used to get pictures of the brain, spine, chest, abdomen and pelvis.

MRI (Magnetic Resonance Imaging)

MRIs use powerful magnets and radio waves to scan the inside of the body without using x-rays. The information is then fed into a computer to provide detailed pictures.

PET Scan (Positron Emission Tomography)

A PET scan uses small doses of radiation to produce three-dimensional colour images of the functional processes within the human body. PET scans detect areas of the body that are very metabolically active. Groups of cancer cells are often very active and can be detected by a PET scan.

Ultrasound

Ultrasound uses sound waves to take pictures of the inside of the body. The pictures can show size, shape and texture of the body parts.

X-ray

X-rays are a type of electromagnetic radiation that provides a quick and simple way of looking at organs and structures. The most common x-ray is the chest x-ray which looks at the lungs, heart and bones making up the chest wall.

Treatments

When a child under the age of 18 is diagnosed with cancer in Ontario, they receive care at one of five pediatric treatment centres in the province (Toronto, Ottawa, London, Hamilton and Kingston). Many patients also receive some of their treatment closer to home at POGO Pediatric Oncology Satellite Clinics carefully established in designated community hospitals.

Although new and innovative methods to treat childhood cancers are emerging, the three main treatment modalities remain chemotherapy, surgery and radiation. All of these treatments act to destroy cancer cells and may be used alone or in combination. Additional treatment modalities include bone marrow and peripheral blood stem cell transplants and biological therapies.


Bill Branson, National Cancer Institute

When a child is diagnosed with cancer, they are placed on a specific treatment plan called a protocol. The age of the child, type of cancer, extent of disease and individual risk factors all contribute to which treatment protocol a child will receive. A protocol can vary in duration from months to years.

All major treatment centres in Ontario are part of an international cooperative study group aimed at standardizing and improving treatment outcomes for children with cancer.

Chemotherapy

Chemotherapy is the use of medications to destroy rapidly dividing cancer cells.

There are many different medications that are classified as chemotherapy agents.

Chemotherapy can be given by mouth (pill or liquid), by injection into a vein (intravenous or IV), by injection into the spinal fluid (intrathecal or IT), by injection under the skin (subcutaneous or SC), or by injection into a muscle (IM).

Oral chemotherapy medications may be given at home, while all other methods of administration are given either while admitted to hospital or in an outpatient clinic.

Chemotherapy medications given in accordance with a prescribed treatment protocol can be given as a single chemotherapy drug or a combination of different drugs. These medications are given in cycles over a period of time (usually a number of days), followed by a period of rest when no chemotherapy is given (usually a number of days or weeks). Cyclical administration allows chemotherapy to optimally destroy cancer cells while allowing the body's normal cells time to recover from damage.

Radiation

Radiation is a treatment that uses high energy rays (electron beams) to destroy cancer cells. Radiation is most often delivered by means of a large machine that aims the high energy beams at a specific area of the body where cancer cells exist. Special measurements are taken to ensure that these rays are delivered only to the intended areas. The treatment itself is not painful and only takes a few minutes to deliver.

It is generally given on an outpatient basis in daily sessions over a period of days or weeks.

Children must remain completely still during their treatments. Very young children may require anesthesia to receive their therapy safely.

Radiation can be used as a treatment modality on its own or in combination with surgery and/or chemotherapy. In some cases, radiation may be used to relieve unpleasant symptoms, such as pain. In a very small number of children with forms of leukemia with an exceedingly high risk of disease to the brain or spinal cord, radiation may be given as a preventative measure. These children receive cranial radiation delivered to the central nervous system where undetectable cancer cells are known to hide.

Attendance at school during radiation therapy is variable and dependent on other aspects of the child's treatment.

When radiation is delivered to the brain or central nervous system, long-term side effects resulting in learning difficulties may result. In the short term, children frequently become quite fatigued during, and for a few weeks after, radiation treatment.

Surgery

Surgery is used in a variety of ways to treat children with cancer. For some, surgery is the only treatment that is required. More commonly, treatment protocols call for the administration of chemotherapy and/or radiation prior to and/or following surgery.

Surgical interventions may be necessary for children who have been diagnosed with cancer for reasons other than the removal of a primary tumour. Surgery may be needed to obtain a biopsy, or piece of tumour, in order to confirm a diagnosis. Surgery may also be necessary to support a child's treatments. For example, surgical placement of a central venous access device may be necessary as a delivery method for intravenous chemotherapy. Finally, surgery may be necessary to reconstruct surrounding tissues following the removal of a tumour.

Bone Marrow Transplant and Peripheral Blood Stem Cell Transplant

Bone marrow is the spongy centre of bones where the body manufactures blood cells. The bone marrow is where immature blood cells, called stem cells, are produced. Stem cells have the ability to develop into a range of mature blood cells. Although stem cells are most plentiful in the bone marrow, they also exist in the bloodstream and in umbilical cord blood.

Sometimes children require very high doses of chemotherapy in order to destroy their cancer cells. As a side effect, the healthy stem cells, which normally grow to produce mature blood cells, are also destroyed. In order to restore these cells, children may receive a bone marrow or peripheral blood stem cell transplant.

Bone marrow and peripheral blood stem cell transplants involve the collection of healthy stem cells either from the bone marrow or from the bloodstream.

The source of these cells can be the child himself (autologous transplant) or a donor (allogeneic transplant). The donor may be a family member or someone who is unrelated to the child. After a period in which a child has received very high doses of chemotherapy, the collected bone marrow or peripheral blood stem cells are infused into the recipient through an intravenous catheter, in a similar way to how blood is transfused. Within weeks, donated cells find their way through the bloodstream and into the child's bone marrow where they begin to produce new, healthy blood cells. While this process is occurring a child can be very ill and is at very high risk for infection. During hospitalization the child will be cared for in an isolation room.

Bone marrow and peripheral stem cell transplantation require weeks to months of hospitalization. After discharge from hospital the child will be absent from school for several months while the immune system restores itself. During this time a child remains at high risk for life-threatening infection and will require home instruction.

Targeted Therapies

Targeted therapies are a group of new and emerging medications that are sometimes used in the treatment of childhood cancers alone or in combination with other therapies. Conventional chemotherapy agents act by killing rapidly dividing cells including cancer cells. However, they also affect healthy rapidly dividing cells such as blood cells, hair cells and the cells that line the intestine. Targeted agents are medications that are specifically designed to interfere with the specific type of cancer cell. Often, targeted therapy is developed because scientists have gained an understanding of the biological defect of the specific cancer cell type. They can then rationally design (or sometimes fortuitously find) a drug that targets that cancer-specific abnormality. Targeted therapies have the potential advantage of being effective at killing cancer cells while doing less damage to healthy cells.

Children may receive biological therapies while in hospital or at home.

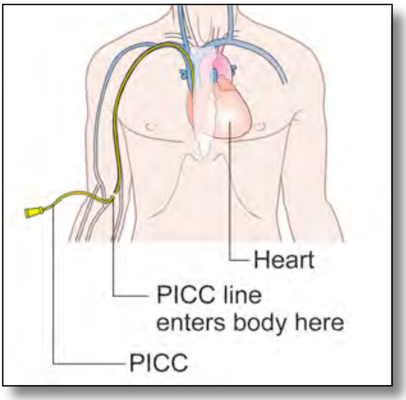
Medical Devices & Care

Central Venous Access Devices

When children require frequent administration of intravenous fluids, intravenous medications and blood sampling, the decision is often made to surgically implant a central venous access device. These devices provide a less painful alternative to peripheral venous access. Upon completion of the child's treatment protocol, the device is removed. The three most common devices and the implications for their care while at school are listed below.

Peripherally Inserted Central Catheter (PICC)

A peripherally inserted central catheter (or PICC line), is a long silicone tube or catheter that is surgically inserted into a vein in the upper arm. The tube is fed internally along this vein and ends in a larger vein leading to the heart. The PICC may have one or two tubes (lines) that are visible outside of the body.



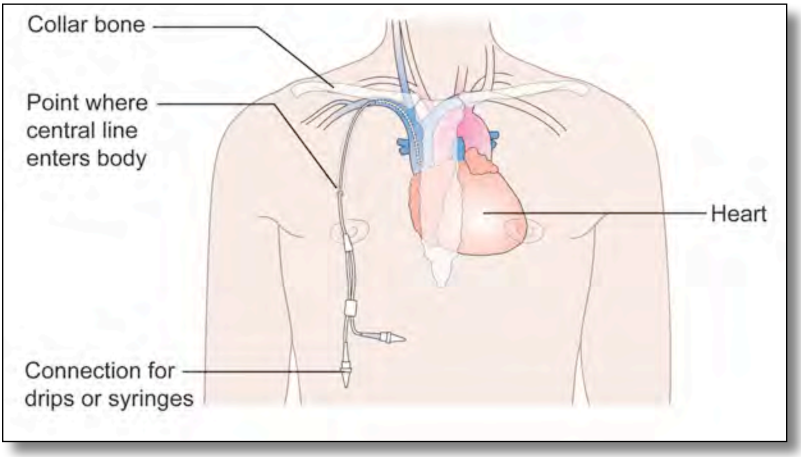
Taken from the patient information website of Cancer Research UK: http://www.cancerresearchuk.org/cancerhelp

When a child is at school, the part of the PICC line that is external to the body will be wrapped in a gauze bandage and secured safely to the arm. The child will travel with an emergency kit in the rare event of accidental dislodging or leakage from the tube. A POGO Interlink Nurse will describe the use of this kit upon the child's return to school. Step-by-step guidelines can also be found in **Appendix 1**.

Rough play and water sports should be avoided when a PICC is in place.

External Central Venous Line

An external central venous line (or CVL, often called a Broviac or Hickman Line) is a long, flexible silicone tube or catheter that is surgically inserted with one end of the catheter sitting in a large vein leading to the heart and the other end extending outside the body through the skin of the chest. The external CVL may have one or two tubes (lines) that are visible outside of the body.

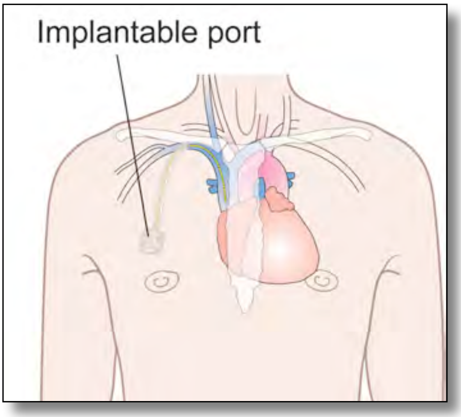


Taken from the patient information website of Cancer Research UK: http://www.cancerresearchuk.org/cancerhelp

When a child is at school, the CVL tubes (lines) will be wrapped in a gauze bandage and safely secured to the chest underneath the clothing. The child will travel with an emergency kit in the rare event of accidental dislodging or leakage from the tube. A POGO Interlink Nurse will describe the use of this kit upon the child's return to school. Step-by-step guidelines can also be found in **Appendix I.**

Rough play and water sports should be avoided when an external CVL is in place.

Subcutaneous Port (Port-a-cath)



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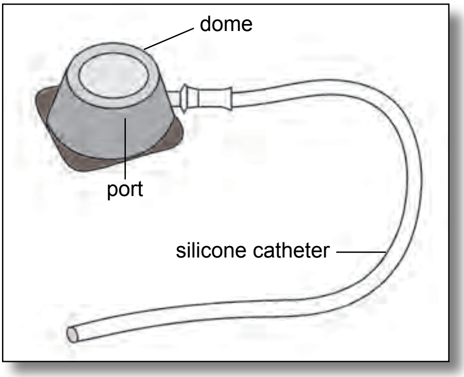


A subcutaneous port (or port-a-cath) is a central venous access device that is entirely inside the body. It is visible as a small, raised dome just under the skin on the upper chest.

The port consists of a small metal disc with a silicone centre that is attached to a catheter or tube. The device is surgically inserted under the skin of the chest, and the tube is tunneled under the skin into a large vein in the neck that leads to the heart.

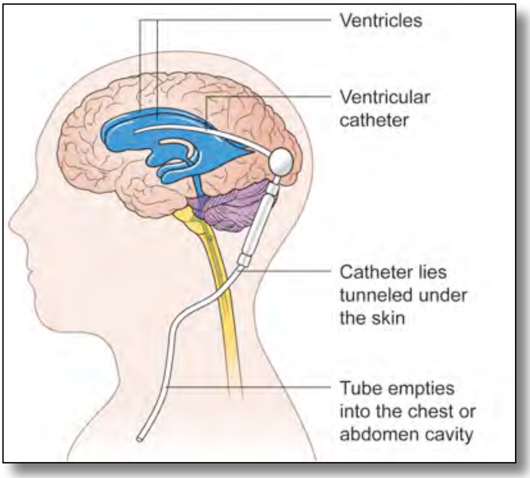
While in hospital, the port is accessed by a nurse. A needle is inserted through the skin into the silicone centre of the port for direct access to the bloodstream. Special numbing cream is used on the skin over the port prior to this procedure in order to minimize discomfort. When blood sampling, medication and fluid administration are complete, the needle is removed.

This device does not require any care or maintenance while at school. While extremely rough contact sports should be avoided, children are able to participate in physical activity, including water sports.

"In the beginning I was nervous about getting a port but now I know that it makes getting my chemo easier. I don't have to get as many pokes in my arm." – Mohammed, 10 years old

Other Devices

Shunt (Ventricular Peritoneal Shunt)



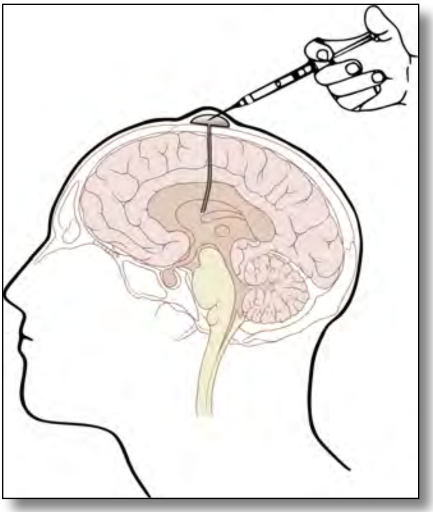
Taken from the patient information website of Cancer Research UK: http://www.cancerresearchuk.org/cancerhelp

A shunt is a surgically implanted device that is used to relieve an abnormal build-up of cerebrospinal fluid (CSF) inside the fluid spaces (ventricles) of the brain. This condition is commonly known as hydrocephalus. Hydrocephalus can occur for several reasons and blocks the regular flow of cerebrospinal fluid throughout the brain and spinal cord. The way to solve the blockage is the insertion of a shunt.

A shunt is a soft, flexible tube that is placed in the ventricles of the brain and is tunneled under the skin to another part of the body (usually the abdomen) where excess fluid can be absorbed. This type of shunt is called a ventricular peritoneal shunt.

Usually, children with shunts do not have restrictions on their activities.

On rare occasions, shunts can become blocked or infected. If a child with a shunt complains of a severe headache, fever, nausea, or vomits while at school, parents should be contacted.



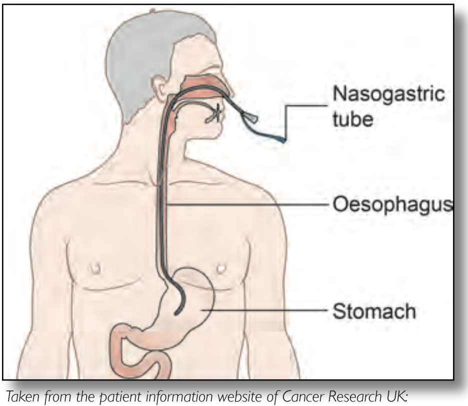
Patrick L. Lynch

Ommaya Reservoir

An Ommaya reservoir is a device that is used to withdraw fluid from, or administer medication to, an area in the brain. It is a dome-shaped device that is surgically implanted and sits just under the scalp. The dome has a small, flexible tube leading from it. This tube may be placed into an area of the brain containing cerebral spinal fluid or into a cyst.

An Ommaya reservoir is visible as a small bump on the head protected by the skin. There is no care or maintenance of this device required while at school.
Usually, children are permitted to participate in physical activity.

Nasogastric Tube (NG-tube)



Taken from the patient information website of Cancer Research UK: http://www.cancerresearchuk.org/cancerhelp

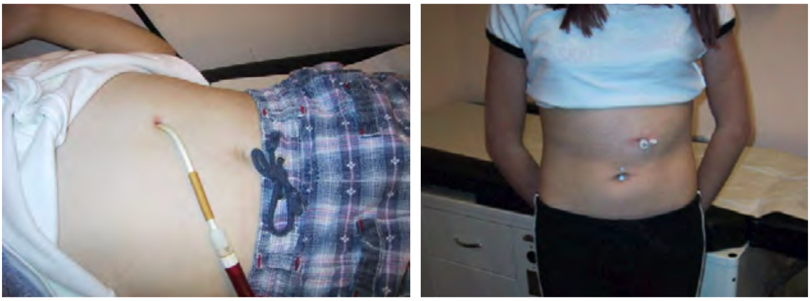
A nasogastric tube, also called an NG-tube, is a device through which nutrition can be delivered into the stomach. This tube is placed by a nurse or specially trained parent and is inserted through a child's nostril, into the throat, ending in the stomach. It is visible as a thin plastic tube secured to a child's cheek with medical tape.

Some children with cancer have side effects that prevent them from eating or drinking enough by mouth.

An NG-tube can serve as the sole source of nutrition or used to supplement oral intake. NG-tube feedings take place while a child is at home, however, the tube itself remains in place while at school.

An NG-tube generally does not require care while at school. If a child's tube is accidentally pulled out, (either partially or entirely), a child's parents should be informed. On occasion, the tape securing an NG-tube to a child's cheek can become loose. This may be reinforced with medical tape provided by the family. If a child with an NG-tube develops abdominal pain, diarrhea or vomiting while at school, parents should be contacted.

Gastrostomy Tube (G-tube)



A G-tube, also called a gastrostomy tube, is a device through which liquid nutrition can be delivered directly into the stomach. This tube is inserted through an incision in the abdomen and leads into a surgical opening in the stomach. It is visible as a slim tube or plastic button that sits on a child's abdomen.

Some children with cancer have side effects that prevent them from eating or drinking enough by mouth. A G-tube can serve as the sole source of nutrition or used to supplement oral intake.

Usually, G-tube feedings take place while a child is at home. If a student requires feedings during school hours, a Community Care Access Centre (CCAC) may be able to arrange for a nurse to administer these feedings at school.

If a child with a G-tube develops abdominal pain, diarrhea or vomiting while at school, parents should be contacted.

Childhood Cancer & School

The School's Role

When a Child is Diagnosed with Cancer

Contact the family. When a child is diagnosed with cancer, families are often shocked and overwhelmed. They must begin the process of understanding the complexities of their child's diagnosis and how this will impact their daily lives. Despite this upheaval, most parents view communication with the school as a priority. It is essential for families and the ill child to know that they remain an integral part of the school and that everything possible will be done to facilitate their child's educational needs throughout their experience. While many parents may not have a clear understanding of the impact of the cancer diagnosis on their child's schooling at this stage, they may have some thoughts about information they would like shared with staff and students.

> Select a staff member who will act as a primary contact
>
> This individual will establish communication with the family and coordinate the flow of information between the family and school. Appropriate staff may be the principal, vice-principal, teacher or guidance counsellor.
>
> Establish the best means for communicating with a family
>
> Negotiating with a family regarding the best means and times to contact them ensures a sense of inclusion and control. Regular contact enables the school to facilitate changes in a student's needs. Phone calls, emails and visits to the hospital or home may all be appropriate means of communicating.

A Note on Confidentiality...

As administrators and teachers, you will have knowledge of medically sensitive and personal information. Although you will not be able to control all the information that is circulated throughout the school community, it is essential to have a family's permission prior to disseminating news. Maintaining confidentiality and allowing the family to guide what is communicated ensures that the best interests of the child and family are being considered.

When enlisting the help of health care providers, it is important to note that they are bound by their professional codes of conduct to maintaining patient confidentiality. Any information they share with you must be with the consent of the family.

Seek assistance from the health care team. Some families have access to a member of their hospital health care team who can assist them in providing education and support to schools. Many families in Ontario work closely with a POGO Interlink Nurse. With the consent of the family, the POGO Interlink Nurse can facilitate the informational needs of the school and help the family to communicate the support needs of their child. This is achieved through telephone contact, e-mail and/or visits to the school.

A POGO Interlink Nurse can support the school in the following ways:

- ✓ Provide information on a child's diagnosis and treatment plan including anticipated length of treatment.
- ✓ Outline the impact of diagnosis on a child's ability to attend school and complete work.
- ✓ Explain anticipated side effects and the physical and emotional impact of a child's diagnosis.
- ✓ Facilitate planning for educational supports while undergoing treatment.
- ✓ Facilitate home instruction if necessary.
- ✓ Assist the school in determining how and with whom information will be shared according to the family's wishes.
- ✓ Provide developmentally-appropriate classroom presentations.
- ✓ Assist the school in identifying ways to support the child, siblings and family in the early days of treatment.
- ✓ Describe special considerations for when a child returns to school on treatment. See section on "When a Child Returns to School."
- ✓ Provide support during palliation.

> ***"It is so helpful to have this level of support when these kids are returning to school."***
>
> – Principal, Elementary School

High School Students

Adolescents often seek the involvement of a POGO Interlink Nurse to help guide academic planning. A school's vice-principal and/or guidance counsellor are often the main contacts to facilitate this planning. A POGO Interlink Nurse can help the student and school to set realistic academic goals while on treatment and assist with practical strategies to fulfill these goals. A student's academic history, personal motivation, course load, anticipated absences and physical ability to engage in studies are all important when setting goals for academic achievement.

Communicate with school staff. It is very important to ask parents what their child understands about their illness and what information they and their child would like shared with teachers, students and the school community. The content, depth and way in which news is shared will be different for each group. Accurate information helps to dispel myths, prevent the spread of rumours and calm fears.

Cultural and religious backgrounds, as well as family coping styles, influence the way in which families approach a child's illness and will impact the type of information they share. Some families prefer to maintain privacy and will choose to limit who has knowledge of a child's situation to select school staff.

Families who speak English as a second language may consent to the use of an interpreter in their communication with the school. This helps to ensure that the family's desires and concerns are clearly understood.

The information that families would like communicated may change over time. As treatment progresses and the practical impact of a cancer diagnosis is more clearly understood, families will often expand on information provided at the time of diagnosis.

Informing Staff

With the family's consent, general information about a student's diagnosis may be shared with the school staff. The news of a child's cancer diagnosis can be very difficult. Many staff will have friends or relatives who have had cancer. Their past experiences with the disease may impact their feelings and reactions when hearing the news of a student's diagnosis. Vast differences exist in the treatments and outcomes for adult cancers when compared with childhood cancers, and it is important not to assume similarities. Feelings of distress expressed by staff must be acknowledged and avenues of support should be provided. These may include open discussions with one another, informational support provided by a member of the hospital team, or access to formal support mechanisms such as Employee Assistance Programs (EAP).

Informing the Homeroom Teacher

More detailed information about a student's diagnosis is usually shared with the homeroom teacher. The impact of a diagnosis on attendance and the ability to complete school work will influence plans for accommodating the child's educational needs. These teachers will also require guidance on what information the child and family would like shared with classmates, who will provide this information, how to answer classmates' questions, and ways to support the ill child, family and classmates.

High School Students

Adolescents typically give a great deal of thought to the personal information that they would like shared with staff and peers. School vice-principals are often their primary contact and they often consent to the sharing of information with administrators, guidance counsellors and the teachers directly involved in their education at the time of diagnosis. Due to the large numbers of students in high schools, some teenagers prefer to share the news of their diagnosis with select peers rather than entire classrooms or the school as a whole. Each student's wishes must be carefully explored and accommodated.

Communicate with classmates. Addressing classmates' understanding of cancer and giving accurate information about their peer soon after the diagnosis helps to minimize misconceptions, dispel fears and build support.

Talking about cancer can be difficult. Many families choose to have their POGO Interlink Nurse give developmentally-appropriate classroom presentations.

Some teachers choose to send a letter home with students announcing the date and time of a classroom presentation with students. A template of this letter is provided in **Appendix 2**.

Classroom presentations by POGO Interlink Nurses provide:

- ✓ A description of the child's illness and treatment plan using age-appropriate terms.
- ✓ An explanation of the impact of the child's diagnosis on attendance at school and participation in social events.
- ✓ Discussion of how peers can support the ill student.
- ✓ An opportunity for classmates to ask questions.

> *"I feel like I belong again."*
>
> *– Grade 8 student after a classroom presentation*

Important Points to Remember While Speaking with Students

- Determine what the word "cancer" means to your students. While many children will have had no prior personal experience with cancer, others will know of friends or family members who have been affected by the disease. Some children may know someone for whom a cancer diagnosis ended in death. It is very important to highlight the fact that childhood cancers are different from adult cancers and that their classmate's story is unique and hopeful.

- Reassure children that their classmate is being well cared for and that the best treatments available are being used to make the child well.
- Inform children that cancer is not contagious.
- Describe to children that, in most cases, we do not know why a child develops cancer. There is nothing the child did or did not do to bring on this diagnosis.
- Emphasize that a childhood cancer diagnosis is relatively rare. They do not need to fear that they will also develop cancer.
- Reassure children that their friend remains a member of the class but may not attend school on a regular basis. If appropriate, provide a description of the in-hospital or home schooling that the child is receiving.
- Encourage children to talk about their feelings and to ask questions. It is okay not to know all of the answers. Be mindful of the fact that some students may be deeply affected by their friend's diagnosis while others may not. Both responses are normal. Support from a school social worker, and in some schools, child and youth worker (CYW), may be appropriate for children who have ongoing emotional difficulties.
- Ask children for their ideas on how to support their classmate. Some ideas for supportive activities might include: sending cards, initiating a letter-writing campaign where children are assigned different weeks to write a letter, sending riddles or jokes, sending a class newsletter to apprise the classmate of class or school happenings, sending e-mails with consent of parents, setting up a video streaming (Skype) system where the ill student is periodically able to interact with the classroom or participating in fundraising events that bring awareness to childhood cancer, etc.
- Reassure children that if their friend does not respond to their attempts at communication, it does not mean that the child does not appreciate their efforts. Cancer treatment is time consuming, requiring many trips to hospital.

Provide educational materials. Children almost always miss some school when they are initially diagnosed with cancer. In the early days, when families are determining how their child's illness will impact their participation in school, parents may request that work be sent to their home or hospital. Although expectations of completion should be minimal, this allows the child to engage in school work when feeling well enough to do so.

It is also an opportunity for the class to send encouraging cards and letters to help the child feel included in classroom happenings.

If a child remains hospitalized for a number of weeks, the child may receive instruction from a school board certified hospital teacher.

High School Students

Facilitating the educational needs of newly diagnosed adolescents presents some unique challenges. Students in semester system schools can miss a great deal of academic content in a short period of time. It is very important to begin planning for students' continued education as soon as they are feeling well enough to participate.

As a general rule, all adolescents are encouraged to attend school if they are medically able to do so. The degree to which students are able to keep up with their studies, however, will depend on their physical well-being, frequency of hospital visits/admissions, individual motivation and the resources that can be put in place to support them. Some students may be able to attend school on a part-time basis while others may focus on one or two credits with at-home support. Highly motivated students may be able to follow a course through e-mail support from their teacher. Some students enroll in online independent learning courses. The POGO Interlink Nurse can help to identify and facilitate access to appropriate resources.

> *"I feel like the pressure is lifted because the school is willing to be flexible with my school work."*
>
> – Grade 9 student

Facilitate home instruction. Some children will not be able to attend school on a regular basis for a prolonged period of time after a cancer diagnosis. This may be due to the need for frequent hospital visits for treatment or physical side effects that prevent them from feeling well enough to go to school.

In Ontario, all children are legally entitled to an education. Public and separate school boards provide three to five hours of home instruction per week for children who are unable to attend school for medical reasons. It is very important to begin the process of facilitating home instruction as soon as it is known that a child will not be able to attend school on a regular basis in order to minimize disruption in education.

A child's POGO Interlink Nurse can help to obtain the medical referral necessary to put this program in place. Once home instruction has been established, it is important to maintain contact with the family to ensure that the process is running smoothly. The school may serve as a resource to the home teacher.

It is also important to approach home instruction with some flexibility and welcome the child into the classroom for visits when feeling well and for special events such as class parties.

High School Students

Creativity and flexibility are required when facilitating the academic needs of high school students. Due to the increased specialization of high school teachers, it is difficult to obtain home instruction for multiple subjects, especially in later years. The greatest success in seeking home instruction for more than one subject can be achieved when grouping similar subjects together (for example, math and science). Some students may be able to follow a course through e-mail support from their teacher.

With the support of the school guidance department, some high school students will choose to enroll in online learning to earn credit(s). Variables that impact this decision include a student's expected length of absence, point in the school year and individual abilities and motivations.

Each high school student will have unique academic goals in preparation for post-secondary education. Some students may choose to defer earning select credits while undergoing treatment.

> *"I just want to graduate with my friends."*
>
> – Grade 11 student

When a Child Returns to School

A child's transition back to school after a cancer diagnosis may be gradual and on a part-time basis or full-time following several months of absence. Some children will have completed their treatment by the time they return to school while others will continue to receive therapy. This transition can be fraught with anxiety for children, parents and schools and will require thoughtful planning and a collaborative effort in order to provide appropriate supports. A POGO Interlink Nurse may provide a class visit before a child returns to school.

"Some people might think it is fun being away from school but I would much rather be at school with my friends."

Communicate with parents and child.

It is often helpful to set up a meeting with the family prior to their child's return to school. The principal, child's teacher(s), a guidance counsellor, the child and parents, and a POGO Interlink Nurse (if involved) are all individuals who can play a role at a school re-entry meeting. This meeting can serve to review the student's experience, current treatment plan (completed or ongoing) and special considerations while at school. Refer to **Appendix 3** for the "Medical & School Data Sheet" that is completed by a child's POGO Interlink Nurse with the family's consent and can serve as a reference for school staff. It is important to discuss feelings and fears about returning to school from the perspective of the child and the parents. Concerns may be practical, academic or emotional. Identifying concrete strategies for managing identified concerns serves to reassure families that the school will work with them to support their child's re-entry.

It is important to consider that, in some cases, returning to school will be the first time a student has not been under the constant, watchful eye of a parent. This can be difficult for some families and parents may wish to communicate with the school frequently at the beginning of re-entry. Expectations and accommodations may also change over time and it is therefore important to facilitate ongoing dialogue about a child's progress in order to help the student, parents and school staff to set realistic goals.

High School Students

School re-entry planning may take a different form for high school students. Often the guidance counsellor takes on the responsibility of coordinating courses and communicating vital information about the adolescent's needs and safety to teachers. This individual often becomes the main contact for the adolescent.

Be aware of treatment side effects and what to do at school. Some children will return to school with temporary or permanent physical changes. Temporary changes might include hair loss, fatigue, increased susceptibility to infection, difficulties with mobility and the presence of a central venous access device (please refer to the section on central venous access devices). Permanent changes may include changes in mobility, the presence of a prosthetic, and visual or hearing disturbances.

Coping with Specific Issues at School

Fatigue

Fatigue is a very common side effect of cancer treatment and can be related to many factors. Some children will experience fatigue due to ongoing treatment while others will have low stamina as a result of many months of absence and inactivity. Fatigue can compromise learning as it encompasses both physical and mental domains.

What to do at School

- Allow for flexible attendance. Some children will require a gradual re-entry, for example, returning to school half days.
- Arrange for periods of rest if necessary. Some children may wish to leave the classroom for a few minutes and have a rest period in a supervised location, such as the office.

- Negotiate a reasonable workload and help the student to prioritize school work. Breaking down expectations and setting small, achievable academic goals may help some students to feel a sense of mastery.
- Provide flexibility in assignment deadlines and additional time for test-taking if necessary.
- Provide hand-outs over note-taking if appropriate.
- Provide two sets of textbooks, one for home and one for school, to minimize the need for carrying heavy loads.
- Allow for frequent breaks and modified activity during physical education if necessary. If unable to participate in physical activity, find ways to involve the child, for example, as referee or score keeper.

Hair Loss

Chemotherapy and radiation may cause total or partial hair loss. This side effect is usually temporary but may be upsetting to children and adolescents.

What to do at School

- Allow the child to wear a hat or scarf if the child wishes. Some children may choose to wear a wig.
- Ensure that classmates are aware of the child's hair loss prior to the child returning to school. This can be accomplished through classroom presentations by the POGO Interlink Nurse.

Increased Risk for Infection

Cancer treatment can lower white blood cells increasing a child's risk for infections. Despite this, many health care professionals encourage children to attend school as much as possible.

What to do at School

- Encourage all children to wash their hands at appropriate times, for example, after using the washroom, before eating and after sneezing.

- Clean classroom surfaces regularly.
- Encourage classmates' parents to keep their child home from school if they are ill.
- Inform classmates' parents to call the school immediately if their child develops any infectious illnesses, in particular chicken pox.

Fever is a sign of infection. For children being treated for cancer, infection can be life threatening. Signs of a fever may include being warm to the touch, chills and/or flushed cheeks. Other signs may include feeling or appearing unwell or a change in normal behaviour. Inform parents **immediately** if you have any concerns.

Chicken Pox and Measles in the School

Contracting chicken pox or measles can have serious consequences for children being treated for cancer.

It is important for families to be made aware if there is chicken pox or measles in the classroom. A letter should be sent home to classmates' parents asking them to notify the school if their child develops chicken pox or measles during the school year. A sample letter is provided in **Appendix 4**.

When the school becomes aware of chicken pox or measles in the classroom it is important to inform the family immediately. Chicken pox is infectious 48 hours before the onset of the rash and until the spots dry. Measles is contagious four days before the rash appears and four days after the rash.

Nausea and Vomiting

Chemotherapy and radiation can cause nausea and vomiting for at least 24 hours after receiving treatment and can sometimes last for several days. This is usually able to be controlled with medication.

What to do at School

- Ensure easy access to a washroom.
- Allow food/fluid intake as necessary.
- Notify parents.

Bleeding

Some children being treated for cancer are at increased risk for bleeding. Parents will inform the school if there are restrictions on their child's activity.

What to do at School

- Follow school first-aid protocol.
- Inform parents.

Mood/Behavioural Changes

A child's diagnosis, treatment and side effects can all contribute to changes in behaviour. Some medications are also known to affect mood. Parents will inform the teacher if their child is receiving this type of medication.

What to do at School

- Be aware of factors that might affect a child's mood.
- Establish normal classroom routines and set limits; children respond well to normalcy.
- Inform parents if you have any concerns about changes in behaviour.

Weight Gain or Loss

Significant weight gain can occur for a number of reasons during cancer treatment. This can be as a result of inactivity and/or the side effects of some medications.

Weight loss can occur when nausea and mouth sores are present.

Changes in appearance may be emotionally difficult for some children and they may be reluctant to attend school for this reason.

What to do at School

- Provide a classroom presentation that includes discussion regarding body image.
- Allow food/fluid intake as required.

Nutritional Changes

Cancer treatment can affect a child's nutrition. A child may require modifications made to the classroom routine to accommodate nutritional intake outside of normal snack periods.

Some children may require alternative methods of feeding. If this is an issue, the school will receive education about supporting a child in the classroom.

What to do at School

- Seek direction from parents on specific nutritional needs.
- Provide a time and place for additional snacks if needed.
- Allow the child to carry a water bottle.

Mobility Issues and Motor Skills

Physical disabilities may occur as a result of a cancer diagnosis. This may be due to the location of a tumour, treatment side effects or surgical interventions. Occasionally children require assistive devices such as splints, wheelchairs, crutches or walkers.

Some chemotherapy medications can affect (weaken) bones and muscles. This may cause discomfort and difficulties with balance and gait.

Rarely, children may experience a limb amputation.

Some children are identified with a physical disability as a result of treatment. The school board's Identification, Placement, and Review Committee (IPRC) may grant a special needs assistant to support the child.

What to do at School

- Initiate a referral for occupational and/or physiotherapy assistance if necessary. The school principal generally begins this process.
- Follow suggestions for school accessibility and safety. Adaptations may need to be made to the environment and physical education programming for the child to be able to participate.
- Consider the physical layout of the school when planning a child's schedule or timetable.
- Allow the use of an elevator if available and appropriate.
- Consider a buddy system for children with mobility issues.
- Allow time for a child to navigate safely between classes when hallways are less crowded.

Hearing and Visual Impairments

Some cancer treatment may result in hearing or visual impairments. Where these effects are anticipated, children will be assessed and followed by the hospital. Reports are compiled and forwarded to schools by parents. Accommodating hearing and visual impairments is essential to facilitating academic success. School principals are responsible for coordinating referrals to appropriate resources within the school board. For example, children who are identified with hearing loss may be referred to a speech/language pathologist in order for accommodations to be made in the classroom.

What to do at School

- Consider seating arrangements to accommodate the impairment.
- Initiate consult with hearing/visual itinerant through the school board to aid in providing support.
- Consider occupational therapy (OT) through the local Community Care Access Centre (CCAC) to assess the school environment for safety and accommodation.

Seizure

Seizures can be caused by a brain tumour, effects of surgery or effects of treatment. Parents will inform the school if their child is at risk for a seizure.

What to do at School

- If the parents have provided a plan of care to follow in the event of a seizure, follow these directions. Otherwise, follow school protocol for any child having this kind of emergency which may involve calling 911.
- Lay the child on the floor to prevent injury. If possible, position the child to one side to keep the airway open while a seizure is occurring.
- For further information on what to do in the event of seizure see www.aboutkidshealth.ca.

Sun Sensitivity

Many chemotherapy drugs increase susceptibility to sunlight. Children may burn easily. Some children may experience photophobia (eyes sensitive to light).

What to do at School

- Remind the child to put on sunscreen.
- Encourage the use of protective clothing, hat, and sometimes sunglasses.

Learning Difficulties

Importantly, some children may develop learning difficulties after their cancer treatment. These difficulties may be present when a child returns to school or may develop over time. This is particularly true of those who have been treated for brain tumours or who have received therapies that are toxic to the developing brain. Children who receive radiation to the brain are at greatest risk for learning difficulties over time. Difficulties may arise in the areas of attention, concentration, memory, information processing and higher-level problem solving. Parents are usually aware when their child's treatment places them at high risk for developing learning difficulties. Often, baseline neurocognitive assessments have already been performed by a hospital developmental psychologist and these children are followed. An individual education plan (IEP) created to accommodate these challenges may be necessary. If the school identifies learning difficulties, please encourage the family to share this information with their treatment team or POGO Interlink Nurse.

It is important to remember that neurocognitive effects will change over time. Ongoing vigilance and longer-term planning are imperative as a child matures and learning difficulties declare themselves.

- **Identify in-house and external resources.** Inform school staff about a child's return to school and identify those who can be instrumental in facilitating a child's transition back into the classroom. The child's teacher(s), office clerks, school social worker, guidance counsellor, special education resource teacher, and others, may all play a role.

  If appropriate, links can also be made to outside agencies for language/hearing, occupational therapy or physiotherapy consultations. If a child returns with significant physical or cognitive limitations, a special request for a teaching assistant may be necessary. A support letter from the child's health care team can facilitate these requests.

- **Facilitate transportation.** Some children will require assistance in travelling to and from school safely. They may not have the stamina to walk to school during the early days of their transition, or may have developed changes in their mobility requiring assistance. Special requests for transportation support can be made to the school board. A support letter from the child's health care team can facilitate these requests.

- **Make accommodations to routine school policies.** Often, special accommodations that are contrary to regular school rules will need to be made to support a child's reintegration into the classroom. These are often temporary. Examples include allowing children who have lost their hair to wear a hat, scarf or bandana to school; allowing for drinks and snacks outside of regular snack times; permitting more frequent bathroom breaks; modifying participation in physical education based on energy level or physical limitations; allowing for children to navigate the hallway/stairs (with a buddy) when corridors are empty; allowing for the use of the school elevator; scheduling classes on one level of a school to minimize the need for stairs.

  Please communicate all changes in routine policy with all members of the school staff.

If a Child's Cancer Recurs

Contact the family. This can be a particularly difficult time for families; they may feel vulnerable as they face another challenge. Treatment may be different from original diagnosis. With this in mind, education is still very important for most families. If the school has already worked with the family at original diagnosis, a sense of what approach works for the family may already be apparent. It will take a few weeks for the child and family to know how much school work can be achieved as they adjust to a new treatment plan. It is important to ask parents what their child understands about the recurrence and what information they want shared.

Seek assistance from the health care team. The family may ask the POGO Interlink Nurse to reconnect with the school and provide information.

A POGO Interlink Nurse can help in the following ways:

- ✓ Contact the school principal and teacher with information regarding relapse of the disease, the treatment plan and expectations of the child's ability to attend class or do school work.
- ✓ Attend class meetings.
- ✓ Provide consultative support to principals and teachers on how to deliver information and support to students according to the family's wishes.
- ✓ Provide developmentally-appropriate classroom presentations.

Communicate with your school. Once the information that a family wants shared has been made clear, the school can be informed. The POGO Interlink Nurse can help with this in the form of class presentations and meeting with faculty. The nurse may have spoken to the children in the class at original diagnosis and therefore she can connect her presentation to this. The approach can still be positive and hopeful.

Staff

With the family's consent, general information about the relapse may be shared with the school faculty. The news of a child's relapse can be very upsetting. Feelings of distress from faculty must be acknowledged and avenues of support must be offered. These may include open discussions with one another, informational support provided by a member of the hospital team or access to formal support mechanisms (Employee Assistance Programs).

Homeroom Teacher

More detailed information about a student's relapse of disease is usually shared with the homeroom teacher. The impact of this information on attendance and the ability to complete school work will influence plans for accommodating the child's educational needs. The teacher will also need guidance on what information can be shared with classmates; who will provide this information; how to answer classmates' questions; and ways to support the ill child, family and classmates.

Classmates

Classmates may have already had information on cancer when their peer was originally diagnosed but it may make sense to repeat this information. Providing accurate information helps to minimize misconceptions and dispel fears that may develop. The POGO Interlink Nurse can give developmentally-appropriate classroom presentations and can include explanation about the recurrence of the disease, treatment plans, impact on attendance at school, ability to participate in social events and ways they can support their peer. **(See "Important Points to Remember While Speaking with Students.")**

High School Students

Most adolescents will have been part of the disclosure of information from the treatment team and will understand the implications in terms of schooling and prognosis. They may not, however, want to share all the details with the school. Adolescents give a great deal of thought to the personal information they want shared and are less likely to want a class presentation. They may choose to have the nurse come to the school and talk to a select number of friends. The school can help to facilitate this meeting or the meeting can be set up at home.

Provide educational materials. Children may miss school when they are initially made aware of their relapse and as the plan of treatment is worked out. Work can be sent home or to the hospital. Expectations for completion of work should be minimal; this approach will allow them to do work when they are feeling well.

The vice-principal and/or guidance counsellor are often main contacts to set up a plan for the student. A POGO Interlink Nurse can help the student and school set up realistic academic goals and practical strategies to fulfill these goals. A student's academic history, including how the student dealt with school while going through their initial treatment, personal motivation, course load, anticipated absences and physical ability are all important when setting goals for academic success. It should never be assumed that the student is too sick to achieve credits. The student may have to do less than peers for a certain period of time but, in general, teenagers want to be successful.

High School Students

Adolescents who have relapsed disease may have already experienced modifications to their education.

Facilitate home instruction. If the child is unable to attend school, home instruction should be set up. Each child is legally entitled to education, which should be taken into consideration when instruction is being organized. School boards are usually quick to agree to three to five hours of home instruction per week and then it is the school's responsibility to find an appropriate teacher. This arrangement should be done as soon as possible. When a child is having their education in this format, it is also helpful if the child can keep connected with the school by being allowed to come to see their classmates and be involved in special days such as celebrations.

Possible Long-Term Effects of Childhood Cancer Treatment

Treatment for cancer during childhood can result in long-term physical and/or neurocognitive effects. The risk for long-term effects depends on a child's age during treatment, disease and what kind of treatment they received. Children can develop changes to body systems over their lifetime and are monitored in POGO AfterCare Clinics into adulthood. Some children develop long-term effects while they are in the school system and will require special accommodations.

Neurocognitive

Long-term effects of treatment on a child's cognitive function can sometimes occur. These effects can impact schooling significantly. Sometimes neurocognitive difficulties show up soon after treatment has ended, however they can also take years to become evident. It is very important for schools to be aware of this possibility so that they are able to recognize challenges and provide supports as soon as possible.

Risk Factors for Long-term Neurocognitive Effects

- Cancer diagnosis at an early age
- Type of cancer that was treated: brain tumours, tumours involving the eye or head, acute lymphoblastic leukemia
- Radiation therapy to the head
- Neuro-toxic chemotherapy

Most Common Neurocognitive Effects

Visual Processing/Visual Motor Integration

Activities which require processing visual information and coordinating that visual processing with a motor response can be a problem. This can be seen when there are difficulties with written language, reading, and higher-order math and science concepts.

Language Processing

Language delays, difficulties finding the right words, slow but short verbal responses and difficulties with reading comprehension are the most common signs that there is a language processing problem.

Memory

Problems in both short-term and long-term memory can be an issue. Children may have difficulty remembering information over time, so they may lose previously learned information. These memory issues can also be specific to visual or verbal information.

Attention

Children may have problems focusing and maintaining attention so they can be very easily distracted. This may present similar to attention deficit disorder by including impulsivity and overactivity.

Fine Motor Coordination

Difficulties with tasks using small muscles, particularly in the hands, can be an issue. In school, that means that there could be significant problems in printing and writing skills.

Processing Speed

Children may be slow to process information. This will mean that they will take longer to both absorb information and produce written work.

Planning and Organization

Initiating and planning an activity as well as carrying it through can sometimes be a problem. As a result, children may often have difficulties both starting a project and continuing it, as they may become easily distracted.

Baseline neurocognitive assessments are often performed by a hospital developmental psychologist if children are at risk for long-term neurocognitive difficulties. Children who have been identified as having difficulties are periodically reassessed. Practical strategies outlined in a neurocognitive assessment can be instrumental in the development of an individual education plan (IEP) to support a child's challenges.

If the school identifies learning difficulties, please encourage the family to share this information with their treatment team or POGO Interlink Nurse.

Some Tips to Bear in Mind

- Consider the most appropriate classroom seating
- Use computer programs to aid with organization and fine motor coordination
- Modify test requirements (additional time, oral vs. written)
- Allow for the use of aids such as calculators for math
- Arrange for extra help in areas of difficulty

Hearing

Some children who have received treatment for cancer will have damage to their hearing. Certain chemotherapy drugs and radiation to the head can cause hearing loss that ranges in severity. When hearing loss is a possibility, children are monitored by an audiologist (specialist trained in hearing disorders) to identify changes.

Hearing loss can have a profound impact on a child's ability to learn. For younger children, language development may be impacted.

In some cases, children may require hearing aids to make sounds louder or auditory trainers (also called "FM" trainers) where the teacher wears a microphone that transmits sounds directly to the child via a receiver in the child's ear. Other accommodations, such as a child's seating in the classroom, may need to be made through an IEP.

Consultation with a speech/language pathologist through the school board can help teachers to make individualized accommodations in order to facilitate a child's learning.

Endocrine

Cancer treatment during childhood may cause endocrine (or hormonal) problems. The risk factors for hormonal deficiencies include cancer treatment at a very young age, radiation to the brain, head and neck, and surgery to certain areas of the brain.

Hormones are chemical messengers that carry information from endocrine glands [such as pituitary, thyroid, pancreas, adrenal, ovaries (girls) and testes (boys)] to the body's cells. The endocrine system is very complex. There are many different hormones in the body that impact many body functions including metabolism, growth, the onset of puberty and regulating the body's response to stress.

Children who are affected by hormone imbalances are followed by an endocrinologist (hormone specialist) and are given medications to correct the imbalance.

Hormone imbalances may impact schooling on a social level. Children who have growth hormone deficiency may be smaller and younger looking than their peers. Other imbalances can create precocious puberty which means that there are signs of puberty (hair growth and breast growth) at a younger than expected age.

Specific hormonal imbalances will result in special directions for teachers. In these rare cases, teachers will receive instructions on medications that may need to be given during the course of the school day.

Eye/Vision

Some children can develop visual disturbances after cancer treatment. High doses of radiation to the eye, eye socket or brain may cause vision loss as well as other eye problems.

Children who require visual support may need consultation with Canadian National Institute for the Blind (CNIB). The school may consult with a vision itinerant teacher to assess the school environment and implement supports.

How the School Can Help Siblings

forte in focus photography

A diagnosis of childhood cancer understandably creates enormous stress for all family members, including siblings.

Parents often are too busy with the ill child or simply find it too difficult to answer questions or correct misinformation. Without open discussion, this misinformation or even lack of information is often terrifying for the siblings.

Often a presentation by the POGO Interlink Nurse in the sibling's class is an informative and stress-relieving intervention for the siblings. Not only are the siblings gaining information and made to feel important, the presentation of cancer facts and treatments helps to make it all seem less frightening.

> ***"I love going to my aunt's after school when my brother is in hospital, but there is nothing like being at home."***
>
> – Megan, age 8

For teachers to be able to help the siblings, it is important to understand some of the emotions that they might be experiencing:

- General feelings of sadness
- Fear of losing their ill sibling
- Fear of getting the cancer themselves
- Feeling left out or not as important to their parents, family and friends
- Feeling resentful and jealous toward their ill sibling; they may feel angry at their parents as well
- Feelings of guilt
- Feeling unsettled by the disruption and turmoil of their everyday life
- Feelings of worry, anger and rage towards the situation in general

Strategies for Teachers

- Enlist the help of the POGO Interlink Nurse to inform the sibling's classmates and teachers about the affected child's care and treatment plan. The sibling's peers can be a great support when they understand and feel included in the information.
- Ask how the sibling is doing as well as the affected child. Find ways to make him/her feel special. Sometimes the simple act of bringing homework home to the affected child can make the sibling feel that he/she is helping.
- Make the sibling aware that the teacher is available to listen. Sometimes having a trusting adult to talk to who is not involved in the situation can give the sibling the opportunity to speak freely.
- Encourage siblings to express their feelings through artwork or expressive writing as well as orally.

- Assist the sibling to work through anger or fear by venting these feelings in physical activities such as sports or active games. This kind of release is particularly helpful when the parents may not be able to transport the sibling to their regular activities.
- Be understanding and flexible with homework assignments. When parents are busy caring for their ill child a sibling may miss out on homework support.

Family Challenges & Palliation

Issues and Concerns

forte in focus photography

Emotional Strain

When a child is diagnosed with cancer and is going through treatment, there are many difficulties for families that the school will often not be aware of. The emotional strain affects the functioning of the home on a daily basis. Parents are unable to maintain regular household responsibilities such as cooking, cleaning, helping with homework and paying bills. Parents may be sleep deprived due to heightened concern about their child's well-being or because their child may require care at night. Parents may also experience guilt over their inability to provide normal care for siblings. This guilt may include concerns about education. The school can help to alleviate this pressure by reassuring the family that they will work around the treatment plans and set up what is needed for the child and siblings to continue to be successful socially and academically.

Financial Strain

Financial strain takes the form of lost income as parents rearrange their work plans around the sick child. There are many unexpected out-of-pocket expenses including travel, parking, childcare, food at the hospital and drug costs.

It is estimated that families can lose up to 1/3 of their after-tax income during the time a child is in treatment.

Palliation and Bereavement

There are times when childhood cancer cannot be cured and despite all efforts to treat their disease, children die. Palliation is a very difficult time for families and can often be more complicated than simply stopping cancer-directed treatment and making a child comfortable. Children can sometimes receive palliative chemotherapy or radiation.

At times, children and adolescents receiving palliative care may feel well enough to attend school. Attending class provides diversion, activity, friendship and hope.

Families deal with the palliative stage in different ways. It is important to maintain open communication between the family, the school and the health care team. The school must be mindful of a family's desires for their child and how much information they would like shared. These wishes are always within the context of the family's beliefs and culture.

During difficult times such as the anticipated or actual death of a child, schools have access to crisis teams to support staff and students. A POGO Interlink Nurse can also provide support and information for the faculty and children by visiting the school and classroom.

During palliation a POGO Interlink Nurse can do the following:

- ✓ Provide updated information on the child's stage of illness to school staff.
- ✓ Provide reassurance that all possible treatment methods have been tried. Unfortunately, in some rare circumstances children with cancer cannot be cured.
- ✓ Arrange a class visit in order to provide accurate, developmentally-appropriate medical information to classmates as well as generate ideas on how to support their friend. Class visits are helpful for classmates as well as the ill child.

  Class visits can also be beneficial when a dying child is not returning to school. A POGO Interlink Nurse can provide an opening for classroom conversations, giving the teacher permission to continue to support the class. Classmates and teachers may want to keep connected by visiting at home, sending cards and communicating online.

Should the Child Die

- A POGO Interlink Nurse can assist at this difficult time by providing information.
- The school crisis team and/or social worker can provide support.

> *“Curtis would have really appreciated the opportunity to bid farewell to his school friends. Thank you for doing that on his behalf”*
>
> – Mother of 12 year-old boy

Considerations When Speaking with Children and Educators

- Provide information without using euphemisms; use the words “death” and “dying.”
- Provide age-appropriate information on what death means.
- Reassure students that their classmate was well cared for.
- Support and provide guidance for school staff.
- Provide time for children to ask questions.

Teachers can continue this support by giving children ideas on what they might like to do to express their emotions. Some schools may wish to organize a memorial service. Classmates may want to send cards to the family expressing a special thought or memory of the child. Children should be reassured that everyone grieves differently. Some children may not feel sad, and this is okay.

High School Students

Teachers may encourage friends of the teen to have contact with the family. Parents may enjoy sharing stories about their ill child.

References

Resources for Educators

Services & Support

Brainchild, www.sickkids.ca/brainchild

Canadian Cancer Society, www.cancer.ca

Candlelighters Simcoe Parents of Children with Cancer (Simcoe County and Muskoka), www.candlelighterssimcoe.ca

Candlelighters (Ottawa), www.candlelighters.net

Childcan (London), www.childcan.com

Childhood Cancer Canada Foundation's Teen Connector program, www.childhoodcancer.ca

Hearthplace Cancer Support Centre, Pediatric Cancer Family Support evenings (Oshawa), www.hearthplace.org

Help a Child Smile, www.helpachildsmile.com

Northern Ontario Families of Children with Cancer, www.nofcc.ca

Pediatric Oncology Group of Ontario, www.pogo.ca

The Hospital for Sick Children, www.sickkids.ca

Wellspring, www.wellspring.ca

DVDs

Why, Charlie Brown, Why?
(Leukemia & Lymphoma Society/School & Youth Programs)

Books

Books about Cancer

A Birthday Present for Daniel
(Juliet Rothman) ISBN 978-1573920544

Chemo, Comfort and Craziness
(Nancy Keene) ISBN 0-9724043-0-9

Chemo Girl: Saving the World One Treatment at a Time
(Christina Richmond) ISBN 978-0763703141

Nowhere Hair
(Sue Glader) ISBN 978-0984359103

Oncology, Stupology….I want to go home!
(Marilyn K. Hershey) ISBN 978-0967355009

The Guinea Kid: The True Story of a Childhood Cancer Survivor
(Sharon Ruth) ISBN 978-1894966016

When Your Brother or Sister Has Cancer
(American Cancer Society)

What about Me? When Brothers and Sisters Get Sick
(Allan Peterkin) ISBN 978-0945354499

100 Questions & Answers about Your Child's Cancer
(William L. Carroll, MD & Jessica Reisman, CSW) ISBN 978-0763731403

Books about Science

An Alphabet about Kids with Cancer
(Rita Berglund) ISBN 978-0962936531

The Magic School Bus: Inside the Human Body
(Joanna Cole) ISBN 978-0545240833

The Incredible Human Body
(Esther Weiner) ISBN 978-0590599283

Books for Teens

Childhood Cancer Survivors: A Practical Guide to Your Future
(Nancy Keene, Wendy Hobbie & Kathy Ruccione)
ISBN 987-0596528515

I Want to Grow Hair, I Want to Grow Up, I Want to Go to Boise
(Erma Bombeck) ISBN 978-0060161705

When Your Brother or Sister has Cancer: A Guide for Teens
(National Cancer Institute)

Books for Teachers

Cancervive Teacher's Guide for Kids with Cancer
(Susan Nessim & Ernest Katz)

Educating the Child with Cancer: A Guide for Parents and Teachers
(Candlelighters Childhood Cancer Foundation)

Educating the Child with Cancer
(Patricia Deasy-Spinetta & Elizabeth Irvin)

Books about Death for Children

Incredibly Lonely, That's Me
(Ben Keckler) ISBN 987-0976909323

Lifetimes: The Beautiful Way to Explain Death to Children
(Bryan Mellonie & Robert Ingpen) ISBN 987-0553344028

Water Bugs and Dragonflies: Explaining Death to Young Children
(Doris Stickney) ISBN 978-0829816242

When Dinosaurs Die: A Guide to Understanding Death
(Laurie Krasney Brown & Marc Brown) ISBN 0-316-11955-5

Books for Adults when a Child Dies

Living Dying
(Max & Beatrice Wolfe Centre for Children's Grief and Palliative Care)

Sources

Broyd Peterson, Bette, Pritchard-Jones, Kathy, & Edwards, Lesley. (2008). *Pupils with Cancer: A Guide for Teachers.* The Royal Marsden NHS Foundation Trust and The Specialist Schools and Academic Trust.

Learning and Living with Cancer: Advocating for Your Child's Educational Needs. The Leukemia and Lymphoma Society.

Keene, Nancy. (2010). *Childhood Leukemia: A Guide for Families, Friends and Caregivers* (4th ed.).

Chambers, Anne, Klinck, Ann, & Rynard, David. *Helping Schools Cope with Cancer: Current Facts and Creative Solutions (2000).* Children's Hospital of Western Ontario.

Appendix 1:

Emergency Care Kit for Your Peripherally Inserted Central Catheter (PICC) or External Central Venous Line (CVL)

Remember to wash your hands before handling any central line.

What to do if the line breaks/leaks:

1. Remain calm.
2. Clamp the line between the break and the child using the green clamp that has been provided in the emergency kit. If you do not have a clamp, bend and tape the line above the break/leak.
3. Clean the line with the chlorhexidine swab provided in the emergency kit.
4. Place clean gauze around the line and tape the gauze to the line.
5. Call parents.

What to do if the cap falls off:

1. Clean the end of the line with a chlorhexidine swab.
2. Take a new cap from the kit and place it on the end of the line.
3. Place a clean piece of gauze around the cap.
4. Call parents.

What to do if the dressing comes loose:

1. Reinforce with tape.
2. If the dressing comes off completely, cover with sterile gauze and tape.
3. Call parents.

Appendix 2:

Template of Classroom Visit Letter

Dear Parents or Guardians:

This letter is to inform you that one of your child's classmates was recently diagnosed with a type of childhood cancer. A POGO* Interlink Nurse (community liaison nurse) will be coming to speak with your child's class about cancer and how it is affecting their classmate. The presentation will include a short video and provide students with an opportunity to ask questions.

If you have any questions, concerns or comments please contact your child's teacher.

Sincerely,

Principal

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* **POGO is the Pediatric Oncology Group of Ontario**, a charitable organization delivering care for children with cancer and their families. Learn more about POGO and its Provincial Pediatric Interlink Community Cancer Nursing Program at www.pogo.ca/Interlink.

Appendix 3:

Medical & School Data Sheet

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO

SCHOOL INSTRUCTIONS FOR PEDIATRIC ONCOLOGY PATIENTS

(HOSPITAL NAME & ADDRESS HERE)

Pediatric Interlink
Community
Cancer Nurses

Your student, ______________________________,
is currently under the care of the Pediatric Oncology Team at ______________________________
for a diagnosis of______________________________.
We believe that a child's school experience is critical for growth and development promoting self-esteem during treatment and in the future.

We encourage children to attend school on all days that are medically possible. However, we recognize that certain accommodations must be made related to repeated school absences. If you think the number of days missed is adversely affecting this child's learning, please advise their parents/guardians that you are concerned and we can devise a plan to address this problem. We are relying on you, as well as the child's parents/guardians, to closely monitor school progress throughout the year. If at any time you are concerned, please do not hesitate to speak with the parents/guardians and us. We hope that you will read the enclosed material and find it helpful to you. Please call if you have any questions or wish additional information.

Current Treatment Plan:

Medications to be taken at school:

Other:

Possible Side effects from disease and/or therapy:

- ☐ Hair thinning/loss
- ☐ Mouth sores
- ☐ Weight loss
- ☐ Weight gain/increased appetite
- ☐ Increased fatigue
- ☐ Nausea/vomiting
- ☐ Mood swings
- ☐ Increased chance of bleeding (gums, nose, bruising)
- ☐ Increased chance of infection

Limitations on Activity:

- ☐ None – unless parents notify otherwise
  ____
- ☐ No contact sports
  ____
- ☐ Crutches/wheelchair
  ____

Anticipated School absences:

Minimal (less than 5 days a month)	Moderate (5-10 days a month)	Significant (greater than 10 days a month)

Comments:

____
____
____
____
____
____

CONSIDERATIONS:

1. Parents should be notified of any acute illness, fever, or change in the child's condition or behaviour.
2. **No live virus vaccinations or immunizations** (i.e. polio, MMR) should be given to children receiving chemotherapy.
3. Varicella (chicken pox) and measles.

IMMEDIATELY REPORT to parents any cases of chicken pox or measles in the classroom.

We urge you to review this sheet with parents. They will keep you informed of any changes in plans or care. And again, we encourage you to call us with any concerns.

Primary Physician: ______________________________
Tel: ____

Primary Nurse: ___________________________________
Tel: ____

Interlink Nurse: __________________________________
Tel: ____

Hospital Teacher: ________________________________
Tel: ____

Date: ____

Completed by: _________________________________

Appendix 4:

Template of Chicken Pox, Measles and Infectious Disease Contact Letter

Dear Parents or Guardians:

This letter is to inform you that a student in your child's class is being treated for cancer. Children receiving treatment for cancer are at increased risk for infection. It is important for this child's family to be notified if the child comes into contact with any contagious illnesses, in particular chicken pox or measles.

If your child develops chicken pox, measles or any other contagious illness during the school year, please contact the school office immediately.

As usual, when your own child is sick please keep him/her home from school.

Sincerely,

Principal

Notes:

POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.

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