



**CANCER AND SCHOOL AWARENESS
A GUIDE FOR SCHOOL ENVIRONMENT PERSONNEL**

(2nd Edition)

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The first edition of this guide was prepared by the School Awareness Services (formerly the School Life Services), a department of Leucan, the Association for children with cancer.

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2nd edition:

- School Awareness Services

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LEUCAN: A FAMILY HISTORY SINCE 1978

Established in 1978, Leucan looks after its families at each phase of the illness by providing specific and adapted services.

Mission: To help cancer-stricken children and their families believe in a brighter future.

Vision: An industry leader active in every region of the province, Leucan is the main source of reference and help for families of children with cancer, partners, and donors.

Services to families in 2013

- Welcome, emotional assistance and support services
- Financial assistance
- Massage therapy (to children, parents and siblings, at the hospital and at home)
- Support services in playrooms (at Sainte-Justine UHC, CHUQ - Centre mère-enfant, and UHC Sherbrooke, and as part of different workshops in other playrooms at Montreal Children's Hospital of the MUHC and at the Children's Hospital of Eastern Ontario - CHEO)
- Socio-recreational activities (regional, interregional and provincial)
- School awareness (support and awareness)
- End-of-life and bereavement follow-up services
- Support to clinical and psychosocial research
- Leucan's Information Centre

Leucan, an extended family with members across the province of Quebec

- More than 3,600 families benefiting from its services
- Nearly 2,000 volunteers
- Over 70 employees
- Head office in Montreal and eight regional offices (Abitibi-Témiscamingue, Eastern Townships, Laurentides-Lanaudière, Mauricie-et-Centre-du-Québec, Montérégie, Outaouais, Quebec, Saguenay-Lac-Saint-Jean)

WHY DOCUMENTATION FOR SCHOOL PERSONNEL?

It is said that by the end of 2013 one out of 1,000 young adults will have survived a pediatric cancer. With such a rate of occurrence, it is highly probable that during your career you will encounter a student who has cancer or has siblings affected by cancer. Such a situation will undoubtedly bring about various questions, feelings, and perhaps some uncertainty regarding your role as a school worker.

Even more so than for other students, school is of the utmost importance to the student who has cancer. Hanging out with friends, learning, interacting, being satisfied with work accomplished or results obtained: here are but a few examples of how a child with cancer can belong like everyone else while being reminded that life goes on regardless of the illness. But the opposite can also be true. Attending school may also create a lot of fear and anxiety. Your part in this adaptation context is therefore essential.

The aim of this document is to guide you in the manner in which you face this situation, in order that the cancer-stricken student may return to class in a harmonious way among peers, and continue progressing in school throughout the illness.

You will find in this reference tool:

- Basic information on cancer, treatments being used, and their side effects;
- Guidelines to help prepare the ailing student's return to class and continued studies;
- Suggestions on how to approach the subject matter with peers;
- Information on the difficult situations faced by ailing student's siblings;
- Useful resources.

A FEW WORDS ON PEDIATRIC CANCER

Childhood or teenage cancers (from 0 to 19 years old) are the proliferation of abnormal cells in the organs or in different parts of the body (brain, kidneys, bone marrow, bones, etc.). As with all types of cancer, childhood cancers are not contagious. Although there may be some genetic predisposition for certain types of cancer, hereditary forms of cancer are very rare. In Quebec, one out of 400 children is diagnosed with cancer.

- Half of the cases of childhood cancers occur before the age of 6.
- The types of cancer varying according to age.
- The most recent available Canadian data indicates that for all types of cancer combined, there is a survival rate of 82% after five years in the group ranging from 0 to 19 years of age. As for acute lymphoblastic leukemia, the most current form of childhood cancer, the rate of survival reaches 85%.

These statistics indicate that there has been significant evolution in treating childhood cancer in the last 40 years—and to think that this illness was almost always fatal in the 1960s.

Pediatric cancer treatments usually involve repeated hospital visits of unpredictable lengths of time, therefore disrupting the schooling of these ailing children. The student's initial scholastic program may require some adjustments due to long and short term consequences of the illness and its treatment. The cured youths may also sustain physical and cognitive sequelae, which can sometimes be permanent. It is important to properly identify these to ensure that students can continue their education among their peers.

Types of pediatric cancer

TYPES	A FEW EXAMPLES	RATIO	TREATMENTS
Leukemias (cancer of the blood)	<ul style="list-style-type: none"> • Acute lymphoblastic or lymphocytic leukemia (ALL) • Acute myelogenous leukemia (AML) • Chronic myelogenous leukemia (CML) 	30% of pediatric cancers	Surgery
Lymphomas (cancer of the lymphatic system)	<ul style="list-style-type: none"> • Hodgkin's disease • Non-Hodgkin's lymphoma 	10% of pediatric cancers	Radiotherapy
Solid tumours	<ul style="list-style-type: none"> • Central nervous system tumours (brain tumours) • Osteosarcoma and Ewing's sarcoma (bones) • Rhabdomyosarcoma (soft tissues) • Wilms tumours/Nephroblastoma (kidneys) • Retinoblastoma (eyes) 	60% of pediatric cancers	Chemotherapy Transplant

FREQUENTLY ASKED QUESTIONS BY CHILDREN AND BY ADULTS

How do you get cancer?

Cancer is not contagious. A child can hug, play, kiss, lend toys to his/her brother, sister or a sick friend, and never become sick. Our body is made of billions of tiny cells which unite to form organs or systems of organs. All of a sudden one of these small cells rebels and refuses to act like the others. It then becomes abnormal, multiplying erratically and giving birth to many other rebel cells such as itself. All these cells are sick. They no longer obey the laws controlling the body and begin destroying everything around them. These are known as cancerous cells.

Does this mean we can get this illness at any moment?

No one is safe from cancer. Cancer can develop in very young children as in the elderly, in people who do not eat well as in those who try to eat right, in smokers or non-smokers, in active or sedentary people, etc. What causes cancer is still a mystery. There are many genetic and environmental factors involved where neither life style nor heredity (except for rare cases) can be said to be accountable. It is the body which has difficulty in protecting itself against the uncontrolled cell division. Many people, researchers, doctors, and specialists are working very hard to find answers to these questions, as well as remedies to heal and cure.

How do you know when you have cancer?

The symptoms vary greatly depending on the type of cancer and the types of treatments administered following a diagnosis. Some cancers may evolve very rapidly while others progress slowly and are more easily controlled.

How is cancer treated?

In order to cure cancer, doctors must use all the weapons that they know of. One of these is called surgery. This means operating to remove the cluster of sick cells (tumour). Surgery is like cutting weeds growing in your garden and throwing them really far away. The doctors say that sometimes radiotherapy (X-rays) must be used to heal a child with cancer. X-rays are like invisible rain which destroys weeds. Another way of treating the illness is called chemotherapy. This means that we get rid of the sick cells by using medication, either in pill form or by injection with the help of a syringe.

Can the cancer reappear?

Yes, we call this a recurrence. We then begin treatments again (chemotherapy, radiotherapy) but more extensively. The doctors sometimes suggest a bone marrow transplant, which forces the cancer-stricken child to remain in his/her hospital room for weeks.

What is most difficult about the hospital?

The most difficult are the needles and the treatments. The cancer-stricken child does not sleep at home and his/her parents are not always there. Sometimes the cancer-stricken child misses his/her friends, his/her brothers and sisters, his/her cat or his/her dog.

When you've had cancer, are you like you were before?

Yes and no. There are many kids who continue doing the same activities without any sequelae—running, jumping, playing. Unfortunately, sometimes there are bothersome physical and psychological sequelae. Thankfully, the doctors can often suggest solutions for relieving such discomforts.

Does it hurt when you loose your hair? Will it grow back?

No, it doesn't hurt. Yes, hair usually grows back.

Can you die from cancer?

Cancer is a serious illness. If it isn't treated or if the treatments don't work, children may die, but in most cases, they survive.

How can I help a sick friend?

To support a friend, you can send him/her some greeting cards or some drawings. Upon returning back home or back to school, he/she should come back to a normal way of life.

CONSEQUENCES ON EVERYDAY LIFE AND SCHOOL LIFE

Although the symptoms may vary depending on the type of cancer, the consequences of the sickness and the treatments are similar.

Symptoms		What to do at school? (Guidelines)
Fatigue	<ul style="list-style-type: none"> • May be related to anemia due to treatments or stress caused by the child's life situation 	<ul style="list-style-type: none"> • Review child's schedule (or class schedule) and include periods of rest • Cut back on timetable (concentrate on mandatory subjects) • Arrange for premises conducive to rest • Adapt schooling activities accordingly
Nausea and vomiting	<ul style="list-style-type: none"> • Chemotherapy treatments may cause these side effects for several days (although vomiting usually subsides within 24 hours) 	<ul style="list-style-type: none"> • Ensure easy access to washroom • Have someone to accompany the student (in case of weakness or fainting) • Advise the parents about the child's discomfort
Loss of hair	<ul style="list-style-type: none"> • Chemotherapy and radiotherapy treatments may temporarily cause total or partial loss of hair 	<ul style="list-style-type: none"> • Support the child • Bring awareness of situation to friends • Offer the possibility of wearing a cap, a hat or a scarf
Vulnerability to infections	<ul style="list-style-type: none"> • Treatments may lower the white blood cell count, which plays a major role in the immune system, leaving the child exposed to infections 	<ul style="list-style-type: none"> • Encourage the washing of hands • Pay attention to the telling signs the child may have (fever, redness, headaches, etc.) • Advise the parents of all contagious infections or illnesses (chickenpox, measles, viruses, etc.) • Ask the other parents to advise the teacher in case of any contagious illnesses
Bleeding	<ul style="list-style-type: none"> • May occur due to low blood platelet count in reaction to treatments 	<ul style="list-style-type: none"> • Advise parents of the bleeding
Amputations or presence of visible scars	<ul style="list-style-type: none"> • Visible physical sequelae following treatments, which modify how affected children or teens perceive themselves 	<ul style="list-style-type: none"> • Ask the child or teenager what information and in what manner he/she wishes it to be communicate to schoolmates, if possible, before returning to school
Pain or feelings of discomfort	<ul style="list-style-type: none"> • May be caused by the treatments 	<ul style="list-style-type: none"> • Quickly contact the parents and stick to the foreseen protocol in the student's intervention plan
Irritability	<ul style="list-style-type: none"> • May be caused by the treatments, a brain tumour, or stress caused by the child's life situation 	<ul style="list-style-type: none"> • Although inappropriate behaviour is unacceptable, must make judgement call regarding consequences

Weight loss or gain	<ul style="list-style-type: none"> • Certain medications either increase or diminish the appetite • Certain medications cause pain (ulcers) in the mouth • Certain medications provoke a gain or loss of weight 	<ul style="list-style-type: none"> • Designate favourable times for child to satisfy his/her appetite • The child must sometimes eat less but more often • Allow the child to eat in class
Loss of consciousness	<ul style="list-style-type: none"> • May be caused by treatments or a brain tumour 	<ul style="list-style-type: none"> • Lay the child on the floor and prevent injury • Keep schoolmates away • Advise parents of child's fainting spell
Motor skill problems	<ul style="list-style-type: none"> • May be caused by treatments, a brain tumour, or effects following an operation 	<ul style="list-style-type: none"> • Adapt the physical education class requirements • Arrange and facilitate accessibility in the location for the child to manoeuvre
Fine motor skill problems	<ul style="list-style-type: none"> • May be caused by treatments, a brain tumour, or effects following an operation 	<ul style="list-style-type: none"> • Allow to the child more time for writing tasks • Adapt the evaluation: oral instead of writing

Short, Medium, or Long Term

The treatments used against cancer may also produce long-term effects. "Sequelae" (somatic, neuropsychological, psychological, cognitive, sensory, and other sequelae) are not systematic. They depend on the type of treatment, the type of cancer, and its progression. They may be more or less debilitating, visible or invisible.

Examples of sequelae following recovery are:

- Certain allergic reactions (hives, swelling, "breaking out", shortness of breath)
- Stunted growth
- Memory problems
- Speech disorders
- Concentration and attention deficit
- Loss of hearing and vision
- Learning difficulties
- Preoccupation with physical appearance
- Emotional turmoil in interpersonal relationships with parents, siblings, and peers
- Fear of failing in school

In order to prevent misunderstandings among peers, it is important for the school community to be well informed regarding the existence of eventual effects and not to confuse them with fatigue or inattention.

Therefore, communicating on a regular basis is imperative in conceiving an intervention plan or in reviewing such a plan with the student, the family, the school nurse, the teachers, and the school administration as a means of facing these multiple sequelae, visible or invisible.

PSYCHOLOGICAL ASPECTS TAKEN INTO ACCOUNT

“You always try to look strong, but you also have to show your sadness. We are not superhuman. You have to allow yourself to be sad.”
(Philippe)

The child's personality and emotional development are affected by the illness and its treatment. But the psychological impact varies from one individual to the next depending upon the affected child's age, personality, resources, previous education, weaknesses, and social context.

The sick child evolves and grows thanks to interactions with the family, the medical team, friends, and school. Difficult moments often occur; this is normal. The psychological effects of the illness and its treatment can be felt long after the end of medical care.

The end of intensive medical treatments can be difficult for a child may then feel a lack of attention and somewhat abandoned. When cancer ceases to be the focal point of their lives, the family and child must resume and redefine their place in society. Problems left aside may reappear and create hard to handle conflicts.

A child or adolescent who has experienced illness will evolve more rapidly and may feel that he/she has different interests and preoccupations than the others. The child's or adolescent's focus of interest may change as well as their behaviour toward learning. They may feel stimulated with returning to normal life or be discouraged by falling behind in school.

It is recommended to be aware of the fears and needs of the student who, within the normal school setting, is confronted by the staring of others because he/she is different. Whether this difference is apparent or not, proper steps aimed at bringing about acceptance among peers must be established. Progressively, through the questioning of fellow students, for example within ethics or religion and culture classes, communication hopefully will transpire and allow for an adjustment in how others perceive and fear cancer. Either the school nurse or Leucan can be employed in developing awareness aimed at informing and defusing the situation.

The ailing teenagers sometimes have more difficulty handling problems caused by treatments affecting their physical appearance (loss of hair, change in physical aspect, loss of motor function, etc.) and therefore differentiating them from their schoolmates. Hence, it is important for these students that school workers establish a realistic intervention plan which is adapted to their needs and future goals. A guidance counsellor is crucial in helping the teenagers in choosing a field of study which is not only interesting to them, but also within their capability.

Children or young teenagers whose treatments produce sterility sometimes have to face questions that are somewhat premature to them, and may also deal very badly with the uncertainty of future parenthood.

SCHOOL AND CANCER

“Up until they sent a teacher to help me with nouns and adverbs, I thought I was going to die. I told myself they wouldn’t send a teacher to make a dying boy do some homework. That’s when I decided—I could get better.”
(From Candlelighters)

School often has a very positive effect on the self-perception of a young person during these difficult moments when fighting against cancer. When this new reality is integrated in the students’ educational quest, and is well prepared for, school to them then represents security, keeping them in touch with their peers, providing satisfaction for work well done, and the realisation that regardless of illness, life goes on.

The role of school personnel is then of the outmost importance. By being well informed and by effectively supporting students with cancer, they can be of great help in facilitating their return to the so-called “normal life”. For these school workers, preparing students with cancer to return to class can be demanding emotionally and in time invested. Here is some advice on the attitude to adopt in supporting sick students and aiding in their return to class to continue their education.

- **The Support Team**

It is important to remember that as a school worker involved with cancer-stricken teenagers, you are part of a team composed of parents, medical staff, psychologists, social workers, other school staff (nurses, school administrators, psychologists, etc.) and teachers from the hospital school services. This team will be able to inform and advise you on how to better support and prepare your students for returning to class.

This team will also support you, or if needed, offer its advice on resources for dealing with your own emotions and specific issues, or even share in the pain of bereavement. The professional health care workers are also encouraged to make use of these support services.

- **Communicating with the Parents**

It is essential to communicate with the parents in preparing the ailing child’s return to class. They are the ones keeping you informed on your student’s situation and will generally be the link between you and the health care team.

Usually parents expect school personnel to keep up to date with their child’s state of health and are more than happy to inform you in this matter. They count on you in the same way in supporting and keeping them informed on their child’s reintegration and progress, alerting them should you notice any significant behavioural differences or symptoms concerning their child’s state of health.

Parents may express some sadness, anger, anxiety, or hostility when communicating with you. Remember the parents are going through a difficult time, and these emotions are not necessarily your fault or even aimed at you.

“When you don’t feel alone in all this, it seems as though you get through it better.”
(Marie-Ève)

PREPARING STUDENTS TO RETURN TO CLASS

1st Step: GET INFORMED

The first thing to do in preparing students to return to class is to get information on their state of health. In order to do this you must contact the parents, the team at the health centre, and the Leucan advisor if needed.

Get information concerning:

- The type of cancer involved, its prognosis, and how it affects the student;
- The treatment plan (type of treatment, frequency, expected duration, etc.);
- Possible side effects on health, appearance, and behaviour of student;
- Estimated treatment schedule, operations, or future tests which could affect the student's school attendance;
- The physical limits and other restrictions the student is likely to encounter during and after treatments;
- What the student knows about the sickness and his/her reactions and fears toward it;
- Matters the student would like to discuss directly with his/her teachers or other school staff.

2nd Step: PLAN

Then plan the student's reintroduction into class. Organize a meeting with the school staff involved. In many instances members of the medical team, social workers, or psychologists from the treatment centre will be able to join you in helping to identify the factors to take into account, in specifying how to proceed in the most efficient way, and in establishing the intervention plan (example in Annex 1).

During this meeting you must:

- Designate a contact-person to ensure liaison between the school, the parents, the treatment centre, as well as the siblings' teachers and the ailing student's other teachers. This person may be a teacher, a special education resource teacher, a member of the school administration, or support staff (psychologist, nurse, counsellor, etc.). The designated contact-person must accept this responsibility and be readily available.
- Identify and allow for means to satisfy the student's specific needs. Depending on the situation, these requirements may include special transportation (e.g. paratransit), a place to rest, to eat something or to be alone, the use of unoccupied washrooms, a means of keeping in contact while being in the hospital, etc.
- Agree on a manner of passing on information to all school personnel involved with the student, including those working with the siblings (e.g. organize a reunion at the beginning of each step) so as to anticipate any problematic or embarrassing situations. Parents and siblings should be invited.
- Discuss the attitude to adopt toward the student and the ways of confronting the situation with his/her peers.
- Decide upon certain modifications or bending of the rules to aid in the student's integration.

The Contact-Person's Role

The contact-person in charge of the liaison between the student and the different parties involved will have to accept the following responsibilities:

- Communicate with the affected students on a regular basis, stay informed on whether they are doing well or not in school or with their peers.
- Keep the parents informed if there is any doubt or changes in the student's attitude or school performance.

- Look for signs of learning difficulties, hearing or vision problems, conflicts the ailing student may be going through, and inform the parents.
- Get in touch with all the student's teachers as often as possible in order to keep up on his/her progress, difficulties, or significant changes that they may have noticed. Having regular contact with the teachers will also enable them to remain informed on the student's state of health or on the potential modifications to the intervention plan.
- Transmit all pertinent information to other school staff (librarian, janitor, monitor, etc.) who may have to work with the student.
- During long periods of absenteeism, ensure that classmates and teachers remain in contact with the ailing students in order for them to feel that they are still part of the group, and provide for a means to pass on information on how they are doing.
- Be attentive to the reactions of the sick student's siblings. If needed recommend that the proper professional support be appointed by the school administration.
- Be on the look out for outbreaks at school involving measles, chickenpox, or other contagious diseases, and immediately advise the child's parents if such a case exists.
- Communicate with the other teachers working with the youth (home, hospital).

What Attitude to Adopt Toward Ailing Students?

To ignore their illness is to neglect an important aspect of the lives of cancer-stricken children. On the other hand, one must not be haunted by it. Children suffering from chronic illnesses, especially during adolescence, need to feel like everyone else, and want to live as normally as possible. We must therefore find a balance between the compromises made to suite their condition, and the need for them to continue to be stimulated by their education while preserving their self-image.

Here are several suggestions in what attitude to adopt toward these students:

- Give them support and understanding without being overly protective. They must follow the same rules of behaviour as their peers.
- Learning demands must apply, but be reasonable. Not doing so would be to rob them of the pride and satisfaction that comes with work well done.
- Continue to support them, but do not hesitate to apply discipline when needed. Boundaries are comforting since they are familiar with them.
- Avoid giving any special treatment, for it may create resentment in other students, and a sense of isolation in the cancer-stricken student. Specific arrangements may be made regarding their condition, for example taking into account the treatment schedule before setting due dates for school work. However, the grading criteria should remain the same as for the other students.
- Be willing to listen if they wish to talk about their situation or the problems they are dealing with, but also be respectful of their choice to be silent if they desire so.
- Let them make their own decisions and choices if possible.
- Make sure the ailing students always feel like they are part of the group. During long periods of absenteeism, ensure constant communication and send them their homework or lessons when possible.
- Look for signs of learning difficulties, hearing or vision problems, changes in behaviour or conflicts with peers, and inform the contact-person and the parents.

Several Possible Adjustments

1. Wearing a Cap or a Scarf

The loss of hair for young people with cancer can be a dreadful ordeal to go through and the cause of much anxiety. If they wish to hide their baldness, they may wear a scarf or a hat instead of a wig. If in your school it is usually forbidden to cover your head in class, perhaps a special permission can be granted to students with cancer. Remember to notify the other teachers to avoid embarrassing situations.

2. Physical Education Classes

Physical education classes are not permitted unless the students have a medical prescription. This prescription must be regularly re-evaluated depending on the treatment and the stage of the illness. The student's intervention plan must be carefully followed, and you must remain in contact with the parents to be informed of any changes regarding the child's medical file.

3. Classes in Dramatic Arts

These classes appear to be particularly beneficial for kids with cancer, should they feel the need to express themselves. Acting classes will allow them to:

- Express themselves as actors and thought-provoking subjects;
- Take part in the community through culture;
- Share in ideas and emotions;
- Free and transform emotions;
- Feel worthy and socially useful in creating individual or collective works. The students participating in collective works may find a place or a suitable role among their peers.

4. Peer Tutoring or Mentoring

Frequent and sometimes long-term absenteeism may slow a student's progression in school, creating anxiety and fear of failing. A means to ensure that the absent students can catch up on school work must be put in place. You can establish a peer tutoring/mentoring system, or perhaps private or remedial lessons.

5. Classroom Relocation

Several youths may have difficulty moving about and will have problems getting to class on time, especially if they have long distances to travel. If this is the case, try to facilitate the student's transportation by relocating the classroom or by being more lenient toward tardiness.

6. Eating

Cancer-stricken children may have a need to eat less but more often, to drink lots of liquids, or to take their medicine at specific times. Provide them with a place to eat or drink during class.

7. Oral Hygiene

Oral hygiene is very important for kids with cancer due to a high risk of developing painful mouth sores (ulcers) following treatments. The use of a mouth wash will help ease the pain. Make sure these students have a place to keep everything they need to do this without being embarrassed, and enable them to leave the class momentarily in order to do so.

8. Timetable and School Rhythm

Timetables can be reduced as long as they continue to satisfy Quebec's educational program requirements. This type of planning must be personalized, reviewable, and adaptable to the potential progression of the illness (intervention plan).

Daily resting periods must be scheduled in at school as well as at home, especially in the afternoon, while classroom and at-home work loads should be reduced in accordance with medical instructions given by the parents.

The goal is to provide an adequate amount of uninterrupted learning periods by having a decisive educational plan with clear objectives, even though these may temporarily be relatively modest.

There are many ways for cancer-stricken students to continue their schooling:

- Schooling in a normal school setting (student's school) when attendance is possible even after treatments;
- Schooling at the hospital: teachers at the hospital ensure an educational follow-up with the student's school by creating a communication network between the hospital, the school, and the home;

- Schooling at home: provided for by a qualified teacher appointed by the school board;
- Schooling via the Internet (FADEL – an online and distance education system).

The teachers from the student's initial school must take into account these different forms of schooling available, and provide ways to remain in contact with fellow teachers when students are either hospitalized or at home (sending lessons, tests and exams, communicating by phone, designating student to bring homework to the family, etc.). You must also prepare the material means (transport, agenda, etc.) as well as the educational means (catching up on certain classes, etc.) for the student's return to class.

9. Exams

Special arrangements can be authorized following agreement with the school board or the student's school administration (school adaptation services). Many hospitals offer specially reserved rooms for students to take exams.

10. School Outings

Parents should be notified prior to organizing any outings. The emergency protocol and phone numbers of the emergency services for the area being visited must be known. Lodging conditions should be considered and precautionary measures must be taken for certain activities when outings involve overnight stays.

11. Vocational Guidance

This requires consultation between the students, their parents, and the guidance counsellor. It is better to begin early when taking steps toward a personalized career plan which must be embraced by the youths. The different stages of the illness should be taken into account along with the educational support needed in this context.

How to Act Toward Other Students?

The fact that a fellow classmate has cancer inevitably provokes a lot of questioning and different reactions on the part of other students. Likewise, the thought of returning to class and facing the reactions of classmates will probably create much anxiety for the ailing student.

“The illness, the treatments, and the risk of recurrence don't really scare me. What scares me is the solitude. The thought that I might someday be abandoned by my friends or my family gives me the shivers. I hope with all my heart that this never happens.”
(Éric)

The manner in which the ailing student's situation is related to the other students can greatly influence the quality of school reinsertion and overall school environment. This may then become a fulfilling and positive experience for everyone. But prior to communicating with the other students on the subject, it is essential to consult with the affected student and with his/her parents about how they wish to approach this issue. Make sure you are aware of your school board's policies concerning such matters. Some school boards may require written consent from the sick student's parents and even from parents of all the other students before allowing the discussion of such matter in class.

When meeting with the ailing students and their parents, get information on the following points:

- Their fears;
- How they wish this to be discussed with other students;
- What they wish to suppress;
- The manner in which the afflicted students desire to be involved in the proceedings;
- What the afflicted students and their families hope the other students will retain from these proceedings;
- Outside resources which can be used in this matter (e.g. Leucan).

Here are some helpful suggestions in guiding the classroom's agenda:

- Develop awareness in your students with activities described in the educational documentation suggested by Leucan.
- Allow students to express their apprehension and try to answer their queries. Consider if the ailing students can agree to spend a little time to discuss their illness directly with their classmates. These sick children often prefer to answer classmates' questions themselves as opposed to becoming a silent and distant object of curiosity.
- Assure your students that cancer is not contagious, that people suffering from this sickness are not responsible for their state of health, and that the cause of the illness is unknown.
- Suggest that your students carry out a research on cancer. This will enable them to acquire some knowledge about their friend's illness.
- In order to add to your intervention with the students, invite a speaker (a member of the medical team, a volunteer from Leucan, or other) to give a presentation in class. You will find a list of available resources in the Annex.
- If you notice any badgering on the part of certain students toward the afflicted child, ensure you discuss the matter with the students involved and try to make them understand the feeling of isolation and rejection that this behaviour is creating for the ailing student.

SIBLINGS

“When she was 8 years old my sister knew she might lose me and she appreciated the time we spent together.”
(Sébastien)

The sisters and brothers of the cancer-stricken children are aware of the illness's psychosocial repercussions and can also be affected in many ways by them. Thanks to the alertness, the support, and the supervision of the school staff, it should be easier for them to go through this hardship.

When cancer strikes, it completely upsets the family's reality and creates various emotions and reactions, which can sometimes be very intense and new to kids. Furthermore, it totally destabilizes the family's daily routine, forcing everyone, especially the parents, to reconsider their priorities and modify their schedule in regard to the sick child and his/her needs.

The emotions experienced in this situation by the brothers and sisters of cancer victims obviously depend on the age of these siblings. Nevertheless, they often appear to share the following feelings:

- Fear of losing a sick brother or sister;
- Fear of getting cancer themselves;
- Bewilderment, worry, anger, or rage toward the situation;
- Fear of the unknown, the future, in seeing how parents react, etc.;
- Missing sick sibling during long-term stays in the hospital;
- Missing parents who must often be absent;
- The feeling of not being as important to parents or circle of acquaintances;
- Frustration from seeing everyday life in turmoil;
- Frustration from feeling their own needs being neglected;
- Resentment toward parents and relatives;
- Resentment or jealousy toward sick child;
- Feelings of guilt for experiencing negative emotions toward affected child or toward parents.

These feelings may provoke various reactions in these children. They may significantly alter their behaviour and create physical illness (nausea, recurring headaches, stomach aches, etc.). As a school worker, it is important to remain alert to the reaction and changes in behaviour of students whose brother or sister is afflicted with cancer. You will then be better able to support them and help the parents make the proper adjustments.

To assist students in this situation:

- Be aware of the stress experienced by these children;
- Consider meeting with the parents to promote communication;
- Allow them to express themselves and be attentive to their feelings;
- Try to answer questions and reassure them to the best of your ability;
- Encourage them to keep in contact with friends and to participate in activities outside of the school to take their mind off things;
- Advise the parents of any unusual reactions, behavioural modifications, or differences in these children's school grades;
- When required, refer them to the contact-person in charge of the ailing child at school, or a professional who will be able to help them (psychologist, social worker, etc.).

HOW TO REACT WITH STUDENTS THAT ARE IN THE FINAL STAGE OF CANCER?

Despite the recent advances in the fight against cancer and the increase in survival rates, modern medicine sometimes fails. As a school worker you may ask yourself how to care for students in the final stages of cancer. What attitude to adopt toward them, toward their parents and classmates, and what to do when death occurs. The following information and suggestions will help guide you:

- Even in the final stages of the illness, the student may still find school to be fulfilling.
- Do what you can to help these students take the utmost advantage of what time they have to live while respecting their capabilities (reviewed schedule, sporadic presence at school, etc.).

The ensuing death will inevitably provoke a lot of questioning, reflecting, and reactions, which are difficult to respond to, as much from students as from the school staff. Do not hesitate to call upon professional support, the staff at the treatment centre, and the different organizations (e.g. Leucan) to assist and guide you during this difficult period.

Students will react differently following the death of their classmate and may express their sadness by various means. Some may have very strong reactions while others may seem almost indifferent to this loss. This is normal. Everyone has their own way of taking in such an announcement and for some students it may be their first contact with death.

- Recognize their pain, but do not force them into talking about it. Most will bring it up themselves when ready to do so. Let them know you are open to speak with them or to guide them toward a professional if they feel the need.
- If the deceased student's parents agree, suggest to students who wish to attend the funeral or pay their last respect at the funeral home to do so. This will allow them to express their sorrow, to better acknowledge the passing of their friend, to say their goodbyes, and to offer their condolences to the family. However, do not pressure anyone to attend.
- Try to answer honestly, simply, and with empathy the questions brought about by this bereavement.
- Some students may want to make a gesture in memory of their friend (fundraising activity, presentation, mural, poem, planting a tree, etc.). This can be a fulfilling experience that may significantly help students through bereavement. Furthermore, knowing that others share in the pain of loss can be comforting to the parents and siblings of the departed student. Do not hesitate in supporting your student in this endeavour.

Keep in mind that most school personnel who have experienced the death of one of their students due to cancer assert that in time it has become a very enlightening and fulfilling experience. The courage and attitude of these youngsters, as well as the wisdom they have acquired through difficult times in facing illness, has touched all those around them. Everyone has learnt much in their company.

TO DO A LITTLE MORE

Here are several suggestions for things you can do to encourage and help cancer-stricken students in their fight against this illness. These can be accomplished individually, with the student's class, or with any student gathering in which the ailing student is part of (school band, sport team, student newspaper, etc.).

- To reduce the amount of anxiety felt by the ailing student when returning to school, organize an informal meeting beforehand with several close friends or colleagues, either at his/her home or outside of school. This will allow them to progressively reconnect with their peers, to be less fearful of being rejected, and to feel that he/she will have allies when returning to school.
- Send emails, get well cards or notes of encouragement to the sick child or to one of his/her close relative. It is sometimes easier to express your thoughts in writing than verbally. The person receiving these notes can keep them and read them again if in need of comfort during difficult times.
- Have your students create an art project that can then be given to the ailing student, to decorate his/her room.

When the student cannot attend school for long periods at a time:

- Invite your students to regularly produce a photomontage (composite of photos) or a video to keep the student up-to-date with the group and to maintain a sense of belonging.
- If it is feasible and if the parents agree to it, recommend that your students take turns visiting the ailing student on a regular basis, either at home or in the hospital.
- Ensure that these students continue to receive school newspapers, student memos, and invitations to special events organized by the school, as well as all other pertinent documentation, in order for them to feel they are still part of the group and are up-to-date on school news.

If you would like to do more for these students or their families but are not really sure how to help, feel free to ask them how you can be useful. They are in a better position to know what they need or not. Do not be offended if your offer is not accepted right away and let the family know that they can call on you when in need. If the family accepts your help, agree on a form of aid that takes into account your limits, and then try to be constant and reliable in the support that you give.

"A bunch of friends came to see me after a surgery. They followed me right up to radiology and one of them asked the doctor if they could take a group X-ray with all their hands on my stomach!"
(Yanick)

To Help the Cause

Organize a fundraising campaign to support an organization engaged in the fight against cancer:

- Wash-o-thon, walk-o-thon, ski-o-thon, shave-o-thon, etc.
- Sport tournament
- Sales (hot-dogs, chocolate, pastries, garage sales, etc.)
- Theme days or events
- Supper outings
- Cultural events (comedy shows, plays, concerts)
- Fundraising events (at work, at school, with the family)
- And many more!

Participate in events coordinated by associations or organizations. Encourage several staff members or students to take up the Shaved Head Challenge or the Leucan 12-hour Ski Challenge—two events presented by Leucan¹. Urge your school to sponsor them!

¹For more info: www.leucan.qc.ca.

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• Public Health Agency of Canada– www.phac-aspc.gc.ca – <i>This Battle Which I Must Fight</i>
• The Fondation Centre de Cancérologie Charles-Bruneau– www.charlesbruneau.qc.ca/en
• The Montreal Children’s Hospital of the MUHC www.thechildren.com/en/health/conditions.aspx?sLg=1 – <i>My child has cancer: How can I help him deal with his emotions</i>

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ANNEX

LITTLE GLOSSARY

Leucan	<u>Leu</u> for “leukemia” and <u>can</u> for “cancer”.
Ablation	Surgical removal of an organ or a tumour.
Amputation	Surgical removal of a limb or part of a limb.
Antiemetic	A drug used to prevent nausea or vomiting.
Biopsy	The removal and examination of tissue, cells, or fluids to establish a diagnosis.
Blood cells	White blood cells, also known as lymphocytes, fight against illness. Red blood cells bring oxygen throughout the whole body.
Blood cell count	The analysis of different elements within blood to establish a diagnosis or to verify a treatment’s efficiency.
Bone marrow	Substance within bones which produces many of the substrates found in blood such as red blood cells, white blood cells, and platelets.
Bone marrow transplant or stem cell transplant	Treatment by which a patient’s bone marrow is destroyed by chemotherapy or radiation to eliminate cancerous cells. It is then replaced by new stem cells to allow the marrow to quickly reproduce itself.
Carcinogen	A chemical or other substance that causes cancer.
Carcinoma	Cancer found in the skin or internal organs.
Catheter	A tube inserted under the skin to ease access to veins (e.g. portacath).
Cell	A basic biological structure consisting of a thin outer membrane (skin), a liquid (cytoplasm), and a nucleus containing information controlling its behaviour in the body. There are <u>billions</u> of different cells which make up our body.
Chemo drug	Different chemicals used in chemotherapy.
Chemotherapy	Treatment of cancer using anticancer drugs.
DNA (deoxyribonucleic acid)	Chemical substance present in all cells of the body. Responsible for the transmission of genetic information controlling cell growth.
Final stage	Last stage, before death, in the progression of the illness.
Hematology	The study of blood and blood disorders.
Hepatology	Concerning the liver.
Immunology	The science that studies the means by which the body usually wards off diseases.
Intravenous	Injected directly into the blood circulation.
Lesions	Damage to organs or tissues.
Lumbar puncture (spinal tap)	The extraction of spinal fluids for testing by inserting a syringe in the spine.
Lymph	A liquid circulating throughout the lymphatic system, saturated with lymphocytes, and surrounding cells within the body.
Lymph nodes	Bean-shaped structures along the lymph vessels acting as filters and protecting against infections.
Lymphocytes	White blood cells that produce anti-bodies which attack viruses and bacteria.
Metastases	New cancer growth that has spread from one part of the body to another through

	blood circulation or via the lymphatic system.
MRI (magnetic resonance imaging)	Means of producing images using a magnetic field. Often used in the diagnosis of tumours.
Oncology	The science that studies the different forms of cancer.
Palliative	Describes a treatment not aimed at curing the cancer but at increasing the well-being of a patient in the final stage of the illness.
Platelets (thrombocytes)	Blood cells that allow blood to clot.
Prognosis	Expected or possible results of an illness.
Prophylaxis	Preventive treatment against disease.
Prosthesis	An artificial limb.
Radioisotope studies (scans)	Tests in which a radioactive substance is injected in order to detect tumours.
Radiotherapy	High-energy anti-cancer radiation treatments.
Recurrence	Return of cancer following a period of time under remission.
Remission	Significant reduction or momentary disappearance of symptoms.
Shingles	A virus that causes skin to break out along the path of nerve endings.
Symptoms	Distinctive signs of an illness which facilitate a diagnosis (ex: fever, pain, vomiting, loss of appetite, bruising, etc.).
Lymphatic system	Network of organs or vessels which produce and store cells that fight infections. The lymph system includes the lymph nodes, the spleen, and the thymus.
Therapy	A group of treatments.
Tomographic densitometry	Radiological imaging used to visualize cross sections (slices) of the body in order to determine the size, shape, and exact location of tumours.
Treatment protocol	Detailed instructions on how to administer treatments.
Tumour	Cluster of useless cells with an abnormal growth pattern. Malignant tumours can evolve and destroy healthy cells in the body. Benin tumours do not affect other parts of the body, and are generally treatable.
Ulcers	Lesions that have difficulty healing.
Ultrasound	Pictures made by bouncing sound waves off of organs and other internal structures.
X-rays	Small doses of high-energy radiation used in cancer diagnosis or high doses used for treatment.

IN CONCLUSION–THE CANCER-STRICKEN CHILD (CHARACTERISTICS, REQUIREMENTS, AND GUIDELINES FOR SCHOOL ENVIRONMENT)

IN THE SHORT TERM (DURING TREATMENTS)

The difficulties vary depending on the type of cancer, the type of treatment, and the illness' progression.

PHYSICAL DIFFICULTIES		PSYCHOSOCIAL DIFFICULTIES	SPORADIC OR EXTENDED ABSENTEEISM
<ul style="list-style-type: none"> • Nausea and vomiting • Pain, feeling ill, or loss of consciousness • Decreased immune resistance 	<ul style="list-style-type: none"> • Bleeding • Loss of hair • Physical changes • Fatigue • Weakness of muscles and bones (motor skills) 	<ul style="list-style-type: none"> • Preoccupation with physical appearance • Difficulty concentrating and attention deficit • Anxiety related to reactions of peers and teachers • Emotional distress in interpersonal relationships with parents, siblings, and peers • Fear of failing in school • Irritability 	<ul style="list-style-type: none"> • Related to treatments • Related to medical appointments • Related to contagious diseases • Related to the child's condition
REQUIREMENTS			
<ul style="list-style-type: none"> • School personnel's knowledge of the illness' impact • Classroom awareness in respect to student's expressed wishes • Feasible regular school attendance • Continued schooling commitment by teacher in charge • Affinity in classroom and in school • Realistic schooling requirements (neither above nor below capabilities) • Flexibility in daily classroom routine • Support in positive self-esteem development • Student participation in inspirational projects • Safeguard against infectious disease from peers • Circumscription from certain physical activities 			
SCHOOL ENVIRONMENT GUIDELINES			
<ul style="list-style-type: none"> • Gathering of information related to childhood cancer provided by parents, school nurses, and Leucan • Identifying resource persons capable of assisting school workers • Organizing school services while taking into account all aspects of education, socialization, and the students qualifications (e.g. possibility of either attending school for certain classes or being taught at home for others) • Including awareness activities for the peers of affected students and their siblings • Adapting education while specifically focussing on the most pertinent courses and school tasks in developing the student's qualifications • Providing a proper place and time for rest periods in the student's schedule • Setting up means of communication between the school environment and the student, during periods of absenteeism • Providing immediate notification when infectious diseases are identified at school • Permitting participation in physical education classes (contingent upon medical restrictions) 			

IN THE LONG TERM (FOLLOWING THE END OF TREATMENTS)

Treatments for certain types of cancer, such as leukemia and brain tumours, increase the risk of suffering cognitive sequelae. These occur more frequently for treatments received before the age of 6. The effects may show up years later.

COGNITIVE SEQUELAE ACCORDING TO TYPE OF CANCER AND ITS TREATMENT
<ul style="list-style-type: none"> • Memory problems • Attention deficit and difficulty concentrating • Speech disorder

<ul style="list-style-type: none">• Visuospatial difficulties
REQUIREMENTS
<ul style="list-style-type: none">• Acknowledging potential long-term impact on cognitive abilities• Establishing expectations• Adapting teaching• Preventing exclusion from school and encouraging persistence and adaptation to the personalized intervention plan• Regularly observing and adjusting measures to promote career guidance
SCHOOL ENVIRONMENT GUIDELINES
<ul style="list-style-type: none">• Establishing a multidisciplinary intervention plan• Teaching compensatory skills (using memory aids such as lists, prompt cards, etc.)• Adapting teaching with respect to established expectations• Taking into account resources and student's capabilities when advising

RESOURCES

Websites

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- Cancervive–www.cancervive.org
- CLIC Sargent–www.clicsargent.org.uk/Publicationsresources/CLICSargentpublications–*Returning to School: Primary School Children with Cancer* and *Returning to School: Young people with Cancer, Talking to Primary School Children with Cancer*
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- The Fondation Centre de cancérologie Charles-Bruneau–www.charlesbruneau.qc.ca/en
- Fondation québécoise du cancer (French only)–www.fqc.qc.ca
- The Montreal Children’s Hospital of the MUHC
www.thechildren.com/en/health/conditions.aspx?sLg=1–My child has cancer: How can I help him deal with his emotions
- Public Health Agency of Canada–www.phac-aspc.gc.ca–*This Battle Which I Must Fight*
- Canadian Cancer Society–www.cancer.ca

Telephone Numbers

- Canadian Cancer Society 1 888 939-3333
- Fondation québécoise du cancer 1 800 361-4212 or 1 800 363-0063 (Quebec residents only)

Some Organizations

CANADIAN CANCER SOCIETY	5151 l'Assomption Blvd Montreal (Quebec) H1T 4A9 Tel.: 514 255-5151 Fax: 514 255-2808 Infoline: 1 888 939-3333 Email: info@sic.cancer.ca Website: www.cancer.ca
THE FONDATION CENTRE DE CANCEROLOGIE CHARLES-BRUNEAU	4515 de Rouen St. Montreal (Quebec) H1V 1H1 Tel.: 514 256-0404 Toll-free number: 1 877 256-0404 Fax: 514 256-2116 Email: fondation@charlesbruneau.qc.ca Website: www.charlesbruneau.qc.ca
Fondation québécoise du cancer HEAD OFFICE AND LODGINGS IN MONTREAL	2075 de Champlain St. Montreal (Quebec) H2L 2T1 Tel.: 514 527-2194 Toll-free number: 1 877 336-4443 Fax: 514 527-1943 Email: cancerquebec.mtl@fqc.qc.ca
REGIONAL CENTRE AND LODGINGS IN THE EASTERN TOWNSHIPS	3001 12 th Avenue Nord Fleurimont (Quebec) J1H 5N4 Tel.: 819 822-2125 Fax: 819 822-1392

	Email: cancerquebec.she@fqc.qc.ca
REGIONAL CENTRE AND LODGINGS IN MAURICIE (TROIS-RIVIÈRES)	3110 Louis-Pasteur St. Trois-Rivières (Quebec) G8Z 4E3 Tel.: 819 693-4242 Fax: 819 693-4243 Email: cancerquebec.trv@fqc.qc.ca
REGIONAL CENTRE AND LODGINGS IN THE OUTAOUAIS REGION	555 de l'Hôpital Blvd Gatineau (Quebec) J8V 3T4 Tel.: 819 561-2262 Fax: 819 561-1727 Email: cancerquebec.gat@fqc.qc.ca
REGIONAL CENTRE IN QUEBEC CITY INFO-CANCER, TÉLÉ-CANCER, DOCUMENTATION	190 Dorchester St. South, Suite 50 Quebec (Quebec) G1K 5Y9 Tel.: 418 657-5334 Toll-free: 1 800 363-0063 Fax: 418 657-5921 Email: cancerquebec.que@fqc.qc.ca

Other Potentiel Resources:

- School nurses
- Psychologists
- Social workers
- Special education technician
- School board's special education services

Books and Audiovisual Documentation²

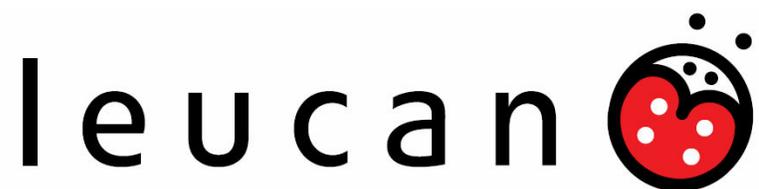
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