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**1-833-222-4884**

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# Childhood **LEUKEMIA**

This tool is for **PARENTS** of a school-aged child or teen with leukemia.



# PLANNING THE RETURN TO SCHOOL

after a diagnosis



As a loving parent, you want to do what's best for your child especially when they are not well. The days and months following your child's diagnosis may be filled with medical appointments or require extended stays at home or in hospital for treatment. As a result, you and your child may worry about falling behind with schoolwork and losing contact with friends bringing on feelings of uncertainty or anxiety. In this document, you will find plenty of guidance and tips to help you communicate with key school personnel now and during treatment, and prepare you for your child's return to class when the time is right.





# Why does **SCHOOL MATTER** now?



Thanks to the advances in research accomplished over the last few decades, the majority of children and teens now survive a leukemia diagnosis. After recovery, most kids can expect to live a normal and active life. For this reason, we recommend that you take the steps necessary to allow your child to remain in contact with his social circle, and to do so from the moment he is diagnosed. Research<sup>1</sup> has shown that kids who continue their relationships with family and friends while in treatment experience a smoother transition back to school. It is common for children and teens with leukemia to want to live a normal life, and as a parent, you can help your child prepare for that.





# INFORMING the school



There are many challenges in the months following a child's initial diagnosis. Meeting with the healthcare team and making decisions about treatments can be tiring. Some kids are even admitted to the hospital the moment they are diagnosed.

Soon after you have discussed the treatment plan with the healthcare team, it will be important to meet with the staff at your child's school. Depending on her age, you could discuss this with her beforehand and decide what information she feels comfortable sharing. Depending on your level of comfort, meeting the school team will give you the chance to tell them about your child's illness, the treatments and the effects she will experience. It might also be necessary to arrange for extra help, such as tutoring, and ensure that contact between the school and the student is maintained, even when your child is absent.





## Team up

At school, teachers, support staff and administrators work together to foster a student's personal and educational well-being. Consider them as part of the extended team that will accompany your child in her journey toward recovery. By including them as part of the team, they will have a better understanding of leukemia and become champions for your child. She will feel supported, less isolated by keeping a strong and constant connection with the school. Your child's transition back to school will also be smoother if the school team is aware of the different types of treatment she is going through.



Classmates play an equally important role in your child's social development. Encourage teachers or the school administrators to give your child's schoolmates simple information about leukemia and answer any questions in a reassuring manner.

Some useful facts you may want to share with the school:

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Leukemia is not contagious. You cannot catch cancer by being near someone who has it.

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Leukemia is a serious, potentially deadly illness, but with the right treatment, most kids with this cancer survive and return to school, enjoy plenty of activities, etc.

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Sometimes, kids with leukemia might feel well enough to attend class during treatment. Other times, they might be absent for long periods at a time. No matter if your classmate with leukemia is at school, at home or at the hospital, she is the same person and remains your friend. So it is important for you to give your friend regular updates on what is going on at school.



**bloodcancers.ca:** There are many tools available on the Leukemia & Lymphoma Society of Canada's (LLSC) website dedicated to kids and parents. You can refer the school team to the website, which has booklets, fact sheets and a video on childhood leukemia.


# Maintaining **A CONNECTION** and an ongoing **DIALOGUE**

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hrough the more intensive phase of treatment, your child will probably be absent from school for extended periods of time. During this time, he may feel alone and lost, as he is no longer part of a social environment that is usually at the core of his daily life. As previously mentioned, maintaining a connection with the school helps the child feel “normal” and gives him something to focus on during treatments.

In addition, returning to school after an extended absence can be a stressful experience for a child and the parents, and even more so for a teenager. By helping your child keep in contact with friends and certain school personnel, you will help make the transition smoother.





Here are some simple steps you can take that can help your child maintain a connection with his social circle:

Take your child to the school yard at recess. There is less risk of contagion, and your child can get some exercise while spending time with friends;

Talk to friends over the phone or by video call;



Invite close friends over to the house or the hospital when your child is strong enough to allow it;

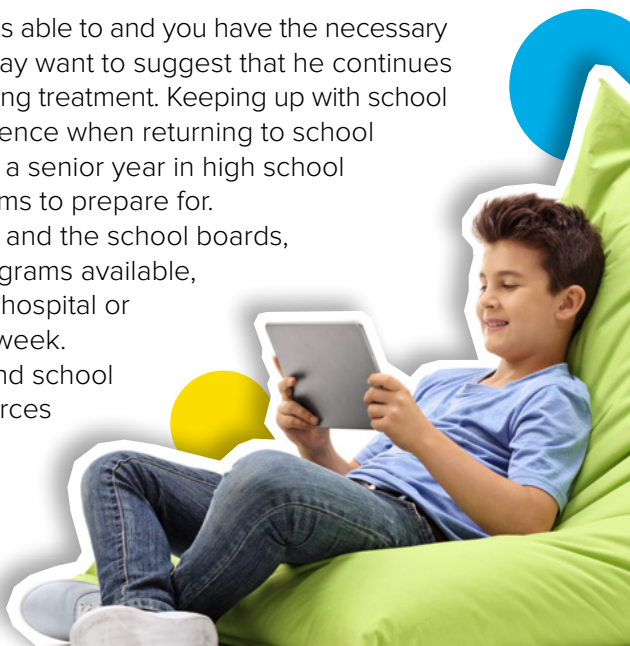
Keep in touch with school friends through letters, emails or text messages;

Ask the teacher to call the child to get updates, send notes or visit;

Exchange drawings or crafts (for younger children).



If you sense that your child is able to and you have the necessary resources available, you may want to suggest that he continues to study a few subjects during treatment. Keeping up with school work can make a big difference when returning to school especially if your child is in a senior year in high school as there are provincial exams to prepare for. Depending on the hospital and the school boards, there may be catch-up programs available, like having teachers in the hospital or at home for a few hours a week. Ask the healthcare team and school administrators about resources available for your child.





# RETURNING to school



oing back to school plays a big role in your child's journey toward recovery and deciding when to return varies from one child to another. It is recommended that kids return to school as soon as their health improves and they are medically and physically able to attend class regularly. Every child goes at her own pace though, and it is always preferable to first talk about it with her and with the healthcare team, who can offer support. They can also help you identify important milestones and steps in the transition back to school.

At first, returning to school will seem like a positive experience for kids. Children cannot wait to play with their friends and get back into a normal routine while teens look forward to regaining their independence and a certain sense of freedom. However, it is also normal for them to feel stressed and worried. Planning the transition back to school with the healthcare team and the school personnel will help make this important step go smoothly. After all, your child is finally getting her old life back and will see that life can go on.



## Be prepared, patient and realistic

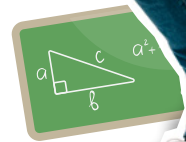
It is important to approach the transition back to school with few expectations. Some things will go back to how they were, others may not. Some steps might be easy for your child, and other steps might be challenging. Planning is the best way to prepare everyone for the transition.

You can help lower your child's stress by talking to her and explaining the steps to come. You can tell your child about the challenges she will likely face and maybe role play with her. This will prepare your child for any questions that her classmates will probably ask about the illness, the treatments, the changes in her physical appearance, the time away or even about the accommodations that have been made for her, which could make it seem like she is receiving special treatment in some way. You can also teach your child that she is under no obligation to answer questions.

It may be helpful to plan a meeting with your child and the school personnel before the official return-to-school date. It would give you the chance to talk to them about the emotional and cognitive challenges your child may face and about any physical limitations she may have. In some cases, people who do not know about leukemia might get the impression that your requests are exaggerated. If this is difficult for you, ask a family member or a LLSC employee to go with you and help explain the challenges to the school personnel and establish a long-term success plan.

## Emotional challenges

Even though your child is regaining some sense of normalcy, there is a possibility that she will not feel the same as before. Her appearance may have changed (weight loss or gain, hair loss, etc.) and these physical and psychological changes can cause anxiety and low self-esteem. During the first two or three weeks back at school, she might experience the "celebrity phenomenon," where she receives a lot of attention from the personnel and other students, which decreases over time putting her in a position to have to relearn her identity in school. This transition of status can cause a child to feel insecure, as she tries to redefine herself. Some friends might have to readjust as well, even going so far




as questioning her illness and teasing or ignoring her. To help the transition go smoothly, look for changes in your child's demeanor and keep an open communication with her.

Even though your child's health has gotten much better, she might be afraid that it will deteriorate again. For kids who are getting their lives back to normal, the fear of a relapse can cause a lot of anxiety. To address this, you can reassure your child that going back to school and other factors such as tiredness and physical activity will not increase the chances of a relapse. In addition, it is important to let her know that the risk of childhood leukemia recurring is slim.

## Physical challenges

During your child's reintegration, it is possible that she will still be taking medications that can cause side effects, which will have to be taken into account. It is crucial that you explain this to the school team so that necessary steps can be made to accommodate your child's needs and ensure her comfort. For example, if your child has lost some or all of her hair, she should be allowed to wear a hat throughout the day. If she experiences dry mouth, she should be allowed to carry a water bottle at all times and, consequently, be allowed to go to the bathroom as often as needed. Your child might also need to eat at



regular intervals during the day. If that is the case, make sure that she is allowed to eat snacks more frequently.

Even though your child is back at school, it is possible that she will still experience fatigue. The school team should be aware of this and respect her pace. If your child is still physically weak, you could ask a friend to carry her backpack or help them get around. When it comes to physical activities, she may have to wear a central catheter as part of her maintenance treatment, which will prevent her from participating in some activities or require special aids to take part. If your child is still physically weak, she should be careful. Physical activity is an important factor in your child's well-being. She should be able to participate in most activities so long as they are adapted to her condition.

While your child is in recovery, she will still have a weakened immune system. Take the necessary precautions to protect her from contagious illnesses and infection by asking her to wear a face mask or keep her home from time to time if you feel it is needed. You may be more concerned about her health than before and decide to keep her home for as long as possible to keep her safe. While that is a normal reaction as a loving parent, delaying her return

can make her transition back to school more difficult. Returning to school is an important part of her physical, cognitive and social development.

## Cognitive challenges

Treatments for leukemia can have effects that will affect your child's academic performance. Some of these effects might be temporary and disappear with time, others might be permanent and require changes to suit her needs. She might have concentration, attention or memory issues. Some kids with leukemia report having a hard time analyzing and structuring their thoughts when they go back to school. A neuro-cognitive assessment could provide more insight into your child's abilities. Talk to your healthcare team if that is something you want to look into.

For a teenager or young adult, it is more likely that she will compare herself to her previous self when she returns to school, remembering her former academic abilities. Realizing how things have changed can cause a degree of anxiety. With the help of teachers, you can ease her transition by planning her integration back to school in stages and giving her a lighter work load. With the school team, assess which scenario is more likely to help your child succeed. It could be a matter of giving her more time to hand in assignments, not giving her any homework at first, pushing back an exam or switching courses with equivalent alternatives. Your child could potentially participate in extracurricular activities to help with her reintegration.







# Planning **A RETURN** to **“NORMAL”** life

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ven though your child’s life is returning to normal, he has still gone through a series of stressful challenges that have taken a toll on him. It may take him a long time to adjust to the physical, emotional and cognitive effects of the treatments once he returns to school. You can support your child by being prepared, positive and realistic. Respect his pace and maintain open communication with him, the school personnel and the healthcare team. Together, you will find solutions to help him regain self-esteem and confidence. Your child can draw on the courage and determination he has shown in fighting leukemia when transitioning back to school.



