



# Heart-filled Hope Stories...

#### AS TOLD BY

Geneviève, 17, sister; Ariane, 14, sister; Catherine, 17, diagnosed; Marilyne, 14, sister; Geodner 14, diagnosed; Laurent-Olivier, 19, diagnosed; Émily, 17, sister; Marie-Michelle, 13, diagnosed; Mike, 19, diagnosed; Christine, 19, diagnosed; Louis-François, 15, diagnosed; Gabriel F., 17, diagnosed; Laurent, 18, diagnosed; Patrick, 25, brother; Valérie, 16, sister; Olivier, 24, brother; Félix-Antoine, 15, diagnosed; Francis, 15, diagnosed; Maxim, 14, brother; Vanessa R., 15, sister; Karl, 13, brother; Delphine, 15, sister; Maxime, 20, brother; Gabriel R., 15, diagnosed; Pascale, 12, diagnosed; Jean-Louis, 16, brother; Marika, 15, diagnosed; Marie-Hélène, 22, diagnosed; Sébastien, 20, diagnosed; Carolane, 13, diagnosed; Joannie, 16, diagnosed; Catherine, 25, sister; Marc-André, 17, diagnosed; Vanessa D., 15, sister;

drawings by Cassandra Carola, 15, sister.

ILLUSTRATIONS



MESSAGE FROM OUR EXECUTIVE DIRECTOR

## MICHEL NADEAU

I have been at Leucan since 2006, first as a volunteer and now as Executive Director. I have the deepest admiration for the courageous teenagers of the Heart-filled Hope support group, who give of their time and energy to help those struggling with the same challenges they face.

This collection is an integral part of who they are. They have poured their hearts in this project to offer both support and hope. These teenagers are our future, and I am proud to work alongside them.



PREFACE

## PATRICK GROULX

Dear friend,

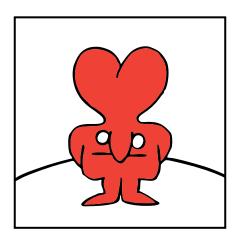
This collection is made of messages of hope from young people aged 12 to 18. A few years ago, they were struck by illness, just like you, and they came up with this great idea to write a few words of encouragement to give you strength.

Strong and courageous teenagers just like you have fought and won their battle against illness. I have met with those brave little soldiers a few times. I was moved by the courage and determination of these hundreds of heroes. Many of them have won over cancer!

The news you have just heard was probably difficult to accept. But you are not alone. You are surrounded by extraordinary, professional and highly competent people who will do their very best to get you through this journey.

Remember one thing: you can get through this. So many youngsters were able to heal. It will not be easy but you must believe in yourself. You must fight and win!

You are in my heart.



# My family and friends

## What I expect from my parents

During my illness, I needed to spend time with my parents; I needed them with me, telling me that they loved me. I needed them to explain what was happening to my brother. I wanted to be included in the process and not feel neglected. I also felt the need to prove myself to my parents by doing well in school or in sports. I also needed my parents to allow me to share privileged moments with my brother. I needed them to trust me. I especially needed for us to remain a united family.

Catherine, 25, sister

I feel my parents were most necessary when I needed to know about my brother's health.

Jean-Louis, 16, brother

I have always needed my parents; from the time I was born until my  $14^{\rm th}$  birthday but to get through this ordeal, I needed them even more. I would have loved to see them more frequently for I often felt alone. I know very well that they were doing everything they could, that they were spending all their energy at the hospital and at work but still, their absence left a big emptiness in my heart during this time. They were doing their utmost at the hospital, both day and night, and all of that on top of work! But I was alone, with nobody to support me; with nobody to give me the love lacking in my life. I do not blame them as this was a difficult ordeal for everyone. I wish I could erase the memory of this period of my life.

Marilyne, 14, sister

I need my parents when I face problems at school or with my friends.

Marika, 15, diagnosed

Even though I understood what was happening, I wish I could have enjoyed normal meals with both my parents at the dinner table. It was a miracle when all seats were taken. My mother was often with my sister at the hospital, and I wished she had been home to kiss me goodnight or to talk with me about this and that. I would have needed my parents to simply spend time with me. Our lives were upside down, and I wished they had reassured me and told me that everything would be OK, even if it was not exactly the truth, only to give me the illusion that everything would get back to normal.

Geneviève, 17, sister

If I need to cry or confide in someone, they are always there. I could even go as far as to say that they are my best friends.

Marie-Michelle, 13, diagnosed

They continually play an essential role. They never judge me. They are so important to me. I could never thank them enough for supporting me. They are together and I hope they will stay together forever. I love them so much. I am convinced that they adore me. They must be really strong to love me this much. I will be eternally grateful for their love.

Laurent-Olivier, 19, diagnosed

I need my parents when I am alone, when I am afraid and when I need someone to listen to me.

Geodner, 14, diagnosed

I might have liked them to take better care of themselves but most of the time, I was happy when my father was with me. I felt that they truly respected me.

Sébastien, 20, diagnosed

In short, I wish they would worry less about me. I know they worry because they care but I know what I am doing.

Mike, 19, diagnosed

I wish they were not always with me so that they could spend time with my sisters too.

Geodner, 14, diagnosed

My father quit his job to be with me during my treatments. His girlfriend would often visit me at night to support me. Sometimes, at night, their presence felt a bit intrusive. I am a very independent person, and I think they wanted to constantly give a little more... but there were times when I wanted to be left alone with my thoughts.

Sébastien, 20, diagnosed

I especially needed my parents during treatments because I needed to clear my head and have a little fun. My father now works in Montreal, and when it comes to my health, he stays with me, which really touches me.

Carolane, 13, diagnosed

I still need my parents... even at 22. I am a big girl but when my heart aches, I need to be surrounded by those I love: my family. My family has always been there for me and I feel very lucky to have them. Thank you!

Marie-Hélène, 22, diagnosed

I need my parents in my everyday life. We need our parents the most when we face difficult things like a disease. They do the best that they can but it is not always easy to be there for us.

Ariane, 14, sister

## What I would like them to do

I wish my parents were more there for me but I know they have to also take care of my brother. I wish they would get some rest and just relax but it is not really possible right now because they need to be there for my brother and me. I wish I could lift the weight off their shoulders. I know they are strong and courageous but I also know they are human and have moments of weakness. This is a difficult situation for them too.

Ariane, 14, sister

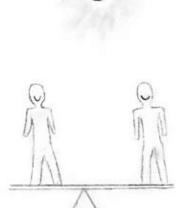
I would like them to respect my need to not talk about it. I have a tendency to deal with my emotions by myself, and I wish they could understand that I do not always want to talk about it.

Émily, 17, sister

I wish my friends would finally understand that I am just like everybody else and that I do not have any mental or health problems. However, with my family, everything was OK.

Carolane, 13, diagnosed

What is the biggest challenge when dealing with my siblings?



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I find it difficult to see my siblings getting less attention. During my illness, I felt spoiled and I did not want all this attention. I wanted to be normal, and I wanted my sister and brother to get the same privileges I got. I hope one day they will forgive me for all the space that I took...

Marie-Hélène, 22, diagnosed

It is very difficult for me to talk about my cancer with my sister... both for me and for her. We are pretty uncomfortable with the topic. When someone talks about it, we just switch topics.

Carolane, 13, diagnosed

I wish we were closer.

Louis-François, 15, diagnosed

I felt like I was monopolizing all the attention. My sister did not live with us so it was not that bad. But still I felt like I was taking this huge space in my home and that there was only a little space left for my brother. I felt especially bad because my brother was entering his teenage years. But he was very mature: I saw him grow up fast. He was very attentive towards me, and very helpful to my parents. If he felt rejected, he did not show it. I did not see my sister much, and it was difficult because I missed her. She did her part and that was amazing. She truly got involved, like when she organized a blood donor's clinic. Every member of my family helped in his or her own way and I am very grateful to them.

Christine, 19, diagnosed

It is more like a fear. I am afraid my sisters will be jealous of all the attention I have received even though I am sure they understand very well why I got all this attention. They were always there for me. I felt like I had three mothers. I love them and I thank them. I adore them and I believe that we are closer now because of all this.

Joannie, 16, diagnosed

The hardest part when it comes to Laurent is to stop thinking about a future including him. I cannot make future plans with him. I am forced to imagine a near future where my brother will be replaced by infinite emptiness. When I look in his eyes, I tell myself it does not matter how much time we have left so long as we make the most of it.

Jean-Louis, 16, brother

Since I was not living at home, there were no hard moments with my little sister. She was doing the best she could to please me. Things were more difficult with my family because they had to visit me at the hospital. At my mother's request, my grandfather took my sister in for six months. It was harder for my sister than it was for me, not because of the illness but because she needed more love.

Gabriel F., 17, diagnosed

To not find the courage to tell her how much I love her. Catherine is amazing and I want her in my life forever. She is adorable, and I get angry at myself when I think of the times when I was impatient with her. She fainted when she saw me after the surgery. When my parents told me she nearly lost consciousness, I felt a big outburst of love for her. I love you, Cathou!

Laurent-Olivier, 19, diagnosed

From a career standpoint, my plans would have been different had it not been for these events. I am about to begin a doctoral degree in biomedical engineering. I chose that field for two reasons: one, I like doing research but mostly, I want to find new ways to prevent or cure cancer and serious diseases. I now hope to change the world, thanks to my brother.

Olivier, 24, brother

It is hard for me to see my sister with a boyfriend or going out with her friends because that is how it should be for me.

Marika, 15, diagnosed

It was hard to not be able to see my brother. It was sad to see what he was enduring. People often tell him he is courageous but he always replies that he has no choice. But I still find him courageous. He remained hopeful that things would look up. It is not always easy to have all this attention focussed on him.

Ariane, 14, sister

During treatment, the hardest part was to visit my brother at the hospital. Going through exams and school and not having a car made it more difficult for me. After the treatments, it was difficult to accept the distance my brother was putting between us.

Patrick, 25, brother

My brother was diagnosed two years before I was so my parents knew what they had to deal with. It made things easier in a way but having to deal with a second cancer was hard for my family. I made a big deal out of hiding moments when I was not feeling so well so as to not affect them. They were always there. I could always count on them, whether it was for a car ride or for my many appointments at the hospital.

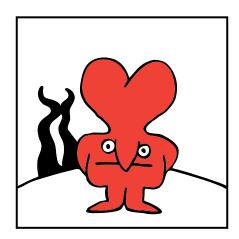
Laurent, 18, diagnosed

The hardest part was to accept my sister's disease, especially during her treatment when she had lost her hair and was exhausted. She could not do what she wanted to do but because I knew it was temporary, it made things easier for me. It never occurred to me that she could die, and that made it a lot easier.

Valérie, 16, sister

It was difficult for my grades. I did not understand how I, who was attending school every day, doing my homework, and listening to my teachers, was getting lower grades than my sister did. She was falling behind at school and in her studies because she spent a lot of time at the hospital to get her treatments. But she was getting better grades, and that was the hardest part for me.

Geneviève, 17, sister



# The illness

## How I found out

It happened in Holland, in the Netherlands. I was visiting some childhood friends I had met when we lived there because of my father's job. I was over at their house and we were wrestling when... Crack! One bad move, and my leg was broken. I was taken to the hospital where I was told it was a simple fracture. I called my father to tell him about it. Two weeks later I was flying back home. I went to the hospital rapidly but had to go back every two weeks to take more radiography. It took seven doctors and two radiologists to finally get to the diagnosis of cancer. It happened in a small and very dark room. And all of this from an ordinary fracture and a very painful leg. I could not believe it. Why me?

Francis, 15, diagnosed

I was only four years old. I remember my sister going through a battery of tests to find out she had cancer. She had surgery when she was three or four years old and I was waiting at home. My father explained it to me but I did not really understand.

Vanessa R., 15, sister

I went to Sainte-Justine with my mother, my brother and my godmother. I entered the doctor's office and, leaning against the examining table was my soon-to-be nurse, Claude. The doctor spoke in technical terms and when he told me the news, I felt this huge emptiness inside of me.

Félix-Antoine, 15, diagnosed

My brother had bumps on his belly and our family doctor sent us to Sainte-Justine Hospital for a more thorough examination. When we got back home, my father burst into tears, and I knew immediately how bad it was. It was the first time I saw my father cry. I was eight years old. My brother Marc-André, who was five years old at the time, had leukemia. I loved him more than anything in the world. With the innocence of youth, I wished the disease had struck me.

Maxime, 20, brother

I had sudden bouts of vomiting. I thought it was due to stress because of my ski competitions but the doctor told me I had cancer: a tumour the size of a golf ball in my brain.

Laurent-Olivier, 19, diagnosed

I was 10 years old when I heard my brother got sick. On the way home from school, I learned my brother was at the polyclinic with a huge bump on his knee. He was transferred to Sainte-Justine in the evening and we still did not know what was wrong with him. I only learned later that night that my brother would not be sleeping at home: he had cancer.

## Olivier, 24, brother

I was spending the weekend at the cottage with my father. During that time, my mother was at the hospital with my sister where they were told she had cancer. When my father and I got back home, my mother was crying and she told my father the news. They explained it to me then but a seven-year-old could not truly understand.

## Émily, 17, sister

My sister had been sick with the flu for a month and my mother was giving her antibiotics but it was not helping. My mother suspected leukemia. My parents took my sister to the hospital where she was diagnosed with leukemia. My father stayed with my sister at the hospital while my mother came back home to explain the situation to my two brothers and me.

## Delphine, 15, sister

My nurse told me the news but it did not sink in. I did not want to hear it...

Marie-Michelle, 13, diagnosed

My sister felt pain in her legs so my mother took her to see a pediatrician but he did not detect anything. Still the pain persisted. So my whole family went to Sainte-Justine and after some tests, she was diagnosed with acute lymphoblastic leukemia. Afterwards, my mother and I went back home while my father stayed with my sister at the hospital.

#### Marilyne, 14, sister

My sister's eyes were always watery and she was constantly blowing her nose. We thought she had allergies. Catherine later noticed one of her right molars was much lower than her other teeth. She could not even close her mouth anymore. My family went to see mouth specialists, and they thought she had a gumboil. Then my parents took her to Sainte-Justine where they took a sample tissue from her cheek. We knew it was flesh as there was blood. So she underwent a battery of tests and was diagnosed with a malign tumour in her cheek. My mother called me at home. I was all alone. She told me she had to stay at the hospital because Catherine had cancer. She asked my father and me to pack up two suitcases for them as they would spend the night at the hospital.

#### Geneviève, 17, sister

I heard the news after a blood sample. I was waiting in a room with my mother when the doctor came in to tell me I had cancer and an 80% chance of survival. My type of cancer is leukemia.

Geodner, 14, diagnosed

I was feeling increasingly weaker over the course of a few weeks but I acted as thought nothing was wrong. My friends asked me why I felt this way. I asked them not to say anything to my parents so they would not worry. One night, the pain was unbearable. I went to the Granby Hospital from where I was transferred to Sainte-Justine. Five days later, I was told I had leukemia.

#### Mike, 19, diagnosed

After several appointments with my family doctor, I got an appointment at Sainte-Justine Hospital a few months later, in the Vidéotron ward. When you are 15, you do not know it is the oncology ward. When I passed through the ward's two doors, I had a feeling something was wrong. I saw all the different-looking kids and wondered if I would be next. If not, why was I here? After a long wait with my parents, I was called in an office and from that point on, my whole life changed. It was in August of 1998.

## Marie-Hélène, 22, diagnosed

I was neither stressed nor sad, because not every 11-year-old understands the gravity of this kind of situation. My brother was in a lot of pain during his soccer games, his favourite sport. We did not know what to do: he was no longer sleeping. We went to the hospital but he was not examined. When his leg became completely infected, we took him to Sainte-Justine where he was immediately diagnosed. My mother told me the news and that is when our whole story began.

Karl, 13, brother

What was my first reaction?

Cassandra Carola, 15, sister

My first reaction was, like I said, "Why me? Why not someone else? Why is this happening to me, a young boy who is doing very well and is having a lot of fun?" I did not cry at first but my mother did. She knew what it was. My cousin had had the same disease. I got depressed and weaker.

Francis, 15, diagnosed

I refused to believe it and I did not want to talk to anybody. I wanted to be left alone...

Marie-Michelle, 13, diagnosed

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It was in December 2001; I was 11. I had a bump as big as an egg on my neck. Since I had no other symptoms linked to this swollen gland, a cytology test was performed by an ORL. When the results came in, I was told there were 9 chances in 10 it was cancer but a biopsy would have to be done to be certain. After the surgery, the diagnosis of cancer was confirmed: big cell non-Hodgkin's lymphoma. The doctor told me the news. I cried at first because I did not know what it was. But I felt reassured later on when I realized I was in good hands.

Louis-François, 15, diagnosed

That is it: I will die. It is over. All the beautiful things I have lived so far are just going to be erased, and all I have yet to experience, I will never get to live.

Félix-Antoine, 15, diagnosed

I had many frustrations. I wanted to visit him at the hospital but I had to go to school, and that caused a mental block for me: something I had never experienced before. I took a big leap in the future, and I told myself everything would be all right.

Karl, 13, brother

I was furious. I wanted to break everything in the hospital room. I did not understand why it was happening to me when I was in better health than other people.

Mike, 19, diagnosed

Acute lymphoblastic leukemia? What? The doctor is talking to me but I cannot understand the words he speaks. So many things are going through my mind anyway. I will lose my hair; I will not see my friends anymore because my nights will be spent at the hospital... And for how long? I will not be able to go to the shows I had planned to attend, and to school. I see my parents crying and that makes me even sadder. I hyperventilate. The doctor suggests I get out of the room because I have probably heard enough for the moment. Indeed I need a breather. I get out of the room and Lucie, the nurse, comes up to console me and to help me understand what is happening.

## Christine, 19, diagnosed

Since I was just eight years old, I could not understand. Idid not know what leukemia was. When I understood what it meant, I went through the whole range of emotions. I was sad and angry at the same time. We always believe it only happens to other people and that it cannot reach our family. The whole procedure was explained to me: chemotherapy, hair loss, and remission but you must remember things do not always go as planned.

#### Ariane, 14, sister

When I learned the seriousness of the news, I became withdrawn and wanted to rebel. I did not want to talk to anybody, I would not pay attention in class, and I did not care about anything: all I could think about was, why him? How could such a nice and honest boy be struck by this disgusting disease? I was submerged by dozens of questions no-one could answer.

Maxime, 20, brother

When I heard I had cancer, I immediately burst into tears. But my sadness was not caused by the disease. Having to cancel the trip we had planned the previous fall was the hardest part. We were supposed to go to Florida, and I had dreamed about it the whole year. I was crying like a baby in my mother's arms, convinced my sister would resent me for the cancellation of our trip. That was my biggest fear at that moment.

## Catherine, 17, diagnosed

I did not understand at the time. The doctor used medical terms I did not understand.

## Gabriel R., 15, diagnosed

The words sadness and denial explain my reaction the best. At the age of 10, cancer is automatically linked to death. For that reason, I was taken over by sadness and I could not accept that my brother might die. I went through denial at school. I did not study normally, I was only going through the motions. I do not even know how I passed the fourth grade.

#### Olivier, 24, brother

My first reaction was to look at my parents in the doctor's office. They were both crying and I did not know how to react. In my mind, cancer was an old people's disease, and I could not have it. So I ignored it until my first chemotherapy treatment at the hospital. I had asked to be left alone to lie down, and that is when I realized I was sick and I had to undergo some treatments to heal.

Marie-Hélène, 22, diagnosed

I was more or less conscious of it at first. But then, I noticed neither Catherine nor my mother were at home. I was convinced Catherine would die. I was often in tears. Later on I was sad because we had to cancel our two-week trip to Florida. We were really looking forward to it. And then school started and everything went back to normal. She started radiotherapy and did not go to school at all. We were no longer visiting her at the hospital at night, like we did during the summer, because I had to study and do my homework. I knew everything was going well. At the same time, I was happy to have the bedroom all to myself. I had peace and quiet; two things I never had when we shared our room because she snored and the tube feeding machine made a lot of noise.

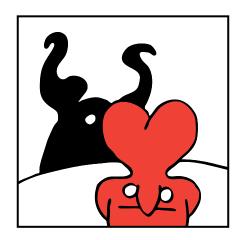
#### Geneviève, 17, sister

I was very sad, and I did not want to accept the fact that my sister was in danger. I was always close to her, attempting to protect her. I wished I could have taken her place, all through her treatments, and even today. I was completely revolted by the fact that she was so sick at the age of two.

#### Delphine, 15, sister

I think I did not really realize what her disease implied or the resulting consequences. I was too young. All I could see around me were sad people, as well as pity and compassion. Maybe I understood some of it but I did not want to believe it. Why was this happening to our family?

Marilyne, 14, sister



# My relationships

I am happy to still be able to have strong feelings for a girl. It is nice to be able to feel love for someone I did not know before I got cancer.

Laurent-Olivier, 19, diagnosed

I had been together with my boyfriend for barely two weeks when I got hospitalized at Sainte-Justine. We had not gotten to know each other very well before we became involved. We remained a couple for a few months until we eventually broke up. Being sick and in the hospital does not really help you in getting to

know someone. He was not ready to get involved in this kind of relationship, and I had other things on my mind. We kept in touch though and stayed friends.

Christine, 19, diagnosed

# What were my friends or my boyfriend/girlfriend's reaction?

I was 12 when my brother relapsed. My friend Véronique was amazing. She really supported me. I knew I could confide in her. She read a lot on cancer so she would know the whole process. I want to thank her for being there for me during those difficult times. She found the right words to comfort me.

Ariane, 14, sister

When I heard about my sister's illness, I talked about it with my close friends. They were really supportive without being overbearing.

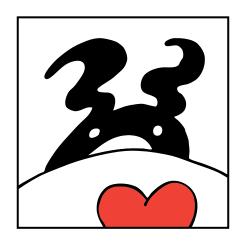
Delphine, 15, sister

Some friends felt sorry for me but my true friends formed a tight unit around me and helped me through those difficult times.

Jean-Louis, 16, brother

A few acquaintances took a step back but my true friends, those you can count on one hand, stayed. They gave me a lot of support and that truly helped.

Maxime, 20, brother



# My fears

One of my greatest fears is to forget some memories of my brother. To forget his face, the way he acted or the sound of his voice. Another fear I have is that this cancer is genetic and that the children I will have one day could get sick. I am afraid to go through this again but as a parent.

Olivier, 24, brother

I have no fear, I think, for I already came to terms with death. My only fear is to leave my family behind...

Marie-Michelle, 13, diagnosed

I am afraid of the future. I am worried I will never get married. I am afraid to give birth to sick children. That would make me feel forever guilty.

Marika, 15, diagnosed

I am not afraid to die: we will all die one day. My fear is to have worked so hard during all those years for nothing, as if it were a failure. Each recurrence is like a slap in the face. I think I will always be scared to get sick because I love life and I have so many projects. I am afraid to relapse for it would mean having to postpone or cancel projects that are important to me. I believe this fear will be there my whole life, every time I go for an examination.

Marie-Hélène, 22, diagnosed

When my treatments began, I was scared to die. But the fear faded away as time went by. I get a medical check-up every three months, and before each exam, I worry the results may be positive for cancer.

Gabriel R., 15, diagnosed

I am afraid to lose or to see the people I love suffer because of me. I could never forgive myself for certain things. Losing a loved one is one of those things. I am worried I will not be able to fully live my life.

Laurent-Olivier, 19, diagnosed

Like any other cancer patient, I am afraid to relapse or to get a weird reaction in my body but, as my mother would say, "we will cross the bridge when we come to it". The meaning of that saying is pretty simple: live your life, do not focus on "bad stuff" and bad stuff will not happen to you. But I am worried my family will get cancer.

Carolane, 13, diagnosed

My greatest fear becomes true every day: to be powerless and to forget my brother regardless of all the wonderful times we shared.

Jean-Louis, 16, brother

My greatest fear was to be rejected and judged because I was different. Also, I was scared to be rejected because I represent a lot of work. People's reaction meant a great deal to me. I did not want to be mocked. As far as treatments, I was worried chemotherapy would hurt or be ineffective, and that I would go through all of it for nothing. I was also scared to die.

Catherine, 17, diagnosed



Cassandra Carola, 15, sister

I was afraid to die. I was afraid of cancer. I was afraid of the unknown. Today, I am no longer afraid of any of these things. I feel lucky to have confronted these fears because I am now aware of how vulnerable human beings are, even if it does not always show. Once I survived cancer, I no longer worried about death but I was scared to live because life is full of the unexpected.

Félix-Antoine, 15, diagnosed

I was afraid to die and to suffer during my treatments.

Pascale, 12, diagnosed

I am afraid that a friend or a member of my family will have to go through the same treatments. I know it is very difficult and I do not wish it on anybody. I am also scared of headaches since headaches led to my diagnosis.

Sébastien, 20, diagnosed

My only fear when it comes to my disease is the thought of Leucan disappearing. It is the only place where I feel fully accepted. More generally, I am afraid to have regrets, and that is what drives me to do things other people refuse to do.

Louis-François, 15, diagnosed

Losing a loved-one.

Vanessa D., 15, sister

I am afraid to die. I am afraid to suffer. I am afraid of recurrence. That would mean starting all over again.

Ariane, 14, sister

The only time I got really scared was when I got out of an abdominal surgery that required epidural anaesthesia. I was paralysed for two days. To simply lose all control over my legs and to see what would happen if I got permanently paralysed and was limited in my movements was the only thing that truly scared me.

Laurent, 18, diagnosed

I am afraid to learn I have cancer. Now that I have seen all that she has been through, I would not want to have it. Whether we like or not, a cancer patient fights his or her battle alone. Even though friends and family are there to help, to encourage you and to hope with you, you are still alone. They cannot take on the pain you endure. You must get through cancer alone. You confront it alone even if there are people around you... And that really scares me.

Geneviève, 17, sister

Throughout his illness, I was afraid my brother would die. And now that he is gone, I am afraid to forget him. I need to feed off my memories of him, and to remember him as he was and not the way I imagine him right now. I want him engraved in my memory. I am also worried diseases will claim other people close to me. Knowing what my parents went through, right now, I worry about giving birth to an unhealthy child. Though those fears haunt me, at the same time, I have to admit they also make me wiser.

Catherine, 25, sister

Suffering scares me, not only my own suffering but that of other people. Every time I take part in an activity at Leucan, I am afraid to find out that a friend suffered a recurrence or that treatments are not going as well as they should. Even worse, I am afraid one will pass away. Through Leucan, I have made the best but also the most painful friendships. Not everybody can get through it.

Émily, 17, sister

My biggest fear would be for someone close to me to get cancer and for that cancer to be more aggressive than the one my sister had. My second fear is to get cancer myself. I cannot imagine it. I do not know if I am strong enough to win over it and to overcome all the obstacles and consequences that come with cancer. My biggest fear is mostly the fear of losing someone. I do not know how I would come to terms with the death of a loved one. I do not know if I could get through it.

Valérie, 16, sister

My fear is better described as a big concern. Since my sister was diagnosed after a flu that would not go away, every time she gets a little cold or she hurts herself a little or suffers in any way, I worry. I frequently worry she might relapse even though she is almost completely healed. I will always have this great concern about my dear little sister's health.

Delphine, 15, sister

I have met lots of people at the hospital. Unfortunately, many of them have passed away due to illness. As such, for a while, I would not speak to anyone at the hospital because I had gone through too much sadness. I have also met people who have suffered a recurrence, which really scared me. However, I have come to realize that most people do survive, and I was able to find faith again.

Christine, 19, diagnosed



# School

# How do I get by at school?

I stayed in school through it all. It was like my little break when I was sick. I have also worked with a private tutor. I was lucky because I never had to repeat a grade. Most teachers were very understanding. Most understand that I often have to miss class but there will always be exceptions. But every year, I will have to explain what I have been through.

Joannie, 16, diagnosed

A teacher was coming home to help me complete the sixth grade. She was very nice and respectful of my learning pace. She became a friend because not only did she teach but she also listened to what I had to say.

Geodner, 14, diagnosed

I experienced illness at school in three stages: high school, college and university. Things went well in high school: I had private tutoring to complete the  $11^{th}$  and  $12^{th}$  grade and I attended school to have a social life, which I really needed. The school personnel was fantastic, and really supported me. Things were different in college and at university. It took me four years to complete my college degree and it was hard to see my friends move on to university. But I stayed in school because it made me feel like a regular student. Since I want to be a teacher, I know school is important.

Marie-Hélène, 22, diagnosed

I had a very aggressive lymphoma but it was easily treatable so my treatments lasted only three months. I did not miss too many days at school.

Louis-François, 15, diagnosed

I was diagnosed on May 9, 2003, during my last year of high school. Since my grades were good, the school agreed to give me average marks for all my classes so I would graduate. The school even gave me a yearbook and had students sign a card addressed to me. Furthermore, my French teacher took the time to write me a letter of encouragement, which really pleased me.

Christine, 19, diagnosed

It is very difficult. I am currently in a natural science program in college and it entails a lot of work. But since I am much more tired at night than the average student, it is more difficult for me to study.

Sébastien, 20, diagnosed

I have two teachers: one for mathematics and one for French. My mother helps me with English and the other main subjects.

Marie-Michelle, 13, diagnosed

My parents were available to help me with school so everything went well but I did have private teachers.

Marika, 15, diagnosed

I have tried to get organized as best as I could even though I repeated a year. I took classes with private teachers at the hospital and at home. I am telling you, even if you are just a little sick, do not neglect your studies because in the long run, you will get behind. I know what that is like, trust me. Obviously, it is difficult to deal with school and illness at the same time but if you have to undergo treatments, think about what is best: doing a lot of work or fall behind?

Francis, 15, diagnosed

I decided not to complete the fifth grade because I had no time for school. When you are sick and you spend most of your time at the hospital, your head must be in one place. So I decided to complete my grade the next year. It is hard to concentrate when you are sick.

Gabriel F., 17, diagnosed

## How my friends heard about it

My close friends heard it from me when classmates were informed at school through my sixth grade teacher. Most of them took it well, and everybody sympathized with me. So much so that on my birthday, the whole class walked to the hospital to sing "happy birthday" and give me gifts. That is a really great memory.

Louis-François, 15, diagnosed

I told my closest friends. My relationships with them were so important that it was critical for me to keep them informed. They deserved to know. I am really glad I did it.

Laurent-Olivier, 19, diagnosed

A friend called to invite me to play outside. Afterwards, I told him about my cancer. At first he thought it was an excuse not to play with him but he believed it after my many absences of school. He then told my other friends.

Geodner, 14, diagnosed

My first friend to know (Vincent) was also the first to know I was cured. But most of the time, when I talk about it, I explain all I have been through. They can ask as many questions as they wish because it is important for them to understand. Most of your friends will want to help and to take a large chunk of responsibilities to help you out.

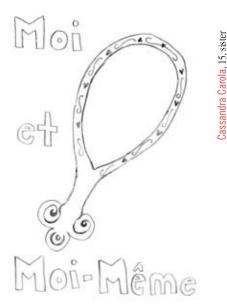
Joannie, 16, diagnosed

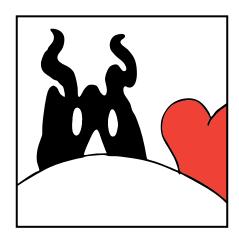
I told them when I was ready.

Félix-Antoine, 15, diagnosed

I realized I had better friends than I thought I did. They were deeply touched. They often came to see me at the hospital, and I really appreciated it. I had a visitor nearly every day. They gave me their full support. Some of my friends are in a band and they wrote a song for me. I was so moved. They really showed how much they loved me and that they were really with me through it all.

Christine, 19, diagnosed





# My treatments

What kind of treatments do I receive?

To cure my cancer, I had both chemotherapy and radiotherapy. As part of a special study case, I was following a research protocol over two weeks. I could not undergo surgery because there was a risk of disfiguration. My tumour was compared to a spider web weaved in a tree. I could have had surgery but parts of the tumour would remain, and so it was of no use.

Catherine, 17, diagnosed

I underwent six weeks of radiotherapy followed by 11 months of chemotherapy.

Sébastien, 20, diagnosed

I had a 12-hour brain surgery followed by 31 radiotherapy treatments. I had chemotherapy during 48 weeks.

Laurent-Olivier, 19, diagnosed

I had chemotherapy and radiotherapy.

Marika, 15, diagnosed

I had dose-intense chemotherapy, which means a two-year treatment administered in one year. I underwent other kinds of chemotherapy followed by radiotherapy. That part is the easiest but also the longest.

Gabriel F., 17, diagnosed

During the first year, I went through six chemotherapy cycles. I had groin surgery and an incision was made to remove my left kidney. Then a portacath was installed and I underwent three lung surgeries in one month. Finally, I had a bone marrow transplant, which lasted three weeks. Now, I am going through radiotherapy treatments and I will take chemotherapy pills at home.

Laurent, 18, diagnosed

I had chemotherapy every week: vincristine and actinomycin.

Félix-Antoine, 15, diagnosed

I went through chemotherapy and a surgery to replace a 27-cm part of my femur by an internal prosthesis.

Gabriel R., 15, diagnosed

I had radiotherapy and chemotherapy treatments: 10 days of radiotherapy and little more than two years of chemotherapy. And a pick-line had to be installed.

Christine, 19, diagnosed

A biopsy was performed to check if I had cancer. Once the cancer was confirmed, I had very intensive chemotherapy treatments as well as lumbar punctures. There were many side effects: nausea, stomach aches, migraines, bone pain, tingling at my fingertips, back aches, and hair loss. During the lumbar punctures, I took sleeping medications, and when I woke up, I was in another world.

Louis-François, 15, diagnosed

I went through chemotherapy and radiotherapy. I also had a bone marrow transplant through medullary cord.

Marc-André, 17, diagnosed

I had chemotherapy treatments. I am currently getting alternative treatments: acupuncture and osteopathy.

Marie-Michelle, 13, diagnosed

## How I feel

During my treatments, I felt physically sick but I kept my spirits up thanks to all the people around me: my family, Leucan, my friends, people at Sainte-Justine, my teachers, my loved-ones... I had to miss school sometimes and I was looking forward to go back to see my friends again. But I tried to stay in good spirits.

Louis-François, 15, diagnosed

I feel strange. I no longer have balance. I practically feel like vomiting all the time. It feels like my soul is floating around, out of my body.

Laurent-Olivier, 19, diagnosed

I felt really tired but my morale was very good in general. My family and friends were always there to encourage me. Of course, since I was weaker, I did not feel like going out. Sometimes times seemed to stand still, and I missed the good old days when I would go out late to party. However, I found many hobbies to entertain myself.

Christine, 19, diagnosed

Since visitors were rare, every one of them was much appreciated. I would spend many hours playing Nintendo games with my brother. The hardest times were during his chemotherapy treatment. I sometimes felt like a protector, there to comfort my brother as best as I could

Patrick, 25, brother

I felt happy at times, and angry at other times.

Gabriel R., 15, diagnosed

Ifelt very bad during treatment, and I felt good at other times. Good can come out of all the bad times!

Gabriel F., 17, diagnosed

It made me feel good to be able to go with her, and I was happy to see her. I really missed her while she was hospitalized for a month. Afterwards, I think I went to the hospital with her every week so she would not feel too lonely.

Delphine, 15, sister

I think many people do not realize that sick people are like everyone else but it is cool at the hospital because I always have something to do. I could tell that my brother appreciated my visits. I also enjoyed the activities in the playroom.

Karl, 13, brother

I did not know what the point was, and it was taking such a long time.

Marika, 15, diagnosed

Truthfully, I felt terribly exhausted because the treatments are aggressive and every year, my body gets wearier. But I believe I will survive, and I have to get through these difficult times.

Marie-Hélène, 22, diagnosed

I did not want to go at first but I have made friends at the hospital, which motivated me to go back again.

Félix-Antoine, 15, diagnosed

## What were the side effects that I experienced?

Chemotherapy provoked minimal side effects. My cheeks and stomach ached, and I had constipation and diarrhea but I never felt nauseated. When my radiotherapy treatment started, it took a turn for the worse. I had tons of ulcers in my mouth and I could not eat anymore. I was tube-fed. I would be easily worn out. I even vomited and felt nauseated. But my cheeks were not hurting as much. Because of my tumour, my nose was constantly stuffed up and my throat was dry.

Catherine, 17, diagnosed

The side effects were: stomach ache, headaches, memory loss, muscle ache, stomach and mouth ulcers, diarrhea, vomiting, loss of appetite or constantly feeling hungry, redness of the skin, chronic pain...

Gabriel F., 17, diagnosed

I experienced zona, chemical meningitis and hair loss.

Marc-André, 17, diagnosed

When it comes to chemotherapy, the side effects were mostly nausea, vomiting and hair loss. Personally, I had a leg surgery, leg and lung biopsy, a respiratory tract infection, and a portacath. There is not much I have not experienced. On top of side effects, I also nearly died due to septic shock. I got really sick after a particular big treatment.

Francis, 15, diagnosed

Asparaginase caused the worst side effects because it enhanced the side effects of other chemotherapy treatments. Vincristine also had really bad side effects like bone ache. And let me tell you there are many bones in one body. I have also had many blackouts. I would feel dizzy, and then everything would get dark and I would fall down. Losing my hair was really hard because I had long hair. I also suffered nausea, vomiting, many ulcers, tiredness, numbness, stomach aches, and my bones got very porous and fragile. I had muscle atrophy as well.

Christine, 19, diagnosed

I experienced many side effects during treatment: vomiting, headaches, stomach aches, hair loss, and thrombosis, to name only a few. Unfortunately, side effects go hand-and-hand with treatment.

Marie-Hélène, 22, diagnosed

I suffered hair loss and nausea.

Marika, 15, diagnosed

The only side effects I experienced were soreness in my legs and vomiting. The worst was what it did to my mind. I was angry for a long time but since everything eventually comes to an end, I turned over a new leaf.

Mike, 19, diagnosed

I no longer have balance, so if I do not hold on to something, I fall. I am losing my hair due to chemotherapy, and my oesophagus hurts because of radiotherapy. Vincristine caused pain in my heels.

Laurent-Olivier, 19, diagnosed



First I have to put things in context: I really am an exception. I never had to slow down. I broke many hospitalization records and proved many statistics wrong. I was always in good spirits, and I enjoy life every day without fail. Apart from hair loss, my body coped well with everything, which accounted for my sparkling mood.

Laurent, 18, diagnosed

## Which side effects bothered me the most?

Hair loss was the worst side effect for me... I know it is only hair but between 15 and 22, every girl wishes to be pretty and noticed. But when you are bald, it changes the way people look at you and, unfortunately, this also affects your self-esteem. Boyfriends become a rarity and your teenage and young adult years are worlds apart from the dreams you once had.

Marie-Hélène, 22, diagnosed

Losing my hair was difficult as I was smack in the middle of adolescence, and my physical appearance was really important to me. Moreover, I had to take morphine to alleviate my back pains. I lost all self-esteem, which undermined my morale. I also suffered muscle atrophy. It was hard to rebuild both my muscles and my self-confidence.

Christine, 19, diagnosed

Meningitis because it was really painful.

Marc-André, 17, diagnosed

Some medications provoked vomiting and neutropenia. You are probably wondering what that is. Neutropenia occurs when your immune system plummets. VP16 caused the same side effects. Methotrexate was the only medication that had no side effects on me.

Francis, 15, diagnosed

Chemotherapy is painful, which is a problem. The treatment basically kills to give back life. I suffered from muscle and general pain because of the chemotherapy, and those were the worst side effects. There are also psychological troubles. It made me think of all sorts of things and it made me do things I had never done before. Those effects stayed with me but there are not as bad today.

Gabriel F., 17, diagnosed

Loss of balance because I cannot practice my favourite sports. Neutropenia because I can no longer go to school with my friends. I miss those things terribly but there is hope. I am completing high school from home, and one day, I will be in a regular classroom again.

Laurent-Olivier, 19, diagnosed

My most bothersome side effect was constipation. It would hurt so much I was terrorized at the idea of going to the bathroom. I would burst into tears simply thinking about it. Intubation also affected me greatly. People's opinion mattered a lot to me, and being judged bothered me. I felt the same way when I had to wear a mask. I hated it to death.

Catherine, 17, diagnosed

Among the side effects, nausea and back pains were the worst. The other effects were more moderate, and I took many medications to alleviate them. As for losing my mop of hair, I took it pretty well: my nickname became "Dalai-My-Louis". I was lucky to have a really round head. I enjoyed the lumbar punctures because they gave me a funny feeling. In the end, the key is to be positive even if it is not always easy.

Louis-François, 15, diagnosed

How did the people near me or strangers react when I had these side effects, and how did it make me feel?

They encourage and support me. My parents, my friends: they are all there for me. It is very important to have your parents and friends on your side.

## Laurent-Olivier, 19, diagnosed

My family took care of me and is still taking care of me. They were there for me, and I do not think it bothered them. In any case, they did all they could so I would not feel different. However at school and outside my house, people looked at me differently, and I felt peculiar. People look at you differently, with pity in their eyes, and that is not fun.

## Marie-Hélène, 22, diagnosed

They have supported and encouraged me because I did not want any pity.

## Félix-Antoine, 15, diagnosed

They took me the way I was. I am what I am and you are what you are.

## Mike, 19, diagnosed

Strangers stared at me sometimes but it did not bother me: I would have reacted the same way if I had not had cancer. Moreover, it is not done out of bad intentions but out of curiosity.

## Louis-François, 15, diagnosed

People close to me told me my hair loss really affected them. It brought instant tears to their eyes. Things were a little strange with my brother. He was really moved by my illness. He never visited me at the hospital. I think it was too hard for him. But he was always there for me at home. I think my sister was a little jealous of all the attention I was getting. And, at one point, she became terrorized she would have cancer as well.

## Catherine, 17, diagnosed

My friends did not know how to react. They did not call me, they did not visit me at the hospital and they did not talk to me. But you must remember it is kind of normal. People are flabbergasted when they hear the word "cancer". My parents were of great help.

## Francis, 15, diagnosed

My friends laughed at me. They say I look like a boy and they still laugh at me.

## Pascale, 12, diagnosed

When I was out shopping, people would give me weird looks because both my head and body were completely hairless. It really bothered and angered me but I could not do anything about it. Those close to me reacted well because they knew what I was going through.

Gabriel F., 17, diagnosed



## Little things which helped me get through it

You must always be willing to fight the negative and let in the positive, whatever life throws at you. My motto is "One life, one chance". Lastly, never put up barriers as you might regret it.

Mike, 19, diagnosed

I had my family to help me get through it: that is the most important thing for a sick child. I also had books, nurses and doctors and many other people to support me.

Gabriel F., 17, diagnosed

You must always stay positive and, especially, be in good spirits when you talk about your disease with your family and friends... You must also find hobbies so you do not have any time to mope. Be realistic but look at the good sides of illness: the people you meet, the medications with funny effects, the activities organized by Leucan...

Christine, 19, diagnosed

Making friends has always been easy for me, and so I had a big social circle. However, people had to accept my brother's condition and had to be nice to him. I wanted to spend as much time as possible with him. I am the one who changed: my brother became my friend, my "plaything". I became very protective of him. I would exclude from my circle anyone who dared humiliate him because of his condition, and I held grudges against them.

Catherine, 25, sister

To deal with my hair loss, I bought a wig. That way, when I did not feel like telling my story to everyone, I could just put it on and look normal.

Marie-Hélène, 22, diagnosed

Arts and music made me feel good. It would take me far away from my ordeal. It took me to another world.

Joannie, 16, diagnosed

The people who visited me at the hospital helped me get through it. I enjoyed their visits because I did not like to be alone. I also kept myself busy by making stained-glass windows, dream catchers, and book markers. I loved playing board games or watching movies with my mother. Her mere presence was enough. When I got really exhausted, crying would truly help. After a good cry, I feel much better.

Catherine, 17, diagnosed

I had a trick to get through my pills. I would place them in the form of a smiley face and try to swallow them in as few gulps as possible.

Louis-François, 15, diagnosed

Think of something else: try to watch a movie, to play a game or to study a little... In short, always have something to do. You can even meditate: that helps a lot.

Francis, 15, diagnosed

Live one day at a time.

Marc-André, 17, diagnosed

Do not give up! You must stay hopeful and give it your all to survive. Always do your best to achieve all you were able to do before. We can all do it!

Laurent-Olivier, 19, diagnosed

# Have there been any changes since?

I could see people I had never spoken to getting close to me. People who never gave me any attention were now always glued to me. All I wanted to do was to tell them to mind their own business. I thought they were all hypocrites. At one point, when I was constantly asked: "How is she?", I would get fed up and say, "She is OK", and then just take off.

Geneviève, 17, sister

My true friends stayed the same and others avoided me out of fear.

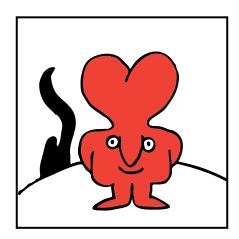
Jean-Louis, 16, brother

Today my friends understand when I talk about the friends I made at Leucan. They know when I want to talk about it and when I want to keep things to myself. They are very understanding and I greatly appreciate it.

Émily, 17, sister

Everybody wanted to be my friends, to know more. I became teachers' pet. It was cool and annoying at the same time.

Karl, 13, brother



# Everyday life

## Do I visit my sibling at the hospital?

Sometimes I would visit my brother because I wanted to spend some time with him. I remember this one time when I could not visit him while the rest of my family could. Obviously, it made me sad but because I understood the situation, it did not bother me as much. I also enjoyed spending time in the playroom. I would do small services for him like getting him a Game Boy cassette. It was truly nice to know I could be useful to him.

Vanessa D., 15, sister

I would go regularly in the summer but now that school has started, I do not go as much.

Karl, 13, brother

My brother had an amputation in the beginnings because of the way his cancer was progressing. During that time, I only visited him once or twice because he was on morphine and he could not really have visitors. Afterwards, during his chemotherapy, he was at home every other week. I would visit him once during his week of hospitalization, and often at the end of his treatment. That would give us a chance to eat together as a family, in a good restaurant.

Olivier, 24, brother

Yes, I visited him regularly. I missed him so much I forgot where I was. I spent a lot of time with him at the hospital. I wanted to see him happy. I wanted him to forget why he was there. We had fun together and that is what really mattered.

Maxime, 20, brother

I would often accompany her to her chemotherapy treatments. I remember going with her in a room where the nurse would take her height and weight. Afterwards, she would lie on a bed, and the nurse would insert a needle in her arm while my mother and I talked. We would go in another room to play games. Since her treatment was administered in the morning, we did not have time for a big breakfast so we would get a bite to eat during her treatment. When she woke up, we had lunch together.

Vanessa R., 15, sister

During my brother's stay at the hospital, I was in my last year of high school. Grade 11 is a big year, not only because that is when you choose a college but also because of final exams. Therefore, I could rarely go to the hospital but whenever I could, I made the most of it and was glad to visit him.

Patrick, 25, brother

# A hope-filled project

In 2005, the Heart-filled Hope support group, made of teenagers from Leucan aged 12 to 18 that either have had cancer or have a sibling with cancer, expressed the desire to prepare a collection of testimonies about how the diagnosis of cancer affected various aspects of their lives.

The first goal of this book is to keep hope alive in youngsters who also face the ordeal of cancer. The second goal is to share thoughts and confidences that will break the feeling of loneliness created by the illness.

The teenagers of Heart-filled Hope open their hearts to you, and are convinced that this document will be of great help to you. They were actively involved in producing this project and in raising the funds that made it possible.

The Heart-filled Hope support group offers socio-recreational activities where teenagers can share their experiences and make lasting friendships. During those activities, they are supervised by a nursing staff and facilitators who fully understand the day-to-day reality of cancer and are always there to help and listen.

Over the last 20 years and counting, hundreds of youngsters became members of Heart-filled Hope through which they have grown in wisdom.

# Heart-filled Hope remembers the angels who made this project a reality:

Thank you, Marie-Michelle, for your kindness, your testimonies and your discretion. We knew our secrets were safe with you.

Thank you, Laurent, for your fabulous energy, your tremendous drive and your lively personality. You have shown us one must always follow his or her dreams.

Thank you, Antony, for your determination, your involvement and your sense of humour. You have shown us one can always swim, even against the tide.

Thank you, Marie-Hélène, for your big smile, your attentiveness and your presence. You are a wonderful example of true altruism.

## Heart-filled Hope would like to thank:

VITTORIO, the big-hearted poster designer, for his beautiful illustrations.

PATRICK GROULX, for his preface: a true statement of his sensitivity for teenagers and their experiences.

ALL MEMBERS OF HEART-FILLED HOPE, for their enthusiastic involvement in this project and their generous heart.

LEUCAN, for its unconditional support.

