My child is having an allogeneic hematopoietic stem cell transplantation

INFORMATION BOOKLET AND DECISION SUPPORT TOOL FOR PARENTS

2016 EDITION

SFGMTC
Société Francophone de GREFFE DE MOELLE et de Thérapie Cellulaire

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Introduction

The doctor and medical team have referred your child for an **allogeneic hematopoietic stem-cell transplant (HSCT)**. It could be a bone marrow transplant, a peripheral blood stem cell transplant, or an umbilical cord blood transplant. All are categorised under the same name "Hematopoietic stem cell transplant". "Allogeneic" means the transplant comes from a donor as opposed to "autologous" which implies that the patient's own marrow is being used.

The transplant can be performed by the team caring for your child or in another unit within the same hospital or in another centre. This would mean getting to know a new team and changing your routine which can be unsettling.

Changing teams is a bit like having to move to a new house, it was everything you knew.
(a young adult transplant patient)

The team that supports you right from the diagnosis and the transplant unit team share information with each other before your arrival. The transplant team will welcome you and inform you of all the important practical information on the day-to-day running of the unit including: meeting the members of the nursing team and the social worker, who

will help you find all the help you need during this period which brings numerous changes to you and your family's day to day life.

The transplant is often the first time a child has stayed in hospital. Everything happens all at once. There's the diagnosis and the transplant referral, while the child and family have to become accustomed to a whole new world.

- *Before the transplant, my child had never stayed in hospital. It was overwhelming for him to go straight in for a transplant. Everything was new to him. (a father)*

- *It's a completely different experience if the transplant represents the first time in hospital…We, the team are there to help the parents prepare for the change. An unknown setting, complicated scientific terms… A sudden diagnosis and then suddenly they're in hospital! (A transplant coordinator nurse)*

It's usually during the pre-transplant evaluation that the transplant physician or transplant coordinator nurse will hand you this booklet. It builds upon the issues discussed orally such as medical and practical information, support available, social and family aspects and so on.

This booklet is also designed to facilitate dialogue between you, your child, the doctor/physician and the entire transplant team.

It highlights the need for honest, open and genuine communication between all the people involved during this scientifically and emotionally complex situation.

Here you have all you need to know in written form, allowing you to take in all the information at your own pace. You can also pass it on to your friends and family. It may help them to better understand what you are going through.

Its aim is equally to help you understand the challenges faced during a hematopoietic stem cell transplant, and see why the decision for treatment was made.

It is by no means intended to replace physical contact with team members. It is instead designed to help you develop strong bonds with the various healthcare partners.

This guide covers allogeneic transplants in general terms and therefore cannot describe each individual case. Each situation is unique and the members of your transplant team will provide you with all the information specific to your child. The specific information that they provide for your child will be based upon the general information provided within this booklet. Please be encouraged to ask them anything at all concerning your child's transplant.

This is the third edition of this booklet. This 2016 edition is the result of collaborative work carried

out in several pilot centres in France and in Quebec. To illustrate the text, interviews were held with families, child donors and child transplant patients. The booklet was then reviewed by transplant centres in France, Quebec, Belgium and Switzerland.

- *Don't read this booklet all alone like I did. Go over it with a doctor who can explain certain terms or complicated sections. (a father)*

- *I had to stop reading it because the part about the risks and side effects was making me worry too much! I can honestly say I would have preferred to learn certain things orally rather than read them like that! (a mother)*

- *This booklet helps parents understand the care and treatment being given to their child and therefore eliminate that feeling of helplessness. (a nurse)*

Notes

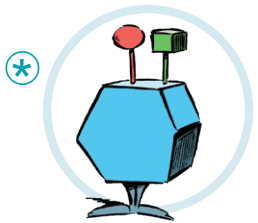
1. THE HOSPITAL STAY AND THE TRANSPLANT

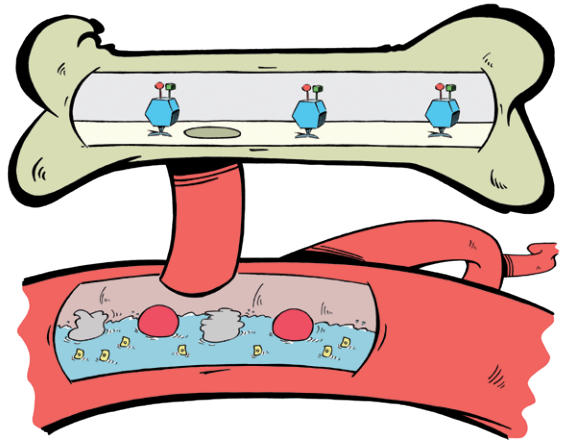
The function of bone marrow

The role of bone marrow

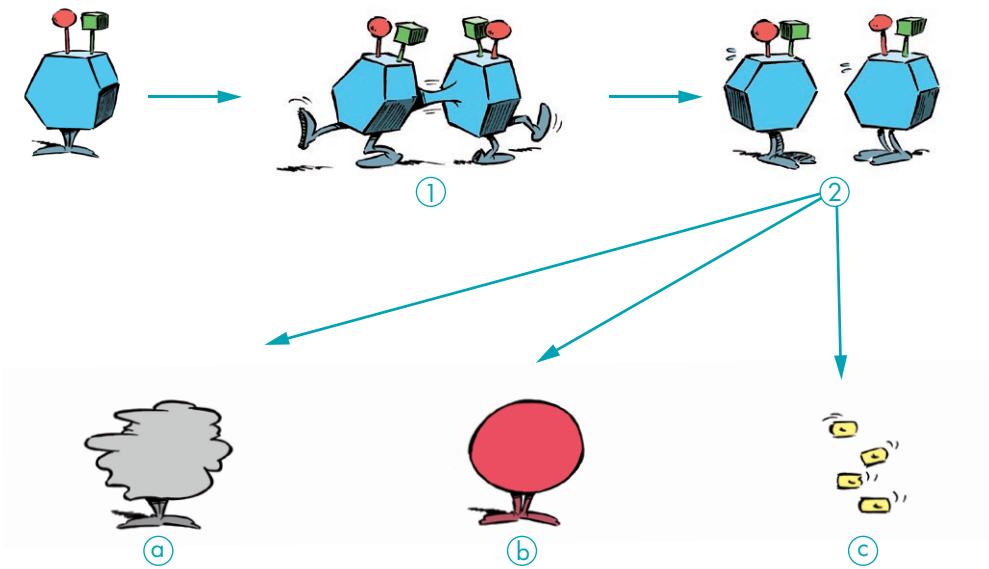
Bone marrow contains billions of parent cells called hematopoietic stem cells ⊛ (HSC). It is where these stem cells produce blood cells i.e. white blood cells, red blood cells and platelets. Bone marrow is a liquid found in the bones. The removal of this liquid for laboratory testing is called a bone marrow aspiration.

Note: Bone marrow is different from the spinal cord which is a bundle of nerves that runs down the middle of your back. It carries signals back and forth between your body and your brain. It is surrounded by a liquid called cerebral spinal fluid (CSF) which can also be removed. This is called a lumbar puncture (LP).





The stem cells divide ① and differentiate ② giving the different cells that make up the blood: white blood cells ⓐ, red blood cells ⓑ and platelets ⓒ.



Stem cells constantly regenerate over time as all blood cells have a limited lifespan. This is called **haematopoiesis** from Greek *haima*, "blood" and *poïesis* "to make".

White blood cells

Also called leukocytes or leucocytes.

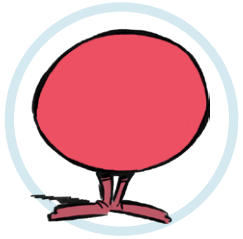
Several types exist. Two types of white blood cells are important during a transplant: neutrophils (or polymorphonuclear leukocyte or PMN) and lymphocytes (in particular B cells and T cells). The white blood cells present in the body of a person make up his or her immune system.

Neutrophils and lymphocytes protect the body against infections caused by bacteria, microscopic fungi, viruses, parasites and against diseased or foreign cells.

A healthy child will have 1,500 to 7,500 neutrophils per cubic millimetre (mm^3) of blood.
Less than 1000/mm^3 of blood is classed as neutropenia and less than 500 as severe neutropenia (often wrongly referred to as aplasia), during which their risk of infection increases.

Bacteria is treated with antibiotics, the fungi with antifungal medicine and viruses with antivirals.

Red blood cells



These are also called **erythrocytes.**

Red blood cells contain haemoglobin which is responsible for transporting oxygen around the blood of vertebrates and gives the blood its reddish colour.

A healthy child will have 4 to 5 million red blood cells per cubic millimetre of blood.

However, it is the haemoglobin count which is important as it measures the ability of the blood to carry oxygen. Anything between 11.5 and 17 grams per decilitre of blood (g/dl) or between 115 to 170 grams per litre of blood (g/l) is considered normal.

When the level of haemoglobin is very low (below 8 grams per decilitre of blood), it is classified as **anaemia**.
If this is the case, a red blood cell transfusion may be required.

Platelets

They are also known as **thrombocytes**.

Platelets are responsible for blood coagulation. It's what forms the scabs from cuts and wounds. Their main role is to ensure haemostasis, or in other words to stop the bleeding.
A normal level is 150,000 to 450,000 platelets per cubic millimetre (/mm^3) of blood or 450 x10^9/l.

A very low platelet count (anything below 10,000/mm^3 of blood or 10x10^9/l) is called thrombocytopenia. In this case, a platelet transfusion may be needed to prevent bleeding.

The blood test used to measure the amount of red blood cells, white blood cells, platelets and haemoglobin count is called a complete blood count (CBC) which is often called a "Numération Formule Sanguine" (NFS) or a "Formulation Sanguine Complète" (FSC) in France.

We don't really know how many blood cells or platelets is ideal! When they increase though, we're happy!
(a mother)

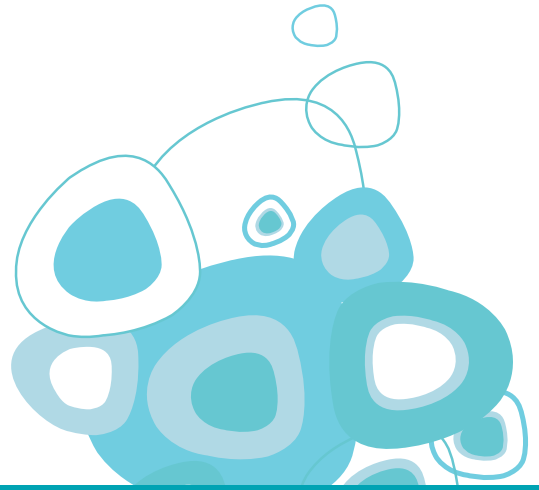
The HLA system

All cells in the body carry proteins on their surface called human leukocyte antigens (HLA).

Collectively, these proteins make up your **HLA type**. In a way, it determines the identity of cells of each individual, including hematopoietic stem cells from bone marrow.

Lymphocytes will use these HLA proteins to identify and destroy anything foreign found in the body, such as infectious agents.

The HLA type can be determined by a blood test.



What is the purpose of an allogeneic transplant?

The idea behind hematopoietic stem cell transplant is simple, however there can be many complications along the way.

The aim of the transplant is to replace the bone marrow of the recipient, your child, with the bone marrow of a person in good health, the donor. In other words both the haematopoietic system and the immune system of your child will be replaced with the bone marrow of a the donor.

The donor's stem cells will replace the bone marrow and the immune system of your child.

The transplant involves:

- the transplant recipient (your child): the patient, also known as the host;
- the donor: a healthy person who is a HLA match;
- the graft: the hematopoietic stem cells of the donor.

The more HLA markers the donor and the recipient share the better, which is commonly referred to as a HLA match. This is because there will be less chance of the donor's HLA proteins being seen as foreign by the lymphocytes of the recipient, and *vice versa*.

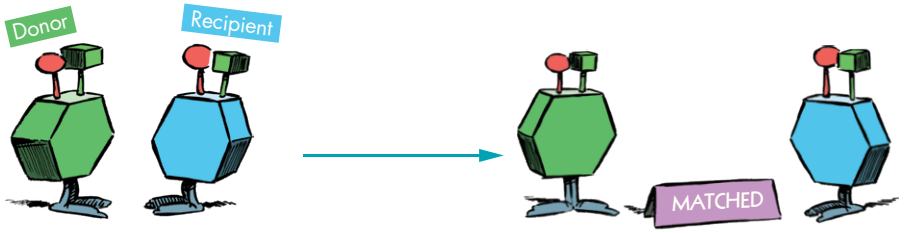
Two things are happening:

- the recipient's (your child's) HLA system identifies the HLA system of the donor, which is required for the engraftment to take place;
- the donor's HLA system identifies the recipient's HLA system.

Engraftment

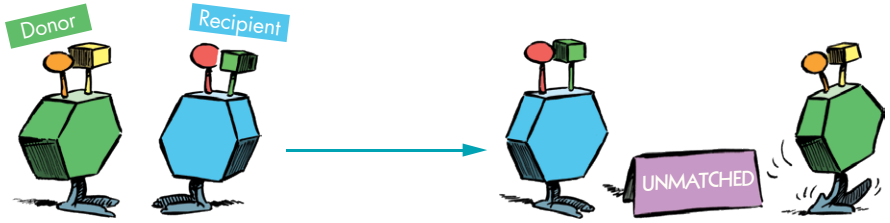
The recipient's HLA system identifies the donor's HLA system:

- if it doesn't consider it to be foreign, the recipient's body will accept it;



The HLA system of the donor and recipient match so the cells are accepted.

- if it detects a difference (in the same way it would for a viral or bacterial infection), the recipient's body will not accept it and develop an immune response.



The HLA systems of the donor and recipient are different so the cells are likely to be rejected.

Fighting residual disease

The donor's HLA system identifies the recipient's HLA system:

The cells in the graft (the new immune system) will identify the "diseased" cells in your child's body as foreign cells.

They will fight to try and destroy them. This is known as the **graft-versus-leukemia (GVL) effect**.

It's the reason why relapse is less frequent after allogeneic transplant.

When is a transplant needed?

A transplant may be needed for three types of diseases: for cancer, for a non-cancerous blood disease or for a metabolic disease. A transplant is only advised if the chances of recovery are greater than the chances of recovery from other treatment.

Cancer

This could be leukemia, lymphoma or pre-leukeamic disorders such as myelodysplastic syndrome (MDS).

During leukemia, the marrow is overrun by abnormal cancerous cells called blast cells.

A transplant is immediately given for certain types of leukemia or after a relapse. A transplant would typically be performed after reducing the amount of blast cells as much as possible with chemotherapy. The aim is to achieve full remission (when tests, physical exams, and scans show that all signs of the cancer are gone) and if possible MRD-(minimal residual disease) negative which is defined as an absence of leukemia when using tests that detect leukemia cells at a lower level than with a microscope.

A successful transplant for leukemia can be explained by two processes. Firstly, the abnormal marrow is destroyed during the conditioning process and replaced with the healthy cells. Secondly, the immunological response from the new cells can destroy the residual leukeamic cells, known as the graft versus leukemia (GVL) effect.

Non-cancerous blood disorders

Aplastic anaemia is a rare disease in which the bone marrow and the hematopoietic stem cells that reside there are damaged. This causes a deficiency of all three blood cell types: red blood cells, white blood cells, and platelets.

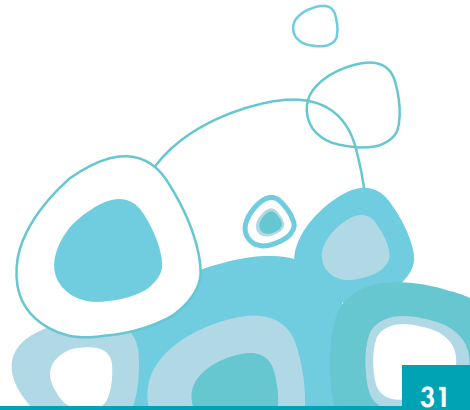
Immunodeficiency disorders are when lymphocytes are not being produced effectively. There are many forms of immunodeficiency that can be cured by a hematopoietic transplant.

Thalassaemia or sickle cell anaemia are blood disorders and diseases in which the body produces an abnormal form of haemoglobin.

There are other rarer diseases that can be treated with a transplant such as Fanconi anaemia, megakaryocytosis and Diamond–Blackfan anaemia (DBA).

Metabolic syndrome disorders

Metabolic syndrome disorders are normally caused by the lack of a particular enzyme. After the transplant, the marrow produces white blood cells that are capable of producing and transporting this missing enzyme.



Who can be a donor?

The donor is a healthy person whose HLA type is as closely matched as possible to the HLA type of the recipient. However, even when the donor's and recipient's HLA type match, there still remains genetic differences between the donor and recipient.

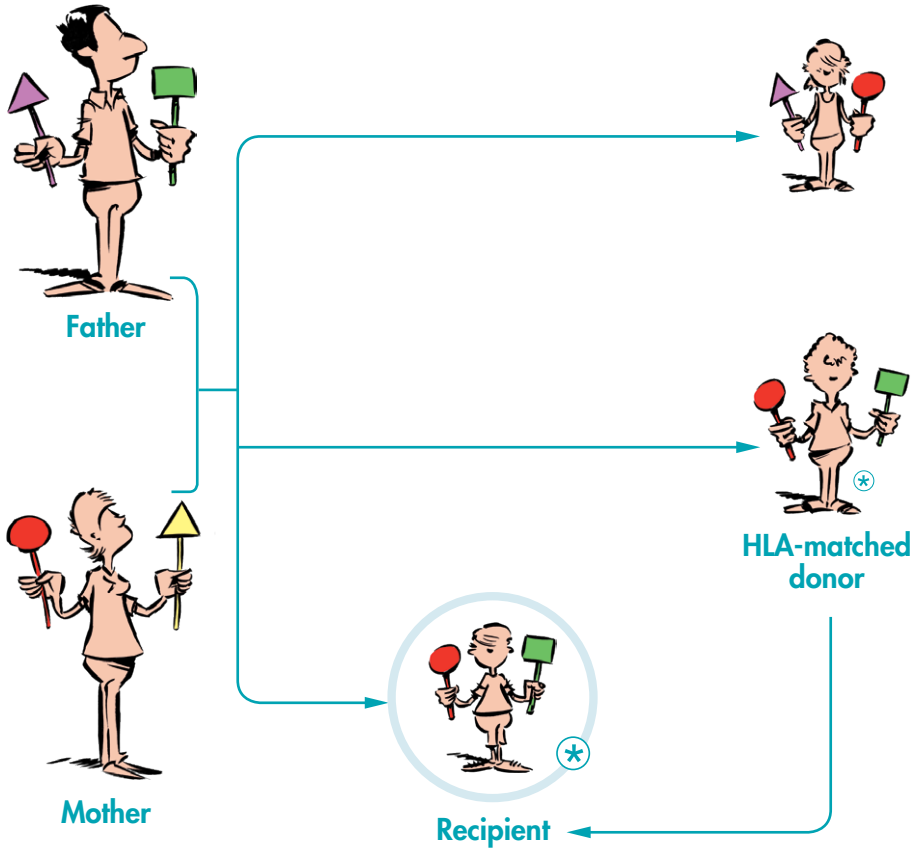
The most likely place to **find an HLA match is among siblings**. This would make them a related donor.

Each sibling has a one in four chance of being a HLA match ⊛ (see diagram opposite).

If your child has no siblings, or none of the siblings are a HLA match, or if they are unable to be a donor for another reason, **it is unlikely that another family donor is pursued.**

See "HLA-haploidentical donor" on page 34.

In such circumstances, a **voluntary donor registered with an international donor registry** is called upon. A transplant involving a HLA-matched unrelated donor is commonly referred to as a MUD (matched unrelated donor) transplant.
The HLA type of the recipient are compared with the HLA types of the voluntary donors on the registries. Finding a HLA-matched unrelated donor can sometimes take a number of months (because of availability of donor, genetics, ethnicity...).



The HLA types listed do not however contain all the necessary information and several comprehensive blood tests must be done to ensure the donor and the recipient are HLA-matched.

The likelihood of finding a donor from the registry varies according to the ethnicity of the patient.

There is also **cord blood banking which involves collecting blood left in a new-born's umbilical cord and placenta and storing it for future medical use**. This is referred to as **unrelated umbilical cord blood (CURD)**. One of the benefits of cord blood is that transplants can be performed even when the HLA of the donor and the recipient is only partially matched. It is also generally available in less than a month.

And finally, a transplant involving a **donor with a semi-matched HLA** which could be the father, the mother or a half brother or sister is something performed in certain cases. This is called a **haploidentical match**.

What's the pre-transplant assessment?

Before the transplant, it is important to ensure that the child is able to endure the procedure without excessive risk and that there are no contraindications.

A comprehensive pre-transplant assessment is carried out including blood tests, X-rays, cardiovascular examinations etc.

The results from this assessment allow us to adjust the transplant procedure (the conditioning, preventative treatment) to your child's condition. It also allows doctors to detect any abnormalities that could potentially lead to complications after transplant. The results from the pre-transplant assessment rarely prevent the transplant from going ahead. This assessment is then used as a reference to compare the tests carried out before and after the transplant.

The **donor** is also given a **pre-donation** assessment to check whether donating puts him or her at risk. The results from this assessment rarely prevents the donor from donating.

These assessments of the donor and the recipient also allow us to see which viruses each of them has been exposed to. This helps to choose the right donor. This also helps in choosing the right prevention measures to take against any complications which may arise after the transplant.

Preparing for the transplant?

As the compatibility between your child and the donor may not be perfect, it is essential to **prepare your child's body so that it accepts the donor's cells in the best possible condition.** This is known as the

conditioning regimen. It is a very important phase which precedes the transfusion of the donor's hematopoietic stem cells.

Conditioning makes room in the bone marrow by suppressing the patient's immune system in preparation for the transplanted stem cells.

Several types of conditioning exist which involve one or several types of treatment such as chemotherapy, radiotherapy and/or immunotherapy (antibodies).

When radiation therapy is used, it is commonly referred to as a Total Body Irradiation (TBI). High energy rays, similar to x-rays are used to kill cancer cells all over the body.

It is preceded or followed by chemotherapy. The treatment is divided across several sessions, usually over a number of days.

It all depends on:

- the age of your child;
- their general condition;
- their disease;
- the results of their pre-transplant assessment;
- the type of transplant.

Myeloablative conditioning – or regular conditioning

There are 3 aims to conditioning:

- to "make room";
- to treat residual disease;
- to assist the engraftment.

The diseased marrow is destroyed during the transplant preparation phase, by using chemotherapy or a combination of chemotherapy and radiotherapy.

It is then replaced by the healthy marrow used for the transplant.

Reduced Intensity Conditioning (or non-myeloablative conditioning)

Certain conditions require reduced intensity conditioning (RIC). This type of conditioning involves lower doses of chemotherapy and radiation therapy than myeloablative conditioning. The risk of short-term and long-term complications and toxicities are significantly reduced; however the risk of the transplant being rejected or relapse of the disease is higher. This type of conditioning concerns certain transplant indications or children whose health condition is not suitable for myeloablative conditioning.

What are the different types of transplant?

Your doctor chooses a transplant based on your child's condition, the availability of donors, his/her experience and that of the transplant teams.

There are three types:

- **stem cells** from the **bone marrow**;
- **blood stem cells** (sometimes referred to as peripheral blood stem cells or PBSCs);
- **stem cells** found in the **umbilical cord blood** that remains in the placenta and in the attached umbilical cord after childbirth.

See "The different types of donations" on page 101.

How is the transplant performed?

Performing the transplant is quite simple. It is not a surgical procedure as is the case with other organ transplants. It is a transfusion, similar to a red blood cell or platelet transfusion.

The graft (or cells) contained in a transfusion bag is administered intravenously into the blood stream *via* a catheter (central venous line). However, unlike red blood cell and platelet transfusions, the stem cells are transfused in order to evolve into blood cells and replace the diseased ones that the cancer treatment has killed.

D-Day, the transplant:

The risk of complications during the transfusion is extremely low. However, despite being a relatively simple, quick and painless procedure, it can be a very anxious and emotional time for all those involved. The team will be there to support you and your child during this moment full of hope.
They will also leave you some privacy if you wish to share this moment alone with loved ones.

D-Day, the transplant.

- *On the day of the transplant, we were both on leave. We were both with our daughter the whole way through the transplant. (a couple)*

- *On the day of the transplant, I found the procedure of transfusing the blood in the bag incredibly simple. The bag was just like any other, but it was "THE" bag. Its contents can be lifesaving! (a mother)*

How are the cells transplanted?

The stem cells are given through a catheter (central venous line) which then goes into the blood stream to migrate and settle in the bone cavity where they take several days or even several weeks to multiply and differentiate. This period where the marrow does not yet produce enough blood cells is known as aplasia. It is during this stage that many complications can arise.

See "Possible complications arising from the transplant and how to address them" on page 53.

The first cells to appear in the blood (usually between 15 to 35 days after the transplant) are **neutrophils**. Their presence is a sign that the transplant was successful. From this point onwards, the risk of bacterial and fungal infection is low.

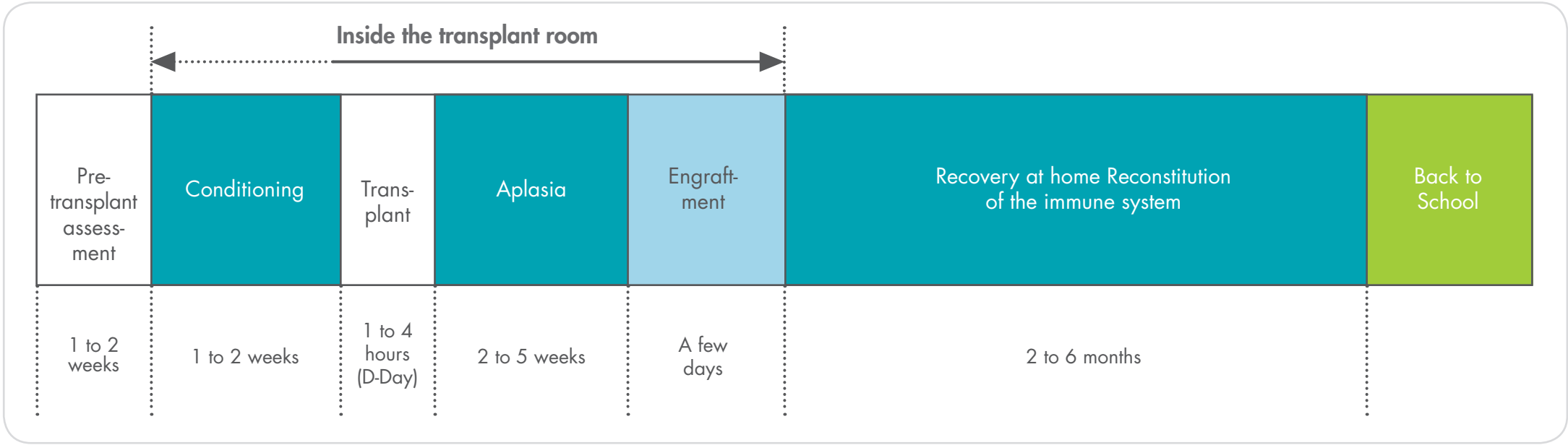
Lymphocytes, another type of white blood cell, generally appear at the end of the first month. That said, they are not immediately able to recognise foreign molecules in the body. To do this, **they need to be "educated"**, which can take several months to several years.

See "The long-term immune reconstitution of the body" on page 43.

Afterwards, **red blood cells and platelets** begin to appear. It can take several months to reach a red blood cell and platelet count that is normal, however this is rarely troublesome as they can always be supported with a blood transfusion.

The transplant timeline

Recovery times and going to school may be delayed by a few weeks to a few months if there are complications along the way or if the transplant was due to "immune deficiency". Often, patients are unable to return back to school during the year following the transplant.



Why is your child in a protected room?

To try and prevent infection, your child will be in a protected room (sometimes called sterile rooms) up until the engraftment stage. From this point onwards, the risk of bacterial and fungal infection is significantly reduced.

See "Isolation, methods used" on page 76.

In theory, your child will not leave their protected room during their stay in hospital. The only times he or she might need to leave this protected room would be if a scan was required or if he or she needed to be taken to the intensive care unit.

See "Complications requiring intensive care" on page 67.

Naturally, you are likely to be concerned should your child need to leave the protected room. Please be assured that the chances of the outcome being positive far outweigh the chances of any potential risks.

When the risk of infection is relatively low, the transplant may not be performed within a protected room. This procedure is most often used for special types of transplants with reduced intensity conditioning.

The long-term immune reconstitution of the body

The immunological reconstitution following transplant is an active phenomenon during which your child's body **will develop "new white blood cells", specifically T-Lymphocytes** from the transplanted stem cells.

It is the thymus gland that is mostly responsible for generating these T-Lymphocytes, which is located in the sternum (breastbone). It gets rid of the overly aggressive cells in your child's body as well as those that are too weak to fight off infection. The thymus gland will therefore only leave T-Lymphocytes that are capable of defending the body that will not potentially attack our own organs. Unlike any solid organ transplant such as a kidney, liver, heart or lung transplant, the body of a patient who has had an allogeneic hematopoietic stem cell transplant will appropriate the new cells. It is referred to as immunological tolerance between the recipient's body and the new marrow. This gradual immunological tolerance means the patient will eventually no longer require "Immunosuppressive" drugs. Immunosuppressive drugs help to reduce or eliminate immune response.

These are also needed as the immunologic memory of the body's natural defence system is lost after

the transplant. It will take quite a bit of time to build it up again. Several months are needed for it to react to vaccines for example. Therefore, vaccinations must be given a few months after the transplant to make up for the lack of immunization or the effect of the pre-transplant vaccinations wearing off. Some vaccines will help fight against infections (such as influenza (the flu) and pneumococcus) that the body is not yet able to manage independently after the transplant.

Questions I have concerning my child's transplant

How do we know a transplant is needed?

When deciding whether a transplant is needed, several factors are taken into account: the diagnosis of the disease, at what stage it is at and its predicted development, your child's general condition and what other treatments are available.

Sometimes the indication for the transplant is not easy to establish. In this situation your transplant team will call upon the experience of doctors belonging to other national or even international transplant teams.

The doctor will explain the situation, go over the possible alternatives to a transplant, and discuss it with you until the best course of action is established, so it is a well-considered decision that is made with your consent. Your child will be informed of this decision and will be asked for acceptance depending on his or her age and maturity. In all circumstances, the doctor will have always carefully considered the risks and the benefits and assumes complete responsibility.

Can we predict what is going to happen?

Doctors will draw upon the team's experience as well as scientific and statistical data to determine whether a transplant offers a higher chance of recovery than other treatment. They cannot however predict what will happen to each individual patient.

That will depend on the disease they are suffering from, the compatibility between the donor and the recipient, as well as the individual risk factors. This means that **no two transplants go the same way**. Therefore, whatever happens to one person may not necessarily happen in the same way to another.

Please be encouraged to discuss these matters with your transplant team. One thing is certain: even if the team is unable to predict what will happen, everyone will do everything to minimize the risks as much as possible, and give your child the best chance of recovery.

Are some transplant teams better than others?

Transplant teams participate in "evaluation and accreditation programs". Their work is monitored and evaluated by independent observers. Numerous studies have shown that the results of different teams are comparable, provided the team performs enough transplants.

Most teams apply the same procedures.
That said, each team can have their own way of doing things, such as isolation and dietary methods, ways of preventing complications arising and so on. Despite these differences, the outcomes are the same.

If you move to a different centre during the transplant process, or if you talk to people who have had transplants performed in other centres, do not be surprised of such changes and as always do not hesitate to speak about it with your team.

Today, French speaking teams, brought together in the "Société Francophone de Greffe de Moelle et de Thérapie Cellulaire (SFGM-TC)" (french speaking bone marrow transplantation and cell therapy association), are working to align the practices in different centres, as is the Canadian Blood and Marrow Transplant Group (CBMTG) in Canada.

- *Everything is so well organized here that we don't ask ourselves if it might be better elsewhere! (a mother)*
- *The trust you have in a doctor plays a major role in the recovery process, no matter where you are! (a mother)*
- *For me personally, it's that sense of trust established by the doctors that will help parents because each situation is unique. (a nurse)*

At what moment will I know the transplant was successful? Does it mean that my child has recovered?

We will know that the transplant was successful when neutrophils begin to appear in the blood (15 to 35 days after the transplant). **Chimerism testing** lets us count the proportion of white blood cells from the donor and the recipient in the blood.

When the engraftment is complete, the chimerism is considered "donor".

When the stem cells are rejected, the chimerism is classified as "recipient". In some cases, the outcome may be

a partial engraftment or "mixed" chimerism.

Engraftment can be partial at first and then later become complete.

In some cases, full engraftment is needed, however, depending on your child's disease, a partial engraftment (a mixed chimerism) may be enough.

There is treatment that can turn a partial engraftment into a full engraftment should it be required. The transplant physician will let you know if this is the case.

Engraftment is a vital stage of the transplant. However, with cancer there is always the risk of relapse occurring.

In the majority of cases, we can confirm that your child has made a full recovery after several years of monitoring.

See "Possible complications arising from the transplant and how to address them" on page 53.

How do I know if it involves research? What is consent for transplant research?

Even if recovery rates for allogeneic hematopoietic stem cell transplants have significantly increased in recent years, **there is still room for further improvement**. This can be achieved thanks to **clinical research** carried out collectively by transplant centres such as: Center for International Blood and Marrow Transplant Research (CIBMTR), Eurocord, European Group for Blood and Marrow Transplantation (EBMT), Société Francophone de Greffe de Moelle et de Thérapie Cellulaire (SFGM-TC) (*french speaking bone marrow transplantation and cell therapy association*), Pediatric Blood and Marrow Transplant Consortium (PBMTC), Canadian Blood and Marrow Transplant Group (CBMTG) or Children Oncology Group (COG).

It is possible that information gathered during your child's transplant is used for clinical research.

This could be:

- **research carried out for databases** (called registries) which keep records of all transplants. All transplant centres record the details of each transplant they perform on an international database (EBMT for Europe, CIBMTR for North America, including Quebec) and sometimes on a registry that is specific to the disease treated. You will therefore be asked to give your consent for the information and data concerning your child's transplant to be submitted anonymously, ensuring that no person with access to these files knows your child's identity.
- **clinical trials (or therapeutic trials).** Any clinical trial that is proposed will be fully appropriate for your child's condition. If you agree for him or her to participate in such a trial, you will need to sign a **research consent form**.

You will receive an **information booklet** which contains all relevant information on the treatment. You and your child are within your rights to refuse this trial proposal.

Even if you give your consent, you can later ask that your child no longer participates in the trial at any moment, without needing to justify yourself. Your child will only be given the best possible treatment and will still benefit from the same quality of care.

Clinical trials are regulated by law and your child will never participate in research without your prior signed consent.

Please be aware that you may be asked to give your consent in situations other than those related to clinical research. For example, this could be in regards to the anaesthetic, the surgery, or taking tissue samples from your child for biological analysis (blood, marrow, etc.).
It may feel as if you are signing a lot of documents. And you may be asking yourself which ones are related to a standard transplant procedure and which concern clinical research. If in doubt, just ask your transplant team who are there to help.

See "Appendices - Research" on page 168.

The transplant – from the parent's point of view

- *The thought of our child having a transplant was hard to stomach at first. The doctors and nursing team though helped reassure us. In the end, we came to realize that it was fortunate that our child was able to receive a transplant. (a mother)*
- *I was so happy that the transplant was possible. I was over the moon happy. (a father)*
- *The most important thing my daughter took from all this is the human experience she had. (a mother)*
- *Children are magical, they always seem to find a joke, give you a little kiss on the cheek, making the atmosphere light hearted even during the transplant. (a mother)*
- *We're not alone. There is a whole team with us... before and after the transplant. (a mother)*
- *With a transplant, you've got to take it one day at a time. You don't think too far ahead. (a father)*
- *Even if a transplant goes well, you've got to sit tight and be patient, it takes time. (a mother)*
- *I was there during my daughter's transplant, but it was her who experienced it first-hand. (a mother)*
- *Initially, I was pretty clueless about the transplant and its implications! And even after they explain it all to you, nothing prepares you for the moment when your child is actually having the transplant. (a father)*
- *Something like that brings the family together, it's very comforting. We're more united than ever. The kids really helped us a lot. (a father) [And the mother added] They are more spoiled than before. We're just grateful that they're alive and healthy! (a couple)*
- *Even though we're not sure the transplant is going to work, we've been given a potential lifeline. (a mother)*
- *We were relieved to know that there was a solution for our daughter. (a couple)*

The transplant – from the child patient's point of view

- *During the transplant, you've just got to do as they say and be patient. (a 13-year-old teenage boy)*
- *I've got good and bad memories. The good ones... Well I should be dead but I'm still here. The doctors said "he's going back to sleep, he's not going to eat"... But really it was the opposite. I was just pretending, I was jumping on the bed. The bad ones... There are too many, I can't tell you all of them. (a 7-year-old boy)*
- *Sometimes I just wanted to get really angry, sneak out of the hospital and be with my parents until the morning. I imagined doing it but it was in my dream, there was a doctor who saw me and... (a 6-year-old girl)*
- *The transplant... Well among the worst-case scenarios, the least bad would have been waiting a while for a donor, and the worst would have been me dying. (a 17-year-old teenage girl)*
- *I've lived on earth for seven years... the other two years I lived in isolation. (a 9-year-old boy)*
- *Even though the transplant period was really difficult for me, it's my best memory so far because the nurses, the assistant nurses, these people are great, extraordinary even. We chatted to each other, they made me laugh, we played video games together. (a 16-year-old teenage boy)*
- *During the transplant, it was a bit difficult to understand why I stayed, but mummy was there for me. (a 6-year-old girl)*
- *I feel like the relationship I have with my parents has changed. As a teenager, I thought I had the worst parents in the world and I couldn't even talk to them. But once the transplant came, everything changed! (a 17-year-old teenage girl)*

Possible complications arising from the transplant and how to address them

The complications (also called risks or side effects) that may arise after a hematopoietic stem cell transplant vary in severity and frequency. Some are completely exceptional. These complications are mainly due to conditioning, aplasia and immunological reactions.

Each step of the transplant journey has its own complications. Depending on your child's condition, you may have already encountered some of them before the transplant, for example hair loss, infections, mucositis and so on.

Some of the children who receive transplants have not previously had chemotherapy treatment and some have never had to stay in hospital before the transplant or have stayed only briefly. Consequently, some of the side effects such as pain, nausea and vomiting are possibly new to them. Their physical and psychological reactions will therefore be different from a child who has already suffered from these side effects.

It is important to bear in mind two things:

- **the severity of each of these risks varies widely** from one situation to another and your child will not encounter all of them.

- **your child's doctor has carefully weighed these risks** before referring your child for a transplant, and firmly believes that the expected benefits outweigh the potential risks.

Furthermore, all measures in the pre-transplant assessment have been taken to assess the risks of complications, to prevent them if possible, to keep track of any appearing and to deal with them when they do appear.

This is a daily follow-up during the weeks following the transplant, which will gradually become less frequent over time. It is provided by the transplant team, with the help of doctors and professionals from other fields who will intervene depending on the problems encountered.

Some complications may arise during the year following the transplant, while others can be years later. Therefore a lifelong follow up is required.

- *Information is key! Knowing the facts really makes all the difference, it's awful having so many unanswered questions. (a father)*
- *The doctors told me all about the risks. They gave really thorough explanations. Hearing that is always going to be a shock, but it has to be said because if it happens, you might be scared and ask yourself: "What's happening to me?" (a 17-year-old teenage girl)*
- *The most difficult thing was finding out about the number of risks involved, but it would be worse if nobody said anything about them. (a mother)*
- *The doctors were very approachable. They took the time to explain the side effects. We always felt welcome. (a couple)*

The pain

The transplant team makes every effort to prevent, treat or relieve any pain encountered by your child. It may be headaches, pain associated with mucositis, stomach or liver pain and so on.

When pain occurs, treatment is immediately given to prevent it.

It may take some time (from several hours to several days) until it is sufficiently relieved.

Sometimes we cannot make it go away completely, but everything is done to make it tolerable.

Pain is a subjective experience and everyone experiences it differently.

It is a fact that we have to accept. It should never be played down by the person feeling it nor by anybody that is aware of it. Do not hesitate to talk about it and do not ever worry about disturbing anyone. Possible sources of pain are numerous. Your child is the best person to measure it. A pain rating scale can help him or her do so.

Generally, painkillers are given to relieve the pain. They are prescribed depending on the type of pain and their action. Mental suffering and anxiety are also taken into account. A pain specialist can be called upon when things get too difficult.

Morphine or a derivative taken orally, intravenously or through a transdermal patch is often used. This is common, and is nothing to worry about. **Using morphine to treat pain does not make a patient addicted to it**. The main side effect of morphine is constipation. Occasionally your child may have hallucinations in which case the dose would need to be lowered or the type of treatment changed.

My daughter was very much relieved of her pain, except that morphine has unknown side effects for a mum. (a mother)

When morphine or morphine derivatives are being discussed, parents often get very worried. (a nurse)

Patient-controlled analgesia (or PCA Pump) may be offered, allowing your child to control the amount of morphine administered to relieve the pain. This method is efficient as it allows less morphine to be administered while still giving the same effect and allows your child to administer their own pain relief.

To relieve the pain, several methods are often combined in addition to pharmacological means such as:

- relaxation
- hypnosis or imagery
- body-mind approaches (Mindfulness, yoga...)

however, these methods are not yet available in all centres.

Physiotherapists also help care for your child by using massage techniques and lymphatic drainage where possible.

If you resort to using other alternative medicine, otherwise known as complementary medicine (osteopathy, auriculotherapy, homeopathy, acupuncture, etc.), you must first consult your child's doctor to check that there will be no drug interactions.

See "Appendices - Pain" on page 167.

The short-term risks (first year after the transplant)

Problems can arise during the first few weeks or months or at any point during the year following the transplant. They are either related to conditioning, certain immunological reactions or aplasia.

▸ Risks related to conditioning

Nausea and vomiting

During and after the conditioning phase, you child will probably experience nausea and occasional vomiting. Nausea and vomiting can normally be prevented with the right medication.

Changes to their sense of taste

During the months following the transplant, some medication will transiently alter your child's sense of taste. Therefore, it is normal if your child mentions that some food tastes strange, or has no taste at all. It will not last longer than a few months.

Mucositis

Mucositis is a condition characterised by pain and inflammation of the body's mucous membrane and breaks down the cells lining the gastro-intestinal tract (which goes from the mouth to the anus). Oral mucositis can cause painful mouth ulcers and sometimes difficulty swallowing even saliva. Gastrointestinal mucositis occurs inside the digestive system and causes pain and diarrhoea which can sometimes be chronic.

Mucositis can make it very difficult to eat. Your child may need:

- **parenteral nutrition (PN),** which is administered through the central venous catheter or
- **enteral nutrition (EN)**, which is administered directly into your child's stomach using a long, thin tube placed through the nose and throat into the stomach.

Fortunately, these cells regenerate quickly. It can take 10 to 15 days until it is completely healed. During this period, you child should swill their mouth with mouthwash several times per day. The pain is often treated with morphine or derivatives.

Physical changes

Hair loss (sometimes including the eyelashes, eyebrows and pubic hair) called alopecia is almost always inevitable, especially if your child had myeloablative conditioning. There is no treatment that can prevent this type of hair loss. Hair starts to grow back and become visible around three months after the transplant. It may grow back finer than it was before. It may also be thinner.

16 is a particularly difficult age to deal with hair loss. (a father)

Losing my hair was hard. I kept seeing my reflection in the tiles in the bathroom so I kept the curtain closed, I didn't was to see what I looked like. (a 13-year-old teenage boy)

Some medication (cyclosporin), on the other hand, can promote **hair growth**. It can also result in tremors as well as renal (kidney) and/or hepatic (liver) toxicity, which will only last as long as the medication is being taken.

While my daughter was taking cyclosporin, she had thick eyebrows and hair everywhere... Now that she's been weaned off it, she's gone back to how she was before. (a mother)

Corticosteroids are often used and cause **the face and the torso to swell up**. Again, this is only temporary and swelling will go down again when the medication is no longer being taken. Stretch marks may also appear leaving lasting scars.

The appearance of the skin may change temporarily with dark spots appearing (caused by the busulfan used during conditioning), redness, dryness, etc.

I had heard about corticosteroids before, but I didn't realize that it caused you to swell up like a hamster! (a mother)

During treatment, your child may complain of fatigue, which can be severe. The inactivity can lead to significant **muscle loss**.

This is temporary and will stop once life gets back to normal with physical activity.

No physical characteristics of the donor are transmitted by the transplant. Some people do tend to worry about this, however they have absolutely no reason to.

- *I'm going to become ginger, I'm going to have freckles just like English people do. (an 11-year-old child when he discovered that his donor was English)*
- *I didn't quite like the idea that our son was going to receive a donation from a young girl. I had always thought, wrongly, that a donation from a man would have been better suited to our 1,94 (6 feet and 4 inches) strapping young lad. (a mother)*

The only characteristics that can be transmitted are those related to the blood such as the blood type and certain allergies.

It is not always easy living with all these changes to the body as they are a visible sign of the disease. Psychological counselling can help your child to cope. Even when in the protected room, you child can talk to a psychologist.

- *Losing my hair was hard. My hair is a big deal for me. The colour of my skin changed, it was darker. I found it hard to swallow. I was tired but I didn't give in to it. (a 16-year-old teenage boy)*
- *As soon as my boyfriend touched me, I was afraid. I had changed, I didn't know who I was anymore! He kept telling me that I was still the same... (a 17-year-old teenage girl)*

These changes can unsettle your child and be felt like a loss of their identity. Try not to worry as this is common and these feelings should disappear after a while.

The risks for the liver

Some of the cells found in the veins of the liver can become damaged, which can sometimes hinder the circulation of the blood in the liver. This is called veno-occlusive disease (VOD) or Hepatic veno-occlusive disease.

This problem which may be severe in certain cases can cause liver pain, weight gain, jaundice and skewed liver tests, sometimes requiring those suffering from it to be kept in intensive care. That said, it rarely leaves any after-effects or puts your child's life in danger. Certain measures are taken to reduce the consequences of this disease occurring, by reducing water intake for example and by regulating urinary excretion (amount of urine and composition, called diuresis).

The risks for the bladder

Conditioning, sometimes the medication, and certain viruses can also damage the cells on the surface of the bladder, resulting in blood and blood clots in the urine. This is called hemorrhagic cystitis which can be very painful. When this type of bleeding occurs, it is usually a few weeks after the transplant.

Therefore, a urinary catheter may need to be inserted, so that the bladder can be properly drained.

It can take anywhere from a few weeks, up to several months to fully recover from hemorrhagic cystitis.

The risks related to aplasia

Infections

The risk of infection is due to the bacteria and microscopic fungi normally controlled by neutrophils. It is mainly present during the aplasia stage, two to four weeks after the transplant. Although this risk is significantly lowered in a protected room, it should not be ignored completely. The bacteria and fungi are susceptible to antibiotics or antifungals. The doctor will put in place medical supervision to anticipate or limit the risk of infection. Infections caused by certain viruses or parasites can be prevented by taking the right medication. They are monitored with blood tests and treated if necessary.

Some tests cannot be performed in an protected room (an X-ray for example) and therefore require the patient to temporarily come out of the room.

See "Why is your child in a protected room?" on page 42.

Blood transfusion

During the period where the marrow does not yet produce enough red blood cells or platelets, blood transfusions are required to make up for their low count.

Significant progress has been made in preventing transfusion-transmissible infections. The current chances of transmission are very low (around one in several million).

During the transfusion, it is not uncommon to suffer from chills, fever or a general feeling of discomfort. This rarely has any severe implications. Treatment may need to be prescribed to avoid another reaction occurring during the transfusions to come. This treatment is called premedication.

After the transplant, very specific rules relating to the transfusion are applied, which take into account the blood groups of the donor and the recipient. Afterwards, a new blood group card can be made as your child will then share the same blood as his or her donor.

The possibility of a transfusion relies on donors volunteering. There is surely somebody in your family or circle of friends who feels concerned and would like to help out. The best thing they can do is to give their blood or their platelets. It may not necessarily be given to your child in particular, but will be an important contribution which can help anyone in need of a transfusion. Feel free to ask your transplant team who will point you towards the nearest blood donation centres such as the "établissement Français du Sang" or Canadian Blood Services or "Héma-Québec" in Canada, "Croix Rouge" (Red Cross) in Belgium, "Transfusion CRS Suisse" in Switzerland or directly at the "Centre de Transfusion Sanguine des Hôpitaux Universitaires de Genève" in Geneva.

See "Donate" on page 171.

The risk of graft-versus-host disease (GVHD)

Graft-versus-host disease (GVHD) is when the donated bone marrow or stem cells attack your child's own body cells. During the first months following transplant, a type of white blood cell called the T cells (T lymphocytes) in the donated cells (the graft) see the tissue, organs or cells in your child's body (the host) as foreign and attack them. This reaction occurs in around half of all transplants and varies in intensity.

GVHD mainly affects:

- **the skin** (cutaneous GVHD) causing a rash and itching;
- **the gut** (digestive system) or (Intestinal GVHD) causing diarrhoea, sickness and loss of appetite;
- **the liver** (hepatic GVHD) and specifically the bile ducts causing yellowing of the skin (jaundice) and affecting the proper functioning of the liver on blood tests.

When graft-versus-host disease appears during the first four months after the transplant, it is called **acute GVHD** or sometimes fulminant GVHD. The severity of GVHD is evaluated by using a scale going from 0 (no reaction) to 4 (a severe reaction). This possible complication of a bone marrow or stem cell transplant can put your child's life in danger.

GVHD is dealt with in two phases:

1. **The prevention phase** which aims to prevent the risk of GVHD by choosing the most compatible donor, by giving the transplanted cells specific treatment and by giving your child immunosuppressive drugs. Treatment is also given to prevent infection.

2. **The therapeutic phase** which involves close monitoring once the transplant has been performed. This is essentially a medical examination which looks out for signs of GVHD (except in the liver which is covered by the blood test). When GVHD is detected, corticosteroids are often the first treatment given.

If the disease persists, other therapies may be used such as antibodies, other immunosuppressive drugs or medicine, photopheresis, etc.

Depending on the severity of the GVHD, this can be a very difficult time as patients often suffer from fatigue and muscle loss. Body image can become an issue due to the side effects of some treatments. For example the long term use of corticosteroids.

Graft-versus-host disease can arise later on, sometimes more than three months after the transplant, however rarely more than a year after. This is known as **chronic GVHD**.

Chronic GVHD is less intense than acute GVHD but it lasts longer, from several months to several years. It requires prolonged treatment but at lower doses than those given for the acute form of the disease. The parts of the body most frequently affected are the skin, mouth and eyes. Other parts can be affected and vary according to each situation. When the lungs are affected, it is classified as "obliterative bronchiolitis". It requires special respiratory medicines and monitoring in a respiratory department.

However, a mild GVHD can in fact help prevent relapse of cancerous diseases. This is because the transplanted cells will also attack the cancerous cells. When they are not all destroyed by the conditioning, the lymphocytes in the transplanted cells can destroy them. This is called the GVL (the graft *versus* leukemia) effect.

- *During the transplant period, you're expecting GVHD at any moment. In fact, you're completely focused on that. You're expecting something and then even for the smallest "thing" you immediately think that it's GVHD! The doctor did of course tell us that:"If the GVHD can be controlled, you've got nothing to worry about", and that is what you want to hear! (a mother)*

See "Fighting residual disease" on page 29.

Other possible complications

The risks associated with the catheter

A central catheter should not usually pose any problems.

However, it can give bacteria or fungus a place to grow, creating an infection.
Antibiotic treatment should be enough to get rid of it but occasionally the catheter needs to be removed and replaced with another.

The catheter can also get clogged up. There are several techniques to unblock it without needing to replace it.

When your child returns home, you will need to follow a few simple hygiene rules to minimize risks. Your transplant team will keep you informed of them throughout your stay in preparation for his or her homecoming.

Complications requiring intensive care

Certain complications such as organ failure (the lungs or heart for example) require specific methods or skills and therefore close monitoring. Under such circumstances, your child will be transferred to the intensive care unit. This can naturally be frightening for your child, and worrying for you and your loved ones because it also means leaving isolation. The aim is to help your child surpass this critical period with close monitoring of his or her condition.

Your child may also be transferred in anticipation of a certain complication, if the facilities in intensive care are able to help avoid it.

Your child is transferred upon the transplant physician's request and with the approval of the intensive care unit. Your child's transplant

physician and transplant team will continue to support you. Decisions are made in mutual consultation between doctors and physicians from both units.

The risk of infection after recovering from aplasia

During the months following the transplant, the T lymphocytes (T cells) are not yet able to recognise a microbe that has invaded a cell in the body. The duration of this period varies from person to person. It usually lasts from two to six months, occasionally more, especially if your child receives immunosuppressive therapy to treat GVHD. This is why patients must wait several months after the transplant before they begin to mix with people again.

Transplant patients are especially at risk of a bacteria called pneumococcus.

Preventative treatment (including penicillin) can help this, and a vaccination against pneumococcus will always be needed. Some children who receive transplants are more at risk than others. These include those who have had transplants for sickle cell disease, transplants after total body irradiation, children who have had their spleen removed and children with chronic GVHD.

The risk is lower after the reconstitution of the immune system or after recovering from chronic GVHD. The transplant physician will specify the level of risk for your child and will tell you what to do in case of fever.

Risks surrounding puberty, growth and fertility

The future sex lives of children who have received transplants should not be affected, although most will not be able to have children naturally. This is because the reproductive cells are destroyed by the chemotherapy or radiation therapy during the conditioning phase.

The progress that has been made in medically assisted procreation (MAP) can offer solutions to infertility for some children in the years to come. Reduced intensity conditioning, when instructed, allow some to preserve their fertility.

If preserving fertility is desired, the benefits and the risks of the procedure as well as the state of knowledge on the techniques will be explained.
As sexuality and fertility are sensitive topics to speak about with teenagers, they must be able to discuss such matters alone with their doctor or any other member of the team, and in particular the psychologist or child psychiatrist. They must also have a say in the final decision.

Before the transplant, your doctor may offer your child the option of preserving their reproductive cells. Collecting sperm for semen cryopreservation can be done

for teenage boys who are at an advanced enough stage of puberty, provided that he has not previously received chemotherapy.

As for younger boys and girls, a sample of ovarian or testicular tissue could be used. This sampling is carried out as an operation under general anaesthetic. Nonetheless, this still remains very much an experimental technique, and its instruction depends on your child's condition. We hope that continued research will one day allow us to use these tissues belonging to your child to let them produce reproductive cells. Please do not hesitate to ask your transplant physician about which technique would be most appropriate for your child.

Sometimes growth or puberty can be delayed or absent after a hematopoietic transplant. More often than not, this is due to deficiency of a certain hormone. As a result, growth, the onset of puberty and hormone levels in the blood will be monitored regularly by specialists called endocrinologists. These hormone deficiencies can be compensated for with a simple and effective treatment.

- *This form of infertility is not irremediable...It isn't a 100% certainty. (a doctor)*
- *As a parent, you want your children to have that possibility as well one day. (a father)*
- *Yeah infertility is a possibility... But he'll adopt his children, he'll have kids another way (a mother)*
- *I've been to the CECOS (sperm bank) to preserve my sperm. It's hard to accept but I will not have a child the normal way. (a young man, aged 16)*

See "Appendices - Fertility" on page 167.

Risks for the bones

There is a risk of bone fragility resulting from treatment received for leukemia before the transplant, as well as from treatment given for the transplant such as total body irradiation or corticosteroids used to treat GVHD. Such complications can normally be limited by increasing vitamin D and calcium intake or with exercise.

The risks of hypothyroidism

The risk of hypothyroidism (especially after conditioning with total body irradiation) requires monitoring by means of a simple annual blood test. Hypothyroidism is treated, if need be, with appropriate treatment.

The cardiac risks

Heart complications are rare. They mainly occur when the patient has had lots of chemotherapy before the transplant.

The ophthalmic risks

Patients who have received irradiation therapy can suffer from cataract years after the transplant. Cataracts are cloudy areas that form in the lens of the eye. Highly effective treatment is available for

this condition, including surgery under local anaesthetic.

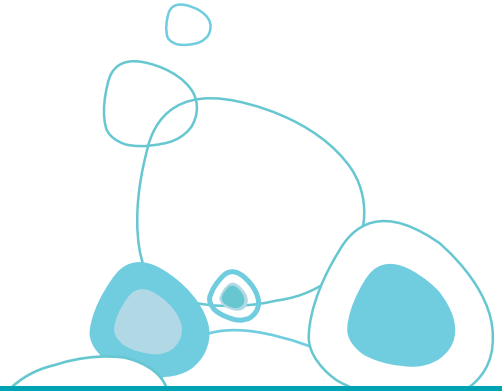
During chronic GVHD, patients may experience dry eye which is treated with artificial tears or certain eye drops. Regular eye tests would need to follow.

The dental risks

Dental defects, especially in the enamel can occur after a transplant for cancer. Regular visits to the dentist are therefore essential.

The risk of cancer

Several years after the transplant, cancer may reappear, particularly certain types of skin or thyroid cancer. This especially concerns patients who have received irradiation therapy. As such, a simple annual examination is required, carried out by a dermatologist (who will look out for abnormal moles and beauty spots on the skin) and by an ultrasound for the thyroid. The chances of a second cancer developing are very slim. Nevertheless, simple and effective treatment exists for these two types of cancer when they are detected at an early stage.



The risk of rejection

There is the possibility that the engraftment of the cells does not occur, which is rarely the case if myeloablative conditioning has be given for leukemia. It is when the neutrophils do not appear in the blood when expected.

There are cases where even after engraftment, the transplant is rejected. When this happens, is it almost always during the months following the transplant.

Treatment can quite often be given for such eventualities and can widely vary depending on each situation. It might be necessary to **perform a donor stem cell boost with conditioning or a second** transplant if the new cells are rejected, or for delayed or insufficient engraftment

The risk of relapse of the disease

Generally speaking, relapse is the main risk after a transplant for cancer. It cannot be ignored and largely depends on each situation. The risk of relapse gradually lowers as time goes on, and after a certain number of years, the risk becomes so low that we can consider it as remission.

Monitoring chimerism (also known as chimera or chimaera), or residual disease allows relapse to be detected early and therefore treatment can be given early, notably a **Donor Lymphocytes (or leukocyte) Infusion (DLI)**.

No prior treatment (chemotherapy or radiation) is necessary in this case.

See "Another donation: Donor Lymphocytes Infusion (DLI)" on page 104.

Are these risks life-threatening for my child?

Whatever the cause of the transplant, your child's condition can deteriorate and unfortunately lead to your child passing away.

- *The doctors explained it all to us, what would happen, that he could pull through, as well as that he might not make it. (a father)*

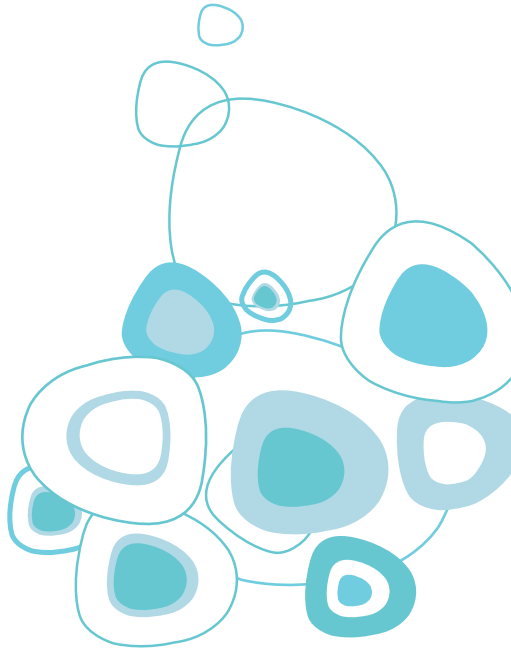
This is very different from what you knew before the transplant. Beforehand, the major risk was related to your child's disease yet with an allogeneic transplant, the risks are also related to the actual treatment.

If your child's condition drastically deteriorates after the transplant and there is no hope of recovery, the transplant team will do all they can to ensure that your child is given all the comfort he or she needs. This includes treatment against the pain or other symptoms of discomfort as well as psychological or spiritual counselling.

- *It's important to give as much support as possible to the child and the family. This means providing a different type of care, which involves supporting children at the end of their lives. (a nurse)*

Everything is done with due respect to your child's quality of life, his or her projects, your beliefs, and with your consent and in agreement with the palliative care team.

Don't be afraid to approach this difficult subject with your transplant team, well before the transplant if you feel the need.



Isolation, methods used

Most transplant teams have prepared documents to help in all the day-to-day aspects of the transplant. Please be encouraged to read them if they have been made available.

Please do not under any circumstances hesitate to ask for any further details, and should any information or instructions not seem clear enough, to ask for some clarity.

Different types of isolation

In most cases, your child will be in a protected area for a period generally lasting three to six weeks. It will be the first time for some children whereas others may have already stayed in isolation in a protected area. Therefore, it will not be as unsettling for the latter when they move into this type of room later.

Aplasia begins approximately eight to ten days from the beginning of the conditioning stage.

During this period, your child's body cannot defend itself and this makes it extremely vulnerable to infection.

It is therefore necessary to minimize exposure to microbes until the marrow has been rebuilt and is functional again (recovery from aplasia).

Depending on the type and cause of the transplant, as well as the practices of each centre, different methods and durations of isolation are proposed. Aplasia is less intense and shorter after a transplant with reduced intensity conditioning. A private protected room is not necessarily needed and the hospital stay generally does not last as long as a myeloablative transplant.

All in all, 4 types of rooms exist.

Rooms without an air filtration system

A single room with or without airlock and without air purifiers or air cleaners, known as a standard room.

Rooms with an air filtration system

A single room with a portable or fixed air purifier installed which cleanses the air of any microbes with a filtration system.

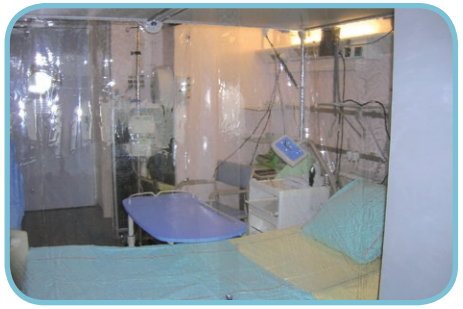
Rooms with an air filtration system and positive pressure

In addition to an air filtration system, positive pressure rooms ensure that air flows out of the room instead of in, so that any airborne micro-organisms or bacteria that may infect the patient are kept away. This means that the air flows towards the corridor, and then from the corridor outside. The room looks no different from any other standard hospital room.

It can be equipped with an airlock or antechamber with two doors (both must not be opened at the same time to avoid air from entering the room).

Laminar air flow rooms

The concept is the same except that the air flow is laminar (the air streams are all parallel). This prevents any microbes deposited on the floor from getting back into the atmosphere. In many rooms with laminar air flow, the bed is surrounded by transparent curtains.



These are only general principles and if you happen to visit several transplant centres, you will notice that isolation methods differ from one centre to the next.

Each team has made its choice by taking into account its own features to ensure that the isolation method works as efficiently as possible.

Similarly, the length of stay in isolation and the precautions that must be taken when leaving hospital are not the same in all the centres and depend on your child's condition.

If at all possible, ask to visit a room similar to the one your child will stay in before the transplant.

- *We felt a lot better once we had visited the ward before the transplant. (a mother)*
- *We had a look at the room which reassured me a lot. (a mother)*

A hospital stay in a protected room comes with constraints, the most obvious one **being unable to leave the room**. It is important to prepare for the hospital stay with your child. You could suggest (provided that it's authorised) that your child decorates the room, brings some home comforts or sentimental items and objects, as well as various fun activities to keep him or her entertained during the stay. Your transplant team will let you know which objects can be brought into the room.

Precautions to be taken when entering and leaving the room

Washing hands and wearing a gown, gloves and in some cases a mask are some of the precautions taken to reduce the risk of microbial contamination. Any person who enters the protected room must respect the clothing and hygiene requirements that will have already been outlined. To protect other patients, washing hands is also important when leaving the room.

- *I sent a photo to my friend of my husband and myself wearing masks and hygiene caps. She replied... "Your daughter is lucky having two surgeons for parents". But obviously that wasn't quite true! (a mother)*
- *In my room, people could not just come in whenever they wanted... It is called [hesitation…] a hotel room! (a 6-year-old girl)*
- *The hospital staff told me that I would not be able to kiss my girlfriend once I'd had the transplant. I had a girlfriend but I preferred to end our relationship. It was hard for me just as it was for her. (a young man, aged 16)*

The comings and goings of the medical staff are limited and the different types of treatment are grouped together in order to keep people entering and leaving the protected room down to a minimum. Visitors may only visit one at a time, although two may sometimes be permitted.

Privacy

It is very difficult to give your child complete privacy under such circumstances. The close proximity between the child, the parents and the medical staff is often quite hard to live with. It is important to leave your child some personal space and privacy at times, physically speaking but also during those moments where they need to be alone. This is particularly important for teenagers, giving them a moment to "let it go" without wanting to make you worry.

- *There is no privacy. There isn't even a small curtain when teenagers need to use the chair which is the toilet. (a mother)*
- *My son is 17 years old and it's hard leaving him on his "island of solitude" in isolation, even if he tells me he needs it. (a mother)*
- *During the transplant, I got the impression that we were bothering him being there! (a mother of a teenager)*
- *We tend to notice that children tread very lightly when talking about the disease. They try to keep their worries to themselves, to reassure their loved ones! (a doctor)*
- *I was alone with the doctor when she explained the transplant to me. It was better that way because it was the only time I was able to cry. When she left, I quickly wiped away my tears and when mum and dad came in, I pretended I hadn't... I didn't want to make them sad. (a 17-year-old teenage girl)*

Diet

Your child's diet will be monitored by a dietician. During the period of isolation, food may be served hot depending on the centre, which can give food a different taste, which is often already a side effect of the treatment and medication. This may result in your child developing different tastes, or even going off certain food altogether.

This is common and is usually temporary although it still must be taken into consideration. The symptoms of oral mucositis will only make eating even more difficult. Due to all these reasons (pain, impaired taste, the quality of the food), your child probably will not eat or will eat very little during aplasia. A meal tray will still be made available just in case.

To compensate for this lack of nutrition and avoid weight loss, patients can either be fed intravenously otherwise known as parenteral nutrition (PN), or with a feeding tube (also called enteral nutrition, EN) in which a tube is placed through the nose and into the stomach. This is extremely important because malnutrition increases the risk of infections and complications.

See "The risks related to conditioning - Mucositis" on page 58.

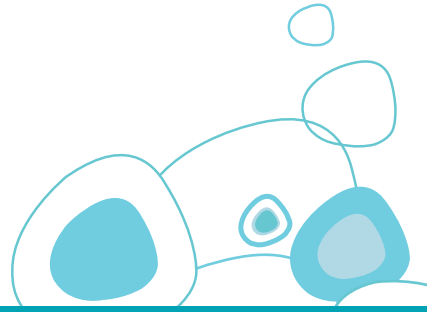
Clothing

Patients are advised to wear cotton as it is comfortable. Furthermore, some transplant centres recommend washing clothes at a high temperature as well as sterilizing them. Cotton is also the most suitable fabric for this type of washing.

Make sure that your child has enough home comforts and things to keep him or her occupied during the day as well as during the night. As well as giving some structure to their days spent in hospital, it's also good for their morale.

Clothing requirements can vary from centre to centre. Clothing may not always need to be washed at a high temperature or sterilised and you only need to wear a non-sterile gown with a mask and wash your hands.

My daughter was in her blanket and I was in my pyjamas. Then I suddenly had a brainwave and I found her style as well as my own. (a mother)



Accommodation during the hospital stay, loved ones

"Ronald McDonald House"

It is not uncommon to find "Ronald McDonald House" which are places where parents can stay while their child is in hospital. They are often funded by charities and offer parents the possibility to prepare meals or to eat in a restaurant with others.

Parent-child rooms

Some transplant centres offer rooms which allow parents to sleep with their child at night. It is not obligatory but remains an option. Try to think about what would be best for your child and your family, what would be best for keeping some stability in everyone's life and what would cause the least worry and fatigue.

Your child's loved ones

During the course of the transplant, family life will be greatly affected, bringing all sorts of repercussions. It could be in material terms, socially or spiritually. It is important to prepare yourselves for this period during which you may go through moments of doubt and discouragement. This is due to the risks surrounding a transplant, the complexity of the procedure, isolation, the importance of not neglecting other members of the family, the sometimes unexpected incidents, periods of waiting, uncertainty and worry, the deep fatigue that affects your child as well as yourself, and the possible intensity of certain side effects.

- *It's hard to be alone. Sometimes I pressed on the button not because something was wrong but just to have a chat with the nurses. (a 13-year-old teenage boy)*

- *In the sterile room, you're isolated, it's hard. I spent a month in there without leaving once. I did what I could to make the time pass quickly. I didn't just give in completely, instead I did some weight training with my dumbbells. (a young man aged 16)*

- *I missed my family back in Cameroon more than anything, especially my grandmother who raised me. She knows me better than anyone. (a young man, aged 16)*

The team – particularly the psychologist, the social worker and volunteers – will help you find the resources needed to give your child all the support he or she needs, and the same applies to you and your family.

▸ You and your child

You and your child will constantly be surrounded by people on a daily basis.

See "Teams, support, assistance" on page 127.

During this time, it is essential to take into consideration not just what your child needs but also what you need and to try and strike a balance between the two so that you do not exhaust yourself during the transplant process. Take the time to recharge your batteries and get enough rest.

- *Every little thing we do that isn't related to the transplant in some way gives us a feeling of guilt. (a father)*

- *Take the time to breathe a little! Revitalising yourself will also help your child relax. (a mother)*

- *We can go home at night with the peace of mind that our child is being looked after by nurses and a whole team of health professionals who are there for his every need. (a mother)*

Physically being there as much as you can for your child is important, although it can be difficult fitting it around the rest of your family and daily life in general. Separation is especially difficult for very young children and it must be taken into account when organising your life around your child.

- *Not physically being there was especially difficult. (a father)*

Here are some pointers that can help you:

The medical team will always clearly explain to your child what is happening, and will always help him or her through difficult moments. Speak to your child, even if he or she is very young.

If your child is a teenager, it can be slightly more difficult as they tend to keep things to themselves. It is not uncommon for them to have mood swings where they become aggressive or refuse to see people. Your child will let you know how far he wants the conversation to go.

- *Some children become aggressive, refuse to take their medication, refuse to see people, sleep all the time... It's up to us as parents to stay positive, to smile and be in a good mood... If the parents stay positive, it rubs off on the child. (a mother)*

- *During my transplant, I just wanted to close the shutters, sleep, and be left alone. (a young man, aged 16*

Listen to them. Encourage him or her to speak to the members of the transplant team.

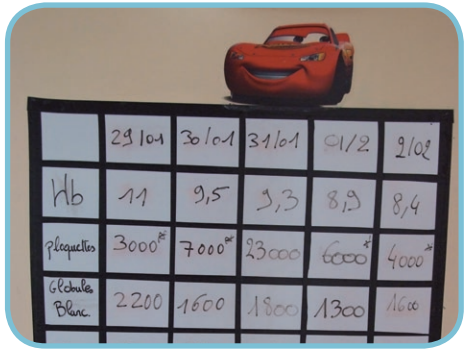
Children or teenagers are often more at ease speaking to certain team members more than others. What's important is that he or she finds somebody that listens to his or her questions and fears.

- *I speak about my illness to my friends. It feels good to talk about it with friends who I trust. (a 13 year old teenage girl)*

- *My son got through it thanks to his dog that he wanted to find, his Lego Star Wars, his friends and his girlfriend. (a mother)*

Really try for both of your sakes, to maintain their relationships with loved ones and classmates, by phone, on the internet (if there's a computer in the room) or in any other way possible.

Try and decorate the room a bit by bringing in objects, games, photos or anything that is authorised in the transplant unit.



Putting laminated photos in the sterile room helps to give a more reassuring atmosphere for the child. It also gives the nurses a conversation starter so that they don't just speak about medically-related things and can see your child as more than just a sick patient. (a mother)

Siblings

Right from the moment your child is diagnosed, his or her siblings often suffer emotionally. They may spend long periods alone and are worried about their brother or sister.

The brothers and sisters are the ones most affected by all this. (a mother)

The doctors should see all the family to explain to them what is happening! Even myself, I would have liked to have seen one when my sister first became ill who explained the blood test, the transplant and all that, and after the transplant to know how it went, if my sister was OK, and why we weren't allowed to see her. (a 7-year-old sister)

They may also get the idea that they do not mean as much to you as before. They cannot spend as much time with you anymore which can inevitably lead to feelings of jealousy between siblings. At the same time, they feel guilty about feeling jealous as their brother or sister is in a critical condition. These complicated, mixed up feelings are difficult for them to cope with, especially as you will not be there much to speak about it with them.

When my sister was having her transplant, dad was always at home but mum was never there and that made me sad! (a 13-year-old girl)

Bear in mind also that they might be sad about not being compatible donors for your child. Tell them clearly that it is not at all their fault and that it's purely dependant on the HLA matching which is entirely random. Mention that they already showed how brave they are by giving a blood test for the HLA typing, and that you are proud of them for that.

My daughter was hugely disappointed when she found out that she couldn't be a donor. (a mother)

On top of all this, there's the fact that siblings may not be able to come and visit your child while he or she is in isolation (young children in particular are more likely to carry germs and microbes) which naturally makes them sad to not see each other every day.

- *The worst thing about the transplant was not being able to see my brother who wasn't allowed to come. At least we could talk to each other on the webcam! (a 19-year-old young man)*

- *If only they could see each other when they wanted... Many children get incredibly depressed when they can't see their siblings. (a nurse)*

It is vital that you remind siblings of their key role, and that you tell them how much they mean to you and how much you love them. Help them be there for their brother or sister in hospital by writing a few kind words, sending them photos, drawing pictures and so on. Find them a role or give them a task to complete during the transplant. Depending on their age, it could be helping around the house. It doesn't matter how big or small their role is, it just needs to make them feel valued and proud of themselves.

- *During my brother's transplant, mum was often not there. I wasn't a compatible donor whereas my little brother was… I made dinner for dad and I liked it because I felt like I had a purpose. (a 14-year-old sister)*

If necessary, a member of the team (a doctor, nurse or psychologist) will come to meet and support siblings throughout this period. They may also benefit from tutoring to help with their school work.

Psychological support may be needed away from the hospital.

You are likely to find somebody in your family, or among your friends or professional entourage that is capable of stepping in to help take care of your child in hospital or his/her siblings at home. It is important, if possible, to dedicate time for your kids who are back at home.

Grandparents, friends

The transplant is also an ordeal for your family as well as for loved ones. The hardships and needs will vary depending on the family situation (single parent, partners, separated or divorced). This can be the cause of problems or misunderstandings.

It is recommended that you designate somebody in the family or within your circle of friends to keep everyone informed and regularly updated on

your child's condition, so that you do not have to spend too much time answering all the phone calls and can concentrate on being there for your children.

- *It's like being a sponge and a buffer at same time when you're the designated contact person. (a mother)*

- *We wrote a message for our friends and family and we sent it to everyone. As a result, we weren't being asked so many questions and everybody had the same information. (a father)*

Grandparents have a valuable role to play at the hospital as well as with your other children as it is them who usually takes care of them in your absence. They help give some structure to daily life.

- *When the donor and the recipient are both in hospital, you've got to be there for both of them. They're on different floors. My eldest daughter has chosen to be with her grandmother whereas we were in the lift on our way to see her little brother. (a mother)*

- *My mother was on unpaid leave. It was to help take care of the little ones back at home. (a mother)*

The families of other hospitalized children

Parents frequently express their desire to speak to other parents "who have been through what they are going through". Feel free to get in touch with the relevant charities and organisations and ask them if it's possible to meet a family that has had a similar experience to yours. This type of meeting can often be very beneficial and worthwhile.

Apart from that, you will be in close proximity with the families of other children hospitalized at the same time as your own. Although families can help support each other, it can also cause you to worry. Children who are suffering from multiple complications need to be hospitalized for a long period, whereas those whose transplant was relatively smooth and without complication return home sooner.

As a result, you are more likely to come across children and families who have encountered complications. Remember that **no two transplants go the same way.**

Whatever happened to one child will probably not happen in the same way to yours. Please also note that each family has the right to confidentiality. This is why members of the team will not respond to any medical questions concerning another child.

If you are feeling worried after speaking to another parent, talk about it with anyone on the transplant team.

- *The mutual support between parents of children receiving transplants is very important. Rather than leaving someone in a bad way, we told them to go and speak about it with the doctor rather than imagine what could be wrong, and the doctors were always there to help. (a mother)*

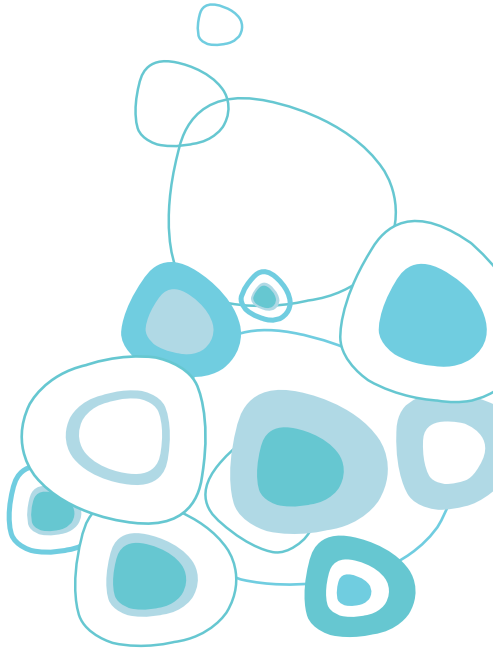
- *Sharing your experience with other parents has the same effect as a pressure relief valve. (a mother)*

- *We met this other family completely by chance during a pre-transplant visit. It really was a wonderful gift for our daughter and ourselves, it gave us hope! My daughter (11 years old) even stayed in contact with this other child during the transplant by using the internet and that really did her the world of good! (a mother)*

- *We forged close friendships with other parents. (a mother)*

- *Listening to other parents is a bit like a double-edged sword. What happens to another child won't necessarily happen to yours. (a mother)*

- *I stopped going to the parent room because I could no longer cope with my own anxiety. (a mother)*



Notes

2. THE DONOR

The donor must carry out different formalities that are precisely specified during pre-donation screening.

Some pre-donation tests are compulsory. This assessment can eliminate potential contraindication and ensure the safety of both the donor and the recipient by making sure that the donation does not put either of them at avoidable risk.

In most countries, donation is regulated by law. The donor must express their desire to donate without any medical or family pressure. Their consent is expressed and signed in the presence of judicial authority, which is the tribunal de grande instance in France (French high court), Quebec Superior Court in Quebec, whereas written consent is sufficient in Belgium and Switzerland. The law allows him or her to withdraw at any time. That said, he or she will have been fully informed of the consequences of his or her decision for the recipient. The donor is aware that withdrawing after the beginning of the preparation for the transplant may be fatal for the recipient.

A related donor that is a minor or under guardianship must also give consent before an expert panel or a court, depending on the country.

Anonymity

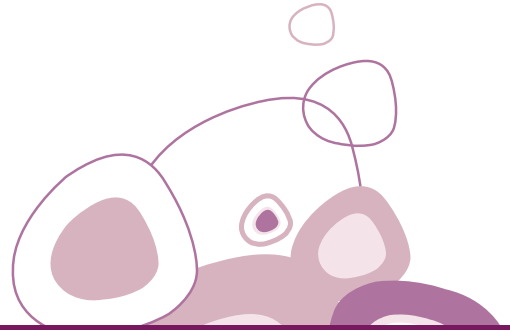
If the donor is unrelated, the donation will be anonymous. This means that the donor will not know who will receive the marrow just as the recipient will not be aware of the donor's identity.

However, in the majority of countries where the donor could be from, the donor and the recipient can send each other anonymous letters if both parties express their wish to do so.

Altruism

The donation is free which means the donor will not receive any money. The donation is therefore a truly selfless act.

Several million people from across the world have agreed to voluntarily donate their marrow and peripheral blood stem cells when they are needed.



The different types of donations

Donating bone marrow

The bone marrow of the donor will replace that of the recipient.

The donor will stay in hospital between 12 to 48 hours. On the day of the transplant, the marrow is collected in an operating room from the hip bone using a needle and syringe, all under general anaesthetic. The needle may need to be inserted into several parts of the hip to ensure enough bone marrow is obtained. The marrow is then sent to the laboratory to be filtered and treated.

If possible, the transplant will take place the same day or the day after. In rarer cases, the donor's marrow is frozen then thawed on the day of the transplant.
The donor's marrow starts to quickly rebuild itself during the hours following its removal. It will have completely recovered after a few weeks, just like a blood donation.
For several days, the donor may feel pain, which is usually only mild, on the points on the hip bone where the injections were made. Taking standard painkillers such as paracetamol or acetaminophen are very effective in calming this pain.
Iron supplements may also be prescribed.
The medical risk for the donor is the general anaesthetic, however it is very small for somebody in good health, whether they're a child or an adult.

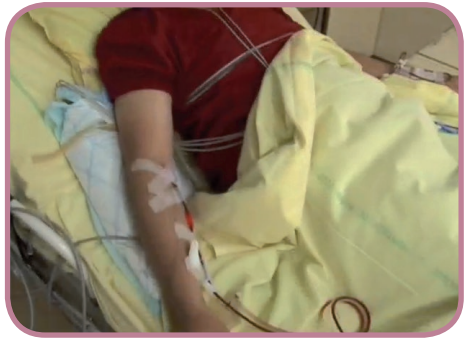
Donating blood stem cells

These blood cells are also called peripheral blood stem cells.

For a few days, the donor is given subcutaneous injections of G-CSF (Granulocyte colony-stimulating factor) at home. It is a type of **growth factor** that stimulates the bone marrow and makes stem cells move from the bone marrow into the blood. Harvesting the stem cells is relatively painless. They are collected through tubes going from the veins into a cell-separator machine. The procedure is done while the donor is awake.

The blood will circulate "out of the body" by going through a single use filter.

The blood is collected from the vein and goes to the machine that separates out the stem cells. The machine only keeps the white blood cells that contain the stem cells needed for the transplant. After going through the machine, the blood (red blood cells and platelets) is injected back into the donor's body.



This procedure generally lasts from three to five hours however sometimes it may need to be done two days in a row if not enough stem cells were collected the first time around.

The transplant either takes place later that day or the day after, or the cells are frozen and stored to be injected later. Due to the use of G-CSF (Granulocyte colony-stimulating factor), minors are unable to donate peripheral blood stem cells in France and Switzerland.

The stem cells will quickly settle into the bone marrow and start producing new blood cells.

The use of growth factor (G-CSF) can cause bone pain, flu-like illness, even insomnia and in rare cases nausea. Standard painkillers such as paracetamol or acetaminophen are very effective in relieving such pain.

Donating umbilical cord blood

Umbilical cord blood from new-born babies contains large quantities of hematopoietic stem cells. If the parents have given their consent, the blood found in the umbilical cord and placenta are collected just after the baby is born and the cord is cut. The procedure therefore does not pose any risks for the newborn or the mother.

The placental blood, or cord blood is then frozen and stored at a cord blood bank for future use. When needed, it will be thawed on the same day as the transplant.

Umbilical cord blood stem cells are less likely to be rejected than bone marrow or peripheral stem cells. This means that they can be used even if they don't perfectly match the HLA type of the recipient.

Another type of donation: Donor Leukocyte Infusion (DLI)

Sometimes, the donor may be asked again to donate lymphocytes for the recipient, i.e. a Donor Leukocyte Infusion.

It is intended to prevent or fight against relapse of the disease and even boosting engraftment by reinforcing the donor's cells.

No medication needs to be taken beforehand. Blood is collected using a cytapheresis device (blood cell separator) with no prior G-CSF injection needed.

It has no consequences on the donor's health. Straightforward screening however is essential.

If the donor is a family member

Transplant is a complex phenomenon where the recipient's body reacts with the graft and tries to incorporate it as part of its immune system. The donor is in no way responsible for rejection of the transplant, relapse of the disease, or for any other complications that could be severe and in some circumstances, cause the death of the recipient. Instead, they have done everything that they could to try and help the patient recover.

It is essential that the donor can express his or her feelings, fears and potential concerns.

Whether knowingly or unknowingly, there is a certain pressure exerted from the medical team and the family on the brother (or sister) that can potentially be a donor. Before appearing before the expert panel, the donor will need to sit down and have a chat with somebody neutral in respect to the transplant so that they are given an opportunity to say how they really feel about it.

A clinical psychologist can distance themselves from the transplant and its implications, and help your child open up about his or her fears and concerns. The various teams must be very attentive to this.

Related donors – from the parent's point of view

- *Our donor son quite often puts things straight by coming out with: "If I had not donated, my sister might not be with us anymore." He also says that he is her "saviour". (a mother)*
- *It was actually extraordinary. When our daughter decided to donate, she wasn't scared at all... The situation had been explained to her. She saw how much her sister was suffering and realized that she could help improve her health and quality of life. I think it was a priority for her. (a father)*
- *I've got two kids, one has received a transplant, the other has donated. From now on, we celebrate three birthdays: both of their birthday and the anniversary of the transplant which just might have become the most important of the three. (a father)*
- *If my son had said no, I would have had to accept it, it's his right after all. But he gets on so well with his brother that I could not imagine him ever refusing. (a father)*

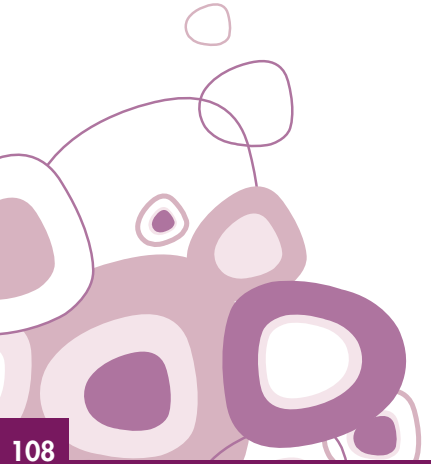
Related donor – from the child donor's and siblings point of view

- *I'll help you out. (An 8-year-old sister donor speaking to her brother)*
- *I was pleased, I wanted my brother to get better but at the same time I was scared about donating... I'm so glad I did it in the end! (a 12-year-old brother donor)*
- *I really want to give him my marrow, but he has to promise to give it back! (a 5-year-old sister donor)*
- *Go find another doctor, one who doesn't need me to make my brother better! (a 7-year-old HLA matched sister)*
- *I am glad that I'm not compatible with my brother; if it had gone wrong, I would have never forgiven myself. (a 13-year-old unmatched sister)*
- *When I found out that I was a match, I thought it was great that I was able to help my brother but at the same time I was scared, scared that it might not work! (an 11-year-old sister donor)*
- *I knew that I could refuse if I wanted, but it never even crossed my mind. If I met a child that refused to donate, I would tell him: "Think hard about the consequences!" And if I were his or her parents, I wouldn't force them to donate but if they refused, I'd tell them: "It's your choice and it's a shame!" (a 12-year-old brother donor)*
- *I was not nervous. They are used to removing marrow, they've already done it so many times. I knew that there was no danger involved. (a 12-year-old brother donor)*

Related donors – from the recipient's point of view

- *My sister donor [ten years old] is a little more assertive and my brother [13 years old] felt inferior and powerless. (A 17-year-old teenage girl)*
- *My sister was my donor. It could have also been my brother and I think he would have agreed to donate. It shows how much we mean to each other. (a 10-year-old boy)*
- *It's a miracle having a donor! To "return the favour", I now need to succeed in my life. I feel really close to him. (a young man, aged 16)*

- *The doctor explained to me that my bone marrow wasn't working and that I needed to find a donor. We thought to ourselves: "That's going to be tricky!" In the room opposite, there was a young child who had seven brothers and sisters and none of them were a match. Just after my birthday, we found out that my sister was compatible. I was glad, I was lucky, but at the same time I was scared for her because she was so young. (A 17-year-old teenage girl)*



Unrelated donors

- *We knew that this bone marrow could save our son and intimately a bond was formed with his anonymous donor. (a mother)*

- *Even if the donation is anonymous, you can still be pleasantly surprised... A few days after his transplant, our son received an anonymous letter from his donor, made possible by the biomedicine agency (l'Agence de la biomédecine) that manages donations. He took news from our son who was able to answer him and thank him! (a mother)*

- *I know that my donor is German. I sent him a letter in German because my mum speaks German and I drew a picture for him. I told him: Thank you for giving me your blood. (a 7-year-old boy)*

Notes

3. AFTER THE HOSPITAL STAY, RECOVERING

Leaving the transplant unit – leaving the hospital

When your child has a normal platelet and white blood cell count, has enough neutrophils in his system, shows no signs of fever, and is eating and drinking enough, his or her condition is considered good enough to return home. The long-awaited day has finally arrived!

Each transplant team will give you information sheets, handouts, booklets etc before your child comes out of hospital. They will contain all the practical information on hygiene (body care, cleanliness around the house), diet and nutrition (foods permitted, preparing meals, conserving food), wearing a mask, lifestyle habits (outings, visits, sun exposure, activities, pets, smoking, alcohol), how to effectively monitor and care for the catheter, taking medication, implementing proper infection control measures, and so on. The transplant team will go through these measures with you and apply them to your situation.

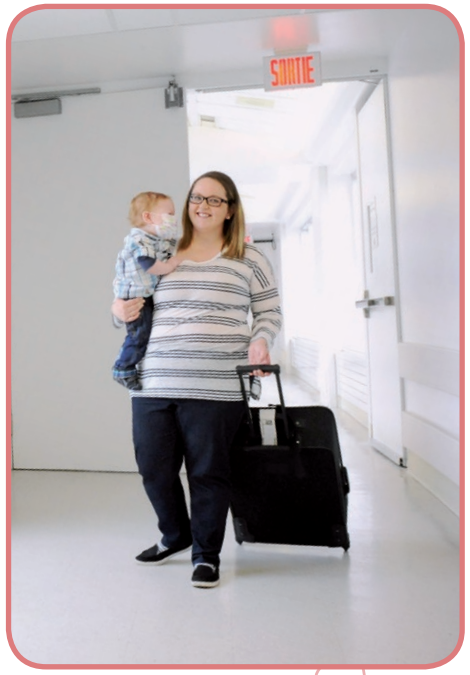
In some cases, a child may be well enough to leave the transplant area but not well enough to leave hospital altogether. Depending on each situation, your child will either stay in the same department but in a "standard" unit or in an aftercare department or in a hospital a bit

closer to home if possible, just until he or she is completely restored to health before the homecoming.

- *The transplant coordinator nurse tells parents all they need to know about their child returning home. Though often parents have already asked us about it at an earlier stage. They've been asking us how it's going to be for quite a while now. (a nurse)*

- *One day, I knew that I just had to go to beddy-byes one more time and then I would be back home, I was really happy. (a 6-year-old girl)*

- *When the doctor told me that I could remove my mask in my daughter's room, I straight away kissed her bald head. It was the best kiss I've ever given. (a mother)*



Coming back home: coping with emotions and fatigue

At first, your child will probably need time getting used to the feeling of being "out in the open air" and other simple things that we may take for granted.

- *When I first came out, it felt weird after being in a sterile room for so long. I was free again, I could see my friends again and sleep in my own bed again. (a 13-year-old teenage boy)*

- *Everything feels new again when you get back after spending 55 days away! Even the slightest sound or movement makes you sit up. Even on the way out of the hospital, you can smell the air. I even wanted it to rain heavily... (a 17-year-old teenage girl)*

Despite this being a moment of happiness for everyone, you may also be feeling worried and getting back into daily life may seem difficult, especially as you are probably exhausted.

- *For a month, I basically didn't sleep. Two years later, I think I'm still recovering from it physically. (a mother)*

It is normal that you are feeling this way as you have been in a rather sheltered environment where there was constantly someone from the team to support you and answer your questions. Now you're the one in charge of caring for and giving treatment to your child, and to watch over his/her condition and monitor any side effects. You will need to establish a new rhythm to everyday life which is adapted to the different requirements of children who have received transplants.

- *The hardest thing about their homecoming is that suddenly we're completely responsible for ensuring levels of hygiene, what our child can or cannot eat... We find ourselves constantly needing to ask the team what we can or cannot do just to feel reassured. (a mother)*

We are confident that with all the information you have at your disposal, coupled with everything you have already learnt from being around your child and the transplant team during the transplant, you will be perfectly capable of caring for your child correctly. Give it time and you'll soon see that you know what to do.

Your child

You child will have been through some challenging periods during the hospital stay, separated from his/her family, friends and way of life. Isolation will have been an ordeal, along with all the treatment. Perhaps he or she was afraid of dying.
It is likely that you'll notice changes in his/her behaviour. His or her reactions could surprise you both. To start with, your child will be tired, surprisingly even more so than when in hospital. The home environment is larger than a hospital room, allowing him or her to move around more. They will gradually regain their energy and strength, and will want to take part in new activities.

Feelings of sadness, discontentment and aggression are not uncommon. They may suffer from disrupted sleep and therefore often wake up during the night. This is to be expected after a bone marrow transplant and is just a phase. As your child will have become accustomed to the nurses quickly bringing him or her what he/she needs, they may appear demanding, and even intolerant. It will just take a bit of time reinstating those family values that were already established before the arrival of the disease.

- *When I returned home, I did not really feel like seeing many people. Mainly because I never told the friends that I used to hang around with that I was going to have a transplant, nor that I had this disease... I didn't tell them about it because I didn't want them to change the way they act around me. (a young man, aged 16)*

This period can be full of ambivalent feelings for teenagers. They don't take kindly to the idea of being "supervised" and highly sheltered like they were when they were a lot younger or as they were during the transplant period. Even if they feel the need to be supported and surrounded and sometimes even protected, they may also want to make their own decisions and make their own choices.

Speak with your child, tell them that what they are feeling is completely normal and that if they wish, they can speak about it with their transplant team, psychologist or anyone else.

Siblings

While your child was in the hospital, they were worried about him/her. They may have been scared that he/she didn't recover. Now that everyone is back home again, they will be happy and think that life will go back to normal again, but it will take a while until everyone stops feeling so tired and worried all the time.

Siblings may think that their brother or sister is being spoilt with all this care and attention. This can lead to them becoming jealous, and they might feel like you love them less than their recovering brother or sister. This is their way of telling you that they need your attention.

Try and make time for all of your children. They will feel reassured to see that you care about them just as much.

Encourage them to share what happened during the transplant period, help them to convey how they are feeling today.

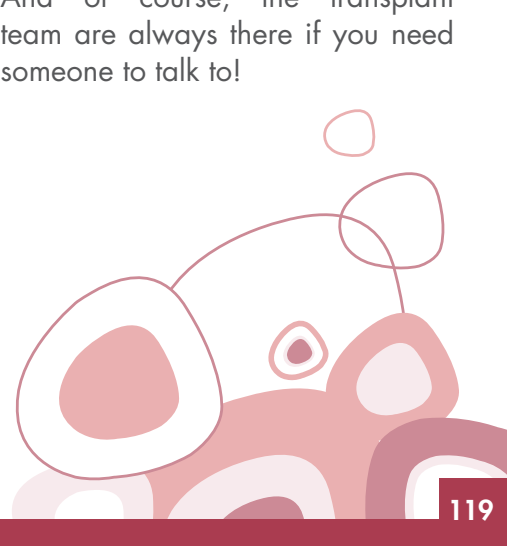
Tell them also about how you're feeling and your fatigue. You could even ask them for their contribution, if they wish, by proposing that they play a significant role in restoring family life to how it was before.

You as parents

This period of transition will also require you personally to make some adjustments. It is quite normal that you are feeling drained of energy, and you may well be feeling depressed. Take it easy and recharge your batteries. Be careful not to overdo it and make sure people are always there to help. Keep in touch with your loved ones but at the same time think about what you need.

- *The whole thing did put strain on our relationship. For seven months, I lived far away from my husband and my son. It almost felt like I only had a daughter. When I came back home again, things were difficult between my husband and I until we got the chance to discuss it. I felt like I'd just got back from a warzone. (a mother)*
- *It always really surprises me that people keep things bottled up and that two people can suffer in silence next to each other without saying a word about it. In reality though, they are going through the same turmoil. (a mother)*

Confide in your loved ones and those that you feel will understand. And of course, the transplant team are always there if you need someone to talk to!



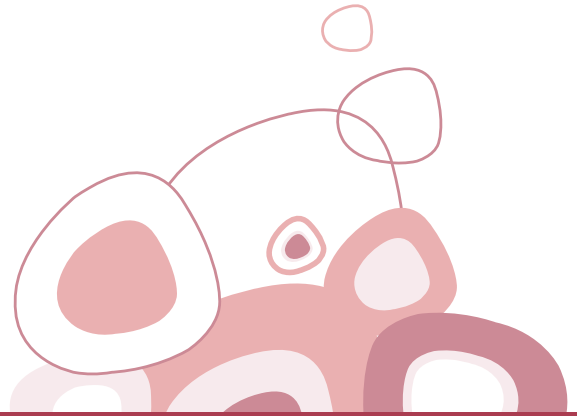
Relatives, loved ones

The resumption of normal family life requires understanding and support from family and friends. It takes time getting used to the rhythm of daily life again.

Your family had to get used to the changes while your child was gone. So naturally it will also take time settling back into the family sphere as well as into your social circle. Tell your nearest and dearest what you need to do, and ask them to be trusting and patient. Neither you nor your child should despair if your loved ones seem to be less and less understanding and patient as time goes on. You might be feeling out of sync with everyone around you.

Even though they want to help, it's hard for them to completely understand what you're going through. Support groups, your psychologist, and even the parents that you met in hospital can help you share your feelings.

- *It isn't easy when your child comes back home. The kids had gotten used to things without their sister there. Everyone needs to adjust to how things were before. (a mother)*



Precautions to be taken

The risk of infection

During the first month post-transplant, the risk of infection and GVHD (graft-versus-host disease) is ever-present.

To prevent infection, certain precautions concerning diet, visits, outings, pets and so on must be taken. Your transplant team will go through these measures with you, and will apply them to your child's condition and surroundings. We strongly advise getting any work done on your house. Building or DIY jobs do not help reduce the risk of infection, and can in fact increase it.

Look out for any unexpected symptoms such as fever, shortness of breath, cough, diarrhoea or rash. As soon as you notice anything unusual, call your transplant team immediately. Time is of the essence and the sooner you act, the more chances there are of controlling the situation.

Diet

Food precautions will need to be taken back at home for several months (6 to 12 months). These are very strict during the first three months after being discharged from hospital.

To avoid food getting contaminated, we recommend that you frequently wash your hands, make sure any meat is well done, wash any fruit and vegetables thoroughly and avoid eating them raw.
If your child is losing weight, tell your doctor.

Medication

Do not stop giving your child any medication without your doctor's approval. Remind your child to take it, and make sure they are aware of why it's important. This is especially relevant if your child is a teenager.

- *My son is too laid-back about it. He forgets to take half of his tablets. (a father of a teenager)*

Tell him or her that he/she will gradually need to take less and less medication the more his/her immune system starts to function as normal again. In the end, most children who have fully recovered from a transplant don't need to take any related medication and lead normal lives.

Vaccinations

Make sure your child receives all vaccinations scheduled by your doctor. They are vital for boosting your child's immune system which was lost during the transplant.

After care and hospital visits

In the early stages, close monitoring is provided in day clinics, starting at one or two visits per week, then once every two weeks, then once a month, or in other words less and less frequently as time goes on. Medical staff will assess how the transplant is developing as well as the disease. Chimerism testing (engraftment analysis) analyses how well the donor's cells are settling into your child's body.

Sometimes patients will need to return to hospital during the months following the transplant due to a complication. This can be worrying for you and for your child but please be aware that most of the time, it is due to a complication with no severe consequences and time is simply needed to understand and treat it. It may take a few days, sometimes a few weeks, although that does not necessarily mean it is serious. As always, if in doubt, ask your transplant team who are there to help.

- *Going back to hospital after the transplant is especially difficult because you feel emotionally and physically drained. (a mother)*

- *I talk to my daughter, I show her photos of herself but she's convinced it isn't her. Maybe she will accept it when she gets older. (a mother)*

When your child reaches adulthood, he or she will be monitored on adult wards where the transplant physicians are used to looking after people who received transplants during their childhood.

When your child gets older, he or she may ask you questions about how things were during and after the disease. You could take some pictures during this period, fill out the logbook section of this booklet, or put together an album or a memory box for example.

- *It's very reassuring knowing that we can go back to the hospital at any time. (a mother)*

A close eye must also be kept on your child's body (physical exercise, rehabilitative care) as well as psychotherapeutic help and mutual aid. This aspect is covered in part 4 concerning the people surrounding your child.

See "Teams, support, assistance" on page 127.

- *My son was feeling pretty down in the dumps when he came back home. He said: "I miss being in hospital!" His mood really started to improve when he went back to school. (a mother)*

- *So, there is a plus side to the disease! Now my son likes being at school, he studies hard, always does his homework... (a mother)*

- *Since the transplant, I've really learnt to fully appreciate all those little happy moments and I'm a lot more concerned about things. Carelessness is a thing of the past! (a mother)*

- *Coming home was hard for our daughter but even more so for us. (a mother)*

- *When parents take their child back home, things can never really go back to how they were before. It's what they would like but it's just not possible! (a transplant coordinator nurse)*

- *That child over there had a transplant and just look at him now full of energy, it's remarkable...It's special moments like these that give us so much encouragement. (a nurse)*

4. TEAMS, SUPPORT, ASSISTANCE

Healthcare professionals can be called different names around the world. We have indicated the different titles.

This section concerns the duration of the transplant as well as the post-transplant period. Some people are only involved while your child is in hospital, whereas others are also involved when your child is at home.

During the hospital stay, despite being in isolation, everything will be done to try and make life as normal as possible for your child. Therefore, various people on the team will be around your child on a daily basis.

Everyone, in their own way and depending on their training and profession, participates in caring for and supporting your child, and where possible, the family as well. They can help you to overcome this difficult stage of your life.

- *Her teacher came in to give her some school work, the physiotherapists were there to try and help her walk, give her a massage or make her feel more comfortable, and the psychologist came to see how she was feeling. (a mother)*

Everybody involved strictly respects you and your child's confidentiality.

During the hospital stay
Your child will be examined daily by a doctor on the transplant team. The entire team are frequently updated on the medical records.
Should your child's doctor be absent, an on-call doctor or another doctor from the team will keep you updated.
Depending on your needs or the tests prescribed, you may meet doctors from other departments and teams.

Back home again
Some care is provided by liberal professionals and your GP has a vital role to play. It is therefore important to create a link between the transplant team looking after your child and all those involved back at home. In France, there are now "care networks" (réseaux de soins) whose role is to strengthen these ties between the hospital and liberal professionals. The nurse coordinator plays a "pivotal" role during this homecoming period. In Belgium, there are often collaboration agreements between the transplant units and regional health centres. In Quebec, it is the pivot nurse at the day centre who occupies this role. In Canada there are close relationships between pediatric hematology/oncology programs and the transplant centers. After transplant there is close communication between the transplant center and the local care sites.

The transplant coordinator nurse

A transplant coordinator nurse can be found on many wards. Their role is to ensure that your child's transplant runs as smoothly as possible. They can also provide you with information and respond to all sorts of questions.

The nursing team, nursing auxiliaries – the patient attendant

The administrative nurse (nurse responsible for the care unit) is responsible for the day to day running of the ward.

The nurses (whether from the day or night team) play a central role in not only your child's day to day life but yours as well. They can usually answer your questions themselves and if not, will inform the doctor of them. A nurse isn't just there to carry out technical tasks and provide care.

They are also trained to take care of numerous other aspects such as ensuring your child is comfortable, supporting the parents, instructing

how to correctly take medication, informing you what precautions to take at home, as well as to pay attention to the psychological aspects. They can therefore work with other people involved, giving you some time to rest.

Childcare assistants and nursing auxiliaries play a very intimate role in the transplant. They are responsible for washing, serving meals and participating in games.

- *The auxiliaries are always there for us. (a 17-year-old teenage girl)*
- *There was a guy taking care of me and when he was busy there was a girl. They took it in turns. They were nurses. When I got better, I thanked them both. (a 6-year-old girl)*
- *When the nurses respond to our questions, it's clear that they know what they're talking about and they often reply using terms that are a lot easier to understand for us. It's not too technical or scientific, it's more helpful and that's how we prefer it to be! (a mother)*
- *The nurses give me strength and are reassuring when they speak to me. They're so patient. They come and see me before leaving to see if I need anything. It's a bit like having a big sister or a second mum. (a 9-year-old boy)*
- *It's not all doom and gloom, there can be moments of happiness. We're always there and you should never be afraid of having fun when you're around children! (a nurse)*

Hospital service agents – housekeeping staff

Their role is to ensure the cleanliness of the rooms. They therefore play an integral role. As they are often close to your child, they help ensure his/her comfort.

Other healthcare professionals

The psychologist, psychotherapeutic help

The psychologist (or the child psychiatrist) is there to support your child and help them before, during and after the transplant. This person may contact you systematically, following your request or even after recommendation from a member of the team.
The psychologist works alongside the care team and everyone else who helps ensure things run smoothly on a day to day basis. They act as a type of liaison officer between the different people involved on the ward, and if necessary, after returning home. They are also there for the team.

- *The role of the psychologist is invaluable. They were so quick to understand, and knew instinctively what to do... (a mother)*
- *The psychologist has been a tremendous help in passing on messages between me, the team and the doctors, because doctors have a certain way of seeing things whereas parents have another. (a mother)*

The meeting with the psychologist gives you an opportunity, in strict confidence, to really think about what is happening and to put emotions, such as anger, guilt, a sense of injustice, and concerns into words, whether they are related to the transplant, the disease, or something else.

You can talk about anything to your psychologist, however sensitive the issue, who will help you and your child understand the situation. They offer a sympathetic ear to listen to

all those things that you can't bring yourself to speak about with others, for example fears, guilt etc. They will also show concern for the other children and what they're going through.

Problems are harder to solve if we let them go on rather than preventing or acting upon them quickly.

Speaking about your worries and sharing them with a trained professional who's there to listen is often a great weight off your shoulders and lets you know you're not alone.

People's experience with the disease will differ depending on the steps and their individual story. The need for a psychological assistance can therefore be expressed in various ways depending on the situation.

It is recommended and never imposed.

In many centres, organisations have put in place various support structures for you and your loved ones, whether during transplant or once back at home. As well as offering psychological help, some centres offer alternative therapy such as hypnosis, art therapy or music therapy. These therapies will be proposed if they are available and deemed relevant for your child.

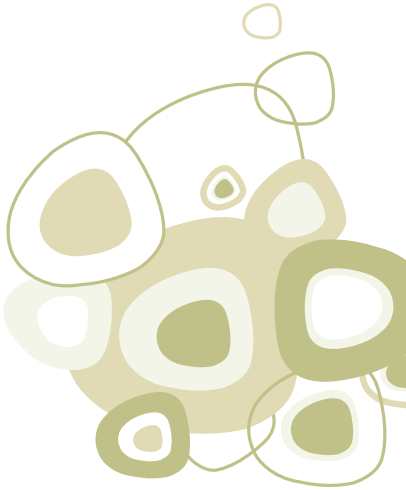
After being back at home for a while, you, your recovering child and your other children may feel the need to talk about what happened with trained people ready to listen or with people who have been through the same situation. It can be alone, as a couple or as a family, with a psychologist or a psychiatrist.

You could also join a self-help group that allows patients and loved ones to share their experiences. Hospitals and organisations organise such groups, more often than not on a voluntary basis. Several options are available. What may be suitable for one person may not be for another. You can join these groups in addition to other support.

The pharmacists

In some centres, the pharmacists directly advise children and family on necessary medicinal treatment throughout the process. In all centres, they have a crucial role in issuing the drugs, and the security and practical preparation of treatment.

Some children do not like certain drugs or prefer taking them in certain forms e.g. tablets, syrup, etc. The pharmacist can change the form of the medication so that it is easier to take for your child.



The nutritionists and dieticians

They have an important role as your child will need to follow a special diet. The main aim of the diet is to reduce exposure to germs. These experts can explain the principles and practical implementation of the set meals. Infection control measures related to the dietary plan will still need to be in place when back home. They can also tell you if certain diets are appropriate such as a low-sodium diet if your child is taking corticosteroids for example.

Feel free to address this topic with them whenever you want, even well in advance if it is a concern.

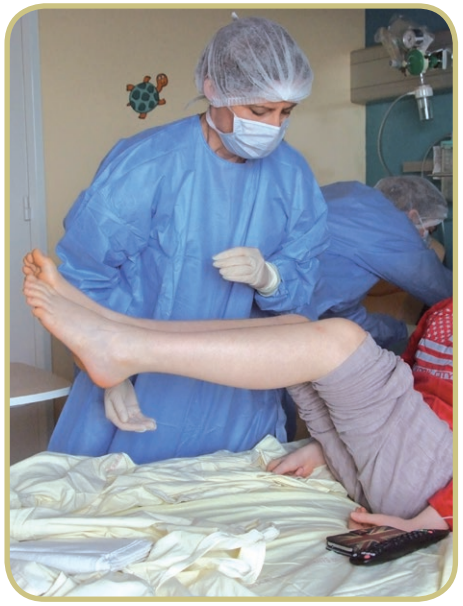
While your child is in hospital, it is possible that his/her calorie intake is below what is needed due to nausea, vomiting and the pain associated with mucositis. In such circumstances, the referring doctor and the dietician will go over with you and your child ways to temporarily compensate for this, by using enteral feeding (inserting a tube through the nose going into the stomach to deliver the nutritionally complete liquid food) or parenteral nutrition where they are fed intravenously.

Eating is essential. It's even better when it becomes a pleasure. There are clubs or recipe books that teach you how to adapt your diet to this new situation. Feel free to speak about it with the hospital's dietician.

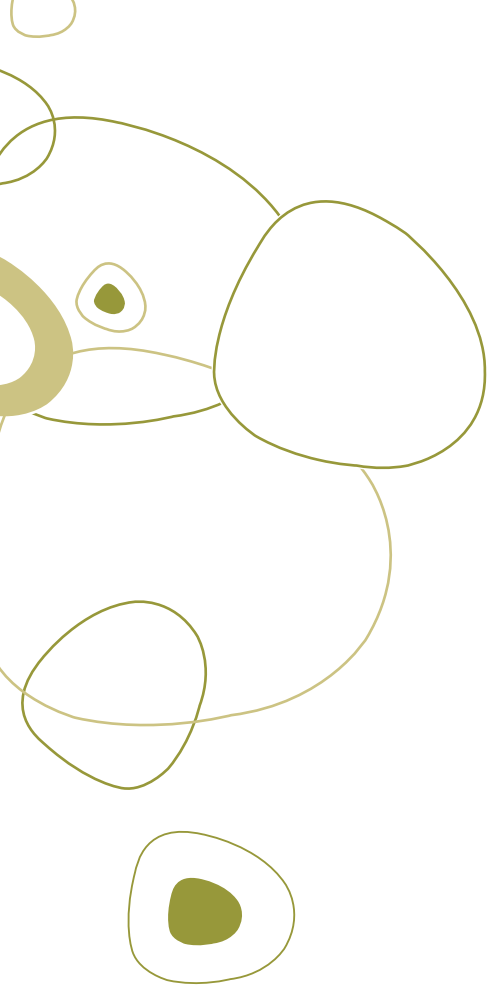
Rehabilitation and physical activity professionals

While still in hospital, physiotherapists and occupational therapists may be called upon by doctors. Their involvement is often crucial. They get your child to do some exercises to prevent muscle loss. Many of them also help with pain management by using various massage and relaxation techniques. They are also there to help maintain children's progress and support them in their development.

Back at home just like in hospital, rehabilitation professionals may be called upon to engage in and improve your child's quality of life. Sophrology, relaxation or massage also help improve well-being. Some are trained to help alleviate physical and moral suffering by using hypnosis.



Taking care of the body is important



and always beneficial, especially as your child's appearance can change which may affect their self-esteem.

Physical activity improves their physical condition as well as morale. It can in turn help you child regain his or her appetite.

If your child or teen is keen on sport and exercise, make sure that they gradually ease back into their activities, to avoid exhausting themselves.

Support, teaching, education, sharing

The social worker

Beyond the financial aspect, the social worker will have worked with many families in similar situations and can therefore use this experience to advise you on how to best organise family life and work life.

They will know what benefits you are entitled to. In respect of professional secrecy and regulations in force, they are there to inform you and your loved ones on existing schemes as well as the steps to take. They can guide you towards improving your living conditions and asserting your rights with respect to social, health, family, income and work-related benefits, both during the hospital stay and after.

- *It's a time for supporting parents through the necessary steps to take, as they are naturally in a state of shock. My role is to help them and to ensure that the hospital stay does not cause families to struggle. This involves accommodation, looking after brothers and sisters if there are any, work-related or financial issues... On top of that, I'm there to support and listen to them. I let them know that I'm there when they need me. (a social worker)*

- *You shouldn't be afraid to ask for financial, material or administrative support. There are times when you need to accept the help that's available, which is not always easy. (a mother)*

Teachers and school

Your child's teachers will often drop by to visit your child in **hospital** and even during the isolation period. Their visits will depend on your child's level of tiredness. It is important for your child to maintain contact with the school they attended before the transplant. With your permission, the teachers at the hospital will contact your child's school.

Once back home again, your child will have to wait a few months before going back to school. This is because the immune system is still too weak to properly fight off infection. Furthermore, your child will probably be feeling far too tired to take part in curricular activities for a few months. However, it is often possible (and important) to give your child home schooling, and that's where the teachers on the transplant ward can step in. Feel free to speak about it with them. This home schooling will be conducted in cooperation with your child's school. He or she will therefore be able to go back there once medically possible.

Depending on your child's academic level and motivation, a transplant does not necessarily mean that the current school year will be lost. The individual tutoring offered by teachers at the hospital and at home can enable them to maintain their academic level and progress onto the next year. This can be a driving force for children.They can also sit their exams (brevet élémentaire, baccalauréat, etc).

See "Appendices - schooling" on page 168 and for more information see the guide "Mon enfant a un cancer : comprendre et être aide", ref. p. 165.

Facilitators and instructors

Having fun is essential for your child's psychological well-being. That's why facilitators and instructors will help your child have as much fun as possible while in hospital.

You can arrange a schedule with them so that they're with your child while you're away recharging your batteries or looking after your other children.

Faith representatives – spiritual advisers

There will be representatives of most religions at the hospital. If you or your child would like to be visited by a faith representative of your choice, feel free to ask.

Volunteers and organisations

Many foundations and charities offer support for child patients and their families, each in their own way and for various aspects. Some of them can be found within the transplant unit in partnership with the hospital, while others are involved once back at home.

Therefore in numerous centres, your child may be surrounded by volunteers. The activities proposed will take into account his/her levels of tiredness and age. There is a wide variety available which will depend on each foundation, and can range from games, reading, storytelling, computer-based activities (if the room is equipped), manual activities and so on. The volunteers will have all been trained on how to prevent infection and will respect the principles of confidentiality. They help your child use his/her imagination, laugh and take part in fun activities which are all essential for your child's mental stability.

- *We're thankful to all those that help us, obviously the nurses, the doctors, but also the charities and the volunteers. We don't really say it much but they really do help us. It's important! They even look after the other children for us. It lets us have a bit of time to ourselves. (a mother)*

- *I was living at a clown's pace. Our weekend was on Tuesday and then Thursday. (a mother)*

- *I won't forget the ladies dressed in pink who came to help me breath from time to time. (a mother)*

- *The people in pink gowns used to come. They were fun and kept me entertained, it was great! (a 17-year-old teenage girl)*

- *On the ward, there is a charming storyteller who has the advantage of having white hair… She wonderfully represents all those grandmothers that are being missed. (a psychologist)*

Depending on their structure and capabilities, organisations also:

- purchase equipment and facilities that can make the hospital stay more pleasant (computers, webcams, etc.), and sometimes contribute towards specific care equipment;

- provide logistical and financial support for families (for example contributing towards costs which cannot be claimed back);

- offer home support during and after the hospital stay;

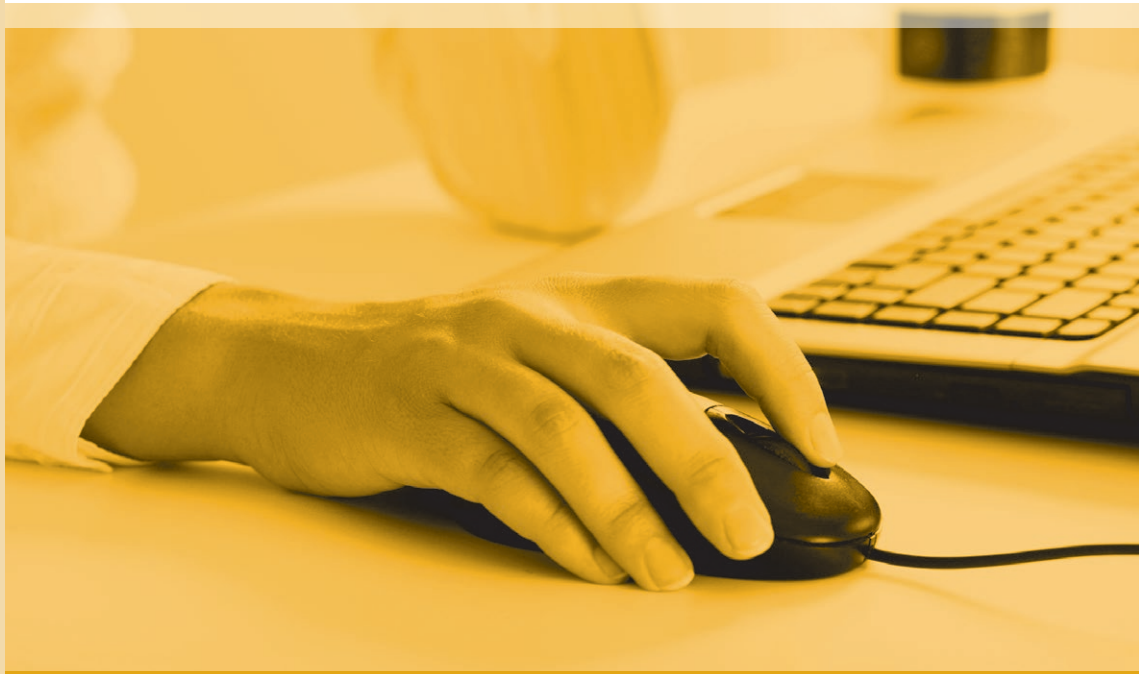
- support clinical research.

The wide array of activities offered by these charities proves their engagement as paediatric care partners.

Ask the team for further information on these foundations and charities, especially those that operate directly on the ward or in partnership with the ward once your child returns home.

5. MY CHILD'S LOG BOOK

6. APPENDICES



Booklets, DVDs and online resources

The websites of the distributors can be found on page 170. Some documents have a fee, details of which can be found on the distributors website.

This selection of information resources is only intended to offer further readings. We do not guarantee the function, accuracy or currency of the information contained within them.

English resources

GENERAL

- AboutKidsHealth - Blood and Marrow Transplant
  www.aboutkidshealth.ca/BMT

- Advocacy for Canadian Childhood Oncology Research Network (A2corn)
  www.curesforourkids.com

- Anthony Nolan - *A Young Person's Guide to the Stem Cell Transplant Journey*
  www.anthonynolan.org > Patients and Families
  PDF version:
  www.anthonynolan.org/sites/default/files/1230PA teen and young persons guide.pdf

- Anthony Nolan - My child is having a transplant
  www.anthonynolan.org/patients-and-families/support-parents-family-and-friends/my-child-having-transplant

- BC Cancer - Bone Marrow/Stem Cell Transplant Websites
  www.bccancer.ca > Our Services > Library

  www.bccancer.bc.ca/our-services/services/library/recommended-websites/cancertreatment-websites/bone-marrow-stem-cell-transplant-websites

- *Blood and Marrow Transplant in Children: A Guide for Parents and Other Family Members* (2007). Bone Marrow Transplant Network NSW.
  www.aci.health.nsw.gov.au > Resources > Blood and Marrow Transplant

  PDF version:
  www.aci.health.nsw.gov.au/__data/assets/pdf_file/0015/272103/BMT_Paediatric_Patient_Family_Guide.pdf

- Blood & Marrow Transplant Information Network (BMT InfoNet) - Preparing For Your Child's Transplant
  www.bmtinfonet.org>Transplant Basics>Preparing for Transplant

  www.bmtinfonet.org/transplant-article/preparing-your-childs-transplant

- Bone Marrow (Stem Cell) Transplant for Sickle Cell Disease (2009). St. Jude Children's Research Hospital Departments of Hematology, Patient Education, and Biomedical Communications.
  www.stjude.org > Care & Treatment > Patient & Family Resources

  PDF version:
  www.stjude.org/content/dam/en_US/shared/www/patient-support/hematology-literature/bone-marrow-stem-cell-transplant-for-sickle-cell-disease.pdf

- Canadian Blood and Marrow Transplant Group
  www.cbmtg.org

- Canadian Cancer Society - Stem Cell Transplant
  www.cancer.ca > Diagnosis and treatment > Stem cell transplant

  www.cancer.ca/en/cancer-information/diagnosis-and-treatment/stem-cell-transplant/?region=on

- Center for International Blood and Marrow Transplant Research (CIBMTR)
  www.cibmtr.org

- Children's Oncology Group - Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers
  www.survivorshipguidelines.org

- Curesearch - Bone Marrow Transplant
  www.curesearch.org/Pediatric-Bone-Marrow-Transplant

- European Society for Blood and Marrow Transplantation
  www.ebmt.org

- Leucan Information Centre
  www.centreinfo.leucan.qc.ca/en

- Leukemia & Lymphoma Society of Canada - Booklet on Blood and Marrow Stem Cell Transplantation
  www.llscanada.org

- National Bone Marrow Transplant Link
  www.nbmtlink.org

- National Cancer Institute - Childhood Hematopoietic Cell Transplantation (PDQ®)–Health Professional Version
  www.cancer.gov/types/childhood-cancers/child-hct-hp-pdq

- National Marrow Donor Program - Transplant for Children and Teens
  bethematch.org/patients-and-families/transplant-for-children-and-teens

- Pediatric Blood and Marrow Transplant Consortium (PBMTC)
  www.pbmtc.org

- Stanford Children's Health - Bone Marrow Transplantation in Children
  www.stanfordchildrens.org/en/topic/default?id=bone-marrowtransplantation-in-children-90-P030622

FOR CHILDREN

- Children's Cancer and Leukemia Group - *Ben's stem cell transplant*
  www.cclg.org.uk > Publications > Treatment

  PDF version:
  www.cclg.org.uk/publications/treatment/Bens-stem-cell-transplant/BENSSCT

- Children's Cancer and Leukemia Group - *Jess's bone marrow donation*
  www.cclg.org.uk > Publications > Treatment

  PDF version:
  www.cclg.org.uk/publications/treatment/Bens-stem-cell-transplant/BENSSCT/Jesss-bone-marrow donation/JESSBMDO

- Children's Cancer and Leukemia Group - *Ruby's stem cell harvest and transplant*
  www.cclg.org.uk > Publications > Treatment

  PDF version:
  www.cclg.org.uk/publications/treatment/Rubys-stem-cell-harvest-and-transplant/RUBYSSCJ

- Children's Cancer and Leukemia Group - Stem cell transplant
  www.cclg.org.uk > Publications > Treatment

  PDF version:
  www.cclg.org.uk/publications/treatment/Stem-cell-transplant/SCTTEENS

- *Me and my marrow : A Kid's Guide to Bone Marrow Transplants* (1999). By Karen Crowe, illustrated by Norm Bendell, Fujisawa Healthcare, Inc.
  www.bridges4kids.org/Disabilities/meandmymarrow.pdf

- *Stevie's New Blood* (2000). By Kathryn Ulberg Lilleby, illustrated by Chad Chronick. Oncology Nursing Press.

French resources

*Most of the information is taken from the guide "*Mon enfant a un cancer : comprendre et être aidé*". Order or download it from the Institut national du cancer (The French National Cancer Institute (INCa)) website.*

SPEAKING ABOUT THE DISEASE WITH YOUR CHILD AND HIS/HER SIBLINGS

- *Votre enfant est gravement malade, pour en parler avec lui* (2003). Association Sparadrap.
  From: Sparadrap.

- *L'Aventure de Jules, une histoire pour comprendre la leucémie* (2001, épuisé). Available on Source Vive's website.

- *Mon frère, mon sang* (DVD, 35 min) – *Le petit frère de Sarah* (DVD, 8 min, 2008) Michèle et Bernard Dalmolin, Association Locomotive.
  From: Locomotive et Sparadrap.

- *Pour nous frères et sœurs pas facile à vivre… Arthur a un cancer* (2005). Association Choisir l'Espoir.
  From: Choisir l'Espoir et Sparadrap.

- *J'ai des soucis dans la tête. Et si on en parlait ensemble ?* (2007). Association Sparadrap.
  From: Sparadrap.

- *Falikou*, Catherine Loëdec, Éditions Le buveur d'encre (2006) – a story on coping with the end-of-life of a child.

EXPLAINING HOW THE BODY WORKS, THE EFFECTS OF THE DISEASE, THE CONCEPT OF THE TREATMENT

- *Les Globulyss, voyage au cœur de la vie.*
  www.globulyss.fr

- Cartoon series *Il était une fois la vie – La moelle osseuse*. Book editions Atlas (2001) and DVD Sony Music (2001).

- The website of Société Francophone de Greffe de Moelle et de Thérapie Cellulaire (SFGM-TC)
  www.sfgm-tc.com > Espace patients et donneurs

- Centre d'information Leucan
  www.centreinfo.leucan.qc.ca/fr

- Société de leucémie et lymphome du Canada > Patients et proches aidants
  www.sllcanada.org

- *Portraits d'espoir* (2012), William Brock, Presses de l'Université de Montréal.

- *Dis-moi globule, c'est quoi ce bidule ?* (DVD, 2007) – explaining the marrow, cells, cancer and treatment. From: Service d'hématologie et d'oncologie pédiatrique, Cliniques universitaires Saint-Luc, UCL, Belgium.

- *Boule à zéro*, Ernst et Zidrou, Éditions Bamboo, comic, 7 volumes – experiencing cancer in paediatrics.

- *Robby-Radio lutte contre les méchantes cellules cancéreuses* (2006), Kinderkrebshilfe Schweiz – an explication of cancer and its treatment. From: La Ligue Suisse contre le cancer.

- *Gaspard Chimio et les méchantes cellules cancéreuses* (2006), Kinderkrebshilfe Schweiz – an explication of cancer and its treatment. From: La Ligue Suisse contre le cancer.

PAIN

- The Sparadrap foundation publishes many guides and fact sheets on pain and treatment: a guide to pain, the MEOPA card, morphine, lumbar puncture, getting settled when taking treatment, etc. Some of which can be downloadable free of charge. List available on the website.

- Pédiadol, a foundation for children's pain and treatment. The website is more aimed towards health professionals, but does also provide information which can be read by the general public.

FERTILITY

- *Être jeune et concerné par le cancer : vos questions, nos réponses* (2008). Association Jeunes Solidarité Cancer. Downloadable on their website.

- *Le CECOS, c'est quoi ?*, Information booklet on the role of the egg and semen banks and research centres. Downloadable on the website of Ligue nationale contre le cancer.

- *Les Hormones, la fertilité*, edited by la Société française de lutte contre les cancers et leucémies de l'enfant et de l'adolescent (SFCE et SFGM-TC). Downloadable on their website > Le suivi.

- *Conséquences des traitements des cancers et préservation de la fertilité – État des connaissances et propositions*, février 2013, by The French National Cancer

Institute (INCa) and Agence de la biomédecine. Downloadable on the website of The French National Cancer Institute.

RESEARCH

- *La participation de mon enfant à une recherche clinique sur le cancer* (2016), collection Guides patients Cancer info, INCa-Espace éthique-région-Ile-de-France-SFCE.

SCHOOLING

- *L'École pour l'enfant atteint de cancer* (2009), brochure conçue par l'association Source Vive, updated and reprinted by Unapecle.
  From: Source Vive.
  Downloadable on their website.
- Scolarité, Institut national du cancer.
  www.e-cancer.fr > Patients et proches > Les cancers > Les cancers chez l'enfant > Scolarité
- *Ma différence, mon histoire : Livret Enseignant* (2017), Les Amis de Mikhy, Institut Gustave-Roussy.
  Downloadable from
  www.lesamisdemikhy.org

AFTERCARE

- Factsheets on each organ, drawn up by the "Suivi à long terme" commitee of the Société française de lutte contre les cancers et leucémies de l'enfant et de l'adolescent.
  Downloadable on their website > Le suivi.

SOCIAL SUPPORT IN FRANCE

Order or download from The French National Cancer Institute website.

- The guide *Mon enfant a un cancer : comprendre et être aidé* provides lots of information on:
  - financial support acknowledgement
  - acknowledgement of the disabled status
  - time off work and available benefits
  - additional benefits or special grants
  - home support
- *Démarches sociales et cancer*, collection Guides patients Cancer info, INCa.

WEBSITES OF DISTRIBUTORS

These websites contain many other resources: booklets, guides, films, testimonies, references, news, official documents, exchange forums and more. Be sure to check them out.

- AboutKidsHealth
  www.aboutkidshealth.ca
- Leucan Information Centre
  www.centreinfo.leucan.qc.ca
- Choisir l'Espoir
  www.choisirlespoir.fr
- The French National Cancer Institute (INCa)
  www.e-cancer.fr
- Jeunes Solidarité Cancer (JSC)
  www.jeunessolidaritecancer.org
- The Leukemia & Lymphoma Society of Canada (LLSC)
  www.sllcanada.org
- La Ligue nationale contre le cancer
  www.ligue-cancer.net
- La Ligue Suisse contre le cancer
  www.liguecancer.ch
- Locomotive
  www.locomotive.asso.fr
- Pédiadol
  www.pediadol.org
- Société francophone de greffe de moelle et de thérapie cellulaire (SFGM-TC)
  www.sfgm-tc.com > Espace patients et donneurs
- Société française de lutte contre les cancers et leucémies de l'enfant et de l'adolescent (SFCE) > Le suivi :
  sfce.sfpediatrie.com
- Source Vive
  www.source-vive.org
- Sparadrap
  www.sparadrap.org

Donate

Blood and platelets

- American Cancer Society - Donating Blood
  www.cancer.org/treatment/treatments-and-side-effects/treatment-types/blood-transfusion-and-donation/donating-blood.html
- At your nearest Établissement Français du Sang (EFS) centre (or during one of the collections organized locally):
  dondesang.efs.sante.fr
- Canadian Blood Services
  www.blood.ca
- Francophone blood service (Croix-Rouge de Belgique):
  www.transfusion.be/fr
- Héma-Québec:
  www.hema-quebec.qc.ca
- In Switzerland:
  www.hug-ge.ch/don-du-sang
  or
  www.blutspende.ch/fr
- NHS Blood Donation
  www.blood.co.uk

Donate hematopoietic stem cells

- Anthony Nolan
  www.anthonynolan.org
- Be the Match (National Marrow Donor Program)
  www.bethematch.org

- British Bone Marrow Registry
  www.nhsbt.nhs.uk/british-bone-marrow-registry

- Canadian Blood Services – Donating stem cells
  www.blood.ca/en/stem-cells/donating-stem-cells/donation-process

- Croix-Rouge de Belgique
  www.31millionchances.org (english)
  www.31millionsdechances.org (français)

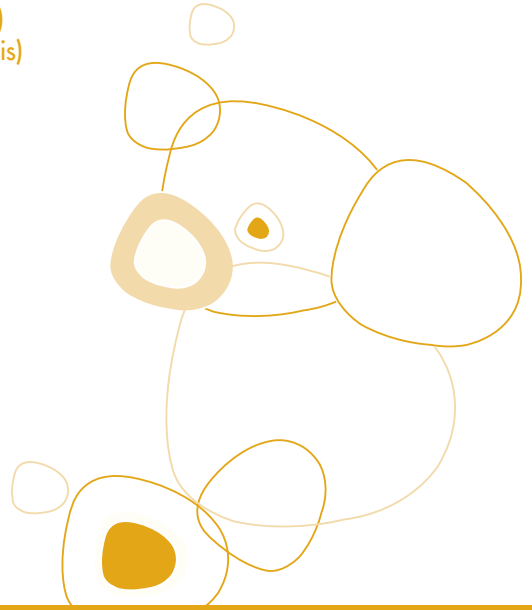
- Don de moelle osseuse
  www.dondemoelleosseuse.fr

- France Moelle Espoir
  www.france-moelle-espoir.org

- Gift of life
  www.giftoflife.org

- Héma-Québec - Information about stem cell donation
  www.hema-quebec.qc.ca/cellules-souches/donneur/index.en.html

- World Marrow Donor Association (WMDA)
  www.wmda.info



Partner federations and charities

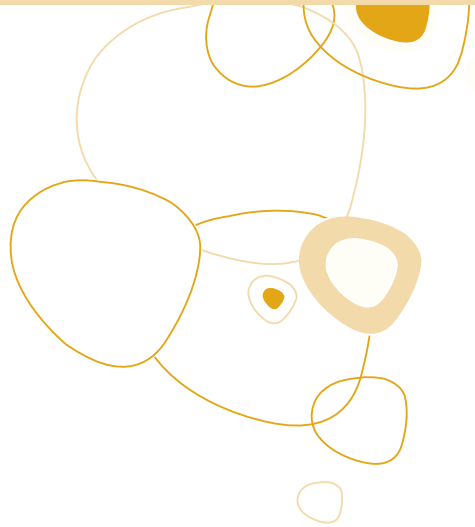
- **Fédération Leucémie Espoir (FLE)**

Fédération LEUCÉMIE ESPOIR

Founded on the 12th March 1994, the FLE brings together charities governed by the law of 1901 from across the country who unite to achieve the same common goal:

▶ **Support children and adults suffering from blood diseases and help their families through this ordeal.**

23 rue de Versailles Beaupreau
49600 Beaupreau-en-Mauges
Téléphone : 06 83 00 69 63
www.leucemie-espoir.org



A state-approved charity (reconnue d'utilité publique) since 2008.

• Fédération enfants-cancers-santé (ECS)

A national federation and long-standing partner of the Institut Gustave Roussy de Villejuif (IGR)-94076

1998: In response to the appeal from professeur Lemerle of the IGR who lacked staff and financial resources to carry out research, Pierre Maclair and members of the Lions Club de Mennecy -91540 created Enfants et Santé. They financed 9.5 full time Clinical Research Associates (Attachés de Recherches Cliniques (ARC)) positions nationally.

2003: The first national Enfants et Santé days for childhood cancer were organized.

2004: Following the federation's efforts, childhood cancer was introduced to president Jacques Chirac's French Cancer Plan.

2005: It became a state-approved public interest foundation.

2006: The first research programs were funded, presented by the Scientific Committee of the SFCE (Société Française de Lutte contre les Cancers et Leucémies de l'Enfant et de l'Adolescent, bringing together paediatric oncologists based in France).

2014: It received the IDEA label (Institut de Développement de l'Ethique et de l'Action pour la Solidarité) for the federation's excellent management.

So far, **130 research projects** have received 7 million euros of funding, with on average 200,000 euros a year extra given to doctors to:

- Structure themselves within the SFCE;
- Communicate between the centres in order to discuss sensitive issues;
- Fund the tumour bank of childhood cancer cells (BIOCAP project).

www.enfants-cancers-sante.fr

• Leucan

For over 40 years, **Leucan** has been committed to supporting children with cancer and their families, right from the diagnosis and through all the phases of the disease.

Supporting hundreds of families, and with thousands of members across Quebec, the association offers **distinctive and tailored services** and assistance, all thanks to a qualified team of people that are highly experienced in the field. On top of this, Leucan provides funding for clinical research and the **Leucan Information Centre**. Thanks to its many offices, Leucan is present throughout Quebec.

www.leucan.qc.ca/fr

• France Moelle Espoir (FME)

France Moelle Espoir is a national network of organisations that fight against leukemia and blood diseases. Founded in 1993, it aims to support patients and their families, to develop the French register for bone marrow donors, to increase the awareness of the public authorities and to participate in the funding of medical research.

For more information about France Moelle Espoir and its member associations, please visit www.france-moelle-espoir.org

• Association Laurette Fugain (ALF)

Laurette Fugain
l'association qui lutte contre la leucémie

Laurette Fugain is an organisation that fights against leukemia, and was founded in September 2002. It has three main aims:

- **SUPPORT** financially medical research on leukemia and blood diseases.
- **ENCOURAGE** people to donate blood, platelets, bone marrow, cord blood, plasma and organs.
- **HELP** patients and their families.

www.laurettefugain.org

• Cent pour Sang la Vie (CPSLV)

Cent pour Sang la Vie
Contre la leucémie

CPSLV has the following missions:

- to inform and increase awareness on donating;
- to fund medical research;
- to support families who are facing leukemia.

For the past two years, the focus has been on:

- welcoming and supporting families in 50 different units.
- raising awareness in primary schools and high schools.
- giving encouragement to communities of families affected by leukemia.
- launching national days against leukemia in 2014.

www.centpoursanglavie.com

Notes

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(p. 20, 51, 83, 88, 137)
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Aurore de Neuville

This booklet can be found on the SFGM-TC website: sfgm-tc.com

Please forward your comments to info@leucan.qc.ca

I was pleased, I wanted my brother to get better but at the same time I was scared about donating... I'm so glad I did it in the end! (a brother donor, aged 7)

I feel like the relationship I have with my parents has changed. As a teenager, I thought I had the worst parents in the world and I couldn't even talk to them. But once the transplant came, everything changed! (a 17-year-old teenage girl)

It's hard to be alone. Sometimes I pressed the call bell not because something was wrong but just to have a chat with the nurses. (a 13-year-old teenage girl)

ESPACE ÉTHIQUE RÉGION ILE-DE-FRANCE ESPACE-ETHIQUE.ORG
Cent pour Sang la Vie Contre la leucémie
Laurette Fugain l'association qui lutte contre la leucémie
Coordination FRANCE MOELLE ESPOIR Union d'Associations FME
Jazz Pharmaceuticals
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enfants cancers santé
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leucan
CBMTG CANADIAN BLOOD AND MARROW TRANSPLANT GROUP
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