

# Hematopoietic Stem Cell Transplantation

INFORMATION BOOKLET  
AND GUIDE FOR PATIENTS

2013  
EDITION

**SFGM**  
Société Francophone  
de GREFFE DE MOELLE  
et de Thérapie Cellulaire **TC**

# Translator's note

Hematopoietic Stem Cell Transplantation: Information Booklet and Guide for Patients is an English translation of a booklet originally drafted by Dominique Davous for the Francophone Society of Bone Marrow Transplantation and Cellular Therapy (SFGM-TC). This booklet is a therapeutic education tool used in all French and many Francophone stem cell transplantation centers. At the request of the President of the SFGM-TC, the Prof. Ibrahim Yakoub-Agha (Lille University Research Hospital), I undertook the translation of the text with a general English-speaking audience in mind.

To that end, I would like to point out a couple aspects of the writing. First, patients, family members, doctors, nurses, nurse's aides, and social workers are often quoted on their personal experience. In the interest of retaining authenticity, these quotations may still sound a little French. Please appreciate their charm. Second, certain social aid structures exist in France that may not make up part of the health infrastructure of the country where you live. To the best of my ability, I have adapted these elements to the reader's potential situation. Please don't hesitate to ask your medical team about what you can do to get informed about your rights to government support during your treatment and your recovery. Third, most information for French-speaking patient associations has been removed from the text. These types of associations most likely exist where you are, and it would suffice to just ask about them. You might also consider doing some online research.

The Prof. Yakoub-Agha and I worked and reworked several versions of the guidebook you hold in your hands. I hope that you will find the information herein useful to your treatment and your healing.

**Rachel Tipton**  
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- Family members and close friends of patients.
- Association directors and volunteers
- Care givers

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*The transplant is a traverse, but not a solo traverse. You have to trust. You have to communicate.*

*dominique Davous*

## In their own words

- *In the past few years, we've seen a significant increase in the effectiveness of transplantation. This therapy provides a chance. A real chance! (doctor)*
- *I remember the doctor told me: "We're counting on you". Then I realized that maybe I had a specific job to do. Me too, I had a role to play. (Nathalie, 35)*
- *Me, I always trusted. When you start the transplantation, it's like getting in a car or on a plane - you have to trust the person at the wheel or in the cockpit. With this medical treatment, it's somewhat the same. Yes, I paid attention and knew what was going on, but I also trusted. (Alexandre, 42)*
- *When talking about the transplantation, it's hard to dissociate before, during, and after. It's all part of the whole thing. (an association director)*

- *With a doctor there needs to be two things, the ability to have complete confidence in him and to be sure to be able to meet his demands. (Mélanie, 20)*
- *There are two types of patients. Those who are very motivated that say, "Finally I'm going to get a transplant!" They act voluntarily. And there are those who are very reticent, that say, "I don't want to leave my work, my family..." "...It's true that a transplantation is a "break" during several weeks, like a bubble in one's life. (social worker)*
- *Between the pre-transplant consultation and the decision, I went back to my hematologist and asked several questions. She told me, "You're young, you're in good health, these conditions are ideal. Now is the time to do it...after, we won't be as sure." That was the only moment of worry that I had. (Alexandre, 42)*
- *The transplant is a path, it's not an outcome; the process is long! It takes patience, but when you get to this level, you're patient. (Samuel, 40)*
- *Even describing transplantation, what I lived will never be what I describe. It's difficult to say; it's apart. (Anaïs, 48)*

- *It's the first time in a long medical journey that I met someone who listened, someone very human, very accessible: If you have other questions, call me, I'll be there. I'll pick up. (Frédérique, 53)*
- *My transplant doctor showed me choices with a lot of humanity. He sat down on my bed; he took my hand to talk to me, such a caring and assessing touch. He spoke in terms a child could understand, It's going to be difficult. There will be moments when you want to stop, but we'll be there, a team of your parents, your sisters, your family, your friends...we're there to help you through this course. He told it to me straight without hiding the difficulty. He was a man of great frankness and humanity. (Matthias, 26)*
- *When patients ask us questions, we tell them to not look at the long term but to advance step by step. (an association director)*
- *To get to the other side, I definitely don't look at the mountain, I lower my eyes and just watch each step, each little, oh-so-little step. I see just each day, each hour such as it is. Whether it's painful or calming, whether it's deserted or ravishing, whether it's meeting or silence, whether it's presence or absence. (Sabine, 44)*

- *Sometimes it's important to know all but all the same to feel that the doctors think it's going to work. (Nathalie, 35)*
- *I told myself that a transplant was going to work, and that it was the end of the tunnel. (Matthias, 26)*
- *You can't let up the fight. There is always hope no matter what happens because we also believed that it was going to finish. (16 year-old girl who was 10 when her father received a transplant)*
- *There's a lot of information provided. But information may not be the patient's lived experience. There's a gap between the information one gives and what the patient experience. (psychologist)*
- *Treatments have advanced. Patients have less pain than before, which is reassuring for us too. (nurse's aid)*
- *Transplantation is a procedure that's rather long. The transplant itself is not the most complicated. It's after...that goes on for 3 months, 6 months, a year...It's a long-term procedure with healing as the goal, but there are side effects, certain of which can leave after-effects. (doctor)*

- *The transplantation continues after the transplant; the "after" is extremely important. (psychologist)*
- *Many think that [the transplantation] will be finished after the transplant and what needs to be made clear is that after there is follow-up care. People have a lot of hope when they get to transplant. (doctor)*
- *For him it's a second life. For him it was truly a rebirth. The first year I was wishing him "Happy Birthday" the day of his transplant; after we forgot. It's a good sign to forget! (sister, donor, 32)*
- *With my wife's transplant, everyone had their share of life changes: the bigger kids grew up a little, I became a little less father and a little more mother, and the littler kids got a little less little. Everyone had a transformation. It was something excruciating, but also was a source for bonding those who were giving support. We were a team at her disposition. (husband of a recipient, 39)*
- *What is difficult for those undergoing a transplant, it's the length of the hospitalization, with all the daily precautions: one visitor at a time. It's also the fact that there is no possibility of direct contact as well as the known risks, GVHD (graft versus host disease) in particular, and uncertainty: Is it going to or not going to work? (psychologist)*



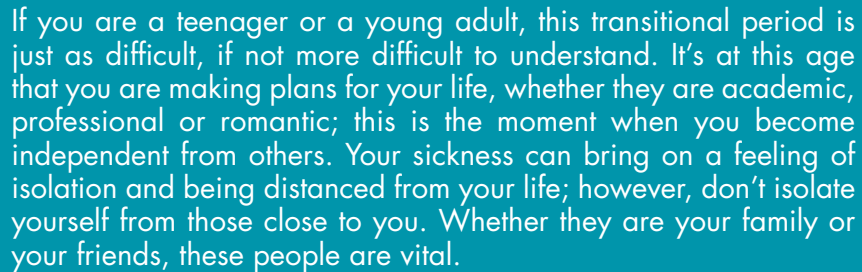
Your doctor and his medical staff have recommended **an allogeneic hematopoietic stem cell (HSC)** transplantation, often called a bone marrow transplantation or marrow transplantation, which is possible thanks to a donor. This can be a bone marrow transplant, a peripheral stem cell transplant or a cord blood transplant. All of these go by the name hematopoietic stem cell transplant.

The transplantation is generally conducted by the team caring for you, but it can also take place in another department of the same hospital or in another establishment.

In this case, you will have to get to know and adjust to another team, which may be disconcerting.

- *Consistency is important. A patient remains attached to the first person that they see but also to the medical staff. This sometimes makes the transition from a hematology unit to a transplant unit difficult. (psychologist)*
- *Changing services, it's a little like moving. You were setting up a life, a complete life. (Joël, 49)*
- *I changed medical teams two times since the beginning of my illness, the second time was for the transplant. Each time they insured that everything was in place for this transition. (Sophie, 42)*

The teams, the one that cared for you during your malady and the transplantation team are in communication with each other before your arrival in the transplant unit. The team in charge of the transplant will welcome you and provide you with practical information concerning how things work in their service: introduction to the members of the medical team, the social worker - the key person who is there to help you and intervene when necessary during the numerous changes to your daily life and that of your family.



If you are a teenager or a young adult, this transitional period is just as difficult, if not more difficult to understand. It's at this age that you are making plans for your life, whether they are academic, professional or romantic; this is the moment when you become independent from others. Your sickness can bring on a feeling of isolation and being distanced from your life; however, don't isolate yourself from those close to you. Whether they are your family or your friends, these people are vital.

So stay in contact with people close to you. Don't isolate yourself and, whatever you do, don't forget that you're not alone!

In an effort to help you understand and you absorb the information, many medical teams use an **audiovisual tool** to assist during the pre-transplantation consultation.

It's generally during the course of this consultation that this booklet in your hands will be given to you by the transplantation doctor or the transplant coordinating nurse. This tool details and reiterates information given to you face to face: medical information as well as info concerning the medical team, available patient support along with social and family support.

**The concept of this guidebook is to facilitate dialogue between you, the doctor, and more extensively your transplant team.** You have at your disposition a written document that can be read at your own pace. You can also offer and suggest it to those who are close to you. This will help them better understand your experience.

The transplantation process takes place in an extremely complex scientific and emotional context. This guidebook clarifies the necessity for direct, authentic and open communication between the different players.

The goal of this written tool is to enable you to better understand what's at stake in a transplantation of hematopoietic stem cells and to bring you closer to your decision for medical treatment.

**This guidebook doesn't replace necessary human connection with the transplantation team;** on the contrary, it is an invitation to seek out, create, and maintain this vital alliance.

■ *I ask them [the patients] to come with another person to the pre-transplant consultation. It's always better when there are two sets of ears listening. Not everybody remembers the same thing. It's also because I tell them there are risks, a vital risk, and it's always better when someone in the family hears it. Certain people come with their donor, but I don't necessarily advise it. (doctor)*

■ *We don't recommend that the patient comes with their donor to the consultation, but rather with their partner or someone close. The same goes for the donor during the pre-donation consultation. We don't recommend that the patient comes along. (transplant coordination nurse)*

■ *If I feel that a patient is upset after the pre-transplant consultation, I notify the senior nurse, and the other nurses who will be providing care. (doctor)*

Doctors are here to respond to your questions. Do not in any way be shy about asking.

■ *It's always practical to have a written support to facilitate discussion. (nurse)*

■ *Most people find hospital language difficult. Giving the guidebook is a means for exchange. (nurse)*

■ *During the consultation with the doctor, there is a lot of information and it's complicated. It's good to have a written tool to which you can return with a calm mind, to revisit certain terms. (Alice, 32)*

■ *During an interview, the mind gets stuck on some information that can be worrying and you forget the rest of the explanation. Whatever is said afterwards isn't heard. It's good to have a written tool to be able to return to when you feel capable. (Catherine, 38)*

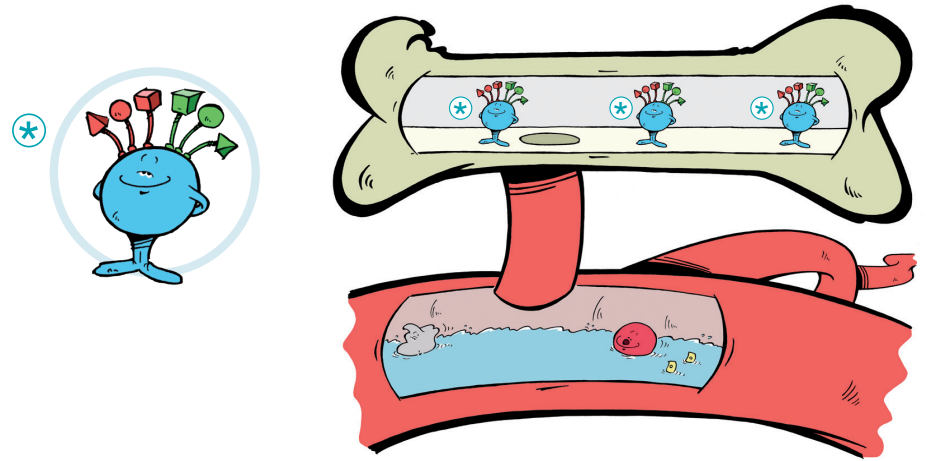
This guidebook takes a general approach to allogeneic transplantation, and doesn't explain each particular case. **Each situation is unique and your transplantation team knows about your condition. For explanation and discussion, they will adapt general information to your particular case. Use this information and feel free to go back to it.**



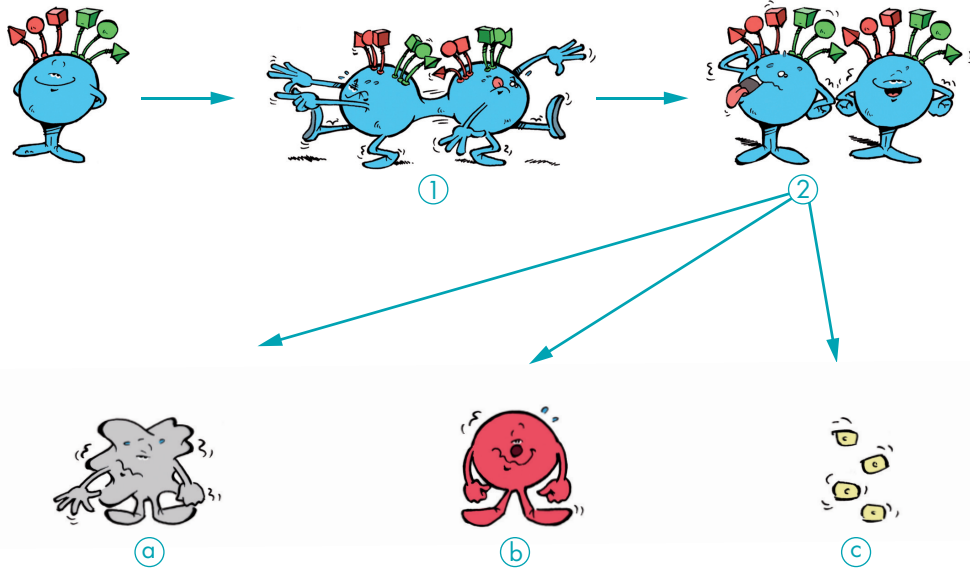
# Bone Marrow

What role does it play in the body?

Bone marrow is a gelatinous tissue found in the hollow cavity of the bone. It contains billions of maternal cells called hematopoietic stem cells \* (HSC). These cells are most often found in the bone marrow. You have probably already had a sample of bone marrow taken for analysis.



These stem cells divide ① and differentiate ② to give rise to the different cells that make up the blood: white blood cells ①, red blood cells ②, platelets ③.



The stem cells continuously renew themselves while blood cells have a limited lifespan. This is **hematopoiesis** (this term comes from the greek words haima, blood, and poiesis, to make).

What are the different cells of our blood? What role do these cells play?

## ► White Blood Cells



These are also called **leukocytes**.

There is more than one type. In transplantation, two types of white blood cells are important: the neutrophils (granulocytes) and lymphocytes (T and B cells).

**Neutrophils and lymphocytes are responsible for the body's defense against infections** (bacteria, fungi, viruses or parasites), cancer cells, foreign cells...

For every millimeter cubed of healthy adult blood, there are 1,500 to 7,500 neutrophils. Patients with less than 1,000 neutrophils (neutropenia) and less than 500 neutrophils (severe **neutropenia**) per millimeter cubed of blood are at high risk of developing an infection.

Bacterial infections are treated with antibiotics and fungal infections with anti-fungal medication. The majority of viruses and parasites are detected by blood tests and treated respectively with anti-viral and anti-parasitic treatments.

## ► Red Blood Cells



Red blood cells are also called **erythrocytes**.

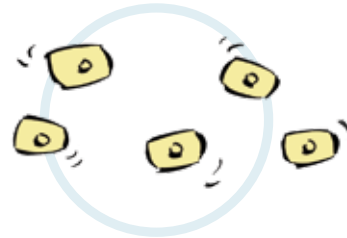
**These red blood cells contain hemoglobin that transport oxygen from the air to the entire organism;** which gives blood its red color.

There are 4 to 5 million red blood cells/mm<sup>3</sup> of blood in a healthy adult.

The hemoglobin level is important because it measures the capacity of blood to transport oxygen. The normal value is between 115 g and 170 g/L of blood. Patients can experience anemia when this level drops below the normal range.

In cases of severe anemia (below 80 g/L), a blood transfusion is needed. Another option is a treatment used to stimulate the hemoglobin level (erythropoietin referred to as EPO: drug that increases RBC count).

## ► Platelets



These are also called **thrombocytes**. The platelets are “fragments” of cells. They are responsible for the phenomena of clotting. They are scab that forms over a wound. **Their principle function is to prevent bleeding.**

A normal platelet count ranges from 150 000 to 450 000 platelets/mm<sup>3</sup> of blood.

Patients with severe thrombopenia (generally below 10,000 **thrombocytes**/mm<sup>3</sup> blood), are at high risk of hemorrhaging and may need a platelet transfusion.

The complete blood count (CBC) test determines the number of red and white blood cells, platelets and the hemoglobin level.

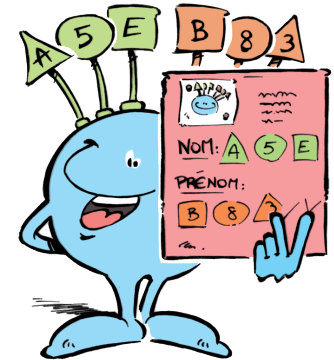
# The HLA System

All the cells of an organism carry Human Leukocyte Antigen (HLA) molecules on their surface acting as a barcode.

The combination of a person's HLA molecules is called the **HLA typing**. In a way it determines the identity of each individual cell, including hematopoietic stem cells in the bone marrow.

Lymphocytes recognize HLA molecules. If these molecules are identified as foreign molecules in the organism (antigens), lymphocytes will try to destroy them; this is the case for all infectious agents.

HLA typing is determined by blood analysis.



# Transplantation

## What is the main goal of allo-transplantation?

The goal of the transplantation is to destroy the recipient's bone marrow (that's to say destroy your hematopoietic system as well as your immune system) to replace it by that of the donor, a person in good health. The transplant (graft) itself is constituted of hematopoietic stem cells drawn from the donor.

Not only will the transplant replace your bone marrow but also your immune system. In principle the transplant will eliminate your disease.

**The HLA type of the donor and the recipient must be as close as possible (HLA compatible).** To avoid donor HLA molecules being recognized as foreign by your lymphocytes and *vice versa*.

Engraftment happens when your HLA system recognizes your donor's HLA system, the condition necessary for the transplant to be accepted. Otherwise graft rejection occurs.



## ► Engraftment

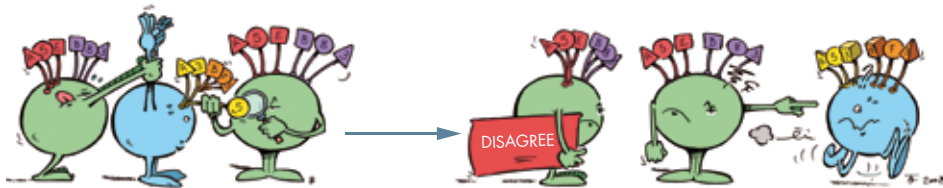
Your HLA system recognizes the HLA system of the donor:

- If no difference is detected, your body is going to accept the transplant introduced.



The donor's HLA system is identical to the recipient's, and the transplant will be accepted.

- However, if a difference is detected (as for a bacterial or viral infection), your body is going to reject the transplant by developing an immune response.



The HLA system of the donor is different than that of the recipient, the transplant is rejected.

## ► Fighting residual disease

The HLA system of the donor recognizes your HLA system:

The transplant cells (your new immune system), will recognize your body's malignant cells as foreign cells. They will fight against them and destroy them. This is the GVM effect (Graft Versus Malignancy). The GVM effect is also called GVL effect (Graft Versus Leukemia).

**In principle, hematopoietic transplantation is simple. But the actual set-up is complex.**

There are three players involved:

- the recipient (you): the sick person, also called the "host";
- the donor: a person in good health who is HLA compatible;
- the transplant: hematopoietic stem cells from the donor.

The transplant (graft) can be from:

- bone marrow
- peripheral stem cells
- cord blood

see p.39

## Setting up the transplant

### ▶ When is allo-transplantation recommended?

Sometimes the marrow ceases to function and too much or not enough hematopoietic stem cells are produced or malignant cells (cancerous cells, also called blasts) are produced.

Among treatments that are often proposed, there is the bone marrow transplant called **allogeneic hematopoietic cell transplantation** (allotransplantation).

Allo-transplantation can be recommended for leukemia, myelodysplasia, myeloma, lymphoma, hemoglobinopathy (drepanocytosis, thalassemia) or other blood diseases (medullar aplasia...). It can also be recommended for certain non-hematological tumors.

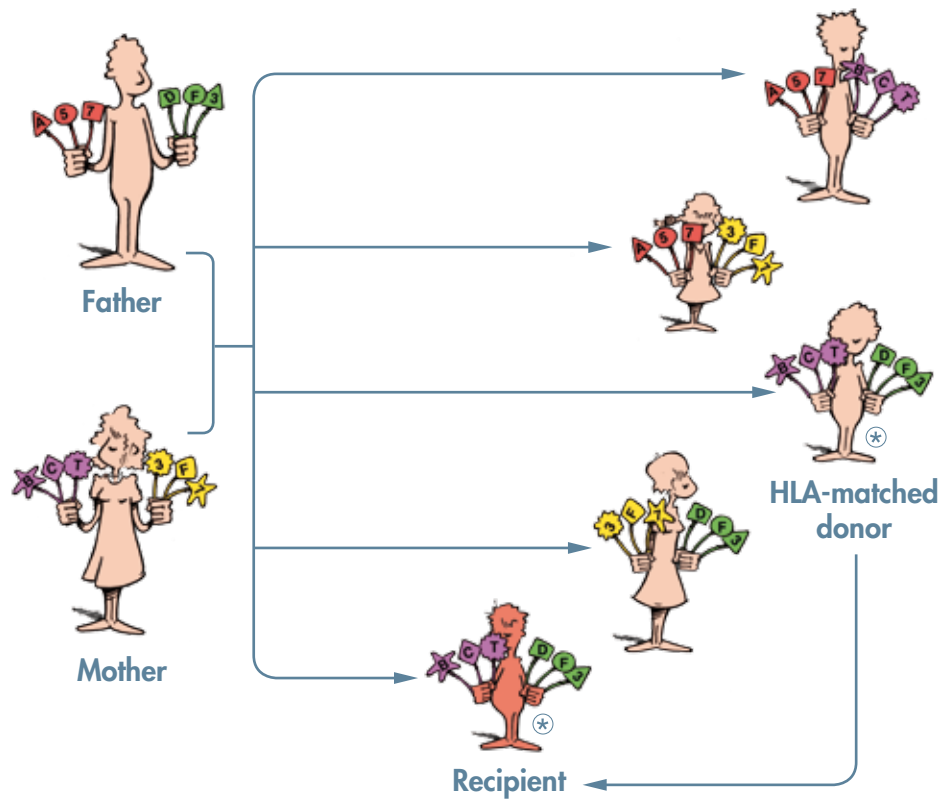
**Transplantation is recommended if it provides better chances of a cure than other available treatments.** Sometimes it is the sole therapeutic option.

### ▶ Who can be a donor?

The donor is a person in good health who possesses an HLA typing as close as possible to that of the recipient. All the same, despite all the efforts deployed to find an HLA-matched donor, genetic differences between the donor and the recipient always persist.

It's often among one's siblings that an HLA-matched donor is found. The research for a donor starts **first among the recipient's siblings**. One uses the terms genetically identical transplant and related donor.

The hope of finding an HLA-matched ⊕ sibling is around 25-30%.



■ *I remember the day when he called me to say that we were a good match. It was great! It was a very strong moment! I am his little sister and there I had the impression to become his big sister. (sister, donor, 32)*

If you don't have a sibling, if there is no compatible donor amongst your siblings, or if the donation proves impossible for another reason, in this case, **it is rare that another familial donor is sought.**

■ *Being an only child, I felt disappointed. There was no possibility of finding a donor amongst my siblings. (Alexandre, 42)*

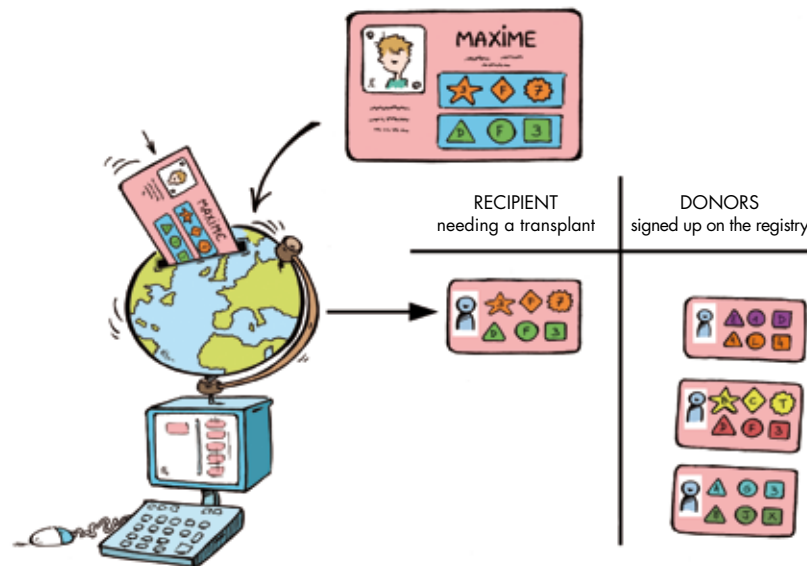
In this case, a search is made for a **volunteer donor signed up on the international registries.** This type of donor is referred to as pheno-identical or unrelated donor.

The recipient's HLA typing is compared to that of volunteer donors in the registries. The wait

for a response can be short but it can also sometimes be long. For starters, all the necessary information and the exams have to be conducted to guarantee a good HLA match between the donor and the recipient.

The hope of finding a well-matched donor from the registry is around 40%.

■ *I believed that they wouldn't find a donor; my brother wasn't compatible. It's difficult to wait. (Frédérique, 53)*



**When it proves impossible to find a sufficiently compatible donor,** transplantation is not going to be a treatment option for you. **Your doctor will propose another treatment adapted to your situation.**

Finally, in certain specific cases, it could be that other family members or a sibling who is not 100% compatible are solicited.

■ *One shouldn't build transplantation up to be too sacred. It is not the last chance, nor is it the sole solution to all problems. It's a medical technique, that's all. (doctor)*

## ► What is the pre-transplant examination?

Before your transplantation, we will need to verify that you can tolerate the procedure without excessive risk and that there are few contraindications. **A thorough pre-transplantation examination** (blood, radiology, cardio tests, etc.) is conducted.

The results of this exam will facilitate the adaptation of the different modalities of the transplantation (preliminary treatment, called conditioning, type of transplant, etc.) to your situation. It also allows the doctors to detect any anomalies that could cause complications post-transplant. This examination will serve as reference and will allow for comparing the results of the completed exams before and after the transplantation.

It is rare that the results of the pre-transplantation exam would preclude transplantation.

**The donor** is subject as well to **predonation testing**, to verify that the donation will not pose any risk to them. It is rare that the results of the predonation testing will cause the refusal of the donation, but this can happen.

The examinations of the recipient and the donor provide information concerning viruses to which each has or hasn't been individually exposed. This can help in the selection of the donor. It is equally useful for taking precautions against complications that could arise after the transplantation.

## ► How does one prepare the recipient for transplant?

Because compatibility between you and your donor can't be perfect, it will be necessary to prepare your organism so that it can accept **the graft in the best conditions possible**: this is called **conditioning**. This is a very important moment that precedes the hematopoietic stem cell infusion from your donor.

■ *There is a lot of hope when patients start to prepare for the transplantation, during the transplant and the days following, it's full of hope! They are ready to endure; they've been informed and they are ready for combat. (nurse)*

The conditioning's main objective is to create the most favorable situation for the acceptance of the transplant by more or less completely destroying your immune system.

There are different types of conditioning that adhere to one technique or to a combination of several techniques: chemotherapy, radiotherapy and/or immunotherapy.

The choice is made according to:

- your age
- you general state of health
- the diagnosis of your illness
- the type of graft being received

## Myeloablative conditioning - or standard conditioning

The goal of this conditioning is three-fold:

- ▶ “make room”
- ▶ treat the residual diseases
- ▶ facilitate the acceptance of the transplantation

The unhealthy marrow is destroyed during conditioning, generally by chemotherapy, or a combination of chemotherapy and radiotherapy. This is a treatment using high energy rays called TBI (Total Body Irradiation).

Your unhealthy marrow will subsequently be replaced by healthy marrow.

■ *These rays! Yes, impressive because you don't see anything, you don't feel anything, it's bizarre...it's there that the situation takes effect. Until then it was words. There it becomes concrete. (Melanie, 20)*

■ *I arrived armed and ready. I was marked with an indelible marker allowing the localization of my lungs within a millimeter, as well as on my head. I looked like some client of a tailor or a seamstress. (Thibaud, 40)*

This type of conditioning can be a source of complications and that's why it is often recommended to people who are rather young.

## Non-myeloablative conditioning or reduced intensity conditioning (RIC)

In certain situations, a transplantation with reduced intensity conditioning (RIC) is recommended, sometimes called a “mini-transplantation.” As the name indicates, it employs a less-toxic conditioning with less risk of immediate complication. The goal is above all to create the most favorable conditions for the transplant.

This generally concerns elderly people or those that wouldn't tolerate a myeloablative conditioning.

## Intermediate or Sequential Conditioning

Today, there is a tendency to propose an intermediate intensity conditioning, that is to say a “reduced toxicity” conditioning. This is also called a sequential conditioning regimen.

It could be that your disease necessitates a treatment for which the intensity is higher than that used in the preceding conditioning. Add to that the necessity to spread out medication during a period of several days with a series of sequences of different medications. So the doctors might propose this type of preparation which is referred to as intermediate or sequential conditioning.

## ▶ What different types of grafts are there?

Your doctor will choose the type of graft according to your physical condition and disease status, the availability of the type of graft, his or her own experience and that of the medical staff.

### There are three types of grafts:

- **stem cells extracted from bone marrow** (medullar stem cells);
- **peripheral blood stem cells (PBSC)** - stem cells mobilized in the blood stream;
- **stem cells contained in the placental blood** of newborns (cord blood).

## ► How is the graft transplanted?

The transplant in and of itself is very simple. It's not a surgery like for other organs. It's a transfusion, like a transfusion of red blood cells or platelets.

The contents of the graft are contained in a transfusion bag and infused intravenously via a catheter into the blood stream. But in this case instead of transfusing a finished product (like platelets or red blood cells), a sort of "factory" is transfused that will produce blood cells in the place of the unhealthy bone marrow.

### The day of graft infusion is called Day 0 (D0).

It is extremely rare that there would be complications during the graft transfusion.

Even if it's a simple, rapid, and painless procedure, this much-awaited event is also very moving.

In this moment full of hope, the team will be with you 100%.

If you wish to share this moment in private with a loved one, let the transplant team know. They will understand and make the necessary accommodations.

■ *At the moment of the transplant, there is a nurse, but there could also be other staff, doctors...sometimes there is a small crowd around the flow. (nurse)*

■ *I would have liked there to have been a ceremony the day of the transplant, that there was my doctor. (Virginie, 38)*

■ *During the transplant is a rather strong moment, I watched every single drop. (Matthias, 26)*

■ *I was expecting something spectacular. I saw the bag, my brother was already in his bed. You have the impression that nothing is happening. (sister, donor, 32)*

## ► How does the graft settle into the body?

Infused intravenously, the cells of the graft migrate and take up residency in the hollow cavity of the bone with the aid of specific receptors on their surfaces. Here they take several days, weeks even, before proliferating and differentiating. During this lapse of time, your marrow no longer produces blood cells. The absence of blood cells is called **aplasia**, explaining the numerous complications of the transplantation.

*see p.55*

■ *Some research is being done in the field of graft infusion. One such case is that of cord blood transplantation in which the graft is infused directly into the hip bone cavity. In this instance the graft is concentrated to a minimum to reduce the quantity injected. (doctor)*

The first cells to appear in the blood (often between 15 and 35 days after the infusion) are **the neutrophils. Their appearance generally announces engraftment.** From then on the risk of bacterial and fungal infection poses a lesser threat.

**The lymphocytes**, another type of white blood cells, most often appears at the end of the first month. All the same, the lymphocytes, at the moment of their birth, are not immediately capable of recognizing molecules foreign to the organism. For that **they must be "educated"**, which can take several months.

*see p.43*

Next appear the **red blood cells and the platelets**. The production of a normal quantity of red blood cells and platelets can sometimes take several months. This is rarely a problem because they can always be transfused.

### ► Why is a protected room necessary?

In an attempt to anticipate infections, you are put in a protected room (sometimes called a sterile room) just until engraftment. From then on the risk of bacterial and fungal infection decreases.

see p.93

In most cases, you don't leave the protected sector except to return home. Unless a CT scan or a transfer to ICU are necessary, you can't leave the protected sector.

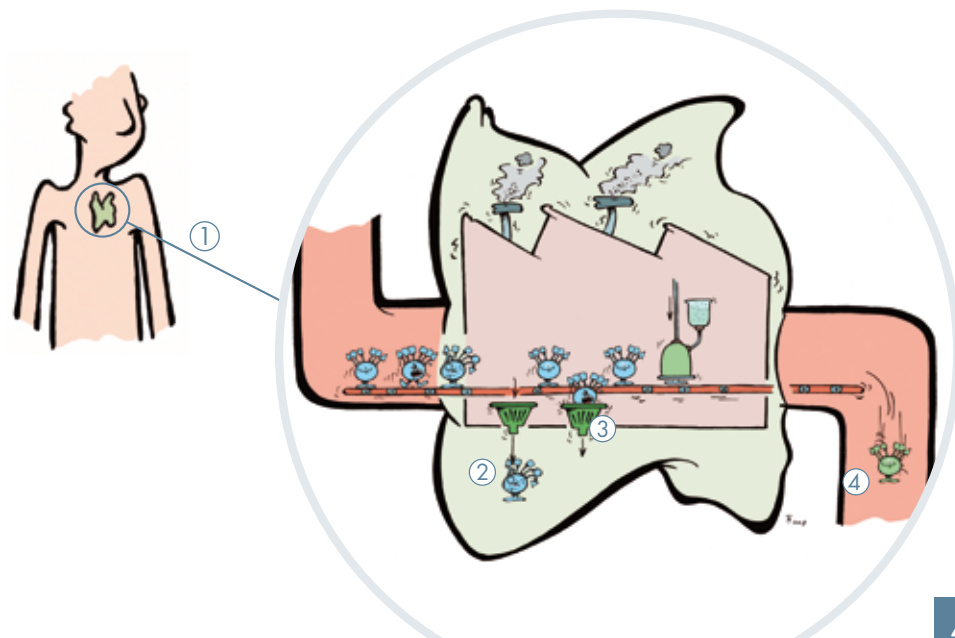
see p.74

Leaving your protected room might be worrying for you. Rest assured that the doctors estimate that the benefit expected from leaving the room largely surpasses the risks.

Sometimes the doctors estimate that the risk of immediate infection is not very high and decide to conduct the transplant outside of a protected room. This scenario is most often proposed in particular situations of transplantation with reduced intensity conditioning. Otherwise and in extremely specific cases, the doctors can foresee a return home soon after the transplant with later hospitalizations if necessary.

### ► Sustainable immune system reconstitution

The immune reconstitution after allo-transplant is an active phenomenon of such a sort that **your organism is going to educate the "new immune cells", i.e. the T-lymphocytes or T-cells from the graft**. This education is conducted amongst others, by a gland situated behind the sternum called the thymus ①. It consists in a dual selection of immune cells of the graft. The thymus eliminates the cells that are too aggressive ② for your body and cells too weak ③ to defend it. Thus the thymus insures that your body only keeps the cells that are tolerant ④ of your organism.



Contrary to what one can observe in the case of a solid organ transplant (like the kidneys, the liver, the heart or the lungs), the majority of patients who receive an allo-transplant are going to accept the transplant, which eventually allows them to stop the immunosuppressant drugs (immunosuppressant drugs are medicine that diminish the immune reaction of the organism).

In the event that the thymus is not able to correctly educate the donor-derived T-cells, the appropriation of the transplant by the recipient is not complete. Therefore the patient can develop a later delayed immune reaction called chronic GVHD.

The factory doesn't work normally and it fails to exclusively select tolerant cells.

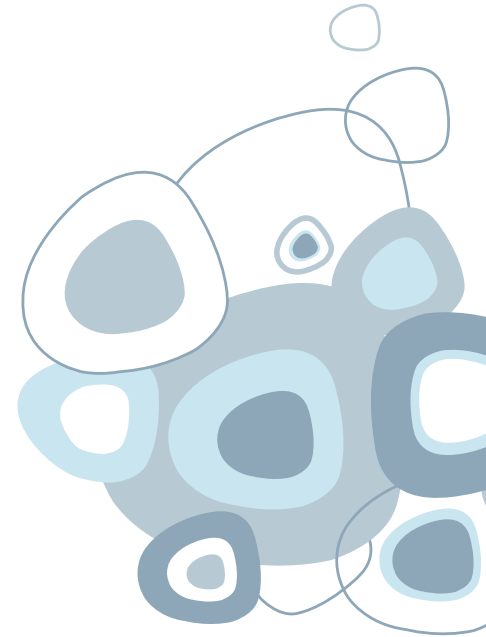
*see p.70*

The engraftment of the transplant's cells is determined by a blood test called **chimerism** whose goal is to study the cohabitation between the donor cells at the recipient's body.

Since the body's defense system memory was lost during the transplantation, it will need a long time to reestablish a functioning donor-derived immune system.

For example, several months will be necessary to acquire a capacity to respond to vaccines. Three months after the transplant, vaccines are provided to correct the absence of **vaccination** or the loss of previous immunization.

Certain vaccines are going to help fight against infections that the organism is not yet able to sufficiently control after the transplant.





## ► How is the decision to transplant made?

The patient's treatment options are discussed during a multidisciplinary meeting. The treatment decision is then put into a written document. In the case that transplantation is decided, the doctors will present and explain this decision to you. You will then be given a version of the written document that is your personal health plan. **Your agreement and adherence to this plan are indispensable.**

Several variables are taken into account in the decision to transplant: the diagnosis of your disease, its stage and evolution and its possible evolution over time, your general condition, the existence of therapeutic alternatives...

Most often the solid scientific data show that the transplant is the better option in your situation.

Your doctor makes this recommendation because he holds the conviction that the benefit far surpasses the risks.

■ *To be honest, if I look at the data that we have, from a medical point of view, it's the best thing to do. (doctor)*

In the absence of an international standard of care for a given disease, the decision for transplantation is sometimes difficult to make. Therefore your transplant team will call upon the experience of national and international doctors who are experts in that field.

Your doctor will explain your situation and possible transplant alternatives, and will discuss with you just until the best decision emerges, a thought-through decision to which you can give your agreement. In all cases, your doctor already carefully and consciously weighed the risks and the benefits, engaging completely his responsibility

■ *I say that one weighs the benefits and the risks and the benefits win out, but that...one takes a risk. I emphasize that the decision has been made by more than one doctor. I say it directly. (doctor)*

## ► Can the outcome be foreseen?

The scientific data and statistics, but also the team's experience allows the doctors to determine if the transplantation offers more chances of healing than another treatment. However, they can't foresee what is going to happen for a given person in particular.

■ *It's difficult to foresee what will happen. For certain transplants, it's foreseen that they will be difficult, really difficult. And then they go fine without complications. And then others we think will go without a problem!...It's difficult to foresee and it's difficult to explain to a family when it goes badly. (doctor)*

Not only does each transplant outcome depend on the disease, but also on the HLA- compatibility between the donor and the recipient and the evaluation of individual risk factors. This is why no two transplants happen in the same exact manner.

**This is why what happens to another person that you know will probably not happen to you in the same way.** Don't hesitate to address these issues during the discussion with your transplant team. Even if it's not possible to know what will happen, **the transplant team does everything in their power to insure your safety and the success of the transplantation.**

### ► Does the transplantation pose a vital risk?

For whatever reason one does a transplant, it can be complicated and one or more complications can end in death.

This is very different than what you have known before the transplant. The essential risk was related to the disease but in the case of allo-transplant, the risk linked to treatments themselves bring a greater risk.

Numerous patients transplanted report that the statement of a vital risk sets off an emotion that makes them forget much of what is said during the transplantation consultation.

This is normal. This guidebook helps but does not fully compensate for this situation. You shouldn't depend solely upon it. If you need to, it's worth getting in touch with your doctor to ask your questions and even schedule another appointment for further discussion.

- *I knew that with the sickness, my life was in the balance. There wasn't a treatment. Effectively, I took a risk with the transplant, but I was also risking the chance that I might live. (Alexandre, 42)*
- *What I heard was, «You can make it through this, or you won't make it through this.» From the delivery of the diagnosis, I knew the risk. (Gilles, 61)*

If sometimes after the transplant, your situation evolves in such a manner that there are no more possible treatments that will improve your condition, the transplant team will put in place measures that will provide you with as much comfort as possible. This step will be taken with respect for your dignity with your agreement and in cooperation with the palliative care team.

- *What's important, is accompanying as best as possible. For me, one engages in another health process that is "accompaniment to the end of life." (nurse)*

If you need to, it's often good to bring up this difficult subject well before the transplant with your transplant team.

## ► Are certain transplant teams better than others?

Transplant teams go through an “evaluation and accreditation program.” Their activities are followed and evaluated by independent observers. Numerous studies show that the results of different teams are comparable provided that the transplant is conducted correctly.

■ *You do well what you do often. (doctor)*

The majority of teams apply the same procedures.

**All the same, differences between transplant teams do exist:** means of isolation, dietary measures, complication prevention methods, etc. Despite these differences, the results are similiares.

Every approach is comprehensive, and it is often difficult to modify a single element without modifying the entire procedure. If you change centers during the transplant, or if you discuss with those who have received a transplant in another center, don't be surprised if you notice some differences. Don't hesitate to refer to your transplant team about what you have seen or heard.

Today, French teams, regrouped in the French Society of Bone Marrow Transplantation and Cell Therapies (SFGM-TC) work to harmonize practices across centers.

## ► When will I know the transplant engrafted? Does that mean I'm cured?

A transplant engrafts when neutrophils start to appear in the blood (15 to 35 days after the transplant). A test that **evaluates the chimerism** allows us to know the proportion of white blood cells from the donor and those of the recipient in the blood and in the marrow.

When the transplant has engrafted and is complete, the chimerism is 100% donor.

In cases of rejection, the chimerism is 100% recipient. There can be intermediate situations where one talks of partial or mixed chimerism.

In certain cases, the engraftment can be partial at the beginning, but becomes complete later on.

Depending on your disease, a complete engraftment might be necessary or partial engraftment (mixed chimerism) might be sufficient.

Certain treatments, if necessary, can equally transform a partial chimerism to a full donor chimerism. Your transplantation doctor will inform you.

Engraftment is an important step. All the same, the risk of complications are not marginalized.

For certain diseases, you can clearly announce healing several years after the transplant.

In other situations, the risk of relapse of the sickness or other outcomes can persist for a long time.

Certain diseases, do not only concern the marrow and the blood but also other organs and cells in the body, like Fanconi anemia for example. In this case, the transplant can only cure the blood part of the disease. The transplant will not improve the state of other affected organs. That's why it can be difficult to talk about full healing. Your transplant doctor, who knows your situation, will know better and will be able to tell you more about it.

## ► How do I know if data from my transplant is used for research? What is consent?

Even if the rate of recovery with hematopoietic stem cell transplantation has considerably increased in these last few years, there is still progress to be made. This has been possible thanks to clinical research,

led in collaboration by transplant centers: Center for International Blood and Marrow Transplantation, Euro cord, European Society for Blood and Marrow Transplantation (EBMT), the French Society of Bone Marrow Transplantation and Cellular Therapies (SFGM-TC), Pediatric Blood and Marrow Transplant Consortium, the Canadian Society of Hematopoietic Stem Cell Transplantation...

■ *As more time passes, more often I think, "There's research... if something happens, maybe there will be new treatments." (Frédérique, 53)*

**It could be that your transplant is part of clinical research programs. Such as:**

- **research conducted using databases** (called "registries") that document all transplants. You will be asked for the authorization to

anonymously record certain data pertaining to your transplantation. Your agreement is solicited, conforming with the law established by the governing body responsible for information privacy, protection and usage (in France, CNIL);

- **clinical trials (or therapeutic protocols).** If you are offered a therapeutic trial, it is because it is adapted to your situation. If you accept to participate in such a study, you will be asked to sign a **research consent form.**

**Written and oral information explaining** the treatment will also be given to you. You have the right to refuse this offer.

If you accept, you reserve the option to discontinue your participation in the trial at any moment without

needing to justify your reasons for doing so. You will still be taken care of with the best known treatments and will benefit from the same quality of care.

The law does not allow for conducting research without your written consent.

Aside from clinical research, your consent will be needed for other procedures such as anesthesia, surgery, transfusions, tissue samples, biological tests.

You may get the feeling you are signing a lot of documents. Possibly you will have questions concerning what the regular procedure of the transplant consists of and what is part of the clinical study. Don't hesitate to bring up your transplant team about this.

# Possible post-transplant complications and treatment approaches

## Preface

- *I needed to know the risks in order to agree to take them. (Anaïs, 48)*
- *During the pre-transplant consultation, copious amounts of information are given, exhaustive even, in order to be as thorough as possible. Information on the risks is not watered down, nor is anything dramatized. The patient has a right to this information. But they leave the consultation with more questions than certainties. After, they expect side effects...they are on the lookout for what's going to happen. (psychologist)*
- *We were looking out for everything afterwards. The difficult part, that was waiting for the GVHD. We knew there were risks. (sister, donor, 32)*

Complications (also called risks or side effects) that can arise after a hematopoietic stem cell transplant vary in severity and frequency. Some are completely the exception.

Each stage of your transplantation has its own complications. Depending on your disease, maybe you will have already encountered some of them before the transplant (loss of hair, change in taste...).

These are usually effects on the organism essentially due to conditioning and to aplasia or from immunological complications.

- *There are side effects from the beginning to the end of the procedure, but the procedure exists to heal the person from the illness. (Alexandre, 42)*
- *I told myself that I was going to get through all of that. (Marc, 30)*
- *At the moment of the complications [septicemia, on a catheter], I thought, "I can't stop mid-stream. I have to get to that other riverbank." – I hung on. (Anais, 48)*

### You must keep two things in mind:

- **the threat of each risk varies** from situation to situation and you will not have, certainly, all the complications;

- **your doctor maturely weighed these risks** before recommending the transplantation, and he consciously considered that the expected benefits surpass the potential risks.

Moreover, all measurements taken during the pre-transplant examination were taken to assess the risk of complications, to anticipate them if possible, monitor their appearance and rapidly control them if they occur.

This follow-up is daily in the weeks following the transplant; then little by little it's spread out. This monitoring is carried out by the transplant team along with the help of doctors and professionals from other specialties who intervene in response to problems encountered.

In all cases, **the transplant team does everything to anticipate, treat, and ease pain** (it can be due to nausea, headaches, abdominal pain, liver, saliva glands...).

When pain surfaces, treatment is immediately put in place in an effort to control it.

Sometimes it takes a certain amount of time (from several hours to several days) before it will subside or be sufficiently eased.

There are times it's not possible to make the pain disappear completely, but the team tries everything they can to make it tolerable.

- *When they [the patients] have excruciating pain, it's bad, very bad...we give analgesics, but it can take up to 24 hours before the pain is controlled. (nurse)*

*I tell them that they will probably feel bad, that we have morphine, that it's rare that the pain is completely eased, that there will be extremely arduous days – definitely for myeloablative conditioning – that they will have a morphine pump, that they'll sleep a lot... the family definitely worries during this period. (doctor)*

Pain is a subjective experience, before which everyone is different. It's a reality that must be recognized. It must never be minimized either by those who experience it or those who are taking care of it. Feel free to talk about it; never be scared of disturbing the team. It can be caused by a number of triggers. You yourself are the best to evaluate it. A pain scale might help.

Pain is broken down into two main categories:

- **acute pain**, more or less intense and transitory;
- **chronic pain** is pain that inserts itself and stays or throbs.

Pain is generally treated by analgesics. The prescription can depend on the type (acute or chronic) of pain and/or its cause. Psychological suffering and anxiety are also taken into account. An algologist, a pain specialist, can help when the situation proves difficult.

Administering morphine intravenously or transcutaneously (patch) is common or an oral derivative is given.

This should not worry you:

**using morphine to treat pain does not cause you to become addicted.** If you doubt its usage, talk about it with your transplant team.

You might be offered a special PCA (Patient Controlled Analgesia) pump so that you can adapt the quantity of morphine to the intensity of the pain. This technique in general allows you to receive less morphine for an identical effect but with the advantage that you participate in pain management.

■ *Morpheus, the great mythological bearded god of Sleep, from which the word "morphine" is derived...(doctor)*

To ease the pain, the current practice is to combine several approaches as complement to pharmacological means: sophrology, relaxation, hypnosis... but these techniques are not all offered in all transplant units. The physiotherapists also participate by using massage and lymph draining techniques when possible.

Alternative medicines, natural medicines (osteopathy, homeopathy, reflexology, acupuncture) are also capable of easing pain. This is always done in consultation with your doctor to verify that there are no contraindications for your case.

■ *Certain insurance policies currently offer plans that include natural medicine. (Nathalie, 35)*

## Risks during the first year post-transplant

Complications can surface in the first weeks, the first month or in the first year post-transplant. They are linked to conditioning, aplasia and certain immunological reactions.

### ► Conditioning related risks

#### Nausea and vomiting

In the days following your conditioning, you might feel nausea that may cause vomiting. Generally, nausea and vomiting are anticipated with medicine. When they occur, they can be alleviated with treatment adaptation and made to progressively disappear.

#### Modifications in taste

Within the first year post-transplant, the sense of taste is altered and foods often taste weird.

#### Mucocitis

The inflammation of the mucus glands can cause the destruction of cells on the surface of the mouth and intestines. This causes canker sores in the mouth making it sometimes impossible to swallow your own saliva. Mucocitis causes pain in the intestines and sometimes severe diarrhea.

■ *I had a huge mucocitis; it was disgusting! (Catherine, 38)*

■ *The throat becomes painful and swallowing becomes a real challenge. (Stéphanie, 37)*

#### Mucocitis presence can make swallowing painful and eating difficult.

To provide your body with all the nutrition it needs, you will receive, depending on the state of your digestive tract:

- **parenteral nutrition** administered via your central venous line;
- or **enteral nutrition**, that brings liquid nutrients directly to your stomach via a long, thin nasogastric feeding tube.

Fortunately, our oral and intestinal cells regenerate themselves over time. It can take 10-15 days to achieve complete scarring. During this period, a mouth wash and sometimes an intestinal decontamination

need to be conducted several times a day. Pain is often treated by morphine or its derivatives.

#### Loss of hair and other physical changes

Hair loss, among other physical changes, is often the most difficult to endure because it is a visible sign of the disease. Certain people, especially adolescents and young adults, are particularly sensitive to these changes seen as an affront to their physical image. Psychological counseling can help with this. Even in the protected sector, you can ask to see a psychologist.

**These changes** can be destabilizing. They may even feel like a loss of your identity. Do not worry. **Quite often they are temporary and reversible.**



**Hair loss** (much less often loss of eyelashes, eyebrows and pubic hair), called alopecia, is nearly inevitable, especially if you receive myeloablative conditioning. There is no treatment to prevent this loss. Hair starts regrowing at the end of conditioning becoming visible two months after the transplant. It sometimes grows back thinner than before. Rarely does it grow back in patches.

■ *I lost my hair but it was not difficult. I think that it's less difficult for a man than for a woman. When it started to fall out it was irregular and not pretty. I asked that they shave my head. The first time you look at yourself in the mirror it's a little surprising, but now that the hair has grown back, it's my wife who cuts my hair very short with an electrical razor! (Gilles, 61)*

■ *The hair loss didn't bother me too much! Three months before, there had been the football world cup, it was the "Fabien Barthez" effect (famous French goalie). I had wanted to know what sort of head I'd have if I was bald...so I was fine with it. I wore scarves and hats. (Anais, 48)*

■ *My hair was everything for me! It was a psychological blow. I found myself wondering if I was man or woman... I had gotten married a year before and I was still in a relationship where seduction was at play. (Nathalie, 35)*

■ *My hair, while short, fell out in clusters. There was a lot on the pillow and the sheets...it itched and was annoying... I decided to totally shave my head. (Jean-Pierre, 45)*

■ *I have and I had fine hair. There's a lot of it. When I passed my hand in my hair, I saw a bunch of hair. That was a shock. (Matthias, 26)*

■ *A nurse's aid came to see me to offer to wash my hair. I asked her to change her glasses because I didn't have any more hair. "Trust me!" she told me. I let her do it and this hair washing without hair was a moment of sweet abandon...(Thibaud, 40)*

■ *When I saw my father again, he didn't have any hair, but that wasn't a shock. I was happy to see him again! (young man of 19 who was 12 when his father was transplanted)*

On the contrary, certain medicines might increase **hair growth** all over the body. They could also provoke seizures and cause kidney or hepatic toxicity. These side effects are reversible and stop as soon as the drug is no longer taken.

■ *I had a layer of facial hair that grew. I told myself I was going to become the bearded woman! (Nathalie, 35)*

■ *Hypertrichosis -super hairiness, I asked about it. It worried me. (Anais, 48)*

Other medications (steroids) make your face and torso thicker. In the majority of cases, this is equally reversible. Rarely do stretch marks appear and leave lasting scars.

■ *Sometimes, people are extremely affected by their physical appearance after the transplant. It may leave an impression, but it doesn't last. (psychologist)*

- *I was very disfigured by the steroids. It was hard to accept. (Frédérique, 53)*

During the treatment you sometimes feel intense fatigue. Inactivity from the fatigue can cause muscular atrophy that is rather pronounced, difficult in particular to experience for adolescents, young adults, and athletic individuals. This is temporary and is reversed when you get back to normal life and physical activity.

- *There was a stationary bike in my room. Following the advice of the medical team, in order to preserve a little muscle mass and physical form, I tried to discipline myself to do 10 minutes of pedaling per day. (Thibaud, 40)*



Teenagers and young adults are particularly sensitive to corporal modifications. At the age of adolescence, appearance is extremely important! It is therefore very difficult to accept and assume the physical changes caused by the sickness.

- *Teens often ask, "Will I be able to do sports again?" - This question causes a lot of anxiety. Also often they ask how long they will stay in the hospital. (volunteer with an association)*
- *My brother was very athletic. Like a lot of boys, I think, he thought he was invincible: I never get sick. I'm stronger than the others. - When it happened to him, he was completely angry... He couldn't handle this image of himself and avoided posting photos on his blog. (sister, donor, 32)*

- *For teens and young adults it's difficult to be forced to stop their activities and change plans. It's complicated to be confined, to not be able to leave the room and for sure there are physical changes... That raises the question of identity. (psychologist)*

The observable physical change is hair loss. For many, girls and boys, hairloss is difficult to endure. Its impact is often underestimated by friends and family. Don't forget that the loss of hair is temporary!

- *I lost my hair. When they shaved my head, it was difficult. The nurse put a towel over the mirror. She told me, "You take it off when you're ready." (Melanie, 20)*

Websites and associations exist that make it possible to exchange stories with other teens who have lived the same challenges

**The transplant doesn't transfer any physical characteristics of the donor.** Some people are scared about this. They shouldn't be.

- *It didn't make me grow breasts. I am not excited when I go into a rugby locker room. (Matthias, 26 – his donor was a woman!)*

■ *I imagined a lot about my donor's personality...I made an entire movie. It bothered me not to know this person. (Anaïs, 48)*

■ *I was scared that I'd grow hair all over. (Alice, 32 – had a male donor)*

■ *My brother is an alcoholic. Will the marrow be good? (Marthe, 52)*

■ *I told my brother he was going to go shopping more! (sister, donor, 32)*

■ *The donor is his brother, my uncle. There are times it seems to me that I find traits from my uncle in my father. It's funny! (a 16 year-old girl who was 10 when her father was transplanted)*

■ *I understand there is the anonymity...I can't do anything to thank him. I gave him a name: I call him Helmut. I said Helmut didn't like chocolate (since I loved it before). I changed blood groups! But concerning profound identity, nothing really changed. (Frédérique, 53)*

The sole characteristics that can be transmitted are those related to blood like blood group and certain allergies.

### Hepatic risks

An alteration in certain cells in the liver's veins can be produced. Sometimes this disturbs blood circulation in the liver and a condition develops called veno-occlusive disease (VOD) or sinusoidal obstructive syndrome (SOS).

This complication, often intense, can cause liver pain, weight gain, jaundice, and disruptions in liver activity that requires being transferred to intensive care. It is extremely rare that this has lasting effects or that your life is in danger. Certain measures are taken to diminish the consequences of this complication: restraining water supply and controlling urine elimination (quantity of urine and composition, called diuresis), for example.

### Risks to the bladder

As a result of certain medications used in conditioning, sometimes the bladder's surface cells can be damaged. This causes the appearance of blood and clots in the urine, causing pain: this is hemorrhagic cystitis. This bleeding, when it occurs, appears several weeks post-transplant.

Sometimes it's necessary to irrigate the bladder by inserting a urinary catheter.

Hemorrhagic cystitis ends almost always by resolving itself, but this may take several weeks.

## ► Risks related to aplasia

### Infections

Risk of infection is due to bacteria and microscopic fungi normally controlled by neutrophils. This risk is present during aplasia, a period lasting two to four weeks following transplant. This risk, although mitigated by the isolated room, remains real.

Microbes and fungus respond well to antibiotics and antifungal medication. Thanks to the monitoring your doctor will put in place, he will be able to tell you the risks of possible infections. Infections caused by certain viruses or parasites can be anticipated with medicine. Others can be monitored by blood tests and treated if deemed necessary.

**Certain tests cannot be conducted in the protected room** (a lung scan, for example). You will have to leave it and this might be concerning. Know that the benefit expected is to orient the diagnosis and consequently to put in place an adapted anti-infection treatment. Precautions are taken to protect you when you leave the isolated sector.

### Risks related to transfusions

During aplasia, when the marrow does not yet make a sufficient quantity of red blood cells and platelets, you may need blood and platelet transfusions.

■ *I was passive, I submitted. They had to do a platelet transfusion. No one really told me what it was. For sure, this was not chocolate! (Nathalie, 35)*

All blood cell products are treated with radiation before injection. Enormous progress has been made in the prevention of communicable infections by transfusion: AIDS, Hepatitis B, Hepatitis C. The actual risk of transmission of one of these illnesses by transfusion is minimal (around 1 in a million).

Very rarely, and despite all the precautions taken, a transfusion bag may contain bacteria responsible for an infection. The team handles this with antibiotics.

Chills, fever or discomfort are possible side effects of a transfusion. This is not serious. These reactions do not necessarily occur for following transfusions. When they happen regularly, certain medicines (steroids) given before the transfusion can mitigate or eliminate these symptoms completely.

After the transplant, you will receive a new blood group card because you will have the blood group of your donor. This changes the very

specific rules of transfusion that keep track of the donor and recipient blood groups.

**Transfusion is made possible thanks to blood donors.** Even your family and friends who are concerned may be able to help. The best means is that they give their blood or platelets. This blood might not be given to you in particular but will allow all those who need a transfusion to benefit. Talk about it to your transplant team, they will tell you about local blood drives.

## ► Risks linked to immune reactions

There is the risk of an immune reaction between the cells of your body and those of your donor.

### Risk of graft rejection

Sometimes the transplant fails. In this case the neutrophils do not appear in the blood at the expected time.

Sometimes also, although the transplant first succeeds, it can be rejected. If this happens, it's almost always in the months after transplant.

In these situations one can often offer a treatment. These treatments can vary depending on the situation encountered.

There is the rare exception that a **second transplant** is considered in cases of graft rejection or difficulties with the implanted graft.

■ *From time to time, a donor is asked for more cells for a second transplant. Because it didn't work so well... they give more cells. (doctor)*

### Risk of the graft versus host disease reaction (GVHD)

In the first months following the transplant, stem cells coming from the graft (the case with T lymphocyte cells) consider some of your healthy organs or tissues as foreign and are going to try to destroy them. This reaction of the graft versus the host is called GVHD.

### These cells notably attack:

- **the skin** (cutaneous GVHD) causing reddening;
- **the digestive tract** and the intestines (gastro-intestinal GVHD) causing diarrhea and vomiting;
- **the liver**, specifically the biliary canals (GVHD of the liver) causing jaundice (icterus).

When the reaction appears within the four months following the transplant, it's called **acute GVHD**. The severity of the GVHD is evaluated along a scale of 0 (no reaction) to 4 (severe reaction). This is the complication of the transplant that can put your life in danger.

■ *She had a GVHD, very strong with spots everywhere; it was a volcano! (husband of a transplant recipient, 39)*

### Managing GVHD:

- **The first phase is prophylactic.** It consists of preventing the risk of GVHD by choosing a donor with the best HLA-matching, submitting the graft to a specific treatment and giving you immunosuppressant drugs. This is done in addition to infection prevention treatment.
- **The second phase is therapeutic.** It consists of establishing strict monitoring soon after the transplant. Blood analysis allows for the detection of any anomaly and to put in place, when necessary, effective treatments appropriate for the given grade of the GVHD.

Depending on the grade of the reaction, this period can be very tiring because it frequently comes with fatigue and muscular atrophy.

Self-image can also be affected as a result of side effects from certain treatment. This is true for steroid use.

Sometimes GVHD appears later, longer than three months after the transplant, but rarely beyond the first year. This is called **chronic GVHD**.

Chronic GVHD is a lot more complex and less aggressive than acute GVHD. It requires prolonged treatments using weaker dosages than used for the acute form of the disease. The organs most frequently affected are the skin, the mouth and the eyes. Depending on the situation other areas can be affected.

When the lungs are targeted it's called obliterative bronchiolitis. This requires specific lung care.

**All the same, a low-grade GVHD can bring good news.** In effect, the cells of the graft also attack your malignant cells. If some of the sick cells were not destroyed by the conditioning, the lymphocytes coming from the graft can finish the job. This is the GVM (graft versus malignancy) effect.

*see p.31*

- *The big worry is the GVHD. It's a bad word! GVHD can instill fear: it really scared me... until the hematologist made me understand that, "No, this reaction can be a friend, it's necessary to have this GVHD." (Alexandre, 42)*

## Relapse risk

The risk of relapse exists and is dependent on your situation. With time, the risk of relapse diminishes. After a certain number of years, the risk becomes so minimal that one talks about cure.

- *Relapse is hard, because we are rooting for them! (nurse's aid)*
- *Relapse is hard for the patient, for us, for everyone. (doctor)*
- *I was scared of relapse - one never knows. But my father is for the most part well, and he has been very courageous. That reassures me a little. He is solid in every way. (a young man of 19 years who was 12 years-old at the time of his father's transplant)*

Monitoring chimerism often anticipates the relapse and allows for the recommendation of early treatments, in particular a transfusion of the donor's lymphocytes, a **Donor Lymphocyte Infusion (DLI)**. No preliminary treatment (chemotherapy or radiation) is necessary.

*see p.89*

The later the relapse occurs the greater the chance of there being a treatment to take care of it.

## ► Other possible complications

### Central-line related risks

Generally a central line does not cause a problem.

**However, bacteria can get in, creating an infection.** Often an antibiotic treatment suffices. It is sometimes the case that the line needs to be removed and another is put in using local anesthesia.

**Sometimes the line gets blocked.** Different techniques solve this problem without needing to change the line. When you are at home you'll need to follow several simple hy-

giene rules to minimize risks: your transplant team will help you during your stay to prepare you for your return home.

### **Complications requiring adapted methods and strict observation**

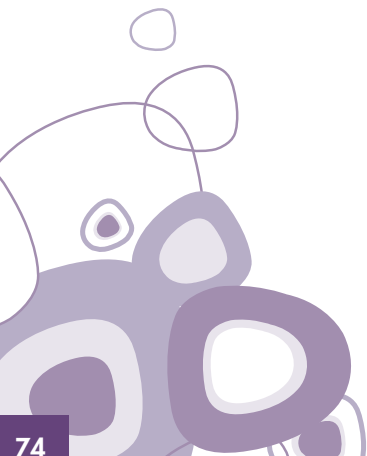
There are certain complications (ex. heart or lung failure) that necessitate methods or specific competencies that implicate increased observation. In this case you will be transferred to an "intensive care unit" (ICU). This situation may cause you and those close to you to worry because it implies leaving **the protected sector**. Treatment methods are adapted to your situation with the objective of helping you overcome complications.

This transfer can also be done to prevent a complication that one anticipates. The methods put in place in intensive care generally allow such complications to be avoided.

- *Trips to the ICU are made as a precaution and not as an emergency. The patient isn't at risk, but the action is taken as prudence because there are indicators that make one think it would be better to have increased observation and intensive care. (psychologist)*

The transfer is made at the request of your doctor in agreement with the ICU team. Your transplant doctor and team continue to follow you. Decisions are made in consultation between the doctors of the two services.

- *There is a policy of pre-emptive transfer because the intensive care unit is rather far and one cannot wait until the last minute. The patients are informed. I tell them that this will not be a protected unit and that this is a unit that knows the risk of infection. We know the unit well and are in communication everyday with them. This is continuous care. It is possible to go to ICU, I tell patients that. (doctor)*



### ► Risk of infection

In the months following the transplant, the T lymphocytes are not yet able to recognize a virus or a parasite that has invaded a cell or the body. The duration of this period is extremely variable depending on the situation. It is generally from two to six months, sometimes more, in particular if you receive some immunosuppressive treatment for GVHD.

Patients who received total body irradiation during conditioning or those having an ablation of the spleen have an increased risk with respect to certain bacteria (pneumococcus, haemophilus influenzae...). The risk can persist several years after the transplant.

These bacteria are very sensitive to antibiotics. A preventative or curative treatment (penicillin) could be prescribed.

The first sign of infection is generally a **simple fever**, but the situation can worsen - to the point of being able to even cause fatality if a treatment is not rapidly put in place. That's why, **you need to quickly treat all fevers (within several hours) with antibiotics**. This treatment, if begun in time, is very efficient.

Your transplant doctor will explain the degree of risk and indicate what must be done in the case of a fever once you have left the hospital.

### ► Risks concerning fertility

Sexual activity is usually normal after a transplant even if sometimes fatigue can cause temporary difficulty.

On the other hand, even before getting to transplant, treatments leading up to it (especially chemotherapy) do alter fertility by the destruction of reproductive cells and provoke other hormonal deficits. Conditioning as well could have the same impact.

- *Women more than men bring up the question of sterility. (psychologist)*
- *Sterility is reversible. But no one is 100% sure. This is essentially a result of the type of conditioning. (doctor)*

- *When you have four children and are already 40, for a woman, as for me, the objective is attained! This is not really a concern. (the husband of a transplant recipient, 39)*

This is a major question and it is completely normal that you ask. This is why it must be anticipated.

Depending on your age, you will have been offered, in a preventative way, to preserve your reproductive cells in a special bank: cryopreservation of sperm for men and of ovarian tissue or ova for women.



■ *I was told that I would not be able to have a child. Cryopreservation of my eggs was suggested...but I did not feel like getting into it before the transplant since it wasn't certain and a little experimental. That was difficult to decide. I weighed the pros and cons. I made my decision. (Melanie, 20)*

The advances in methods of assisted procreation can help resolve this problem. It is also possible to envision adopting. Get informed about adoption methods.

- *When patients tell us about a birth, it's good...even if it's complicated with a lot of steps. And then there is also the possibility to adopt. It's a life plan that takes off. (doctor)*
- *To have a child you must want it, it's another struggle. All the same, this works sometimes. (doctor)*
- *During one of our association meetings, we had the pleasure of seeing a mom who had been transplanted come with her husband and two children! (volunteer association director)*



In a couple or for a single person, sickness often poses the future question of love and even more when it comes to teens or young adults. For them, the question of uncertain fertility is particularly important even though at this age it is closely related to questions of desire, self-image and sexuality.

The risk of infertility has a particularly strong impact. It's not only that this touches upon your intimate life, but it's connected to what comes after the transplant. Speaking of when you will be better, of life, of hope. The possibility of recovering and the possibility to become a parent are implied.

Even if the plan for children can seem far off, the question of fertility must be approached to anticipate the future. While these may be delicate subjects, don't be scared to talk about them.

■ *For boys, it must be talked about if puberty has already been reached. It's hopeful to think about something for when you will have found the woman of your life. (Matthias, 26)*

■ *For sure, the doctor has to talk about infertility but also about what comes after. There are questions about work and school. Talking about afterwards is talking about life. (Matthias, 26)*

Know in the end that it is not rare to meet people who have had children after a cancer or transplant.

For women, gynecological care is very important post-transplant. The prescription of a substitutive hormonal treatment in the case of oncoming menopause allows to control and to limit osteoporosis (when bones become brittle, increasing the risk of fracture).

### ► Risk of hypothyroidism

Risks of hypothyroidism (notably after a conditioning that involves total body radiation) requires observation. Hypothyroidism is corrected, when needed, by an appropriate treatment.

### ► Cardiac complications

It is rare that cardiac side effects arise post-transplant. This is encountered by people who receive several pre-transplant chemotherapies.

### ► Eye complications

Transplant patients who have received radiation can encounter cataracts several years after the transplant. This is a clouding of the eye's lens. There are treatments available for this condition (specifically a surgery with local anesthesia). Along with a chronic GVHD, the eyes can become dry. This is treated with eye drops and collyrium.

Ophthalmological care is necessary. A new kind of lens, the sclerocorneal contact lens can also be obtained.

### ► Dental complications

Dental problems, notably with the enamel, may occur post-transplant. Dental care is indispensable.

### ► Exceptional risk of a second cancer

Several years after the transplant, a second cancer can appear, notably certain skin cancers. **This is a very rare condition.** If necessary, it needs care and treatment.

- *The transplant is scheduled. I think of this unknown individual thanks to whom I will be able to get out of this. (Alice, 32)*
- *He or she anonymously enters a hospital to donate the famous bone marrow stem cells. A generous gesture exceptional for its anonymity. Like the athlete in a relay, he or she is going to pass the baton that's going to make me run towards life. This baton, I'm going to take it with open hands! (Stephanie, 37)*

Whether the donor is related or not, they have different steps to take that are carefully detailed during the **predonation consultation**. This is with the transplant doctor and most often a transplant-coordinator nurse.

Certain examinations are required before donation and blood is taken from the donor in view of an eventual autotransfusion. This exam allows the elimination of any potential contraindications and guarantees the safety of the donor as well as that of the recipient. This assures that the donation will present neither the donor nor the recipient with any avoidable risk.

**The donors have to give their signed consent.** They have the right to step down at any moment. However, they will be perfectly informed of the impact this will have on the recipient. They know that backing out after the start of the conditioning could be fatal to the recipient.

- *The donor - recipient relationship is interrelated. (social worker)*

■ *Her brother was found to be compatible. But she was very scared that he would back out from one day to the next. For me, her reaction was incomprehensible. To this day that stays an enigma for me...In the end her brother accepted! (husband of a recipient, 39)*

**The donor** (whether or not related) must go before a notary of the public to sign the consent form.

A related donor that is still a minor or under guardianship, must give their consent before an expert committee.

■ *The only thing that left an impression on me was going to court to give his consent. I was rather astonished that people can back out after giving their consent. I asked about it, and they said: No, no, that doesn't happen very often. (sister, donor, 32)*

**When there's an unrelated donor, the donation is anonymous.** That means that the donor cannot know to whom they are giving their marrow, and in turn, the recipient, them too, cannot know who their donor is.

**The donation is free**, that's to say that a donor is not financially compensated.

On the other hand, in France, the fees incurred by this donation (transport, examinations, hospitalization...) are taken care of by the health center in which the donation is made.

Therefore, **the donation is completely altruistic.**

More than a million people around the world have accepted to be ready to voluntarily and benevolently give their marrow or their periphery stem cells the day that someone will need them.

## Different donation types

### ► Bone marrow donation

A donor's bone marrow will replace that of the patient.

A hospitalization of 48 to 72 hours is usually needed. The donor is hospitalized the night before the transplant and must fast through the night. The day of the transplant, under general anesthesia and in an operating room, the marrow is harvested by inserting a trocar into the pelvis bone. The marrow is then treated in a way adapted to each situation. A filtration is always necessary in order to eliminate little bits of bone or fat that are normally found.

■ *It's like I was given a role. If people talk to me, I'm going to encourage them to donate...It wasn't a big deal for me to do it, and that's why I tell people that it's worth doing and that the risk to the donor is minimal. The benefit for the patient is no small thing. After my brother's transplantation, I signed up to be on the list of voluntary donors. (sister, donor, 32)*



When possible, the transplant takes place the same day. If not, the donor's marrow is frozen and then thawed the day the graft is infused.

**The donor marrow rapidly regenerates itself during the hours after the withdrawal.** It is fully reconstituted within a few weeks.

For several days, the donor will feel pain, generally moderated, in the areas where the marrow was harvested (near the iliac crests). Pain killers are used for the pain. Depending on the volume of marrow withdrawn, on rare occasions, **it may be necessary to give the donor an auto-transfusion of blood.**

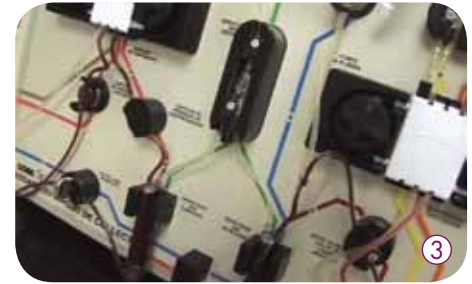
The medical risk for the donor is only that of general anesthesia and this

risk is miniscule for an adult in good health. Today the transplantation of bone marrow represents less than half of all transplantations.

### ► Peripheral blood stem cell donation

At home for several days prior to donation, the donor receives a subcutaneous injection of G-CSF (granulocyte colony-stimulating factor). This is a **growth factor** that causes the hematopoietic stem cells to migrate into the blood. The harvest, totally painless, is made thanks to a procedure **called cytopheresis**. The cells are collected without anesthesia. Of note, the G-CSF injection can cause fever and some pain that can be calmed by pain killers and simple antipyretics.

The blood follows an “extracorporeal” (outside the body) circulation thanks to a sterilized disposable kit. The blood withdrawn from the vein ① of an arm is continuously drawn out thanks to a machine ② that is going to separate the cells ③. White blood and stem cells necessary for the transplant are selected and retained in the device. After passing through the cytopheresis device, the blood (red blood cells and platelets) is returned to the donor via a vein in the other arm ④.



Cytapheresis takes three to five hours but it might be necessary to do two additional sessions if the first harvest is not sufficiently rich in stem cells.

The transplant will take place the same day. Otherwise the stem cells are cryopreserved in order to be transfused later.

### **Stem cells are quickly regenerated in the donor marrow.**

The G-CSF treatment, the stimulating factor can cause bone pain, flu-like symptoms, usually insomnia and more rarely nausea. These inconveniences are easily controlled by pain killers and anti-nausea medicine (antiemetics).

Often a blood count one week after the cytopheresis is recommended to verify that the count is back to normal.

■ *The withdrawal, that was nothing at all. In addition, I give blood regularly. I am not frightened of hospitals or needles. That took two half-days to collect the little bag, the itty-bitty pouch of stem cells. (sister, donor, 32)*

### ► **Cord blood donation**

Cord blood, blood from the umbilical cord and the placenta at the time of birth, contains a large quantity of hematopoietic stem cells. With the parents' consent, the blood contained in the umbilical cord and placenta can be collected just after the baby's birth. **The withdrawal is without risk to the newborn or the mother.**

Placental blood, also called "cord blood", is conserved at a very low temperature in a blood center called the "cord blood bank". It is thawed the day of the transplant.

Transplantation of cord blood is better tolerated than bone marrow or peripheral blood stem cell trans-

plantation. This presents the advantage of being able to use a graft that is not totally HLA identical to that of the recipient.

■ *I'm waiting until I have a baby; I want to give my cord blood but there are few places that you can do it. (sister, donor, 32)*

### Another type of donation: donor lymphocytes – DLI

It's sometimes the case that the donor is asked again to give their lymphocytes. This is called a donor lymphocyte infusion (DLI).

The objective is to prevent or treat the disease relapse or again to reinforce the acceptance of the graft, giving an advantage to donor cells.

The donor has no prior medication to take. There is just one withdrawal of blood by cytopheresis. This has no effect on the health of the donor. Sometimes the donor will need some examinations beforehand.

Whether the donor is an adult or a minor, obtaining a secondary consent is not necessary.

## When the donor is a family member

It's preferable that the donor can express what he or she feels, his or her fears or concerns. The doctor and the psychologist from the service are there for him or her.

The transplant is a complex phenomenon and the body of the patient interacts with the graft and works to appropriate it. The donor is not responsible if the graft does not take or if there are severe complications that could prove fatal to the patient. However, everything is done to aid in the healing of your loved one.

- *I was only hoping one thing, that was to save his life. Will it be that my cells will eat his cancer cells? But it was more his fight than mine and I told myself that the bigger part of it was for him...for his body. (sister, donor, 32)*
- *I was fortunate to have a compatible donor [from the list]. I was happy that it wasn't my little sister's. I told myself: «If that doesn't take, they won't feel responsible for healing me or not...» Now the oldest has signed up as a volunteer donor. (Melanie, 20)*
- *My donor sister, I call her the marrow squatter. Every year I take her to a restaurant. (Matthias, 26)*
- *I often think about my donor! (Anaïs, 48)*

- *Six years after, I wrote to my donor. I didn't do it before because I didn't know it was possible. That was pure emotion. One doesn't write to their "blood brother" without shedding tears and giving infinite thanks. (Thibaud, 40)*
- *My sister's marrow flows in me. I chose Bach's first cello suites to accompany this moment. Before the pouch emptied, someone knocked at the door. It's my sister. She advances and speaks to the bag of marrow. I don't know what she tells it. I look at her smiling. She gives it precise instructions. Then we look together at the marrow flowing gently. This moment is full of emotion, but it is without graveness. (Sabine, 44)*
- *I have two children, one who has been transplanted and one who donated. Today there are three anniversaries: each of theirs and that of the transplant, which has become maybe the most important. (father of an adolescent transplant recipient)*
- *We feel more like twins than brother and sister. There's this side a little surreal of saying that a part of me flows in his veins. My parents were happy to see that that brought us closer together. (sister, donor, 32)*
- *In the structure of the transplant, one has contact with the outside. There can be a patient living in Paris but maybe the brother or sister is in the country of origin in Southern or Northern Africa...I work a lot with transplant coordinators. We have to get them to come, pay for the plane ticket, find a place for them to stay, welcome them on arrival, assure the accompaniment of the donor. (social worker)*

# Isolation: What you can expect

## Preface

Most transplant teams have established information to help you in all daily aspects of the transplant: read what you're given in the transplant unit. But for sure, don't hesitate to ask for clarifications and additional information. Also, if information or instructions don't seem clear to you, request that someone explains them to you.

## Isolation approaches

**In most cases, you are going to be in a protected sector** (sometimes called the sterile sector) for a period lasting, in general, from three to six weeks. For some, it's the first time. Others may have already experienced the isolation sector. If this is the case, there won't be any surprises. Aplasia starts almost 8 to 10 days after the beginning of the conditioning. During this period, you no longer have any defense and this makes you very susceptible to infections.

It is necessary to reduce exposure to microbes up until the marrow is reconstituted and functioning. Depending on the type and the reason for the transplant, and equally depending on each center's practices, different methods and durations of isolation are recommended. In the case of a transplant with reduced conditioning regimen, aplasia is less intense and much shorter.

The protected room is not necessary and the duration of hospitalization generally shorter than for a myeloablative transplantation.



There are four types of rooms:

- **room without air filtration:** this is an individual room with or without a SAS (special air space) entry, without a particular device for treating air, a simple and standard room (photo 1).
- **room with air filtration:** this is an individual room in which a fixed or mobile air purifier is installed (photo2).
- **room with air filtration and positive pressure:** the air, after having its microbes removed by a filter flows continuously into the room. Then it circulates from the room towards the corridor, then from the corridor to outside of the building. This room resembles a regular hospital room. It is often supplied with a SAS or an anti-chamber, with two doors (one should never

open both doors at the same time so as to avoid the entrance of air into the room) (photo 3).

- **room with laminar flow:** the principle is the same, but in addition, the filtered air flows in a laminar way (the air currents are parallel). This avoids microbes that have been deposited on the floor from returning into the atmosphere of the room. In many laminar flow rooms, the bed is surrounded by transparent curtains (photo 4).

- *The space of the room will be reduced to almost 6 m<sup>2</sup> by the two transparent curtains. This is what establishes the sterile zone, into which no visitor can enter. Only the personnel wearing a mask, gloves and a head covering are allowed access. To present what that resembles, it is sufficient to imagine a large, upside down, plastic, rectangular aquarium suspended above the ground. (Sabine, 44)*

This is the general idea because, if you happen to visit several transplant centers, you will notice that isolation methods differ from one center to another. Each team makes choices taking into account its own characteristics to insure the best means of isolation.

On the same note, the duration of the stay in isolation and the precautions taken in leaving the hospital are not the same in all the centers.

Within the limits of possibility, ask before the transplant to visit the room where you will be hospitalized (or a similar room).



Photo 2



Photo 3



Photo 1

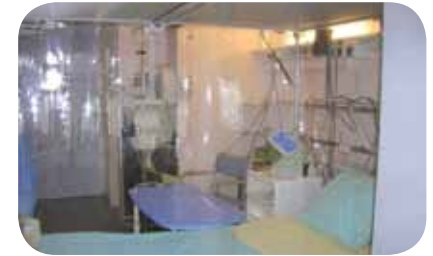


Photo 4

Life in the protected room implies constraints, the main one being that you are not allowed to leave your room.

- *I knew how the sterile room was constructed; there is not a lot to discover. I had visualized this sort of bubble where I was going to be, at the margins away from others, in this reduced space. (Gilles, 61)*
- *This isolation is an exceptional experience of solitude, where one sets down their life as one sets down their suitcase. (Thibaud, 40)*
- *I took the time to get accustomed to my new surroundings. I told myself that it wasn't so small, that it was well organized, that it was for the most part comfortable. I contemplated the bike, this strange object in a place more medical than fitness. It seems to indicate that this little space can become a place to live. (Sabine, 44)*
- *The most difficult for patients, it's being cooped up and then the treatments that are difficult. (nurse's aid)*
- *The sterile rooms are difficult. There is an interphone that two times out of three doesn't work. Everyone is in the corridor; everyone here's everyone else! (social worker)*

**Precautions** (hand-washing, scrubs and in certain cases, a mask, gloves, etc.) are taken to minimize the number of microbes. Each person that enters into the protected room must submit to certain dress and hygiene standards that are explained to them.

The comings and goings of health personnel are limited and care is grouped to limit the entrees and exits in and out of the protected room. Visits are also limited to one person and sometimes two at a time.

- *What was hard, that was the distance between her and me, no right to touch! (mother of a young recipient)*

All the material that enters the room is carried at a high temperature.

Intimacy is difficult to respect in these conditions and, often, this is a difficult experience.

- *I first saw the sterile room from outside. They showed it to me, but now I'm on the inside. I'm in a mini-room where I am going to have to live for five weeks with a bed, a very small sink and a commode... a room with glass windows...At the level of the commode, there are drapes a bit more opaque, creating a bit of privacy, but I'm not kidding you, this is not easy to experience. (Gilles, 61)*

■ *The commode, I called that the monarch's seat. It's difficult to make do. (Nathalie, 35)*

■ *Life in isolation is a place without conveniences where sacrificing one's modesty is inevitable. It's accepting, that's all! You also know that the nurses know that! (Thomas, 55)*

**Nutrition** is supervised by a dietician. During the isolation period, food is highly controlled. This changes the taste of food, even though already, often, the medicine alters your sense of taste. That can profoundly modify your relationship with food even to a point where you refuse it. This aversion is frequent, in general transitory, but must be taken into consideration.

In effect, an insufficiency of food generally results in weight loss with a risk of malnutrition that can increase the risk of infection and complications.



Therefore a dietician is consulted who can prescribe oral nutritional supplements or an artificial means of nutrition (parenteral or enteral nutrition).

*see p.61*

■ *I was not able to eat. The smell of the food in the room gave me nausea! (Nathalie, 35)*

■ *My sheer disgust for cellophane wrapped apple sauce lasted several years! (Thibaud, 40)*

■ *The thing the most difficult to experience for me was the loss of appetite, the disgust, and I had been a good eater...the odors. It was horrible to experience that. The moment when the famous tray arrived with sterilized food-already not too appetizing at the hospital-you could say that what was on the tray was worse! (Gilles, 61)*

**For clothing**, fabrics in cotton are recommended because they are comfortable to wear but also because

cotton is able to support being exposed to high temperatures (or sterilization), this also limits contamination by microbes.

■ *I dressed every day in the sterile room. I coordinated my t-shirt colors with my bandanas. (Nathalie, 35)*

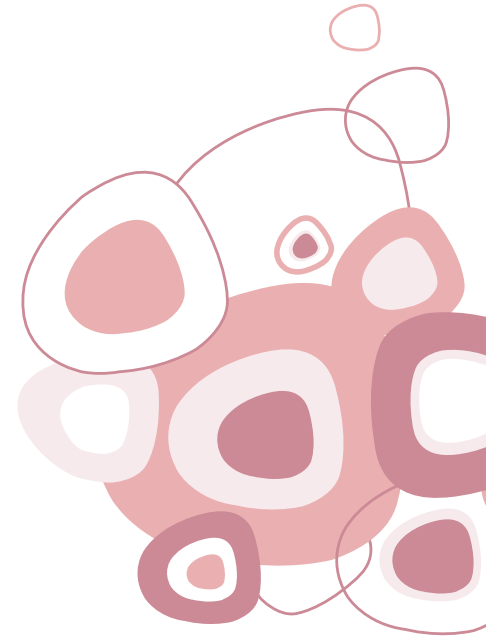
■ *Every day, since day one, I get dressed. It's unthinkable for me to spend the day in pajamas. And it is equally unthinkable for me to spend the day in bed. I spend my day on top of the covers, even if I pull a blanket over myself when I'm cold. I am not under the sheets. Day is not night. Activity, while minimal in itself, does exist during the day. (Sabine, 44)*

■ *I wanted to stay attractive, even in the sterile room. I had friends who asked me what they could bring. "What if we buy you some pajamas?" There are some you can find that are not too expensive and that are pretty. I advise cotton pajamas because they are more comfortable, not too tight because you gain weight and lose it and gain it back. (Mélanie, 20)*

Also think about what is and isn't allowed in the room to keep yourself occupied: objects that mean something to you, photos, books, magazines, but no newspapers because all these items need to be exposed to high temperatures.

■ *In the sterile room, I made myself a scrapbook with paper where I put texts that I like a lot, photos of good times, and that helped me through. I also wrote everything that went through my head. In a humorous way, I wrote about what was happening to me. I will maybe publish it, for my nephews, family testament. (Anaïs, 48)*

■ *Without knowing it, you actually have a lot of reserves. It's spontaneous. Just like that it happens. Music helped me a lot. I discovered classical music during my allo-graft, and now I can't do without it. (Frédérique)*



In this period of transplantation, your life and that of those close to you is going to be turned upside down, with repercussions on multiple levels: material, psychological, social or spiritual. It is important to prepare for these difficulties.

**This period can be marked by significant psychological suffering with moments of doubt and discouragement.** This is due to the danger posed by the transplant, the complexity of the procedure often difficult to understand, the isolation, unexpected events, periods of waiting, uncertainty and worry, intense fatigue that you can feel, sometimes also the intensity of certain side effects.

In addition, the transplant can cause hallucinations and you might see worrying visions.

**The transplant team, your family, and your friends are there to help and support you.**

■ *Yes, that's going to last, yes it's a long process with daily side effects-this can be treated; pain- this can be eased. There's an entire team around you, your family, your friends. Yes, there can be moments when you want to stop. You need to get it out, express it, talk it out with someone you connect to the best. (Matthias, 26)*

- *What helped me the most was feeling welcomed in the unit, the humanity, the gentleness of the health care team, the psychologists. What warmth!...You're in a place that's heavy and the people are very humain. (Thibaud, 40)*

## Key Players

- *"Having a cafeteria in the hospital is not at all like having a cafeteria in a factory or on the street corner." She was someone transplanted who often came before her transplant and after, she came to tell him that it had gone well and he brought her some chocolates. For me that means that care must be understood in the wisest sense possible. (story of the head of the cafeteria reported by a volunteer).*

Numerous people from the team will surround you every day and all of them, depending on their training and function, will come alongside you, support you, and, to the degree possible, are also there for those close to you. They can also help you get through this difficult period in life.

- *From the outside, it's scary, it seems like a place without life. Although in fact it's a little bit like a big family.*
- *There is good collaboration with the doctor. There's no false humor. Patients often tell us that they feel there is a team.*

**Confidentiality is respected by each of the key players.**

## ► The medical team

You will be examined daily by a doctor. Medical information is subject to regular discussion by the entire team.

- *In the absence of your doctor, the doctor on duty or another doctor from your team. The major quality of a team, that's understanding and listening. (nurse)*

Moreover, depending on your needs or the exams prescribed, you might be taken to meet specialists who work outside your transplant team.

## ► The nursing team, the medical assistants and nurse's aides

The team is orchestrated by a nurse or a head nurse responsible for the organization of care.

- *For me, my role as senior nurse, it's to be the communicator between the doctor's consultation and the patient's expectation. Also my goal is to undramatize the hospitalization during the transplant, to tell them that they'll create connections with the team, what one is going to do to maintain connections with friends and family in allowing the facilitation of access to them. It's also to keep them informed about the organization of care. (head nurse)*

In a number of transplant units, there is a transplant coordinator (or coordinating nurse) whose role is to see that everything related to your transplant goes well. She can also give you information and answer your questions.

**The nursing team, whether it's the day or night one, plays a major role in your daily life throughout the transplantation.**

- *The personnel is fantastic, certainly the nurses, or rather that they are there, present. You establish a rather close connection with these people. (Alexandre, 42)*
- *I had a special connection with one of the nurses with whom I exchanged some comic books. I think that she had found this as a way of communicating with me. In the end I told myself, "I've been had!" In fact, she was passing information from our conversations to the doctors. (Matthias, 26)*
- *The doctors are overwhelmed, luckily the nurses are there. (Catherine 38)*
- *The nurses are particularly attentive to patients sleeping. They often have a*

*small pocket light that they keep in their hand so as not to awaken the patient. Providing care with the delicate discretion, being the attentive guardian of the fragile sleep of patients or becoming a comforting presence when worry or pain comes to invade the space, such is the work of the night team. (Sabine, 44)*

- *The visit from "my" nurse is very comforting. I tell her about my little miseries, she listens to me attentively. (Thomas, 55)*
- *As for the nurses, they don't shirk their duties and are remarkably devoted, very touching. (Paul, 50)*
- *The sick are worried about the functions they are going to lose, their autonomy. From the first day, we tell them that we are partners. When they can put their faith in us, they don't hesitate to let us know about degradations. (nurse)*

- *Trust comes with the availability of the team, the reactivity and always saying to patients that they are not bothering us. People are always scared to bother us. (nurse)*
- *We talk a lot in the team. We have moments where we share. It's necessary to be attentive to primary needs (eating, relieving waste,...) because that is what shows us if things are getting worse. All of it counts. (nurse)*
- *With teens, there are friendships that form. The fact of being closed in creates an immediate closeness. They talk a lot to us and tell us what they feel. (nurse)*

**The nurse's assistants** participate with the nurses in caring for patients. They insure bathroom duties, meals and maintaining the rooms. These people are close to you during your stay.

- *For us, nurse's aides, our work is not very technical, it is more so relational. When patients arrive, we explain how the service works, the room, what they can bring...and then we sit and discuss with them. We also give massages; I received training in that. For the face, the back or the feet. (nurse's aide)*
- *The patients talk to us about everything: sports, family, their grandchildren, their life, what they do, their work. (nurse's aide)*
- *Every morning it gave me lots of pleasure to chat with the nurse's aides, they were devoted and understanding. (Paul, 50)*

- *In terms of support patients have a lot of expectations for the doctors. There are also strong connections with the team, with the nurses, with the nurse's aids. (head nurse)*
- *When fatigue is too intense, going to the bathroom by yourself and cleaning up becomes impossible. With my weakness, it's the gentleness and tenderness of the nurse's aid that lifts me up. She washes me on my bed, as if she were washing a child. I feel like a small child in these careful and respectful hands. (Sabine, 44)*
- *When there are holidays, Christmas, New Year's...last year at New Year's it was great, some of our nurse's aide colleagues, formidable women, decided to give everyone a good laugh. They made disguises out of the hygiene caps and sang songs for the patients. There was a young patient in relapse who laughed so hard she cried.*

## ► The psychologist

The psychologist is there to support you and accompany you as well as those close to you. They introduce themselves to you of their own accord to present the help they might offer or they might respond to the request on your part.

- *For me, the psychologist's role is to go see the patients, to introduce themselves and to ask the patient if they want to see them. That can be done at any moment. They are also there for the team, so they can talk about their difficulties as well. And they're there for those close to the person receiving the transplant.*
- *The psychologist introduces themselves to patients and she says that she is also there for those close to the patient. (doctor)*

- *I don't systematically meet all the patients, what is important to me is that the team informs patients about the presence of the psychologist (or a psychology team), that there is always a possibility to meet a psychologist at any given moment if they wish. The same for their family and friends. (psychologist)*

The psychologist works in collaboration with the health care team and all those who contribute to the maintenance of daily life. **The psychologist assures the functioning of the link between the different players at the heart of the service and, if necessary, after the return home. They are also part of the team.**

- *The psychologist is a relay person between the patient and the doctors and the nursing team as well...But when people need to be reassured, they want it to be the doctor or a nurse that reassures them. (doctor)*

- *I attach a big importance to the collaboration of the team. (psychologist)*
- *The psychological care is not reserved just for the psychologist. It's the whole team that's concerned! (Michèle, 24)*
- *This is not so much done during the treatments, but it's the aftershock and for the family as well. (psychologist)*
- *We have regular meetings with the team, not only in crisis situations! I watch and stay as often as possible in the nurse's rooms, to also be there for them. (psychologist)*

Meeting a psychologist allows to take, in all confidentiality, the time to reflect on what is taking place and to put words to the emotions (anger, guilt, a sense of injustice...) and preoccupations, whether they're about the disease or the transplantation.



This is also a moment where you can ask questions, explain the potential difficulties to communicate with those close to you, share your worries.

The psychologist can understand the suffering that's difficult to articulate and will help you understand the imposed adjustments of what is happening to you.

**Resolving problems is often longer and more complex when the difficulties insert themselves and are aggravated.**

Talking about worries and sharing with a professional trained to listen often allows a relief and a minimization of the feeling of isolation.

Living with the disease is different depending on its stage. This experience is different depending on each person in the family. **The need for psychological help can express itself in different ways depending on the moment.**

**It's proposed, never imposed.**

■ *The psychologist...that's the first time that I saw a psychologist inside a hospital. So I saw a shrink. This was not a desire that I initially had...but, they proposed psychological support and I found that it was quite welcome. My wife also saw her and each time I returned to the hospital for day visits I saw the psychologist. (Gilles, 61)*

■ *In the hospital I was seeing the psychologist...I had asked. The transplant brought to the surface things I wanted to talk about. (Anaïs, 48)*

■ *On the psychological front, you shouldn't hesitate to get some support, to ask to meet a psychologist. Don't hesitate to talk about your anxiety, say when you're hurting, and ask questions... but also to have confidence in your own resources! (Virginie, 38)*

■ *My mother wanted to bring me to see a psychologist. I never wanted to. I didn't want to talk about it. (young man of 19 who was 12 at the time of his father's transplant)*

Moreover, in the numerous centers, **associations** have put in place a variety of support structures for you and those close to you, during the transplant or after the return home.

Ask the team about these possibilities.

## ► The social worker

The transplant often has professional and financial consequences. It is important to anticipate social and socio-medical difficulties that you could encounter.

The social worker is there to help anticipate these eventualities. With professional confidentiality and regulations, she puts at your disposition and that of your family or those close to you, to inform you about existing packages, and the steps to take. **She is familiar with aids that you might benefit from and can orient** you to improve your condition of life and give value to your rights on a social, health, family, economic and professional level.

You can ask for the social worker during or sometimes after the hospitalization. She will intervene at your request or at that of a third party.

■ *I perceive my role as link, a link between the hospital and the outside world. I am at the hinge between the two. I have a foot in both worlds. One foot in the hospital where there is the world of the sickness, the transplant, suffering, all the complications the patient might have, the anxiety, and another foot in everything that the sickness induces on the social world: the problem of housing, financial problems, childcare, readapting to the work environment, leaving the hospital... And the transplant, that's a long period that needs to be organized. (social worker)*

■ *I think of an adolescent who seemed not to want to see his father after the transplant. His mother was worried. I was able to talk to him. In fact, he was scared to death to go see him. I talked about it with the doctor who was able to tell the adolescent what was happening with his father. He was able to tell him that the transplant was going well, that he was hopeful, even if his*

*father was living a difficult moment in his life. I try to be the link. I had the feeling of being useful that day. I felt that he was calmer. (social worker)*

### ► **Nutritionists and dietitians**

They elaborate these diets adapted to your needs as well as the digestive and nutritional consequences related to the sickness and other treatments and, if possible, to your taste.

You will also see them when you are released. They will help you readapt to a balanced diet suited to your needs when you return home.

### ► **Physical reeducation specialists**

Physiotherapist, ergo-therapists, occupational therapists, speech pathologists... help you to train your muscles and to restore confidence in your body.

■ *Living folded over on myself like a child inside his mother's womb, my muscles naturally went to mush. The joints swelled, the tendons shortened. The body needs to be put anew under tension, elongation, and muscle strengthening. (Sabine, 44)*

These specialists, unfortunately, are not in all of the transplant units. When they are there, they intervene at the doctor's request at the hospital or at home if your body needs reeducation (depending on the program of functional rehabilitation determined by the doctor).

**Some of these specialists participate in taking care of pain control** by using massage techniques, lymph drainage, sophrology, relaxation, etc.

■ *For the transplant, we are not moving my body, but to soothe and to release tension, a physiotherapist comes every day to do some very helpful massages. (Sabine, 44)*

If you have the impression that certain interventions would be good for you, don't hesitate to talk to the team about them.

### ► **Pharmacists**

You will not meet them but they have an important role in the preparation and the delivery of medications, the security and practical organization of the treatments.

## ► Faith group representatives

Most faith groups are represented at the hospital. If you desire to have a visit from a representative of a faith group of your choice, don't hesitate to ask.

■ *There is the chaplaincy, other representatives of different groups of faith... We can call them and we let people know they are there. (psychologist)*

## ► Associations – volunteers

Many associations invest, each in their own manner, in diverse domains around people targeted by cancer and their families. Some of them are present in transplantation services thanks to special agreements with the hospital. **The volunteers receive training and they respect the principle of confidentiality.**

**Depending on their structure and their possibilities, associations also invest in:**

- purchasing equipment that allows improving the daily quality of the hospitalization (computers, webcams), sometimes they also help obtain specific health material;
- logistical and financial family support (participation in non-reimbursable fees for example);
- clinical research support;
- home aid during and after hospitalization;
- putting apartments at the disposal of those close to you during treatment or apartments for rest;
- offering group support or psychological support.

- local and national counseling services that provide information about the disease and support of those close to the patient;
- donation promotion (marrow, peripheral blood stem cells, red blood cells, platelet donation)

Most of these organizations have a website.

The diversity of activities deployed by members of associations prove to be a vital link in the oncology care chain.

Ask the transplant team to get information about these associations, in particular those that work in the service.

■ *One is neither care giver nor patient, yet a part of the hospital all the same. (volunteer)*

■ *At the time that I was in the service, I was pleasantly surprised by the visit of a volunteer, a former recipient told me his story and that did me good to see someone after their transplant. (Alexandre, 42)*

■ *The volunteers passed by with chocolates for Easter. There was a boy who had just finished his first few years of university and we had a good chat... (Mélanie, 20)*

■ *A volunteer visit in the transplantation room is a window that opens to someplace else. (senior nurse)*


- *There is a free-ness, the generosity of all these volunteers that offer their time to be with the sick, to share a hope, to break the solitude, to be there, simply. (Sabine, 44)*
- *Knowing that technology helps patients, it's one of the most beautiful realizations of the association. (volunteer)*
- *As a former patient, when you're there to hang around the halls, it gives hope. (volunteer)*
- *The therapy department, that's a place where you're ok. It's like you're home. (Lionel, 45)*
- *The volunteers, patients like to see them because that also allows them to talk about other things than just the sickness. There are volunteers that do that quite well. (doctor)*
- *We intervene by tip-toeing. (volunteer)*
- *We start by going to see the nurses and ask them if there are people who wish to have a visit from an association, or who don't have a visit. It's these people to whom we give priority. We propose, we don't impose. We see a lot of families as well. (head of an organization)*
- *With us, patients can discuss things other than the sickness. (volunteer)*
- *Sometimes you become the confidant, the resource. (volunteer)*
- *A young woman transplanted really opened up with a volunteer of the same age. (head of an association)*

## ► **If you wish to meet other allo-transplant recipients**

It might be that you feel the need to talk to other people that have "been through it." Don't hesitate to contact associations to ask if you can meet people who went through this experience if you wish it. This allows exchanges and precious support.

- *What I was missing was someone that had experienced the same thing and gotten through it. That is, to know there is a chance. (Mélanie, 20)*
- *I am someone rather logical and I was looking for raw information and it was for me to digest and extract what I wanted to know; I did not feel the need to meet people who had received a transplant. (Alexandre, 42)*

- *Volunteers, we count on them to meet with people who are isolated...patients who sometimes come from far away. (psychologist)*
- *The association allows the capacity to break the isolation of the family. (volunteer)*
- *I asked if there was an association... there wasn't one! I asked the hematologist caring for me if I would be able to meet someone that had been through it. (Frédérique, 53)*
- *Often they meet someone that has had a transplant. I don't know how it happens...they use an association. And then when you're sick you realize that other people have been sick, and there are those around you, neighbors, who were sick once. It's another network that creates itself and often you meet someone else that was also transplanted not far from where you live. (doctor)*



If you are still in elementary school or a student, you can ask to receive a visit from a teacher during your hospitalization, but also after at home. They will know how to adapt to your level of fatigue.

When you are safely back home and if you are not able to attend classes, there are options for you to continue your studies.

If you wish to have exchanges with other youths, there are associations that offer forums or discussion lists.

## ► Places for exchange and getting information

Different networks are in place inside and outside the hospital such as Meeting and Information Centers, information kiosks on cancer, among others that can be found throughout France. Access to these structures is free. Their mission is to listen, council, inform, and guide or direct you and those close to you. They do not propose medical consultation nor diagnosis, nor prognosis of a condition. You can contact them directly or talk about it with your team that will know how to help you.

### Friends, family, and those close to you

- *My parents were very close. My mother did not let go of my father for a second. (a young man of 19 who was 12 at the time of his father's transplantation)*
- *People around me were attentive to the evolution that took place. Friends supported us a lot, by watching the children...parents offered us material and financial aid. (Gilles, 61)*
- *My grandparents were present, this allowed my parents to breathe a little. (Matthias, 26)*
- *A visitor is also someone who lets life in this small confined space. (Sabine, 44)*

**Your family and friends are there to help you and support you. This is why it's necessary that they also have the opportunity to be supported, accompanied, and to have a break.** They can suffer greatly by seeing you tired and in pain. They might also fear for your life. This might also cause difficulties or misunderstandings between them and you. The doctor, psychologist, social worker, and volunteers from associations...are there to help and to orient, them too.

- *There was a moment when I had the impression that my husband was not conscious of the amplitude of our daughter's sickness. I had the impression that he wasn't getting it. It made me a little fed up with him! (mother of a young transplant recipient)*
- *Those closest to the sick person do not come away unscathed. As they gather the weakness and the incapability of the other, it's really giving a part of themselves. No one heals all alone. (Sabine, 44)*
- *Our grandparents lived far. They were also elderly. They didn't see my brother once during the sickness. I think they didn't dare; they were scared to not be able to endure. Seeing him and then leaving with that image was too much for them. (sister, donor, 32)*
- *When they get to transplant, patients have almost always been down a long path...and what you hear from family and friends, they're a little worse for the wear. It's difficult for those around them to at the same time be present for the rest of the family and for the hospitalized patient. That's to say, to be present on all fronts. (psychologist)*

- *I was scared the transplant would go badly. I thought sometimes about his death. I wasn't sleeping at night. During the day, I didn't think about it too much! (a young woman of 16 who was 10 when her father was transplanted)*

### **Know also that there are specific "family support" leaves of absence.**

Certain associations organize conversation (or support) groups for those close, teens, and children. **Also, some associations organize listening services (phone or not).**

*see p. 114*

In a general way but also in relation with those around you, it's essential to respect your needs and not to go

beyond what works for you, what you are able to do.

You might allow yourself to sometimes refuse a visit, a call, even if it's one of your children, or one of your parents. You can explain to those close to you your fatigue - your need to stay alone.

- *You can get out of a visit by explaining your need to sleep. Sleep is sometimes a refuge...(Nathalie, 35)*
- *This calm does me good. I think of the organization of the visit, limited to two per day. I can already hear those who will tell me that they will come visit today or who come without giving notice...not everyone will be able to come. (Sabine, 44)*

It is nevertheless important to, as often as possible, – definitely if you're an adolescent or a young adult – **keep in contact with those close to you**, to not isolate yourself, to stay in connection with those around you. Accept their visits, even if it demands an effort at times. If you can only receive one visit per day, choose the one that does you some good (this could be a friend rather than a person from the family).

- *My brother needed people to be present and positive. He did not do well with people who were a bit stifling, too worried, sad, etc... (sister, donor, 32)*
- *Support from friends did me a lot of good. I had one friend I called when I felt down and I'd ask him: You don't have a joke, do you? – Two minutes later he'd call me back! (Nathalie, 35)*

- *Hearing others talk to me about their life, that helped me a lot. (Alice, 32)*
- *What I definitely appreciated was my wife coming to see me every afternoon. (Gilles, 61)*
- *It's invaluable to have someone to talk to, to confide in. The memories that stay the strongest are those that you share with others. (Nathalie, 35)*

Try to **make contact as much as possible** by telephone or by Internet if the room has a computer.

- *There was Internet, and we'd bought a laptop. That was some contact with the outside world. I watched films as well. (Mélanie, 20)*

- *When they told me I could have Internet access, I wept because it's a connection with the world with some choice. If I want, I connect. If I don't want to, I don't do it. I did some errands for our house, chose some baby food for my daughter; I felt like I was participating in something. (Nathalie, 35)*
- *All our younger patients – not that young, maybe less than 30 years old – they often go on the Internet. It's almost all the time turned on. They communicate a lot. This includes parents with their children. (nurse)*
- *The webcam was difficult for my wife: hearing the children's voices, being far from them, not being able to physically touch them. (husband of a transplant recipient, 39)*

- *My brother had a blog to keep people updated about his health. He had a lot of responses from family and friends. That did him a lot of good. (sister, donor, 32)*



## If you have a kid or children...

You are going to be absent for several weeks, far from your home and from your daily life with your children... **They can feel sad, even like they've been let go during this period and might start to ask themselves questions, definitely if they are little.**

You can also experience physical changes and that can worry them.

**They need to be informed** in a way that's adapted to their age. If it's possible, the child needs you to explain the situation to them – or someone close to them needs to do it: their other parent, an uncle, an aunt, a grandparent, or someone close to you who they trust and who is capable of **talking to him or her with simple words, in a productive way with direct language.**

■ *My father didn't talk to me a lot about himself. I missed that, but I don't blame him!... You need to respond directly to children without worrying them. (a young man of 19 who was 12 when his father became a transplant recipient)*

Maybe your children will be able to come see you at the hospital. Beforehand ask your doctor's opinion.

■ *Knowing that we couldn't go see him, I was happy that my mom was able to go see him. That pleased me. (a young man of 19 who was 12 years old when his father received a transplant)*

■ *They allowed a young woman of 13 to enter the sterile room. Her mother had been hospitalized for a long time and the young woman respected well the rules for hygiene. There are rules. But to improve the condition of the sick person, we know when and where to bend the rules. (nurse)*

■ *There is a lot of flexibility with the visits... you're always accommodating, even for children. It's the parents who decide if their child can come into the room. We're there to facilitate. (head nurse)*

■ *For visits I think we're less strict than other services! For children, before the cut off age was at 15. That's been lowered to 10 years old. Our psychologist in the unit found it better for children to see rather than imagine what it was all about. (doctor)*

■ *I'm at the same time for and against children's visits at the hospital. For, because when you're a child you want to see Papa, to see if he misses you. At the same time, for children, it's maybe better to only see them after the transplant. (young woman of 16 who was 10 when her father received a transplant)*

■ *The most difficult has been being far from my children. (Gilles, 61)*

**Be inventive about communicating with them**, by telephone, by Internet if there's a computer and depending on their age. Certain services accept webcams in the protected sector that allow you to see them via distance. Get them to send messages, ask them to send them to you. Ask those around you to talk to you about them, to give news about you.

**There are books** that help with talking to children about a parent's serious disease. This allow children to express their worry, to put words to what is happening and what they feel.

*see p. 161*



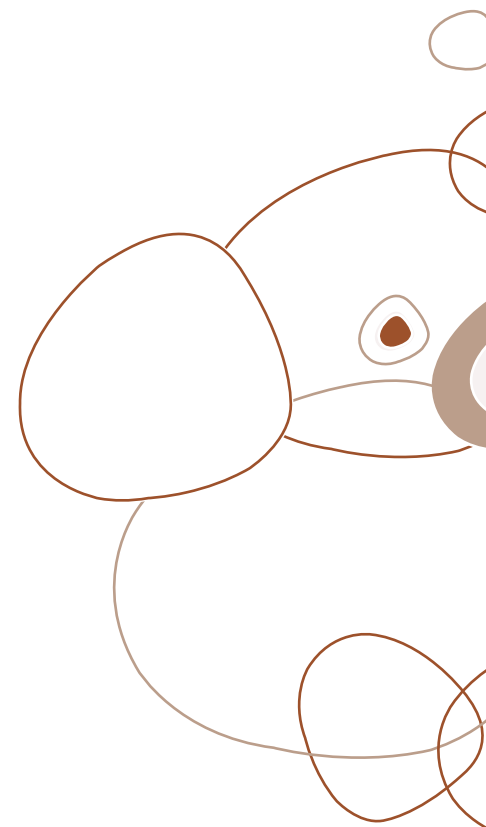
**During your hospitalization or after it might be that your children need specific support:** meeting with a psychologist, being part of a support group... The transplant team or associations can provide more information.

- *The children, it might be good if they can talk with a psychologist. I don't know... I didn't hide anything from them. With the older ones we used the word "cancer"... You should at least suggest it if you've talked a little bit about it. (39 year-old husband of a transplant recipient, 4 children).*
- *My life at school changed. I did my work, but with friends it wasn't going so well. I went to see a psychologist – it's my mother who suggested it – who told me that I had to be more mature than the others and that's why it didn't go so well. (young woman of 16 who was 10 when her father received a transplant)*

Your children will be happy, no doubt, to see you again at the end of your hospitalization, even if you will have to relearn daily life together.

- *I think of a young mother who had a small boy of 9 months, a long time absent for an allo-transplantation with complications; this was not easy. She was impatient to see her baby and at the same time scared to return home for fear of hygiene-related infections. Another question bothered her, "Am I going to regain my child, regain my place?" The grandparents had taken on a larger role than they would have ordinarily. We tried to work on that together. (social worker)*

- *The littlest was barely 3 years old. We gave the impression of not being worried [by the mother's illness]. I didn't stay on the webcam. The day when she returned home, he took two or three seconds to realize that it was her because her physical changes were profound. She had a wig and sunglasses. He saw who got out of the car with me. And when he understood, his eyes lit up and then he got it. My daughter was more sensitive to the distance. She often cried, which isn't much worse; it's good to cry! (husband of a transplant recipient, 39)*



- *Bone marrow transplantation is rather vast...it doesn't stop at the transplant. It's after the transplant as well. It's long and at times heavy. There are physical repercussions from the transplant. (Jean-Pierre, 45)*
- *For me, the transplantation is the period post-transplant...it's long. (Alexandre, 42)*
- *The year after the transplant, you have to pay close attention...nothing will be like it was before, work, physical activities, sexual activity. (Gilles, 61)*
- *We have to be attentive to what's going to happen post-transplant. How is a patient going to recover as normal of an existence as possible? How is he going to be able to – beyond the concerns linked to the transplant, medical appointments, and examinations – leave this experience behind? To integrate it, to make it their own? How is he going to be able to reestablish a full and entire life with all the modifications imposed by the transplant—physically as well as psychologically? The team needs to prepare for and anticipate all of that. It's the patients who guide us! (psychologist)*

The day you've been waiting for is finally here... **Despite the joy of return, it might be that you're a little worried to leave your protected room, the security of the hospital and return to the outside world.**

■ *Release from the protected room, opening the door: "You can leave!" Yet here there is a feeling of void. You were cocooned by the entire service. You learned to take precautions there; then the door opens! You've got your shoes and you are going to leave. That's hard! All the while there should be joy, but it's complicated to manage. (Thibaud, 40)*

■ *The doctor enters my room, looks at me behind the plastic transparent curtain with a certain air that says we are going to share a moment of silence. She lifts her arm, pulls back the curtain, a simple gesture that then and there liberates me from this forced enclosure that's gone on for four weeks. (Thibaud, 40)*

■ *When I leave the protected room to go into the hall, it's an intense moment. It gives the impression of a birth. You're in the little protected cocoon and you exit into an outside universe. (Matthias, 26)*

■ *During hospitalization, patients think of nothing but leaving. And when they are at the point of leaving, they are worried. (psychologist)*

■ *The transplantation involves a huge team being around them and then when it's finished, when they leave, they are a little lost. (social worker)*

■ *You say good-bye. It's emotional. We shared so many difficult moments together, some of joy and of wild laughter. I feel at home in the service with this team that has become like a family. I will return every week to the hospital, to the basement, so I know I can come up here to say hello, we can run into one another. This reassures me, I am happy to leave and it's hard for me to leave them. (Sabine, 44)*

■ *The return home: at first, you're happy, but you realize quickly that healing – if one can talk about healing, because you're really not yet healed – it's centimeter by centimeter. It's day after day, it's a reconstruction of everything, intimately. There is a pile of things for which we weren't at all prepared. Normal everyday life takes a long time to get going again. It's impossible to live like before. You're not the same as before. (husband of a transplant recipient, 39)*

### ► The first steps...

There is first the surprise of getting out into the free air, of reestablishing simple acts.

■ *When I left, I can remember the first time I felt the wind. I was shocked! (Nathalie, 35)*

■ *Returning home is initially a simple re-discovery, so banal that you don't give it any attention: to have a real bath with privacy, a toilet; to take a shower; read your newspaper. Each thing takes on a new taste, becomes a gift because the privation makes you understand that everything I'm rediscovering is not something at everyone's disposal. (Sabine, 44)*

■ *The first time that you feel the air and breathe, when you drink water from a tap...! (Matthias, 26)*

■ *When I returned home, the first thing that I did was put lotion on my face with cotton. (Nathalie, 35)*

■ *Taking my first real shower in 4 months, from my head to my toes, splashing everything around me with the joy of an infant! (Sabine, 44)*

Most people, having returned to their rhythm and habits, experience **contradictory emotions** that surprise

them. You can feel sad, discontent, and aggressive. All that is normal after a transplant and will not last longer than a certain period. Little by little you regain your energy and an appetite for regaining activity.

**Fatigue** is often present, real... You need to accept it and not hesitate to ask for help.

■ *The first days at home are difficult, you are very weak; you find it difficult to take a few steps, to stay seated long enough for a meal in your own home. (Gilles, 61)*

■ *Yes, you will have to ask for help. In fact, it was periods of fatigue. I was not exhausted all the time. And then I still had a cold...after the transplant, you're still fragile. (Nathalie, 35)*

■ *When he came home, he couldn't do anything. He had the air of an old man and in addition he was frustrated*

*to not be autonomous. He was physically hurting. He was always hurting somewhere on his body. His body was just not bearing it. (sister, donor, 32)*

■ *I learned to listen to my body, I rested; I hadn't expected to be fatigued. I paid attention to what I was doing. (Frédérique, 53)*

■ *The problem, is that the head is full of energy, but the body doesn't want to follow. (Marthe, 52)*

■ *When he returned he was often fatigued. Before he had been in good shape. (young woman of 16 who was 10 when her father received a transplant)*

When you return home, some of you have the fortune of finding your family, those close to you, and are surrounded. Other individuals are alone or less surrounded at this time.

■ *I always try to make an evaluation of the situation, to inform and be there. There's not always a lot of time. And yet you need time to be available and to listen. It's impossible to evaluate a situation in 5 minutes. If the patient is fatigued, if he lives on the 4th floor without an elevator, if the family says: We will not visit too much. - I try to evaluate with the patient their real capacities to return home and the risk they take returning home. If the person is isolated and fatigued, there's a risk returning home. I also discuss it with the doctor. (social worker)*

All that to say that before returning home temporary care in a **health center such as a re-adaptation or rehabilitation center is sometimes recommended**. This is decided with your doctor considering the state of your own health and the local possibilities that one of these establishments is adapted to your medical situation.

The social worker is there to provide addresses and to help you with the steps. Get informed about your health plan to better know how the costs will be dealt with or if you qualify for cost reimbursement. A medical prescription is often necessary when asking to be cared for in one of these centers.

- *In our service, we recommend that a patient does not return home directly, but transitions in an SAS in a convalescence home. But you always have to take into account their desire to be there and of course the possibilities of being accepted... (psychologist)*
- *In our service, after the transplant, it's rare that the person returns directly home. (doctor)*

- *Sometimes we receive strong requests from families that the patient be placed in one of these structures. (social worker)*
- *She explained to me the objective of this time following care: sufficiently regaining an autonomy to be able to return home, all while being watched and protected during this post-transplant period where I'd be particularly fragile and vulnerable. (Sabine, 44)*

The return to "normal life" is to say a life where the illness no longer preoccupies you. This is **done over several months by progressively regaining activity. Be patient and vigilant. Accept as much help as necessary.**

- *He came back on my birthday. I turned 11. I would have preferred that he stayed longer at the hospital. He demanded to be released sooner, but this was not "the right thing." It did him a lot of good to return home earlier, he didn't expect that. But when he returned home he couldn't take care of himself too well... (young woman of 16 who was 10 when her father received a transplant)*
- *During the return to my home, I discovered that I had to practice several things that I hadn't done for a long time: anticipate; take into account the future. I realized that this had been easy all my life. But today, for me, it demands a real effort. (Sabine, 44)*
- *The patient cannot rapidly regain a normal life. That's for sure! (psychologist)*
- *A normal life is work, to have an apartment on your own, get back into sports, go out normally, meet your friends. It also took time for others to adapt. For a long time we still saw him as sick. It was later that we reestablished connections. (sister, donor, 32)*
- *Certainly, sexuality is not everything in a couple...but it has not been simple. (husband of a transplant recipient, 39)*
- *He did beautiful things at the house: sculpting. That took him some time. One time, he prepared a meal at home. I don't think he would have done that before. He really got into it – a great meal! (young man of 19 who was 12 when his father received a transplant)*

■ *With my brother, we helped my mom a lot. We did things to help out that we never did before! (young woman of 16 who was 10 when her father received a transplant)*

**Your transplant team will always be at your disposal to respond to your questions.**

■ *Patients can always call the [transplant] service. The nurses respond when they can and if not they pass the question on to us. We always call back the same day, the evening. (doctor)*

### ► Precautions to take – Vigilance

Before your release from the hospital, you will receive practical information about hygiene (body care, maintaining the house), alimentation (foods allowed, meal preparation, food conservation...), mask wearing,

daily habits (going out, public places, visits, sun, activities, house pets, tobacco, alcohol...), observing and maintaining your catheter, taking medications, respecting infection prevention measures, etc... Your transplant team will give you these instructions in detail by adapting them to your situation.

Don't stop any medication without the doctor's opinion. Be vigilant with any unexpected symptom: fever, shortness of breath, cough, diarrhea, rashes. **Immediately contact your transplant team with any unexpected symptom. The quicker the intervention, the easier it is to control the situation.**

■ *When you have a fever, you are used to wait. It's a huge mistake: tell the doctor. (Frédérique, 53)*

■ *There is a final worry. It falls to me to take responsibility for my health today: temperature taking daily, checking my catheter, checking for signs of GVHD, taking medicine at the right hour, balanced nutrition, physical exercise, etc. I know that it doesn't scare me for fear that I'll do it wrong, but fear that I'll break everything the team succeeded in doing...(Sabine, 44)*

Respect the vaccination schedule recommended by your doctor. They are indispensable for replacing the vaccinations lost during the course of the transplantation.

### ► Follow-up care and hospitalizations

At the beginning, during this period, often called the "100 days," a strict observation using hospital visits is put in place: one or two times per week, then one time every 15 days,

one time per month, then visits are more and more spaced out to evaluate the evolution of your transplant but also of your illness.

■ *The 100 days having passed, I changed my status: I do not come every week for a hospital check up, but every month for a consultation. It is a big change! (Sabine, 44)*

**The objective of these visits is to evaluate the evolution of your transplant but also that of your sickness.** The chimerism test evaluates the coexistence between your organism and the cells of your donor.

■ *Several days later, the doctor told me that the results were good: my marrow is rich, polymorphic, and productive. In the end, positive qualifications! Certainly that says nothing about the future and relapses are always possible. But that means that today, they can't give me better news! (Sabine, 44)*

In addition, independent professionals can provide care. In this your family doctor who treats you will be given priority. That's why **it's important that there is a link between the transplant team that treats you and the care you receive at home.** Today there exist "healthcare networks" that play a role in coordinating between the hospital and private professionals. There often is a coordinating nurse who plays the role of "hinge" in this period of return home.

Because of complication, sometimes a **subsequent hospitalization** in the months following the transplant is possible. That is a source of worry, but know that, more often than not, it's for a complication not too bad but that takes some time to understand and treat. It could take several days, even several weeks, without it

necessarily being that serious. Don't hesitate to speak about it directly with your transplant team.

■ *There is always that question of uncertainty, that's to say that patients are informed of this possibility of re-hospitalization. While knowing that one can neither tell them when, nor the duration...nor if it will even happen. (psychologist)*

Several services have created "**follow-up care logbooks**" that allow you not to forget anything and to inform the different health professionals of the care you're receiving and about your situation.

**When all will be well, an annual visit will be arranged and will be necessary for several years.**

## ► **Body care, nutrition, physical activity**

Taking care of your body after the trial that is the transplant is important and always beneficial. This is all the more true when body image changes and self-esteem is altered.

Certain individuals feel a rupture with their bodies...this goes so far sometimes that they don't dare to look at themselves in the mirror or even touch their own body.

■ *On the physical aspect as with all transformations, it's hard to personally rediscover yourself. At home I never took off my bandana, even at night sometimes I kept it and I lost it! There is a period of relearning body image. (Nathalie, 35)*

■ *My wife physically changed. She developed abundant amounts of hair; she became rather strong with cortisone... a physique that wasn't her before. She passed through a period of acceptance. That was difficult for her and for me too. When you are married to someone you like, of course you stay by their side, that's not the problem...but it's also...to be physically attracted by a woman, even by your wife, she needs to be attractive. (husband of a transplant recipient, 39)*

## **Physical rehabilitation**

Physical therapists, speech pathologists, occupational therapists, physiotherapists... collaborate to improve your quality of life.

■ *The physiotherapists at the rehabilitation home! The patients go on about them afterwards. (doctor)*

Sophrology, relaxation, massages, also participate in your well-being.

### Esthetic care

Estheticians, in practicing care of face and body, contribute to giving you back the pleasure of being touched. That matters for women as for men.

■ *Taking care of the body, sophrology, but also esthetic care during hospitalization and after, for women as for men, are often asked for. Because this care does you good. (psychologist)*

### Alimentation

During several months (six months to a year), it is necessary to take food precautions. **These precautions are very strict during the first three months.** Avoid eating cheeses made with raw milk, blue cheeses, or that has a fermented exterior, as well as giblets, shellfish, or crustaceans because of the microbes they carry. Wash your hands regularly to avoid contamination. Cook meat well, and correctly wash fruits and vegetables.

Don't hesitate to talk about this with a dietician.

Notify your doctor of any involuntary weight loss.

■ *Often at the moment of release those close to the patient ask about the nutrition needs: if it's a man, it's his wife who asks us; if it's an adolescent, it's the mother! If it's a woman, she doesn't ask any questions! The woman is going to cook for herself. We give a lot of nutritional advice. We also tell them that they can have an appointment with a dietician. (nurse)*

■ *The diet after is hard, but you know that it's temporary. I adored cheese, shellfish. I wasn't able to eat them. (Frédérique, 53)*

Eating is a basic need. It's even better when it becomes a pleasure. Get some help. There are also clubs and recipe books that teach you to adapt food to your new requirements.

### Physical activity

Practicing a physical activity, even gently, encourages a good physical state and fosters moral. That can also influence your nutrition.

### ► Psychotherapy and group support

After some time, you maybe will experience the need to talk about what happened to you with people trained to listen or with people having lived a similar experience of their own. This can be an individual action or one taken as a couple with a psychologist, a psychiatrist or even to be part of a support group that allows for exchanges about the experience of being sick. Hospitals and associations organize these types of groups (most often these are volunteer organizations).



Several possibilities are offered to you: what suits one person does not always suit another person. Certain methods are used in tandem.

- *It did me a crazy amount of good to understand what had happened to me, to share with other transplant recipients. My husband came with me...That did me a lot of good. (Catherine, 38)*
- *After my transplant, I met people that had recently received a transplant. During the group session, I was there to give hope, to show them that after a transplant you can live like everyone else, working. (Gilles, 61)*

## ► Those close to you

Regaining “normal life” demands understanding and support from those close to you. It takes time and psychological time (which you need) cannot be superimposed on medical and social time.

- *Post-transplant, there are complications; the family is not exactly prepared. (Anaïs, 48)*
- *At the beginning, my friends were coming, calling me and then little by little, they didn't do it anymore. They didn't know what to say to me. (Elise, 17)*

Tell those close to you what you need. Tell them to trust and to be patient.

- *I talk easily. I try to talk about this illness, about what bothers me. (Frédérique, 53)*

Your family had to reorganize itself in your absence. You will little by little reestablish your plans in your familial and social universe.

- *You have to relearn to do things together. With your husband, your child. They had created their own habits! (Nathalie, 35)*

Sometimes those close to you will want to protect you... sometimes maybe too much!



Adolescents and young adults live a period of transition that comes with a lot of ambivalence. They have difficulty accepting being “under surveillance,” highly protected, like when they were much younger. Even if they show a need to be supported and surrounded and sometimes even need protection, they can wish to make their own decisions, and make their own choices. It's all the more true if they return home to their parents after the transplant when they already had left home.

- *My mother continued to worry. It's normal! When my brother got the results of his analysis, he'd drag it out before telling her. It's his life. He thinks he has been rather cocooned, protected...(sister, donor, 32)*
- *My mother would make me hot chocolate like when I was little. That bothered me! (Quentin, 16)*
- *It becomes an obsession! I didn't stop cleaning her room. I was scared that she'd get sick and it'd be my fault. (mother of a young recipient)*

Allow yourself to tell your parents what you want. For example, sometimes you may want them to accompany you to a medical visit and other times no. Help them to better understand your needs, your expectations. Ask them to be patient and to trust you. For example, if you want to have dinner with friends, go to a concert, etc. Going out, even if it exposes you to certain microbes, can also have good effects on your morale.

Returning home changes the family balance and everyone individually is affected by it. If you have brothers or sisters, they were worried for you during your illness, during the transplant. They often live a great solitude, especially if they are young. There are documents to talk about the illness with young brothers and sisters.

You really need time to recover, regain confidence, regain activity... **Don't be discouraged, even if sometimes, with time, your family and friends seem less understanding or lack patience.**

- *When it goes on for awhile, those around you have had enough "of you bothering them!" (Anaïs, 48)*
- *Family, friends - it's normal because they have put up with a lot - they tell you, "You got out of the hospital so it's over, it's ok. And now you have to live. - Yes! You are tired; then rest!" (Nathalie, 35)*

### ► Obtaining a handicapped status

French law for the equality of rights and opportunities for the participation of handicapped citizens recognizes **a debilitating health complication as a handicap.**

This law allows access, depending on the situation, to resources but also to "compensation rights" concerning the consequences of the handicap.

The evaluation of the degree of handicap differs from patient to patient.

The social worker can help you evaluate if this request could be suitable to your situation.

### ► Access to care

#### Specific Situations

- Coverage in the European Economic Community (EEC):

if you benefit from social security in your country of origin, your health insurance plan could accept to cover the care you will be given in France. For this, you will receive the E112 form to organise the care adapted to your condition.

- Foreigners from outside the French economic space:

you can sometimes be insured by a qualified organization from your country of origin: social se-

curity, private insurance, embassy, consulate... Get informed about the legislation concerning this in your country of origin

### ► Social assistance, help for daily life

**Each situation is unique** (depending on your age, your familial situation, your resources...) **and aid is diverse.** Moreover there can be specifications depending on the health insurance plan you depend on (full-time employees, farmers, artisans, students, job seekers).

There also exists specific aid for parents of children under 18 who have received a transplant.

■ *It's often a relief when I say to a patient that there are financial solutions. But I also say that – whatever you do – there will be a decrease in revenue, and it's difficult. Many artisans have not taken insurance in order to have an indemnity in the case of illness. The allotment for handicapped adults means several months of waiting before you receive it. (social worker)*

Information and the steps to take may seem complex. The social workers for the service know the make-up of all the packages. They are there to inform you and assist you and your family with the steps to take. Don't hesitate to get in touch with them. Meet them as soon as possible to start the necessary steps.

Because social laws are constantly changing, the social workers will be there to give you the clarifications you need.

**As soon as you return home, depending on the nature of your request and your situation, you might also contact a social worker outside the transplant department:**

- services provided by your local government;
- your health insurance plan;
- government housing assistance for families;
- social security or your retirement plan;
- community organisations;
- social services provided by your employer.

**These associations** can sometimes provide additional help. Get informed with the transplant unit and don't hesitate to contact an association.

■ *Even if family solidarity exists, families are also often frequently dispersed. When you have your sister who lives 300 km away, who works and who has children, she's going to give 8 days to come help you, but she will not come for 6 weeks. In this case you need to contact social organizations that can help you care for children... (social worker)*

Additionally there are **numerous sources of information**: guides, Internet sites, etc.

**It is important to know the types of financial aid available, types of leaves of absence and other support**

**that might benefit you as well as the legislation involved:**

- revenue during a leave of absence depending on your social security;
- financial aid you might qualify for and benefit from;
- time off for you and time off offered for those close (time off for family support; this time off, in general, is not compensated);
- professional and housing credits, consumer loans and insurance;
- rehabilitation centers for the post hospitalization period;
- going back to work;
- rent assistance;
- home assistance.

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- professional and housing credits, consumer loans and insurance;
- rehabilitation centers for the post hospitalization period;
- going back to work;
- rent assistance;
- home assistance.



If you are young and you show an aggravated health risk, and you wish to borrow (consumer, housing, and professional credit), the AERAS convention, in effect since January 6th 2007, aims to facilitate borrowing. You can consult their website at [www.aeras-infos.fr](http://www.aeras-infos.fr).

■ *Loans, it's terrible because the insurance companies don't want to insure. You see young people for whom the transplant goes well. They go back to work; for some they have a family life and they want to buy and they are blocked because they are told, "You're sick." (leader of an association)*

You will find information concerning access to credit and insurance help in the guide edited by the JSC: "Being Young and Concerned with Cancer."

**The home aid packages are allotted as a function of the consequences of the handicap.** This can be technical aid (bringing meals, home repairs...) or personal aid. It can be cleaning help (housework, cooking, running errands...), a care giver (hygiene, meal preparation...), a social and familial intervention technician. The universal employee service check is a payment method for those you hire at your home, notably for domestic and family tasks. Get information from the social worker who will advise you on the steps to take.

**Certain fiscal advantages** (tax reductions on revenue and local taxes...) are allowed under certain conditions. Get information from different organizations.

## Going back to work

If you have a professional life, **in most cases you are going to go back to work little by little.**

**At first, you can easily benefit from going back part-time** for therapeutic reasons (therapeutic part-time). In accordance with the law, this requires the agreement of your employer in consultation with your doctor.

■ *I have the fortune of having a career that pays well and a good employer and I didn't have any administrative annoyances. (Alexandre, 42)*

■ *When you go back to work, they don't give you a gift! (Anaïs, 48)*

■ *I often contact employers...It's difficult to know what to tell them to help the person and what not to tell them to help the person! A balance needs to be found with the agreement of the person. The patient, there is a history. When they arrive at this step, we want to protect them and to care for them, we shouldn't forget that they have a life that we don't know about. (social worker)*

■ *He went back to work, that was a good thing... he was getting bored at home. (young man of 19 who was 12 when his father received a transplant)*

You have the right to **get in touch with the doctor for work and take a return to work appointment**. His role is very important. He can help you evaluate your situation taking into account the state of your health and foreseeable professional constraints. He will know how to counsel you on what you can do.

Going back to work is compromised as a result of unforeseeable complication. After the medical visit, if you are declared inept to work by the doctor, the employer is held to an obligation of changing the worker's status within the limit of possibility. It can also be useful to look for structures engaged in the employment of handicapped individuals.

It is advisable to speak with the work doctor about your possible options in terms of partial or full disability benefits. It might be possible to adapt your job to your specific needs.

- If you are in school, school is really the central structure for the return to a normal life.
- *I can think of a young person who was excessively worried about his educational future. I was there to tell him about school at the hospital, how he can continue his classes at home. I told him about the structures available. Frequently young people are worried. They see an abyss opening at their feet. They don't know exactly where they're going medically and stopping their schooling or their studies worries them. (social worker)*
- If you ask questions concerning your professional future or your current professional activity, some guides may provide such information.

It could be that certain priorities in your life change after the transplant; a long sick leave can allow you to think about other possible paths. Get informed about your rights to specific educational or professional programs.

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- *I hear a lot of people who have received a transplant say that «transplantation changes everything.» For me, I don't find there to be much different in my way of being. (Frédérique, 53)*
- *When you see them again and you see that things are working, we're happy. We really like when they come back and remember us, our first name, it's a pleasure. (nurse's aid)*
- *I became acutely aware of the phrase «carpe diem.» I don't put off until tomorrow things that will bring me joy. (Catherine, 38)*
- *After, what I find great is when we get a visit from a transplanted person: a smile a person comes to thank us, it's one of the greatest goods! What else can you ask for? (senior nurse)*

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