

We would like to recognize the McGill University Health Centre Patient Education Office for their support throughout the development of this booklet, including the writing, design, layout, as well as for the creation of all the images.

Funding for printing was provided by Lundbeck Canada<sup>™</sup> and the Patient Education Committee of the McGill University Health Centre.









**IMPORTANT: PLEASE READ** 

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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Centre universitaire de santé McGill



Office d'éducation des patients Patient Education Office



This material is also available at: MUHC Patient Education Portal **muhcpatienteducation.ca**  This booklet was brought to you by the MUHC Hematology and Stem Cell Transplant team – Adult site

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A special thank you to our wonderful patients who took the time to read this document and give insightful comments:

Maria and Tony D. Filomena and Carlo S.

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# A special message to you from our team

Your doctor has told you that you need a stem cell transplant because:

- It is your best chance for a cure, or
- It might help to control your disease, or get it into remission.

This booklet is meant to guide you through the stem cell transplant process.



"Remission" is a period of time during your illness when your disease is not active. During remission, you may notice fewer signs of the illness (that is, you may feel less sick). For some people, all signs of the disease can completely disappear.

Using our experience and what patients have told us, we have designed this booklet so that it might be useful, practical and easy-to-read. You will find information on:

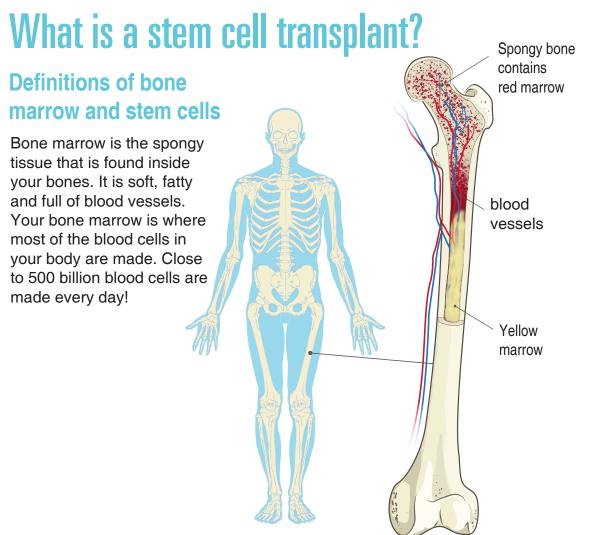
- types of stem cell transplant
- each step of the process
- what to expect before, during, and after a stem cell transplant
- helpful tips and instructions to guide you

Most importantly, this booklet will explain how you can play an active part in your recovery. Research has shown that, by following the instructions we have included here for you, you can help prevent some complications. You are also more likely to recover faster.

# Your transplant team

Over the next weeks and months, you will meet many different health care professionals who will provide you with lots of information and important care. These professionals are all members of your stem cell transplant team. Your team is made up of: doctors, nurses, pivot nurse, stem cell transplant program coordinator, stem cell transplant program quality officer, pharmacists, social workers, nutritionists, physiotherapist, occupational therapist, psychiatrist and stem cell lab technologists. As experts in this area, we are all here to support you.



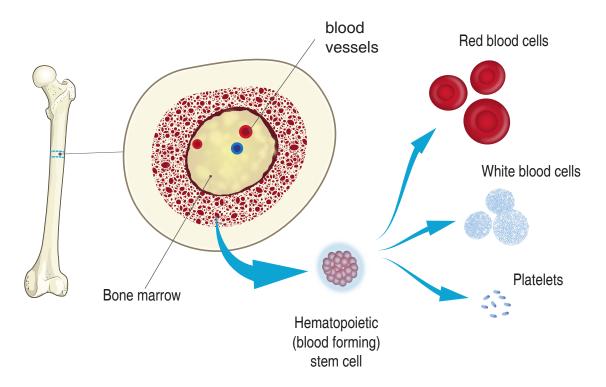




Cells are the building blocks that make up the tissues and organs (e.g. heart, stomach, liver) of your body. When a cell (e.g. blood cell) gets old or is damaged, your body repairs it or clears it away. A brand new cell then grows and takes its place.

There are billions of cells in your body and these cells are constantly growing and being replaced by new cells. Stem cells are found in many of your body's organs. Also called "progenitor cells", they are sometimes referred to as "master cells". As stem cells are not fully developed, they have the potential to grow into any type of cell in your body. (Your body has more than 200 types of cells!) One type of stem cells are "bloodforming" stem cells, ("hematopoietic" stem cells), these are formed in your bone marrow. These stem cells eventually grow into all the different blood cells in your body, such as:

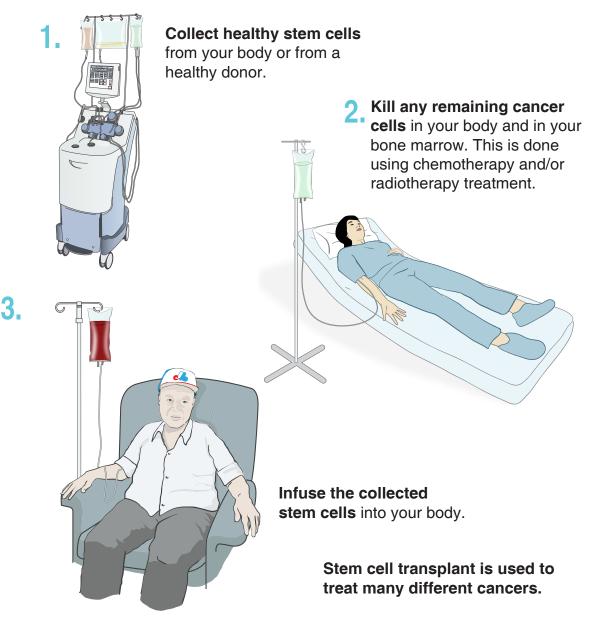
- White blood cells these help to fight infection
- **Red blood cells** these help carry oxygen to all the organs in your body
- Platelets -- these help the blood to form clots (e.g. to stop bleeding)



"Blood-forming" stem cells are made in your bone marrow. They continue to grow here before they move into your blood.

# Stem cell transplant

**Hematopoietic stem cell transplant** is a procedure that allows you to grow bone marrow that is healthy and free of disease. To do this, your stem cell transplant team will:



"When we say stem cell transplant, we must remember that there is no actual organ removed from the donor or implanting procedure to the patient. The terminology is used to facilitate the wording. The actual transplant is the filtering of blood from the donor and then this filtered substance is introduced to the patient via intravenous into his blood system. This procedure is relatively simple and painless for both parties."

-- Carlo, stem cell transplant patient



Before we can proceed with the collection of your stem cells, we need to make sure your disease is stable or in remission. This means that we will only proceed with the collection of the stem cells once we have a documented response to your regular chemotherapy treatments.

# **Types of stem cell transplant**

There are two different types of stem cell transplant:

1. Autologous transplant

The stem cells come from you.

### 2. Allogeneic transplant

The stem cells come from a donor. This could be a relative (usually a sibling), or an unrelated donor (an adult or umbilical cord blood). This transplant may be used when your bone marrow has been affected by your illness.



The type of transplant that you will have will define the following aspects of your care:

#### Before your transplant:

- How you will need to prepare and care for yourself
- Your chemotherapy treatment

#### During your transplant:

 How you will receive the stem cells during the procedure

#### After your transplant:

- What to expect during your recovery
- The length of your hospital stay
- · How to take care of yourself
- Your follow-up appointments and care plan with the transplant team

Your doctor will speak to you about the best transplant plan for you. Your transplant team will support and guide you throughout the process (before, during and after your transplant).

### Autologous stem cell transplant

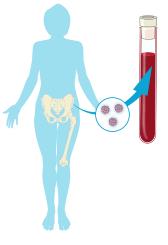
If you are having an autologous transplant, the stem cells will be your own cells. They will come from your body.

Here is how it works. Your stem cell transplant team will:

# 1.

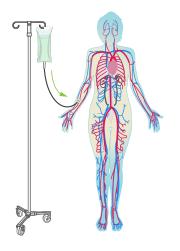
Increase the number of stem cells in your blood. We do this by giving you either chemotherapy or other drugs that stimulate the bone marrow to make and release more stem cells into the bloodstream. This treatment is referred to as your **mobilization** treatment. Your doctor will tell you which mobilization treatment is best for you.

We may also give you injections, called growth factors, at specific times after your mobilization treatment. These injections will help your body make more blood cells and increase our chances of having a successful collection.



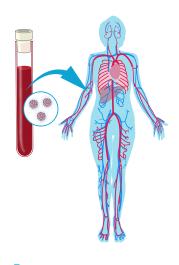
# 2.

**Collect healthy stem cells** from your body. This is usually done shortly after your mobilization treatment. This is normally when new blood-forming stem cells have started growing and traveling to your blood. Your collected cells are then preserved and frozen. They will be infused to you at a later time.



# 3.

Kill cancer cells in your body and in your bone marrow. This is done using chemotherapy. This chemotherapy is different from the chemotherapy you received before the stem cell collection. It may be stronger than any treatment you have received before. This is what we call your conditioning treatment.



Return the stem cells we collected to your body.

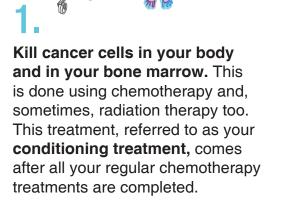


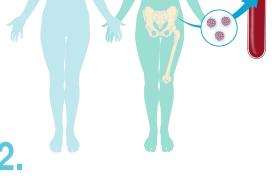
We may need more than 1 day to collect cells for your transplant. Whether your stem cell collection lasts one day or more depends on how many cells are collected on each day.

### Allogeneic stem cell transplant

If you are having an allogeneic transplant, your stem cells will come from a "**matched**" donor. This type of transplant is often used when your bone marrow has been affected by your illness.

Here is how it works. Your stem cell transplant team will:

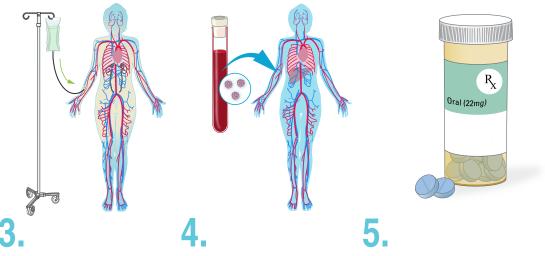




**Collect healthy stem cells** from your donor. This is usually scheduled ahead of time to coincide with your day of transplant.

The stem cells from your donor will not usually be frozen or preserved. As it is collected so closely to the time when you will receive it, you will receive it "fresh" within 2 days of the collection. For this type of transplant, the conditioning treatment usually starts before stem cells are collected from the donor.





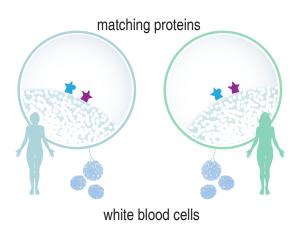
Prepare your immune system to receive the donor cells. This is done using drugs called immunosuppressors.

Infuse the donor stem cells into your body.

**Prevent graft rejection.** This is done using drugs called immunosuppressors.



Proteins sit on the surface of your blood cells. Everyone has their own set of proteins. These proteins are called HLA markers (or Human Leukocyte Antigens).



To find the best "matched" donor, your proteins will be compared with the proteins on your donor's white blood cells. This test, called "HLA-typing," will check to see how many of these proteins are the same. Your immediate family members are most likely to have similar proteins to yours. However, it is possible for someone who is unrelated to match your blood cells too.

## How it works First steps: meeting the team, tests & planning

#### 1. Meet the team

Whether you are receiving care at this hospital for your illness or have been referred from another hospital, the very first step will be to meet with the transplant team.

During this visit, your transplant doctor will explain:

- the kind of transplant that is best for you
- the type of preparation and chemotherapy treatment you will receive
- possible health problems (complications) that you may experience, and
- the chances that your treatment will work for you

To start, we will give you an appointment to meet our team at the Cedars Cancer Centre (see hospital map and floor plan on **back cover**). When you arrive that day, we will ask you to take some blood tests. You will then meet one of our transplant doctors and our Stem Cell Transplant Program Coordinator.





We will give you a lot of information during your visit. It is nearly impossible for anyone to remember it all. Here are some suggestions to help you keep track of all the important details:

- Write down your questions ahead of time
- Take notes during your visit
- Bring 1 or 2 family members or a significant other to every appointment
- Read this booklet carefully and bring it with you to subsequent hospital visits

#### We will also ask you many questions. Please come prepared to share:

- your health care history (illnesses, medications, surgeries and treatments you are receiving or have had in the past)
- Finally, you will be given time to ask your questions and to voice your fears or concerns. Please remember: we are here to help!
- names and contact information for your full siblings (same mother and same father)

### 2. Take some more tests

After your first visit to the Cedars Cancer Centre, we will plan for many other visits. We will also arrange for you to take more tests. This is what we call the "pre-transplant screening". These tests will give us more information about your general health condition and your disease. They will help us make the best stem cell transplant plan for you.

Your tests may include any of the following:

- X-rays
- MRI
- CT scans
- blood tests
- lung tests
- heart tests
- bone marrow biopsy
- lumbar puncture



During our meetings with you, we will explain what tests you will need, how to prepare, what to expect, and what your test results mean for you.

### 3. Have some important check-ups and appointments

#### Dentist

If you have some or all your natural teeth, we will ask you to see a dentist. You will need to carry out all your dental work before the transplant. This will lower your chances of having any infections.





#### Vaccinations

We always recommend that you are upto-date on all your vaccinations before you have your transplant. Be sure to discuss this with your hematologist.

#### Social situation and support network

You will meet our psychiatrist, and social worker if needed. Both are members of your stem cell transplant team. They will work with you to address your readiness, identify your support network and address any social issues before your transplant.



#### Planning your stem cell transplant

All these visits, tests, and check-ups are important for your transplant team to be able to plan all the important steps and details for your stem cell transplant. It is important to keep in mind that a stem cell transplant is not a quick process. It requires a lot of time to plan and prepare. **Many weeks or months may go by** between your first visit with the stem cell transplant team and your actual transplant day.

# Finding a donor

If you need an allogeneic stem cell transplant, we will need to find a donor for you. Here is how it works:

#### Have any siblings?

If you have full siblings, the first step will be to see if they might be a matched donor. To do so, you will need to provide us with a list of their names and contact information. Our Stem Cell Transplant Program Coordinator will call them to arrange a special blood test (called "HLAtyping") that will identify if they are a match. For quality purposes, it is better that this blood test is taken at our hospital. However, if your family member lives far away, we can arrange for the blood test to be done in another hospital.

If your sibling is found to be a match, he/she is now a possible donor. We will ask him or her to meet with one of our stem cell transplant doctors. During the first visit, we will review the whole donor process in detail with them and answer any questions they may have.



Just as we did for you, we will give your sibling a lot of information during this visit. It is nearly impossible for anyone to remember it all. Here are some suggestions to help your sibling keep track of all these important details:

- Write down questions ahead of time.
- Take notes during the visit.
- Bring 1 or 2 family members or a significant other to every appointment

Did you

know

 Read this booklet (also available at muhcpatienteducation.ca) carefully.

### No sibling donor?

If no sibling donor is available, we will look for a matched donor through the international bank of volunteer donors. This is a bank of potential donors from around the world. All the volunteer donors registered in this bank have taken HLA-typing tests. Simultaneously, we will also look for a matched umbilical cord blood unit through cord blood banks.



If your stem cells come from a volunteer donor, we will organise the collection and transport of your donor's stem cells to our hospital. This way, they will be ready for the day of your stem cell transplant.

#### Rules protecting you and your donor

The process around how donors are chosen is very strict. In addition to being a match, the potential donor's overall health, illnesses, travel history and lifestyle habits will be discussed, to protect both your donor and you.

### Respect for choice and privacy

Every potential donor has the following rights:

- The right to choose whether they would like to donate their stem cells. It may happen that a sibling does not want to donate their stem cells. It is important that we respect this choice.
- The right to privacy and protection of personal health information. To respect this right, we cannot share the results of a sibling's blood test with you or other family members. We will leave this in your sibling's hands.



If you will be receiving stem cells from an unrelated donor, we will not be able to tell you where the stem cells are from.



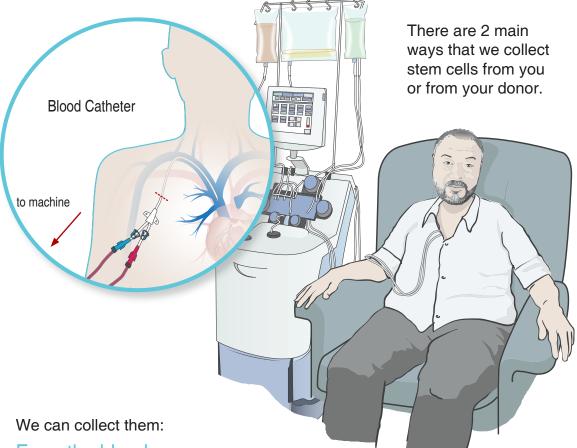
You are not allowed to have any information about your donor for 1 year after your stem cell transplant. For some countries that are part of the international stem cell donor bank, contact between recipient and donor is not allowed at all.

For more information on the international donor bank, visit Hema-Quebec's website: www.hema-quebec.qc.ca

#### We need to start early!

Please keep in mind that finding a donor can be a very long process. It can take several months. For this reason, we suggest that we start the donor search **as early as possible**. Let us know if you have any questions or concerns. We are here to help.

# Stem cell collection



#### From the blood

This is the method that we prefer and use most of the time. It is fairly simple and very similar to how someone makes a blood donation.

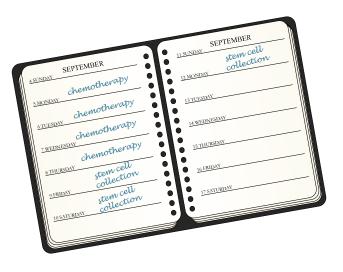
To do this, some patients may need to have a central venous catheter placed in their upper chest. This is done in the Radiology Department (sibling donors do not usually need a central venous catheter). All the blood that is collected will run through a machine that will separate the stem cells from the rest of your blood. Once the stem cells have been separated, we will return the remaining blood to you. This procedure is the same for a donor.

The collection can take up to 4 full days.

The number of stem cells in a person's blood is very small. For this reason, before any collection, we will activate the stem cells and their production so that they move from the bone marrow into the blood.



If we are collecting your own stem cells (for an autologous transplant), we will usually schedule your collection shortly after a session of chemotherapy, because chemotherapy tends to push a larger number of stem cells into the blood. In some cases, if it is not possible to time your collection after a chemotherapy treatment, we may instead give you a combination of special medications a few days before the collection.





For an allogeneic transplant, we will give your donor a special medication called growth factor for 3 days before the collection.

#### From the bone marrow

Using a special needle and syringe, we will draw out bone marrow from the hip bones. There will be more than one place where we insert the needle to collect. For this reason, this procedure is done in the operating room under general anesthesia. This way your donor will be asleep and feel no pain during the collection. This method of collection is now used much less frequently.



No matter what the plan is, we will always explain the collection process, possible unwanted reactions (side effects) and health problems (complications) in detail to you and your donor before we begin.

# What you need to know about your hospital stay

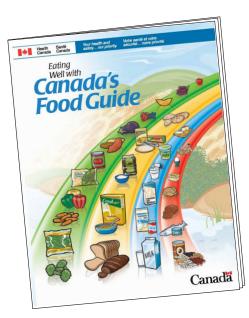
### How long you will stay

The average hospital stay is **4 weeks** if you are having an autologous transplant, and **5-6 weeks** if you are having an allogeneic transplant.



#### How to prepare

In addition to all your tests and visits, there are a number of things you can do to prepare for your stem cell transplant:



### Embrace healthy living

- Be active. Having a transplant when you are in good physical condition will help reduce the chances of having complications. A short walk every day is enough to build your muscle strength and energy bank. For other examples of appropriate exercices, please speak to your doctor, nurse or physiotherapist.
- Eat well. Keep a balanced diet. Please refer to the Canadian food guide for advice on this topic. We can refer you to our nutritionist if you need it.



- Stop smoking. Studies have shown that smoking increases the risk of pulmonary complications during and after a stem cell transplant. We can refer you to our smoking cessation program if you need help with this.
- Take care of your teeth. Oral hygiene is important to decrease the risks of dental infection. It is recommended to brush after each meal and at bedtime, using a softbristle toothbrush. You should not floss if your platelet count is low.

#### Ask family or friends for help with:

- Pet care
- Paying your bills
- Taking care of your home (e.g. snow removal, mowing the lawn)
- House cleaning Vacuuming floors, carpets and furnitures, disinfecting the kitchen and bathrooms and washing bed linens. This will lower your chances of infection when you return home.

\*\*You will not be able to do these things during your hospital stay and for a few weeks after you have left the hospital.

### Plan your meals ahead of time

If you are considering planning your meals ahead of time, **ask to meet our nutritionist before your hospital stay.** You will need to know about certain food restrictions during and after your transplant. The nutritionist will also give you meal and snack ideas.





#### Remove your house plants

Remove all natural plants and flowers from your home. These may carry microbes (such as bacteria or fungi) that can lead to infections.



Talk to someone. Share your feelings and fears. If you have any concerns or questions, call your Pivot Nurse or Stem Cell Transplant Program Coordinator. We are here to help.

### What to bring

You may bring the following personal items to the hospital:

- pajamas or night gowns
- non-slippery slippers
- comfortable, loose-fitting clothes
- scarves or head covers
- a small alarm clock
- electronics, such as a cell phone, iPad and laptop
- books, magazines, pen and paper
- clean blanket or quilt (this will have to be washed once a week by a family member.)
- pictures of loved ones
- soft-bristle toothbrush, toothpaste, soap, shampoo, deodorant, tissue paper



\*\*Please do not bring stuffed animals. These may carry microbes (such as bacteria or fungi) that can lead to infections.

Please leave valuables such as jewelry, money and bank cards at home. If you will have electronics with you at the hospital, bring a lock so you may secure them safely when you are not in your room.

Keep in mind that the hospital is not responsible for lost or stolen personal items.



### Your hospital room

Your hospital room will be a private room with a private toilet and shower, a phone and a TV. There will also be a chair and a sofa bed in your room for a family member to spend the night. There is a weekly fee to use certain features on the TV. Speak to your treatment team during your hospital stay if you have questions.



lower the chances of infection. For this reason and for your safety, please note that the room window is sealed and cannot be opened.

#### **Your visitors**

Our hospital is a patient and familycentred health care centre. We strongly encourage your family and friends to visit as we believe that support from your loved ones is very important during your hospital stay.

Visiting hours are from 8AM to 9PM.



A 2-week or monthly parking pass is available for your visitors at a lower cost. There is a family room with a kitchenette on the transplant unit that is available to you and your visitors. You may also need some help to find lodging near the hospital for your family member.

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Please speak to your nurse or social worker for more information or if you have questions.

#### Help us protect our patients from infections.

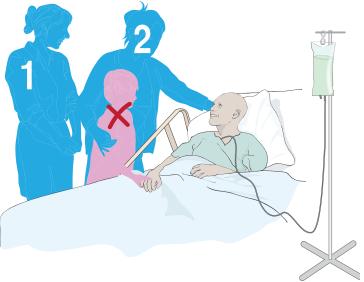
While visitors are welcome and encouraged, protecting our patients against infections is also very important. For this reason, we ask that:



Only 1 to 2 visitors may come at the same time.

Children under 12 years old should not visit.

- Visitors wash their hands before entering and before leaving your room.
- Visitors only use the public washrooms on the unit. (The washroom in your room is only for you to use).
- Only 1 to 2 visitors come at the same time.
- Children under 12 years old should not visit.
- Children who have not received their regular vaccinations should not visit.
- Anyone who is ill or has been in contact with someone ill within the past 2 weeks should not visit.
- Natural plants or flowers are not brought into the unit. These may carry microbes (such as bacteria or fungi) that can lead to infections.
- Food brought in a patient's room is not brought back to the kitchenette afterwards.



# **During your hospital stay**

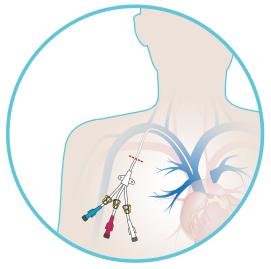
### **Admission day**

The day that you are admitted for your hospital stay will be busy. Your doctors and nurses will ask you lots of questions. To be absolutely sure nothing is forgotten or missed, we will go over a number of details again that we had previously explained to you.

Ŵ		Programme de Greffe de Cellules Souches Stem Cell Transplant Program Calendrier-Calendar								
Protocol		BUSULFAN + CYCLOPHOSPHAMIDE								
Patient's Name										
Week Day		Ven/Fri	Sam/Sat	Dim/Sun	Lun/Mon	Mar/Tue	Mer/Wed	Jeu/Thu		
	Date	4-Dec	5-Dec	6-Dec	7-Dec	8-Dec	9-Dec	10-Dec		
BMT Day		Day -10	Day -9	Day -8	Day-7	Day-6	Day-5	Day-4		
Medications				Septra Ursediol Dilantin	Septra Ursodiol Dilantin Zofran	Septra Ursodiol Dilantin Zofran	Septra Ursodiol Dilantin Zofran	Septi Ursodis Dilanti Zofna		
Chemotherapy					BUSULFAN	BUSULFAN	BUSULFAN	BUSULFA		
Mouth Care										
Other					Region Benadryl and	Region Benadryl pro	Region Benadryl pro	Region/Benodryl pr		
	Date	11-Dec	12-Dec	13-Dec	14-Dec	15-Dec	16-Dec	17-Dec		
BMT Day		Day -3	Day -2	Day-1	Day 0	Day+1	Day+2	Day +3		
Medications		Septra Ursodiol Dilantin Acyclovir Fluconazole Pepcid	Septra Ursodiol Acyclovir Fluconazole Pepcid	Ursediol Tacrolimus Acyclovir Fluconazole Pepcid	Ursodiol Tacrolimus Acyclovir Fluconazole Pepcid	Ursodiol Tacrolimus Acyclovir Fluconazole Pepcid	Ursodiol Tacrolimus Acyclovir Fluconazole Pepcid	Ursodic Tacrolim Acyclov Fluconazol Popci		
Chemotherapy		Zofran Mesna CYCLO	Zofran Mesna CYCLO	Zofran	Stem Cells Infusion (5)	MTX		MT		
Mouth Care		Nystatin MMW	Nystatin MMW	Nystatin MMW	Nystatin	Nystatin	Nystatin	Nystati MMX		
Other		Regiss/Bensfryl pro	Regian/Benadryl pro	Regian Benadryl pro		Region Benadryl pro	Region Benadryl pro	Region/Benodivi pr		

If you have not had one already, we will insert your **central venous catheter**. We will place this special infusion line in your upper chest or in your arm at the Radiology Department. You will meet with our pharmacist (who specialises in cancer medications). Our pharmacist will explain the medications that you will receive during your hospital stay.

We will give you a **transplant calendar** (we call this your "protocol"). This treatment road map will cover what to expect in terms of medications, starting from the day of admission and leading to your recovery day.

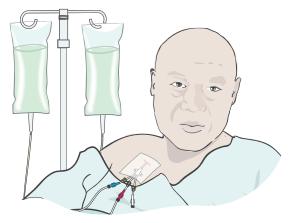


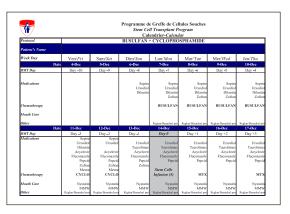


You may be in hospital for 3 to 11 days before your transplant. (This all depends on your transplant care plan, which we will review with you.)

#### Between admission and transplant day

The time between the day you are admitted for your hospital stay and your actual transplant day is called the **conditioning period.** During this time, we will give you a number of different medications in order to prepare your body for the stem cell transplant. You will also meet with our nutritionist who will discuss special food safety recommendations, how to manage changes in your appetite and how to meet your nutritional needs during this time.



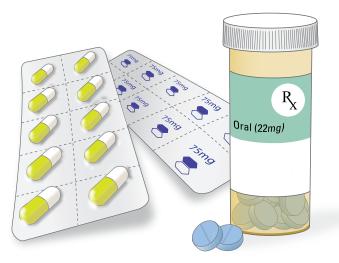


During this preparation time (or conditioning period), we will give you fluids, chemotherapy, antibiotics and other medications (e.g. anti-nausea or pain medications). We will most often give these to you **intravenously** (that is, through the central venous catheter inserted in your upper chest or in your arm). Different types of chemotherapy and medications are used for autologous and allogeneic transplants.

It is very important that you share any new **symptoms** (changes in your body that you notice) or health problems with your nurse or your doctor. **If you have any fears, questions or concerns, please tell us.** Your nurses and doctors are here to support you throughout your hospital stay.



If you are receiving an allogeneic transplant, you will also need immunosuppressive medications. These medications lower the strength of your immune system.



Your immune system keeps you healthy and balanced. It keeps you from getting sick by defending your body from germs (e.g. bacteria, viruses, mold) that are all around us. In the same way, your immune system may react to your new stem cells as if they are foreign germs. If it does, it will try to fight them. This is called **graft rejection**. Your new cells may also react to your body and immune system in the same way and try to fight them. This is called **graft-versus-host disease**. This does not mean that the transplant has not worked.

By taking **immunosuppressive medications**, you will lower the chances of rejection and graftversus-host disease.

#### **Transplant day**

We call your transplant day "day 0". All the days after your transplant day are counted as "plus" days (e.g. day+1, day +2, and so on). On the morning of your transplant day, your nurse will give you an approximate time when the stem cells will be infused.

The transplant will appear very much like a blood transfusion. Here is an idea of what will happen:

- Our lab technicians will bring the stem cells from the lab. (If the cells were frozen, they will arrive in a special container and will be thawed on the unit.)
- Your nurse will then infuse the stem cells into your body through your central venous catheter. If the cells were thawed, your nurse will infuse using a syringe. If the cells are "fresh", they will come in a bag which your nurse will connect to your central venous cathter.
- The stem cell infusion usually takes less than one hour.
- Your nurse will check your breathing, blood pressure, heart rate, temperature (and more) before and after the infusion.
- Loved ones (excluding pets) can be present during the infusion.

#### Side effects (unwanted reactions)

Frozen stems cells are preserved with a chemical called DMSO (or dimethylsulfoxide). DMSO is what causes the most side effects during the infusion of the cells. Although fresh stem cells are not mixed with DMSO, side effects can still happen but are less common. If you are receiving thawed stem cells, you may experience the following side effects at the time of the infusion or in the days following the infusion:



nausea

vomiting





stomach cramps

DMSO leaves your body through your lungs as you breathe. For this reason, you should take slow, deep breaths during the infusion of the stem cells. This will push the DMSO out of your body faster and help control your side effects. Your nurse will be there to remind you.

It takes 24 to 48 hours for the DMSO to leave your body completely.

DMSO has a peculiar smell. While your visitors may notice the smell, you may not notice it yourself (except during the infusion). You may also find that your urine is red for a few hours after the transplant. This is normal.

Your transplant day may be very emotional. We encourage you to share your hopes, fears and feelings. If you have any questions or concerns, we are here to help.

## Your recovery

It usually takes **2 to 3 weeks** for your new cells to engraft and to grow. During this time, there is a risk that you may have the following health problems:

- infections
- bleeding
- anemia

For this reason, we will watch you very closely. You will need blood transfusions as well as antibiotics or other medications. Throughout this recovery time, it is very important that you share any **new symptoms** with your nurse or your doctor.



#### Taking an active part in your recovery

We know that this is a difficult time for patients. However, there is a lot that you can do to help yourself recover smoothly and quickly during your hospital stay:

- Shower every day. This helps prevent infections and protects your skin
- Wash your hands after going to the bathroom and before eating

- Carry out your mouth care routine, at least 4 times a day (this routine will be explained to you early on during your hospital stay )
- Use a soft toothbrush
- Get out of bed at least 3 times a day, for at least 30 minutes each time
- Walk around in your room or on the unit 1 to 2 times a day

- Do your breathing exercises (we will explain those to you early on during your hospital stay)
- Eating is important to recover. Our nutritionist can help you if you have problems with your appetite or with keeping food down. It is also important to follow explained nutrition guidelines
- Tell us if you notice any changes in your body • (new symptoms)
- Speak to us if you have questions or concerns

#### During your recovery in hospital, you should avoid:

- Flossing
- Using razors or scissors.
- \*\*These can lead to bleeding and infections.



- Wash with soap and water, or
- Use an alcohol-based hand rub if a sink is not available.

#### Hand hygiene

Keeping your hands clean is a good way to stay healthy and prevent infection.

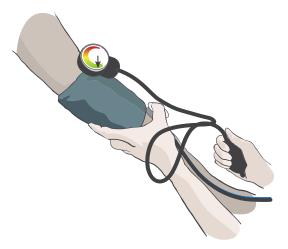
For this reason, visitors (and hospital staff) should always wash their hands before and after they have had any contact with you, your body fluids, your blood, soiled linen or clothing.

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#### **Hospital routine**

There are a number of things that are part of our **daily** hospital routine. You will become familiar with them and should expect that these happen throughout your hospital stay:

- Every morning around 6am, you will have your blood tests. Blood will be drawn from your central venous catheter.
- We will weigh you 1 or 2 times a day.
- Your nurse will do your complete physical check-up 2 times a day.
- Your nurse will watch your vital signs closely throughout the day and night.
- We will watch your fluids carefully (how much you drink, urinate, or stool). Be sure to tell your nurse about everything you drink. Save all your urine, vomit and stool in the appropriate containers. You nurse will measure these.





- Your doctor will usually come to see you once a day.
- You will also meet with other members of the stem cell transplant team (nutritionist, physiotherapist, etc) on a regular basis.
- We will provide special care to your central venous catheter every 3 days.
- If you wish, you can also meet with our social worker, psychiatrist or with our spiritual care team at any time during your hospital stay.

#### When can you go home?

Before you can leave the hospital, we will make sure of the following:

- Your neutrophil counts are higher than 0.5
- You have been without fever for at least 24 hours
- You need only 1 or 2 transfusions a week (not more)
- You are able to take all your medications orally, as they were explained to you
- You are able to eat and keep your food down
- You are able to drink enough fluid each day



Before you leave, you will need to:

- Go over your medication list and schedule with our pharmacist
- Discuss your nutrition plan with our nutritionist
- Make arrangements for transportation and where you will stay after you leave the hospital (speak to our social worker if you need help with this)
- Review any special home care instructions with your nurse

You will need special care of your central venous catheter once you are at home. We will arrange for this to be done by your CLSC nurse, every 7 days.





You may feel both excited and fearful about going home. This is normal. Most people feel nervous about leaving the safety of the hospital. You may also have concerns about how you will care for yourself at home. Share your feelings or concerns with your transplant team. We will help you and your caregiver to plan ahead.

### At home What to expect

You may find that the first few months after leaving the hospital are very difficult. You may still feel weak and very tired (for as long as 6 months after your transplant). Regular tests and appointments during this time period will certainly add to this. If you are concerned about this, speak to your nurse or doctor. We can help!

You may also find it difficult to deal with your emotions. Patients often tell us that they feel as though they are on an emotional roller coaster after their transplant. Some feel a loss of control. Many feel that their patience runs out at times. These emotions are normal. Be patient with yourself and others. It may help to share your feelings with the transplant team. You are also welcome to join one of our support groups. Information on our support groups is available with CanSupport.

#### After an autologous transplant

If you had an autologous transplant, our team will care for you for a total of 100 days after the transplant. After you are discharged from the transplant unit, you will need to visit us at the Cedars Cancer Centre at least 2 or 3 times until day +100. If you need blood transfusions, you will visit the clinic more often. At every visit, we will do blood tests. This will help us better understand how your body is responding to the transplant. Finally, we will arrange that you have some tests (e.g. another CT scan or PET scan). This will tell us if you are in "**remission**". If this is the case, we will arrange for the removal of your central venous catheter. This will be done in the Radiology department.

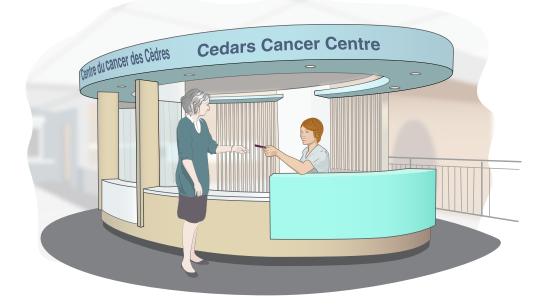


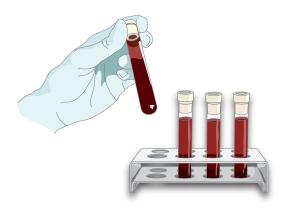
"Remission" is a period of time during your illness when your disease is not active. During remission, you may notice fewer signs of the illness (that is, you may feel less ill). For some people, all signs of the disease can completely disappear.

After these 100 days, you will no longer need to visit the transplant team at the Cancer Centre. At this point, you will only need to have visits with your regular hematologist.

#### After an allogeneic transplant

If you had an allogeneic transplant, you will need to visit the Cancer Centre two times a week for the first 90 to 100 days after transplant, or for as long as you are taking immunosuppressive medications. The strength of your immunosuppressive medication (your "dose") may need to be adjusted regularly, depending on your blood test results.





At each visit, we will do blood tests. We will regularly give you **intravenous** medications (through your central venous catheter). You may at times need blood transfusions or hydration during these visits.



On the day that you are to come to the Cancer Centre, please do not take your immunosuppressive medication. This can change your blood test results. For this reason, please bring your medication with you and wait until after your blood tests are done to take it.



Once you have stopped taking immunosuppressive medication, you will only need to visit the Cancer Centre once a week. We will arrange for the removal of your central venous catheter around this time. This will be done in the Radiology department. After this, you will be able to come less often, once every 2 weeks. This will also depend on how you are feeling. Eventually, you will only need to come once a month or less.

After your allogeneic stem cell transplant, you will need to be followed by our transplant team for the rest of your life. For this reason, you will not return to your regular hematologist.

**Centre Days** 

#### How to stay healthy

There are a number of things you can do after you leave the hospital to help you recover:

• Drink lots of fluids - at least 6 glasses (or 1.5 liter) of nonalcohol fluids each day. This will help reduce the side effects of your immunosuppressive medications.





- Exercise everyday. Staying active is very important. A few short walks everyday is enough to maintain your muscle strength. Bicycling is also a good exercise (as long as your platelet counts are high enough). Some people find yoga and tai-chi very helpful.
- Eat well. If you cannot eat a lot at one time, eat several small meals throughout the day. Please follow our food safety instructions for at least 6 months after your transplant. The Canadian food guide offers good advice on balanced nutrition. You can also find valuable information in the Canadian Cancer Society booklet "Eating Well With Cancer".



• Take care of your mouth and teeth. Oral hygiene is important to decrease the risks of dental infection. We recommend brushing after each meal and at bedtime, as well as using a soft-bristle toothbrush, but no flossing.





- **Take your medications** as they are explained to you.
- Take care of your skin. Use gentle soaps and apply moisturizing cream every day. Applying sunscreen should be a part of your daily skin care routine.
  - See some friends. Do not isolate yourself.
- **Rest**. Try to find a balance between rest and your activities.

#### Avoid the following:



- Alcohol
- Smoking
- Herbal supplements, vitamins, and over-the-counter medications – avoid anything that has not been prescribed by your doctor. These can interact with your regular medications and weaken or change their effects. If you are interested in taking something not prescribed, please speak to your nurse or doctor first.
- **The sun** if you have to be outside, stay away from the sun and protect your skin with sunscreen (SPF 30). Sun exposure may provoke graft-versus-host disease.
- Perfumes and anti-wrinkle cream
- Eating at restaurants and buffets in the first 6 months after transplant.
- Drinking water from a well
- Crowds (e.g. a parade, big party, a busy mall)
- **Gardening** avoid mowing the lawn, raking grass or leaves for 1 year after transplant.
- Swimming in a lake
- Litter boxes, fish tanks or birdcages –avoid cleaning these for 1 year after your transplant.
- Sick children or adults Being around people who are unwell can increase your chances of getting an infection.

# **Getting help**

#### When to call your nurse

Call your nurse if you notice:

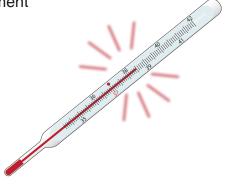
- A new cough
- You are short of breath at rest or with mild exercise
- Changes in your bowel habits
- A new skin rash
- Mouth sores
- A sore throat

- You have trouble swallowing
- Changes in your urine
- Any new pain
- Nausea or vomiting that does not go away
- A change in your appetite
- You are unable to take your medication
- Problems with your central venous catheter
- Any change in your body that concerns you

#### When to go to the emergency room

Do not wait. Go to the emergency department of the MUHC Glen Hospital, if you have:

- A fever (your temperature is 38.3 Celsius or more; or if it has been higher than 38.0 Celsius for 1 hour)
- Trouble breathing
- More than 3 liquid stools per day
- Chest pain
- Severe nausea or vomitting



# Life after stem cell transplant

#### **Emotions**

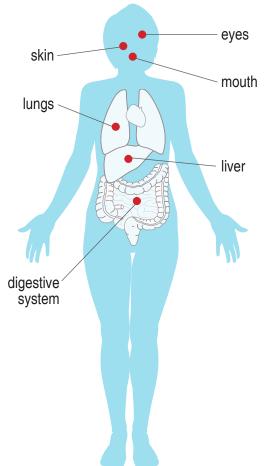
Stem cell transplant can be a stressful experience, not only for you but also for your family. It can be emotionally challenging. Some of the medications you take may not help this. Speak to your nurse or doctor. Share any feelings or concerns you have. We are here to help.

#### Graft-versus-host disease

Graft-versus-host disease (GVHD) is a common health problem that is seen in patients who have had an allogeneic transplant. It is the result of the battle between your new graft and your body, who are not used to living together. This does not mean that the transplant has not worked.

Graft-versus-host disease may be mild to severe. For some people, it will last only for a short while. For others, it can continue for a longer period of time. Graft-versus-host disease can affect any organ of your body. More commonly, it may affect your:

- skin
- digestive system
- mouth
  - liver, orlungs
- eyes



A little bit of graft-versus-host disease may be a good thing. It shows us your new stem cells are working well. But be sure to call us right away if symptoms appear, as we don't want it to go too far and make you sick.



If your graft-versus-host disease is serious, we will need to treat it fairly quickly. To help us do this, it is very important that you tell your nurse or doctor about any new changes in your body that you notice right away.

#### **Sexuality**

Sexual activity is normal and an important part of your recovery. This will, however, depend on how you feel. As well as practicing "safe-sex" at all times, there are a few things you will need to keep in mind:

- Sexual intercourse is not recommended if your platelet count is below 50 000 or your neutrophil count is below 0.5. Below this number can increase your chances for bleeding and infection.
- There are no health risks related to kissing, hugging and touching.
- Oral and anal intercourse may increase your chances of infection.
- Women often report vaginal dryness, irritation or tightness after a stem cell transplant. Using a water-based lubricant can help. Speak to your doctor if this is a concern to you.
- Men often report erectile problems after transplant. Speak to your doctor if this is a concern to you.



Speak to your nurse or doctor if you have any other questions or concerns around your sexual health. We are here to help.

#### Traveling

You should avoid traveling for 6 months after an autologous transplant and for 1 year after an allogeneic transplant.





#### Vaccination

Chemotherapy and stem cell transplant will erase your body's memory of any previous vaccinations you might have had. For this reason, you will need to take all your vaccinations again. We will arrange for you to have your first vaccinations 6 months after your transplant. Your vaccinations should be completed 26 months after your transplant.

#### **Returning to work**

Stem cell transplant patients are usually able to return to work 6 months after an autologous transplant and 1 to 2 years after an allogeneic transplant. Everyone, however, recovers differently after a stem cell transplant. Speak with us regularly about how you are feeling, and we will help you plan your return to work.



### Looking for more information? Finding the right health information



Be wary of the information that comes your way. Many people may try to give you health advice without knowing the details of your illness and treatments. You may also find information in books or on the internet which are confusing or misleading.

The internet offers a lot of information. However, not all of it is correct. Also, not everything you read will apply to your unique situation.

Write down your questions or bring any information you have to share with your stem cell transplant team.

We are here to help you make sense of the information you have found and learn how it may apply to your health and your stem cell transplant plan

#### Websites:

Here are a few websites that we would recommend, if you are looking for more information:



MUHC libraries: www.muhclibraries.ca

Cedars Cansupport: www.cansupport.ca MUHC Patient Education Office: www.muhcpatienteducation.ca National Bone Marrow Transplant link: National Marrow Donor Program: www.bethematch.org One Match: www.onematch.ca The Canadian Cancer Society: www.cancer.ca Cancer Centre: transplant.pdf The Leukemia and Lymphoma www.llscanada.org Society of Canada:

BMT Infonet: www.bmtinfonet.org Canada's food guide: www.healthycanadians.gc.ca/eatingnutrition/healthy-eating-saine-alimentation/ food-guide-aliment/index-eng.php Hema-Quebec: www.hema-quebec.qc.ca www.nbmtlink.org Upstate University Hospital www.upstate.edu/hemonc/pdf/uuh\_

## How to reach us

#### **Contact information**

MUHC Glen Site 1001 Decarie Blvd Montreal, Que. H4A 3J1 T: 514-934-1934

The Outpatient Clinic is located at the Glen Site, Cedars Cancer Centre Building, Block D, Level RC, T: 514-934-4400

The Stem Cell Transplant Unit is located at the Glen Site, RVH Building, Block D, Level 10 T: 514-934-1934 ext. 35755 Doctor`s office Dr.Gizelle Popradi Dr.John Storring Dr.Jonathan How T: 514-843-1558 F: 514-843-1418

Stem Cell Transplant Program Coordinator Katia Bellegarde T: 514-934-1934 ext. 36076

Pivot Nurse Lynda Desrochers T: 514-934-1934 ext. 31781

Brigitte Pépin T: 514-934-1934 ext. 36025

#### **Other Hospital Resources**

Cafeteria: located off the Adult Atrium on the S1 level Vending machines: Block C, Level 1 Adult Resource Centre: Block B, Level RC Cancer Resource Centre: Cedars Cancer Centre, Level RC Prayer and Meditation room: between Blocks C and D, Level 2, room 1178



#### Internet access:

Network: CUSM-MUHC-PUBLIC Username: public Password: wifi

### Notes

# Looking for information on



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Search: Cedar Cancer Guides Chemotherapy PICC & Portacath Radiotherapy Pain control Cancer and fertility

# Visit the Patient Education Collection

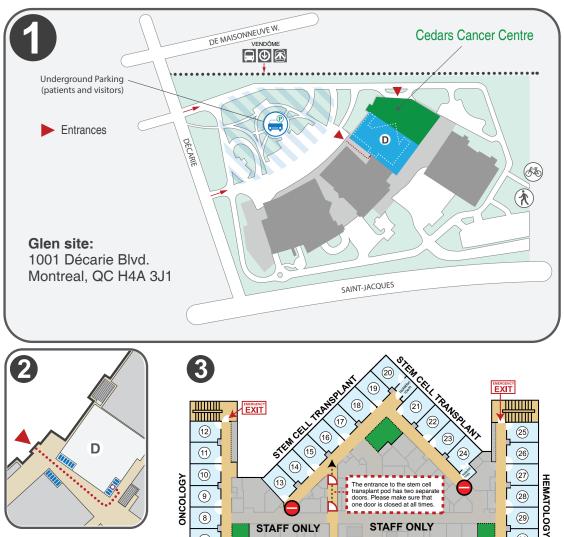
muhcpatienteducation.ca



Centre universitaire de santé McGill



Office d'éducation des patients Patient Education Office



Take the elevator to the 10th floor (D10)

Elevator

會情

Patient room

Nursing station

DO NOT ENTER

Public washroom

This area is for staff only.

STAFF ONLY  $\overline{7}$ \*11 (6) (5) (36) (4) (3) (2  $\left[1\right]$ Family room ONCOLOGY Patient resources Staircase EXIT **Emergency exit** EXIT Use only in the case of an emergency. If used for other

reasons, you will be locked out of the unit. Please use

the public elevators.

D10 ONCOLOGY, HEMATOLOGY & STEM CELL TRANSPLANT UNIT

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HEMATOLOGY

CanSupport welcome desk

35 34