

Allogeneic Bone Marrow Transplant

Information for patients and families



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Section 1

- Introduction
- What a bone marrow transplant involves
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Introduction

The bone marrow transplant team has written this booklet to help patients and families learn about bone marrow transplantation. Depending on the source of the cells used for the transplant, the procedure may be called a stem cell transplant or a bone marrow transplant. In this book, we refer to the procedure from either source as a bone marrow transplant or BMT.

As you read the book you may want to take notes or write down questions. There is a lot to learn about a BMT. Take your time and please ask us to clarify what you do not understand.

It can also be helpful to talk with others about BMT such as:

- your doctors
- your nurses
- other members of your health care team
- people who have already had a BMT
- the transplant coordinators, who can provide written materials

What kinds of bone marrow transplants are there?

There are 2 types of bone marrow transplants:

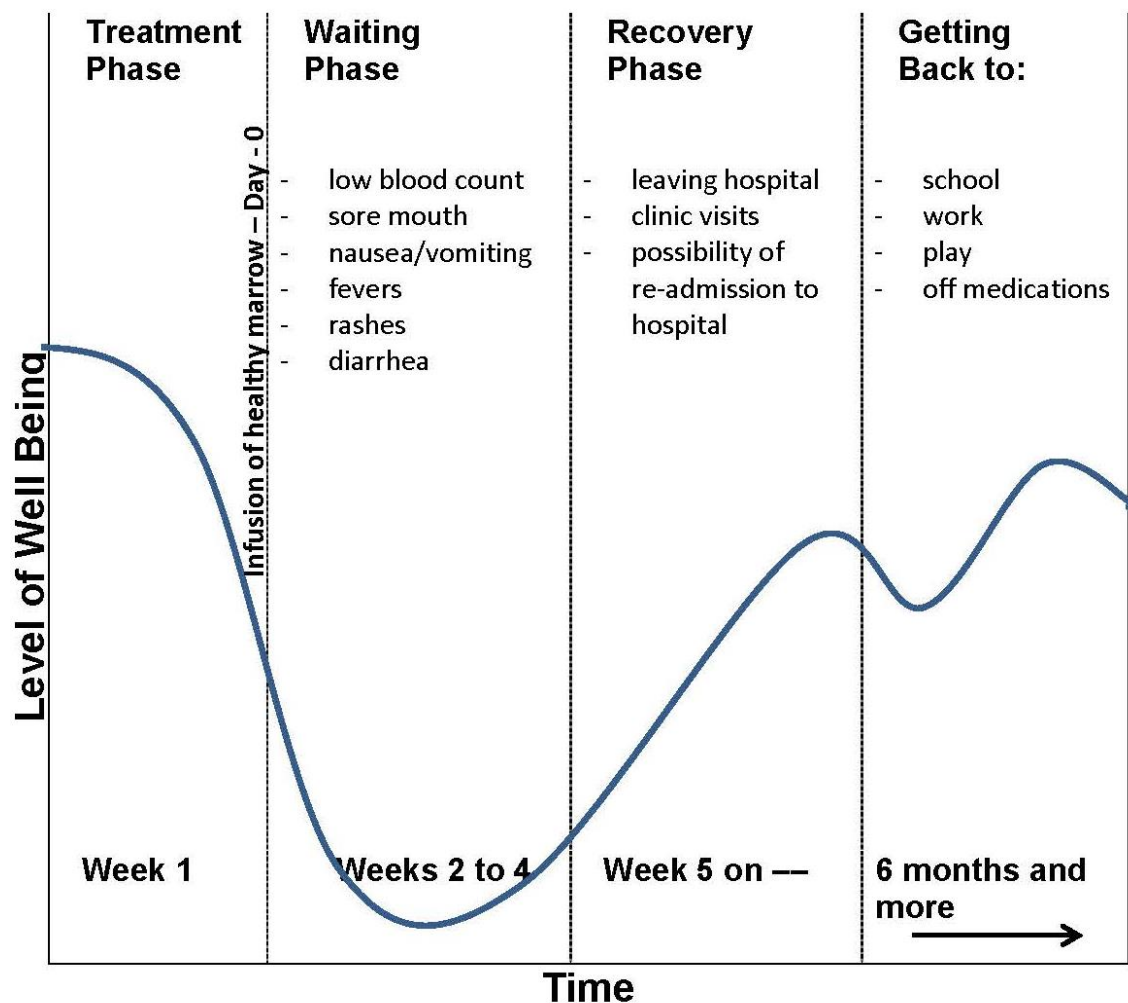
- **allogeneic** – where the bone marrow donor is another person. Stem cells from another person, the donor, are removed. These stem cells are given to the patient with the diseased marrow after they have been prepared to receive it. Special blood tests are done to make sure the donor's stem cells are compatible (matched) with the patient.
- **autologous** – where the patient's own bone marrow is used. Stem cells are removed from the patient and stored before they receive high dose chemotherapy or radiation treatment. After the treatment, their own stored stem cells are given back to them.

Depending on the type of disease and the patient's overall health, his or her doctor may recommend either an allogeneic or an autologous transplant.

This booklet is about the allogeneic type.

What is involved in a BMT?

- Treatment with high dose chemotherapy and radiation to destroy existing disease and prepare the patient's body for the transplant.
- The infusion or putting the healthy bone marrow cells (stem cells) from the donor into the patient's bloodstream.
- The wait for new bone marrow to grow and make healthy blood cells, which is called engraftment.
- Recovery and growth of new bone marrow.

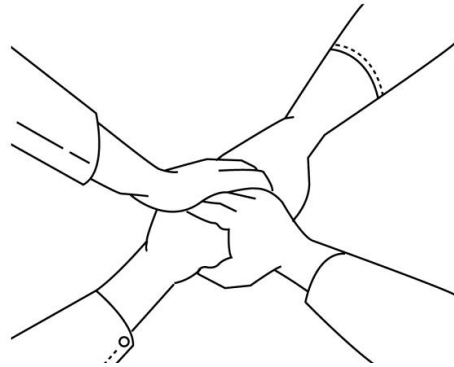


Physical and Psychological Well Being

The BMT Team

BMT team members include the patient and:

- allogeneic transplant nurse coordinators
- doctor
- nurse practitioners
- nurses
- dietitian
- pharmacists
- social workers
- chaplains
- physiotherapists
- the patient's support system: family and friends



These are the people on the BMT team who will be caring for the patient before, during and after transplant.

Other medical specialists (doctors) may become part of the BMT team if they are needed. These doctors may include a lung, kidney, infectious disease or skin specialist.

Section 2

Who can have a Allogeneic Bone Marrow Transplant

Who can have an allogeneic bone marrow transplant?

People with these life-threatening diseases of the blood system:

- Chronic Myeloid Leukemia, or CML
- Aplastic Anemia
- Myelodysplastic Syndrome, or MDS
- Acute Myeloid Leukemia, or AML
- Acute Lymphoid Leukemia, or ALL
- Types of Lymphoma
- Chronic Lymphocytic Leukemia, or CLL
- as research in the area of transplant advances, new diseases are being treated.



Are there other treatments for these diseases?

Yes, and they are different for each one.

Chronic Myeloid Leukemia (CML)

CML is a slow growing cancer of the bone marrow. It has three phases: chronic, accelerated and blast crisis.

The chronic phase is controlled with medications such as chemotherapy or targeted therapy. People with CML in this phase feel healthy. New treatments, called tyrosine kinase inhibitors (TKIs), keep most patients in the chronic phase and living normally. In a few patients, TKIs do not work well and transplantation may be needed. Progression to accelerated phase or blast crisis is very unusual these days. Patients mostly stay controlled on TKIs or have transplants before progression is allowed to happen.

In the accelerated phase, there are too many blasts or immature blood cells and this means the body cannot fight infections the way it normally would.

In the blast phase, the number of blasts or immature blood cells grows very rapidly and the symptoms become severe.

Aplastic Anemia

In Aplastic Anemia the bone marrow is attacked by the patient's own immune system and does not produce enough blood cells. It is an autoimmune disease (other examples of autoimmune diseases are systemic lupus erythematosus and hypothyroidism). Therefore, Aplastic Anemia is often treated with immunosuppressive treatment to hold back the body's immune system.

Aplastic Anemia can be moderate or severe. Severe Aplastic Anemia may be treated with a bone marrow transplant after considering factors such as: a patient's overall health, age and the severity of the disease. Aplastic Anemia is not a cancer.

Myelodysplastic Syndrome (MDS)

In Myelodysplastic Syndrome the body's bone marrow slows down or stops working. Depending on how severe the MDS is, it may be treated with blood transfusion support or medications to help control it. The doctor may advise a bone marrow transplant depending on the patient's age, overall health, type of MDS, and other risk factors found in blood and bone marrow tests.

Acute Myeloid Leukemia (AML) and Acute Lymphoid Leukemia (ALL)

People with AML or ALL are treated with high doses of chemotherapy until the leukemia goes into remission. Remission means that tests cannot find any leukemia cells and a patient is symptom-free. This is called induction chemotherapy.

Consolidation chemotherapy is given after a person is in remission to eliminate any diseased cells that may be left. Leukemia may recur after remission. This is called a relapse. If the disease relapses, different chemotherapy or different doses may be considered.

Transplantation is recommended either at the time of remission if tests at the time of diagnosis show a high risk of relapse or after relapse occurs, but only after the patient is once again in remission after another course of chemotherapy.

ALL is a fast growing cancer of a type of white blood cells called lymphocytes. The diseased lymphocytes do not fight infections very well and they grow quickly. This growth crowds out the bone marrow so it cannot make enough of the other blood cells, such as red blood cells, white blood cells and platelets that the body needs.

AML is a fast growing cancer of the blood and bone marrow where the blast cell or immature white blood cells do not develop properly. They grow quickly and crowd out the healthy cells such as white blood cells, red blood cells and platelets in the bone marrow.

For some patients with ALL and AML, chemotherapy alone will result in long term remission. Some patients may not be able to complete the chemotherapy treatment program or may have higher risk factors for the disease to relapse. Risk factors include looking at changes in the chromosomes of the leukemia cells. Some changes can predict a lower or a higher risk of the disease relapsing. For these patients chemotherapy alone may not be enough and a bone marrow transplant may be considered. Your doctor will discuss which category your disease falls in.

Lymphoma

Lymphoma is a cancer of one type of white blood cells called lymphocytes. There are many different types of lymphoma depending on what type of lymphocyte is affected and how aggressive the disease is. Management ranges from watchful waiting when the disease is slow growing to treatments such as chemotherapy, radiation, immunotherapy, or a combination of these.

Some types of lymphoma are treated by autologous bone marrow transplant and some by allogeneic bone marrow transplant. Bone marrow transplant is often considered if chemotherapy is not effective or if the disease returns.

Chronic Lymphocytic Leukemia (CLL)

CLL is a slow growing cancer of the lymphocytes, a type of white blood cell. Lymphocytes help your body fight infections. In CLL, the lymphocytes do not work properly so the body does not fight infections as well as it should. The diseased cells can crowd out healthy cells such as white blood cells, red blood cells and platelets in the bone marrow. A patient may live years without any treatment needed before problems arise.

Treatment may include targeted therapies or chemotherapy. If these treatments do not work well, bone marrow transplant may become a treatment option. Management for CLL ranges from “watchful waiting” if the disease is mild to chemotherapy or other medications, such as targeted therapies, once symptoms appear. It may be years before symptoms appear and further treatment is needed. If these treatments do not work very well for a patient, bone marrow transplantation may be considered.

Multiple Myeloma

Multiple Myeloma is a disease when the plasma cells in the bone marrow crowd out the normal blood cells in the bone marrow. When transplantation is used in this disease it is often the autologous type of transplant.

There are risks involved with any treatment. Bone marrow transplant can cause life-threatening problems, which may cause death.

Every patient is unique. The transplant doctor will consider a patient’s diagnosis, disease status, the risk of the disease relapsing, the patient’s overall health, and other factors unique to each patient before recommending a bone marrow transplant.

Section 3



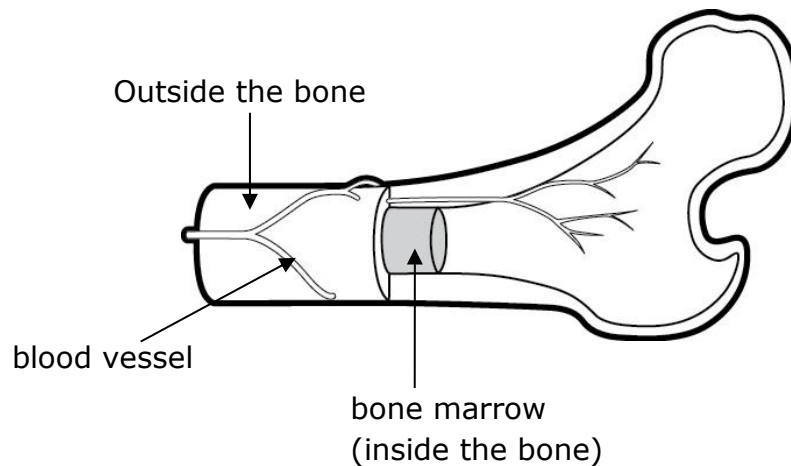
Common questions about
Bone Marrow Transplants

What does bone marrow contain?

Bone marrow is the soft blood forming tissue inside the bones. The job of the bone marrow is to make blood cells. The bone marrow has a rich supply of stem cells.

The bone marrow contains:

- red blood cells, which carry oxygen
- white blood cells, some of which fight infection and others make up the immune system
- platelets, which prevent bleeding



How does a bone marrow transplant work?

A healthy bone marrow is needed to live. A diseased bone marrow does not work well. A bone marrow transplant involves putting a healthy donor's blood-forming cells called **hematopoietic stem cells** into a patient's bloodstream. The patient receives these cells through a vein (intravenous, or IV), very similar to getting a blood transfusion. The stem cells find their way to the bone marrow; they won't settle in other parts of the body.

The diseased bone marrow is destroyed with high doses of chemotherapy or a combination of chemotherapy and radiation. The diseased bone marrow is then replaced with healthy bone marrow from a donor.

The immune system in the healthy bone marrow fights any remaining disease that was not destroyed by the radiation and chemotherapy. This is known as the graft vs disease effect.

What are stem cells?

Stem cell is a term used for cells in the body that can grow into more specialized cells. There are different types of stem cells based on what kind of cells they will grow into. **Hematopoietic stem cells** are cells found in the bone marrow that produce the blood cells found in your body. When we mention "stem cells", this is the type of stem cell we are talking about.

There are 2 ways of obtaining **hematopoietic stem cells**, either directly from the bone marrow or from the blood.

Stem cells found in the bone marrow are called **Bone Marrow Stem Cells**.

Stem cells found in the blood are called **Peripheral Blood Stem Cells**. Both of these develop in the bone marrow.

Transplants from either source can be referred to as Bone Marrow Transplants because this is where the transplanted cells from the donor will grow. The doctor will recommend which source of cells is best for the bone marrow transplant based on factors such as disease status, overall health and donor considerations.

How is healthy bone marrow collected?

The bone marrow is collected from the donor's pelvic (hip) bone. There is a small operation for the bone marrow donor. The bone marrow donor has a general anesthetic in an operating room. A small amount of their bone marrow is taken out of the hip bones by needles. The anesthetic lasts about 1 hour and there are no stitches. The bone marrow is collected into bags.

For the donor:

There is some discomfort in the back of the hip. The donor is often sitting up and walking around on the same day their bone marrow was taken.

Pain medicine, which is non-prescription can be bought at any drug store, can be taken to control the discomfort. Pain medicine is not usually needed after 2 days. Sometimes, donors have mild discomfort lasting a few weeks.

The donor usually goes home several hours after the procedure or the next morning and is back at work within a few days. The amount of bone marrow taken is small. New bone marrow will grow back in a few weeks.

For the patient:

The bone marrow is given to the patient through an IV, in a way that is similar to getting a blood transfusion.

How are stem cells found in the blood collected?

There are normally a few stem cells in the blood. Giving a hormone-like medication called a growth factor to the donor causes the stem cells to grow faster and move from the bone marrow into the blood so that they can be collected.

The stem cell collection:

The donor receives injections of a growth factor called GCSF (also called Neupogen or filgrastim) for a few days to stimulate their bone marrow to produce extra stem cells.

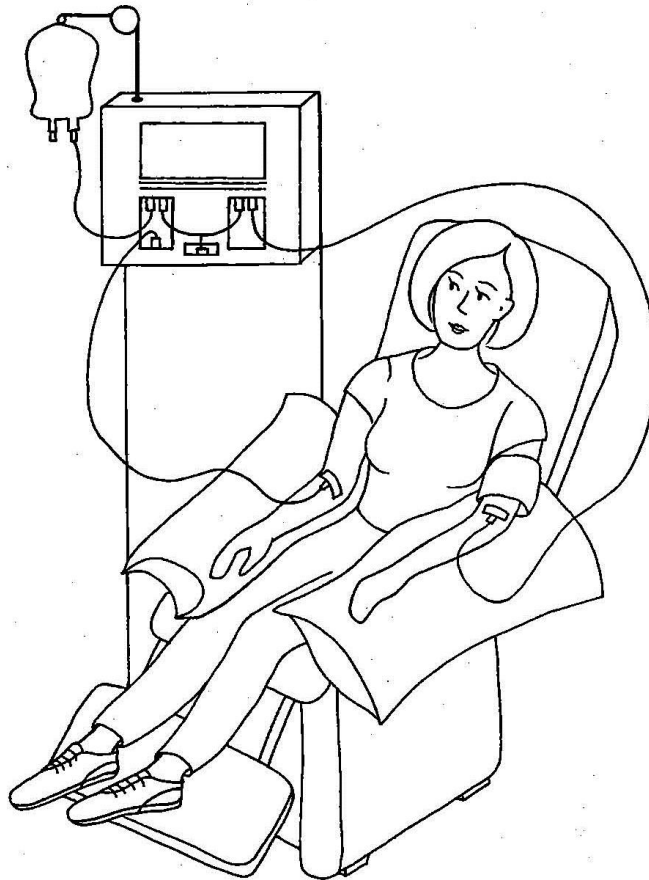


When donors are given injections of GCSF the stem cells leave the bone marrow and are found, temporarily, in large amounts in the bloodstream. These stem cells can then be collected. The stem cells are collected into bags by using a machine called a cell separator or apheresis machine.

This machine separates the stem cells from the rest of the blood, which is given back to the donor during this procedure. This procedure is called leukapheresis and lasts several hours. One or two collections (the latter over 2 days) may be needed to collect enough cells for a transplant.

For the donor:

There can be some discomfort or bone pain from the GCSF injections. The donor does not have to be admitted to the hospital for this procedure. It is done in an outpatient clinic.



For the patient:

The stem cells are then given to the patient in a process that is like a blood transfusion. Usually after this type of bone marrow transplant, the recovery of the bone marrow is slightly faster than when a traditional bone marrow is used. Recovery of blood cells is often within 2 to 4 weeks.

What is a Reduced Intensity Transplant?

Chemotherapy, medications, radiation therapy, or a combination of these treatments are given to prepare the patient for the transplant. When the traditional preparation for transplant is used, we refer to the transplant as a **Full Transplant** or a **Myeloblastic Transplant**.

This preparation both reduces the amount of leukemia and suppresses the immune system so the body accepts the new marrow.

In some cases, the transplant doctor recommends less intense preparation and this type of transplant is called a **Reduced Intensity Transplant** or a **Non-Myeloblastic Transplant**. This type of transplant is sometimes considered for patients who cannot have the stronger chemotherapy due to age or health concerns. This type of transplant has different risks and benefits and is not used for all the types of diseases treated with the full transplant.

The Reduced Intensity Transplant (Non-Myeloblastic Transplant) is usually done as an outpatient with frequent visits to Oncology Day Services rather than being admitted to the hospital.

Why can a BMT be dangerous?

There are 3 main reasons why a BMT is dangerous:

- Radiation and chemotherapy will harm your normal tissues such as the intestines, kidneys, liver and the lungs. Usually, this is temporary but it can be severe and life-threatening.
- The new immune system does not work very well during the first few months after bone marrow transplant. This can result in infections.
- The immune system in the new bone marrow recognizes that it is in a new body and can react against it. This is called **graft-versus-host disease**. This is often referred to as GVHD.

What is graft-versus-host disease (GVHD)?

GVHD is the donor's immune system reacting against the patient.

During the BMT the immune system, which is part of the bone marrow, is destroyed. The patient's immune system is replaced by the immune system of the donor.

The patient's body rarely rejects the donor's bone marrow because the patient's own immune system has been destroyed or suppressed. However, the donor's immune system, which is the bone marrow, can react against the patient's body. This reaction is called graft-versus-host disease (GVHD).

Drugs are used to control GVHD. Sometimes these drugs cause problems such as infections, nausea and high blood pressure. In most cases these problems do not last very long. Until the patient's tissues heal and the immune system adjusts, problems can occur.

GVHD can also help. It can kill leukemia cells which have survived the radiation and chemotherapy. This is called graft versus leukemia effect. Patients who have GVHD are often at higher risk of infection.

Why would GVHD happen if a donor is a perfect match?

The only really perfect match is when the donor is an identical twin. In this case, GVHD never happens. However, we can lose the benefits of the graft versus leukemia effect, as well.

We test the blood for certain **Human Leukocyte Antigens (HLA)** or markers on the white blood cells. The patient's immune system uses these HLA markers to know which cells in the body belong and which do not. Each person has many HLA markers that makes their white blood cells unique. We know that matching certain who would HLA markers is critical to make a transplant successful.

Everyone has many HLA markers. Half are inherited from your mother and half from your father, so each brother and sister who has the same parents have a 25% chance of matching you. Some HLA types are more common than others. Some HLA types are found more often in some ethnic groups. This is why some patients face a greater challenge in finding a matched donor.

Even when the donor is a brother or sister, GVHD can happen. This happens because there are some other HLA markers that we cannot test for.

Even when the donor is fully matched (on the HLA markers that we test for), but is not related, these unknown HLA markers may be even less matched. GVHD may occur and may be more severe in transplants from unrelated donors.

What are the chances of getting GVHD?

GVHD usually occurs in all patients to some degree. The severity of GVHD depends on many factors such as the type of disease treated, the age of the patient and the type of the transplant.

What happens when GVHD occurs?

Sometimes GVHD causes only a temporary skin rash or a mild effect on the liver. When the liver is affected, blood tests are abnormal and skin may turn yellow (jaundice). Symptoms are not always present when the liver is affected. GVHD can also cause diarrhea nausea and/or vomiting. GVHD can range from mild to severe.

There are 2 classifications of GVHD: acute and chronic. **Acute GVHD** occurs in the first 100 days after transplant and usually affects the skin, stomach, intestines and/or liver. **Chronic GVHD** usually occurs 3 to 6 months after transplant, but can be later.

In most cases GVHD can be controlled with medications. In time it can go away as the new immune system learns about its new body. Sometimes, GVHD can be severe and life-threatening. The immune system may not work well to fight infections like pneumonia. Infection is a potential problem that we watch for very carefully.

There is some good news in all this. The graft-versus-host reaction is also killing leukemia or lymphoma cells which might have survived the chemotherapy and radiation (remember, the graft versus leukemia/lymphoma effect). Leukemia or lymphoma can recur after transplant, but the risk is lower in patients who experience GVHD. Ideally, what we want is a bit of GVHD, which we can control, but not too much.

What are the chances of cure with a BMT?

The chance of cure depends on many factors unique to each patient such as:

- the type of disease
- the stage of disease
- the type of donor
- the patient's age
- the patient's general health status

What about waiting to do a BMT until it is really needed?

In some cases waiting reduces the chances of success. A BMT cannot be done once the disease is not controlled. It is best if the patient discusses their unique situation and possible options with the transplant doctor.

Why might a BMT fail?

Reasons include:

- infection
- organ damage
- severe graft-versus-host disease (GVHD)
- disease relapse

Who would be the best donor?

The typing that is done is called “HLA tissue typing”. We test the blood for certain **human leukocyte antigens (HLA)** or markers on the white blood cells. We know that matching certain HLA markers is critical to make a transplant successful. This is not the same as blood typing. You can be a different blood type and still match for these HLA markers.

The best donor is a sibling, that is a brother or sister. A sibling has the best chance of being a matched donor. Half of each person’s HLA markers are inherited from their mother and half from their father. So each brother and sister who has the same parents have a 25% chance of matching. Family members, other than full siblings, do not have a high chance of being a matched donor. This is why we do not complete HLA testing on these family members.

If there are no suitable family donors, then an unrelated donor can sometimes be found. Some HLA types are more common than others. Some HLA types are found more often in some ethnic groups. This is why some patients face a greater challenge in finding a matched donor. The BMT Coordinator will work with the Unrelated Donor Registry, One Match Stem Cell, OneMatch Stem Cell and Marrow Network, to search for a matched donor. Finding an unrelated donor may take several weeks or longer.

If there are no family donors available or in the registry, a partially matched transplant may be considered. This is known as a **Haploidentical Transplant**. In this case, a relative such as a parent, child, brother, or sister who half matches the HLA type is the donor. The risk of complications is higher with this type of transplant when compared to a well-matched donor. Researchers are investigating ways to decrease this risk.

In some centres, cord blood stem cell transplants are offered as an alternative choice to haploidentical transplants, for those without matched related or unrelated donors. Cord blood stem cells are available through OneMatch.

What does finding the best HLA tissue typing involve?

HLA tissue typing involves a blood test. For the person having the test, it means giving a blood sample. However, it is a complex test for a laboratory to do and an appointment has to be made. Sometimes, you may need to give blood a second time.



Some siblings who might be able to be BMT donors live far away. We attempt to contact them to arrange to have their blood samples shipped to our hospital for HLA typing.



If this is not possible, we sometimes have the HLA typing done where they live and have the results sent to us. However, as this is a very specialized test, there may be very few hospitals where the blood test can be done.

How long will it be before patients go home and return to work or school?

The time varies, but on average:

- A hospital stay will be about 6 weeks for patients having a Myeloblastic Transplant (full transplant).
- Non-Myeloblastic Transplants (less intense chemotherapy given to prepare for the BMT) are usually done as an outpatient. These patients are not admitted to the hospital. Patients come to the hospital every day during the transplant.
- After either type of transplant there are visits to Oncology Day Services in the Juravinski Hospital. These visits vary from 3 times a week to once every 2 weeks up until about 100 days after a BMT. Sometimes the patient may have to be admitted into the hospital because of infections or graft-versus-host disease.
- After about 100 days after transplant, if everything is going well, some of the medicines are stopped and the doses for other medications may be decreased. Check-up appointments may be at the Juravinski Cancer Centre (JCC).

- Sometimes patients are ready to go back to work or school 4 to 5 months after their BMT. More often, it can be a year or longer before returning to work.
- It will take at least one year to return to a normal life after your BMT. Sometimes it may even take longer to get back to normal routines.
- Transplantation is for a cure. What the patient's level of health will be afterwards is unfortunately difficult to predict. It is possible to be perfectly normal, but in some cases the price for cure is a lower level of health.



Section 4

- As a patient receiving a Bone Marrow Transplant
 - from start to finish

As a patient, please tell me about Bone Marrow Transplant – from start to finish

Once you have made the decision to have a BMT and there is a donor, this is what usually happens:

Getting started

- Your doctor will have referred you and sent your health records to the bone marrow transplant team.
- You will meet the nurse transplant coordinator, social worker and doctor to discuss BMT.
- You will attend an information session about BMT. You can invite your family and friends to this session. There are usually several members of a family and/or close friends present. This meeting will last for 1 or 2 hours.
- If your preparation for transplant includes radiation, arrangements will be made for a meeting with the doctor who supervises the radiation. During this visit you will find out about the radiation treatment and have measurements taken of your body. You may be shown the room where this treatment is done and the radiation machine.
- You will have an appointment with a doctor (Interventional Radiologist) who will put in a catheter. This is usually done about a week before you start your chemotherapy to prepare for transplant. The catheter is removed around 100 days after treatment.

The catheter is a thin tube surgically placed into a large vein, often on your chest. It is often called a Hickman Catheter. Local freezing is used when it is put in. The catheter will be used to give you blood, fluids, medication and the bone marrow or stem cells for the transplant. It may be used to take blood samples. It is recommended that you do not work once the catheter is put in place.

- Appointments will be made for tests such as chest x-ray, heart tests, breathing tests and an CT scan.
- A bone marrow biopsy is done before your BMT. This will usually be done in the outpatient clinic.

- You may have an appointment to see the nurse practitioner.
- You will have an appointment to see a doctor who specializes in infections before the transplant.
- If you are female, you will see our gynecologist.
- If you are male, you may want to consider sperm banking. Please speak to your BMT doctor or nurse about this.
- You will be given a schedule from the transplant coordinators that will list all your appointments and where they are located.

Ways to prepare yourself

- Read this book, there are more resources on pages 41 to 45. Talk it over with family and friends and your doctor. Bring your questions to your appointments, ask us to clarify information that you do not understand. Make sure that your friends and relatives know what to expect. If you wish, we will arrange for you to meet someone who has already had a BMT.
- Talk with your children. They may want to come to the information session. It is helpful to tell their school teacher what is happening.
- Take care of any financial or legal items.
- Exercise and keep fit.
- Have a dental check. Please talk with your BMT doctor before you see your dentist.
- Get your weight back to normal if you have lost any. If you need help about your diet, ask to speak with our dietitian.



The focus during transplant should be on your recovery.

To help you be comfortable, we have given you some information on:

- relaxation techniques
- family support
- financial information
- personal things to bring to hospital

Relaxation techniques

Other people who have had a BMT have found relaxation techniques helpful. You may want to practice these techniques before you come into the hospital.

Relaxation techniques include:

- breathing exercises
- visualization tools

They can help you during the time you are isolated in your room and during treatments. We can provide you with resources if you would like.

Family support

The emotional support of your family and friends during your bone marrow transplant is very important. They will need a place to stay if you are in the hospital.

The social worker with the BMT team can give you information about places to stay and their costs.

If you are having a full or a myeloblastic transplant: During your transplant, you will be in the hospital for at least 6 weeks. You will be in a private room and it is important for you to be as comfortable as possible.

If you are having a non-myeloblastic transplant: You will come to the Oncology Day Services as an outpatient. You come in for treatment and then go home. During this time patients are advised to avoid crowded areas and people with infections.

Financial information

Financial assistance information before, during and after your BMT could come from the:

- Canadian Cancer Society in your hometown
- Canada Unemployment Office about your unemployment insurance benefits
- benefit clerk at your work regarding your Canada Pension and long term disability benefits

The social workers have financial information that may help you and your family assist with travel and hotel costs. There may be tax deductions available for you. Please talk with the social workers to find out more. You may want to meet with a Pharmacy Technician regarding drug benefits.

For more information, see the handout “[Applying for financial benefits – money concerns and cancer](#)”. You can find this handout by going to the Hamilton Health Sciences website, under Patient Education Library, and enter the keyword “benefits”.

Full or a myeloblastic transplant: bring into the hospital

Some of the things you may want to bring from home include:

- pictures of your family and friends
- a device to listen to music
- a PC device such as a laptop , iPOD, or tablet (WiFi is available for a charge)
- televisions and phones are available in the rooms for a charge
- books or talking books
- crafts, puzzles, cards and games
- posters
- your own pillow, quilt or comforter (please wash them first)
- comfortable clothing and shoes
- pajamas, robe, slippers
- clothes for when you go home

Non-myeloblastic transplant: while at home

Some of the things you may want to have easy access to at home include:

- a device to listen to music
- a PC device such as a laptop computer or tablet
- books or talking books
- crafts, puzzles, cards and games
- your own clean pillow, quilt or comforter
- comfortable clothing and shoes

Before the transplant:

- For about a week before the transplant day, chemotherapy and possibly radiation are given to prepare you for the transplant:
 - **For full or myeloblastic transplants:** you are in the hospital during this time.
 - **For reduced intensity or non-myeloblastic transplants:** you receive chemotherapy every day in Oncology Day Services. **You are not in the hospital.**
- Chemotherapy is given through your catheter into your vein each day to prepare you for the transplant. Usually, you will not feel anything during the infusion. You may lose your appetite and may have nausea and vomiting. There are medicines to help you with this.
- Some of the preparations for transplant include radiation, but not all of them. At the time you receive radiation, you may not feel anything different. After the radiation you may have a small amount of nausea for a few hours.



If you are having a full or myeloblastic transplant with radiation:

After the last radiation treatment you go into isolation in the hospital. What this means is that you will stay in your own room with the door closed until engraftment. **Engraftment** is when the new blood-forming cells start to grow and the healthy blood stem cells show up in the blood.

There is a bathroom and shower inside. Two visitors at a time are welcome. Anyone entering the room will wash their hands before coming in. Items taken into the room need to be cleaned first. No fresh flowers or plants are allowed in this room.

The transplant

- The bone marrow or stem cells will come in bags and look much like blood for a transfusion. The bone marrow or stem cells are given through the catheter into the vein. It takes about an hour for the stem cells to be given, about 3 to 4 hours for bone marrow.
- A nurse will check your temperature, blood pressure, and pulse often while the bone marrow or stem cells are going in. Usually, you will not feel any different. Most patients feel either thrilled or relieved that it has finally happened.
- We call the day you receive the stem cell or bone marrow **Day 0** and every day after is called “day plus 1, day plus 2, and so on”.

After your transplant

- During the next 2 to 3 weeks we will be waiting for the donated bone marrow to grow. This is called engraftment. **Engraftment** is when the new blood-forming cells start to grow and the healthy blood stem cells show up in your blood. It is an important milestone in your transplant journey.
- Your own bone marrow and blood cells will disappear. This means that you may need blood transfusions to keep your blood counts up.

Packed red blood cells may be given to maintain your red blood cell count. These cells carry oxygen.

Platelet transfusions may be given to raise your platelet count. Platelets prevent bleeding. You may need platelets every day.
- It is not possible to give transfusions of white blood cells. These cells prevent infections. You may develop a fever, which is a sign of infection. Antibiotics are given when you have a fever. There are some medications used to decrease the chances of severe graft-versus-host disease such as:
 - methotrexate, a mild chemotherapy drug given through a vein (IV)
 - cyclosporine, an anti-rejection drug taken by mouth
 - Cellcept (mycophenolate), an anti-rejection drug taken by mouth

Which medications you receive depend on the type of transplant. For patients receiving a non-myeloblastic transplant, the nurse practitioner will meet with them before the transplant date and review the medications that will be taken at home.

While you are waiting for bone marrow to grow, you may feel or have some of these symptoms:

- sore mouth
- heart burn
- stomach pains
- lack of appetite, nausea and vomiting
- diarrhea
- sore anus or bum
- skin rash
- fever
- loss of hair
- loss of energy
- yellow jaundice

Side effects or problems vary after a BMT depending on the type of transplant, the disease being treated, your general health and the treatment given to prepare for the transplant. There are medications which can control most problems. Please talk with your transplant team about any discomfort you have.

Full or myeloblative transplant: hospital

While I am in hospital waiting for my new bone marrow to grow, will I be able to:

- eat?
- use the bathroom/shower?
- have visitors?
- exercise or move around in my room?

Eating

You may be able to eat some of the time. It is important to get good nutrition during and after the transplant. A dietitian will be keeping track of what you are eating. If you do not feel like eating, a small flexible tube will be placed through your nose and into the stomach. Food will be put through this tube for you. Even if you have this tube, it is still important for you to try to eat. You may bring food from home if you wish. Information on food safety at home will be given at the family meeting.

You will be weighed often, so we can make sure you are not losing too much weight or retaining too much fluid.



Bathroom

You will have your own bathroom.
You will need to shower every day.



Visitors

Yes, you can have visitors as long as they are healthy. Anyone with an infection should not visit. Visitors will be asked to wash their hands before coming into your room. Please have any visitors check with the nurses if they have any concerns. Young children must be cleared by the team before visiting.



Exercise

You can walk around your room. You should exercise every day. We can put an exercise bike in your room if you wish. Exercise will keep your muscles strong and help in your recovery. A physiotherapist is part of the transplant team.



While in your room

You will be hooked up to one or more IV's and pumps most of the time while you are in the hospital.

You will need to stay in your room until your new bone marrow grows.

Sometimes serious problems happen. You may have to go to the Intensive Care Unit. This can be hard for both you and your family. The transplant team will see you every day. The staff in the Intensive Care Unit know how to care for people who have had transplants. Any extra tests and procedures needed will be explained before they are done.

When will I be able to go home from the hospital?

The usual time to go home is 4 to 5 weeks after your BMT. This is about 6 weeks after coming to the hospital.

To be able to go home, the following needs to have happened:

- engraftment (new blood forming cells growing)
- be eating more than 1000 calories a day
- be drinking 2 liters of fluid a day
- be able to walk around the unit
- be taking medication by mouth
- have symptoms of GVHD controlled
- be without or have no evidence of infection

Before leaving hospital, you will be give some information about what will happen when you are at home and what to look out for.

All of these are outlined in the “Going Home Book”. You will receive this booklet before you go home.

Non-myeloablative transplants

While you are waiting for your new bone marrow to grow it is best to:

- Avoid crowded areas.
- Avoid people with infections.
- Wear a procedure “face” mask when away from home.

You will need to:

- Shower everyday.
- Eat nutritious foods. You will be weighed during your appointments at Oncology Day Services and Juravinski Cancer Centre.

How will I know when my new bone marrow is growing?

A bone marrow test is not done right away and in most cases is never needed.

We will know that the bone marrow is growing by your blood cell count.

These counts will show that your white blood cells, red blood cells and platelets are rising. You will need blood transfusions less often as your blood counts rise.

After Non-myeloablative transplants new marrow takes time to “takeover”.

There is a special blood test for patients after a non-myeloablative transplants to show when the new marrow is growing. This blood test is called chimerism and shows how many of the blood cells are made by the new marrow.

Chimerism is a state in bone marrow transplantation in which bone marrow and host cells exist compatibly without signs of graft-versus-host rejection disease.

What about graft-versus-host disease (GVHD)?

Around the time that we expect your new bone marrow to grow, we will be looking for signs of graft-versus-host disease (GVHD).

The first sign of GVHD is usually a rash. Sometimes we need to decide whether a rash is from GVHD or an allergy to a medicine. We may ask for the help of a skin doctor who may want to do a small skin biopsy. A skin biopsy involves taking a small piece of skin to examine under a microscope.

Symptoms of GVHD include:

- skin rash
- yellowness of skin or eyes if the liver is affected
- pain on the right side of the stomach near the ribs, if the liver is affected
- diarrhea, stomach cramps, nausea and/or vomiting if the intestine is affected

During each clinic visit, blood tests are done to see how the liver is working. It may be necessary to have other tests to confirm that you have GVHD. This may involve a biopsy of the liver or other organ.

GVHD is treated with medications, called immunosuppressants or steroids, that suppress the donor immune system. Some examples of these include: cyclosporine, mycophenolate, sirolimus and prednisone. It is important that you do not stop medications without letting your doctor know. If you cannot take them for any reason, inform your doctor. If you cannot swallow your medications, you may need to take them by IV for a while.

After your transplant:

- Until day 100, you will need to wear a procedure “face” mask when outside of your home environment. As well, you will be advised to avoid crowded areas and people with infections.
- You will have frequent check-ups for at least 3 months (about day 100) after transplant in Oncology Day Services. These visits usually start off from 2 to 3 times a week and will gradually decrease to less often. After about 100 days, the visits may be moved to the Juravinski Cancer Centre (JCC). We encourage you to have someone drive you to appointments. If this is not possible, please contact The Canadian Cancer Society (www.cancer.ca) about their Volunteer Driver Program.
- You will be watched very closely for GVHD and for infections. We will be checking for lung infections and pneumonia.
- Sometimes you may have to be admitted back into the hospital because of infections or GVHD.
- If you come into contact with someone with chicken pox, let us know right away.
- Oncology Day Service and clinic visits always involve blood tests. This will be done in either Oncology Day Services or in the JCC Outpatient Lab one hour before your clinic appointment.
- There is a BMT support group. This group can help you and your family by talking about your concerns with other people who have been through a BMT.
- You will be taught to care for your catheter. Arrangements will be made for a visiting nurse to help care for your catheter at home. Dressings need to be changed at least every week.
- You will need to watch for these symptoms: fever, cough and skin rash.

**If you have these symptoms or any other questions or concerns,
please refer to your contact information sheet.
You will receive the handout “Going Home after Transplant”
with more detailed information.**

We are here to help!

Recovering after a BMT is often slow. You may become frustrated with what may seem like a lack of getting back to your normal life. It is not uncommon to have problems in coping with your emotions and the physical and social changes that may occur during the months after transplant.

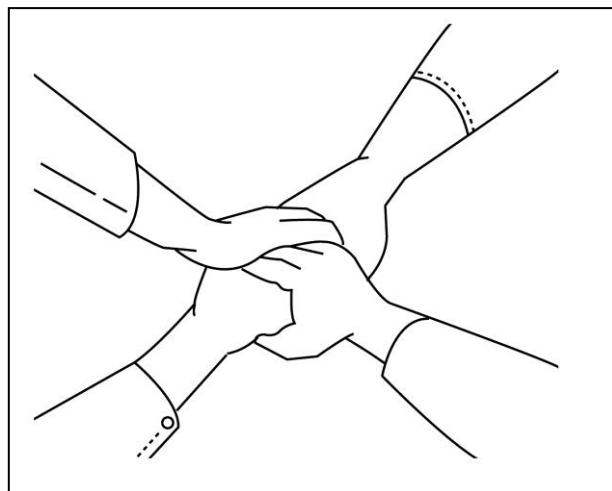
Many people find that the Bone Marrow Transplant Support Group is helpful. Others may find that they need additional support getting through the recovery phase. We understand that this may be a difficult time for you and your family.

Do not be afraid to ask for help.

Your decision to have a BMT is not an easy one. If we did not believe that a bone marrow transplant was a worthwhile treatment for you, we would not be offering it to you. We believe it provides the best hope for a future for you, free of your disease.

Once you have made the decision to have a bone marrow transplant, it is best to have a positive attitude. You will find the BMT Team upbeat and helpful in keeping a positive outlook.

All of us are here working together for you and your family. Our goal is to have you return to a normal, healthy lifestyle. The BMT Team hopes to see you cured, working and enjoying life to its fullest!



Resources

Community resources

To find out if the following resources are available in your area, check your local phone book.

Financial support

Canada Pension Plan/Disability Insurance

1-800-277-9914

www.servicecanada.gc.ca/eng/isp/cpp/cpptoc.shtml

- Must have enough Canada Pension Plan contributions and have a severe and prolonged disability.

Department of Veteran's Affairs

905-572-2531 or 1-866-522-2122

www.veterans.gc.ca/eng/

- Provides financial assistance for home maintenance to eligible veterans.

Ontario Disability Support Program

1-905-521-7280

www.mcass.gov.on.ca/en/mcass/programs/social/odsp/

- Provincially funded income assistance program for people with low incomes.

Trillium Drug Plan

1-800-575-5386

http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx

- Provides assistance to eligible individuals and families who spend a large portion of their income on prescription drugs.

Information services

Bone marrow Information Online

www.bmtinfonet.org/

Canadian Cancer Society (Ontario)

www.cancer.ca

Brant	519-753-2566
Cambridge	519-623-7144
Halton	905-332-0060
Hamilton.....	905-575-9220
Kitchener-Waterloo	519-886-8888
Niagara	905-356-3151
Norfolk	905-426-3953
Wellington	519-824-4261

Cancer Information Services

1-888-939-3333

- Confidential, dependable information about cancer, from around the world.

Patient and Family Resource Centre

www.jcc.hhsc.ca/

Juravinski Cancer Centre (Level 1, main lobby)

- 905-387-9495, ext. 65109

Wellwood

www.wellwood.on.ca/

- 905-389-5884 (hospital location)
- 905-667-8870 (community location)
- Provides various programs including a computer resource for information needs of cancer patients

Personal support

Trillium Drug Plan

1-800-575-5386

http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx

- Provides assistance to eligible individuals and families who spend a large portion of their income on prescription drugs.

Cancer Assistance Program

www.cancerassist.ca

905-383-9797

- Provides respite care and baby-sitting services to Hamilton patients.

Canadian Cancer Society

www.cancer.ca

905-383-9797

- See information services for out-of-town branches.
- Provides numerous supports including: Peer Support Groups, Transportation, Wig & Turban Service (905-575-9220) and Lakeview Lodge.
- Information on available support services is at the information desk at the Cancer Clinic or by calling the Cancer Society.

Hamilton Niagara Haldimand Brant Local Health Integrated Network, HNHB LHIN (Formerly CCAC)

www.hnhblhin.on.ca/

1-800-810-0000

- Provides a single point access to information, coordinated health care and support services.

Brantford	519-759-7752
Haldimand-Norfolk.....	905-426-7400
Halton.....	905-639-5228
Niagara.....	905-684-9441
Waterloo.....	519-883-2110
Wellington, Dufferin, Guelph.....	519-823-2550

The “Grocer-Ease” Program

www.grocerease.org/

905-545-1175

- Provides grocery shopping assistance for a minimal fee.

Homemaking Services

- See the yellow pages of the telephone book.

Look Good Feel Better

www.lgfb.com/

905-575-9220

- Free program that teaches techniques to help cancer patients with such things as makeup application, use of scarves and wigs. Sponsored by the cosmetics industry.

Meals-on-Wheels

www.von.ca/en/home/default.aspx

905-522-1022

- Provide a hot, nutritious mid-day meal. Funded privately.

Nursing Services

- See the yellow pages of the telephone book.

Wellwood

www.wellwood.ca

905-389-5884 (hospital location)

905-667-8870 (community location)

- Provides various programs including a computer resource for information needs of cancer patients.
- Wellwood has two locations, both of which are open to you for free programs. The hospital location is on the first floor (near the west elevators) of the Juravinski Hospital. The community location is at 501 Sanatorium Road (where Rice meets Sanatorium), near Chedoke Hospital. The community site has free parking.

Spiritual support

Chaplaincy Services

905-527-4322

- Provided by the Chaplain at the Juravinski Hospital, ext. 44259.

Hospital Chapel

- Visiting hours: The chapel is open 24 hours a day and is located in the 60 Wing of the Juravinski Hospital.

Equipment support

Cancer Assistance Program

905-383-9797

www.cancerassist.ca/

- Provides equipment to Hamilton patients. In some cases may also help out-of-town patients.

Canadian Cancer Society

www.cancer.ca

- For equipment, see the Information Services section for Canadian Cancer Society telephone listings.

Canadian Red Cross Home Equipment Service Loan Program

www.redcross.ca/

905-522-8485

- Rents sick room equipment for a fee.

Getting to the Juravinski Hospital and Cancer Centre, 699 Concession Street, Hamilton, Ontario

From St. Catharines

Take the QEW to the Centennial Parkway/Red Hill Valley Parkway exit.
Follow the sign for the Red Hill Valley Parkway exit.
The parkway becomes the Lincoln Alexander Parkway (LINC).
Exit onto Upper Gage. Turn right on Upper Gage and travel north to
Concession Street. Turn left on Concession Street. Travel several blocks.
The hospital and cancer centre are on the right.

From Cambridge

Take Hwy #52 to Hwy #403 and exit at the Lincoln Alexander Parkway (LINC).
Follow the LINC exit to Upper Wentworth Street.
Travel north on Upper Wentworth Street.
Turn right on Concession Street. The hospital and cancer centre are several
blocks up on Concession Street on the left.

From Brantford

Take Hwy #403 and exit at the Lincoln Alexander Parkway (LINC).
Follow the LINC exit to Upper Wentworth Street.
Travel north on Upper Wentworth Street.
Turn right on Concession Street. The hospital and cancer centre are several
blocks up on Concession Street on the left.

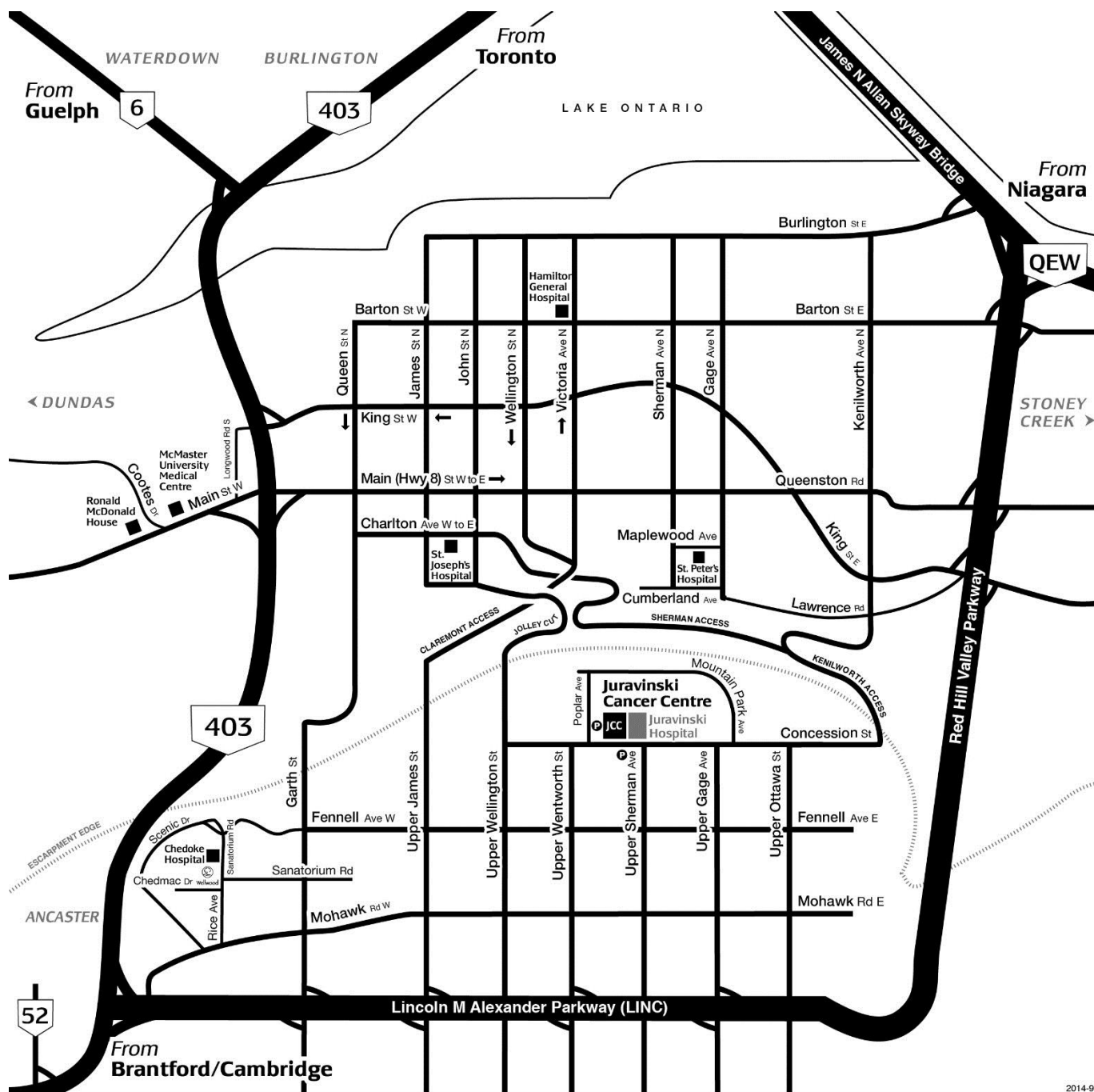
From Toronto

Take QEW to Hwy 403.
Exit onto the Lincoln Alexander Parkway (LINC).
Follow the LINC exit to Upper Wentworth Street.
Travel north on Upper Wentworth Street.
Turn right on Concession Street. The hospital and cancer centre are several
blocks up on Concession Street on the left.

From Guelph

Take Hwy #6 to Hwy #403.
Exit onto the Lincoln Alexander Parkway (LINC). Follow the LINC exit to Upper
Wentworth Street. Travel north on Upper Wentworth Street. Turn right on
Concession Street. The hospital and cancer centre are several blocks up on
Concession Street on the left.

Allogeneic Bone Marrow Transplant



2014-9

Important:

1. The Juravinski Hospital and Cancer Centre has 2 entrances. The Cancer Centre is **Entrance J** at 699 Concession St. and the Hospital is **Entrance A** at 711 Concession St.
2. Juravinski Innovation Tower (Charlton St.) and Juravinski Centre for Integrated Healthcare (West 5th) are part of St. Joseph's Healthcare and **not** related to the Juravinski Hospital and Cancer Centre.

Parking instructions

There are two parking lots near the Juravinski Hospital and Cancer Centre. One is on Concession Street right across from the hospital. The other is on Poplar Avenue right next door to the Cancer Centre.

How to contact a volunteer driver

The Canadian Cancer Society offers a transportation service to those who may have no other means of getting to cancer related appointments.

To see if you are eligible for this service call your local Canadian Cancer Society office or the Cancer Information Service at 1-888-939-3333.

There is a \$100.00 registration fee. Transportation is a busy service, so please give at least 2 full business days notice.

Transportation for specific service needs is often available through:

Canadian Cancer Society, Hamilton-Wentworth	905-575-9220
Cancer Assistance Program.....	905-383-9797
Red Cross Society (for medical appointments and day programs).....	905-522-8485
Victorian Order of Nurses (VON) (for medical appointments)	905-522-0053
Ancaster Community Services, Volunteer Driver Program	905-648-6675

Glossary

Allogenic Transplantation	A transplant in which the cells infused come from a donor.
Antibiotics	Medications used to fight bacterial infections.
Apheresis (pheresis)	A painless procedure by which your blood is withdrawn and circulated through a machine that removes the stem cells and then returns remaining cells back to your bloodstream.
Aspiration	To draw out the marrow by suction using a syringe.
Autologous Transplantation	A transplant in which the tissue infused comes from the individual receiving it.
Biopsy	Removal of small piece of tissue for microscopic examination.
Blood Counts	A routine test that determines the number of white blood cells, red blood cells and platelets in a sample of blood.
Bone Marrow	Spongy tissue inside the bones where the blood cells are produced.
Catheter (Hickman)	A small, flexible tube inserted into the chest through which drugs and fluids can be given; often called a Hickman catheter.
Chemotherapy	Anticancer drugs or combination of drugs designed to kill cancer cells.
Clinical trial	A carefully controlled and monitored research to test a new drug or therapy, involving human patients.
Engraftment	The process in which reinfused stem cells begin to grow in the bone marrow and make new blood cells.
Growth Factors	Natural substances that stimulate cells to divide and grow.

Hematologic	Relating to blood and blood forming tissues.
High-dose Chemotherapy	Higher than standard doses of anticancer drugs which is sometimes needed to destroy tumor cells.
Immuno-suppression	Suppression of the immune system.
Infusion	The introduction of a liquid into the body through a vein.
Neupogen (Filgrastim)	A colony stimulating factor given by injection which mobilizes stem cells from bone marrow into the bloodstream.
Peripheral Blood Stem Cell	A stem cell that has left the bone marrow and is circulating in the blood stream.
Platelets	Cells that are needed for blood to clot.
Red Blood Cells	Cells that pickup oxygen from the lungs and take it to tissues throughout the body.
Remission	Complete or partial disappearance of symptoms of a disease in response to treatment.
Stem cells	“Parent” cells in bone marrow from which all blood cells develop; also known as progenitor cells.
Stem Cell Collection (Harvest)	The process of taking stem cells out of the blood; see apheresis.
Subcutaneous Injection	Injection into the fatty layer under the skin.
Targeted therapies	A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells.
White Blood Cells (WBC)	The blood cells that fight infection.

