My health care team

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Non-myeloablative transplant
(Mini-transplant)
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Questions for my transplant doctor and clinic nurse

Write down your questions and bring this booklet with you to your first clinic appointment.
9. How is a potential donor tested for match?
A special blood test called HLA typing is arranged by the transplant coordinator at Hamilton Health Sciences. The blood sample can be taken at a specific lab near the donor and then sent to Hamilton Health Sciences for testing.

10. How can someone sign up to be donor?
They can go to OneMatch stem cell and bone marrow website www.onematch.ca to register and become a donor.

11. Are there any good websites where I can find information on non-myeloablative transplant?
As this type of transplant is still fairly new, little information is available online for patients. A doctor’s site with reliable information is the Center for International Blood and Marrow Transplant Research (CIBMTR) at www.cibmtr.org

A patient brochure called “Allogeneic Post-Transplant Patients’ Guide” is also available on this website, for patients transplanted with bone marrow or blood stem cells from a donor.

The Blood & Marrow Transplant Information Network website www.bmtinfonet.org is another good resource.

Any information from websites should be used as a reference only. Be sure to talk to your doctor about your own health condition.

There is a type of transplant called non-myeloablative transplant. It is often called a mini-transplant. Your doctor has referred you to our clinic at Hamilton Health Sciences to see if this type of transplant is right for you.

Reading this booklet will help you learn about a non-myeloablative transplant and what to expect of your clinic appointments. Please write down any notes or questions you may have to ask the doctor or nurse during your visit.

We recommend that you bring a family member or friend with you to listen and take notes.

Checklist before coming to the clinic

Please bring the following to your appointment:
- Drug coverage information
- A book or magazine to read while waiting
- Lunch or snacks
- Medications you need and the list of all medications you are taking

Plan some extra time to find a parking place. Do not schedule anything else on your appointment day.

Having drug coverage and staying close to the hospital are very important for a successful transplant. Please read the following information and discuss your concerns with us.
Drug coverage

After a non-myeloablative transplant, you will need to take several drugs for at least a year. You may have to take some drugs longer. These drugs are very expensive. You need to know how you plan on paying for them before your transplant.

If you are working you may have drug coverage with your health insurance benefits package, check with your employer about your benefits. If needed, you may wish to discuss drug coverage options with a social worker.

Ontario residents with private/third party coverage – please provide your insurer’s name contact information, your ID and the plan number. Also please review your plan to check the amount of coverage. Some plans have limits such as 80% coverage up to $20,000 for a lifetime.

Ontario residents without coverage – check to see if a Trillium Drug Program application will help with paying for the drugs.

The Trillium Program provides financial help to Ontario residents who have high drug costs. You may need to plan ahead to allow enough time to process your application.

Bring all of this information with you when you come to meet the transplant team.

6. What is involved in being a stem cell donor?
The stem cell donor receives needles of a natural substance called growth factor. The growth factor helps the bone marrow produce more stem cells than is normally needed in a short period of time.

Then, for 1 or 2 days (6 to 8 hours a day), the donor is hooked up to a special cell separating machine. Blood enters the machine from a vein in one arm and the returns to the donor through a different vein. The machine collects the stem cells and returns all other types of blood cells to the bloodstream.

Donating stem cells is simpler and involves less discomfort than donating bone marrow. The donor may feel a small amount of bone discomfort for a short time. Usually the donor returns to work or normal activities within a few days after donating.

7. Do potential donors have to be in good health?
The potential donor should be in good health and must be eligible as blood donors. Another doctor will check to see if they are eligible.

8. Can other family members such as half siblings, cousins, aunts and uncles be tested as my donor?
Other family members are welcome to sign up as donors if they are 35 years or younger through the Canadian Unrelated Registry called One Match Stem Cell and Marrow Network. However, they will not be specifically tested as your match. If they are not a full sibling, their chances of being a match are about the same as everyone else on the unrelated bone marrow registry.

When your family members sign up as donors, they will be entered into a donor database that is available for ALL patients. It does not necessarily increase your chance of finding a match.
Questions often asked by patients and families

This section provides answers to some common questions about non-myeloablative transplant. If you would like more information, write your questions down and discuss them with your doctor or clinic nurse.

1. How long do I have to wait to get an appointment at the clinic?
The clinic at Hamilton Health Sciences is busy place. We see patients from all over the region. You may have to wait a few weeks for your first appointment.

2. How long do clinic appointments take?
A clinic visit can take up to a whole day. Review the checklist in the "before coming to your appointment section of this booklet.

3. Can I come alone to my transplant?
We recommend you come with a family member or a friend. The non-myeloablative transplant treatment is long and complex you may need to be at Hamilton Health Sciences for 4 to 6 weeks. The whole course of treatment requires a great deal of support. Therefore, it is always helpful to have a family member or a friend come with you.

4. Where should I stay?
It is more convenient to stay close to Hamilton Health Sciences for your appointments. If needed, ask the nurse or social worker for some information about places to stay.

5. Why is the follow-up period so long after the transplant?
After your transplant, we carefully watch your health and the success of the treatment. Sometimes problems or complications happen. Your follow-up schedule is based on you and your response to the transplant. Usually, follow-up lasts 2 to 3 years, and sometimes even longer. Please refer to “Follow-up Care”.

Places to stay

You will have many hospital appointments for about 4 to 6 weeks at the time of your non-myeloablative transplant. During this time, staying close to Hamilton Health Sciences will make it easier to get to your appointments. Ask the nurse or social worker for the information about places to stay. Please keep in mind that this information provides options on where to stay. It is your responsibility to find, make arrangements and pay for where you stay.

Learning about non-myeloablative transplant or mini-transplant

What is a traditional transplant?
A traditional transplant uses stem cells from the donor's blood. The stem cell is the seed-like cell that normally produces all the cells in your blood (red blood cells, white blood cells, and platelets).

There are two types of transplants:
- Peripheral blood stem cell transplant
- A bone marrow transplant

In both types, the same stem cells are used, but they are found in different places of the body. With a traditional type of transplant high-dose chemotherapy, and sometimes radiation therapy are used. As a result, your immune system is destroyed, so your body does not reject the donor stem cells. Such high-dose chemotherapy can cause severe side effects and even death. These side effects can be worse for older patients and even some younger patients who have other medical problems.
What is a non-myeloablative transplant?
A non-myeloablative transplant is another type of transplant. The term mini-transplant is widely used, but it is misleading. The side effects can still be severe, can last for a long period of time, and can change your quality of life. For this reason, we only call it non-myeloablative transplant.

Less side effects allow treatment for older patients or very sick patients. With non-myeloablative transplant, chemotherapy and/or radiation therapy are used, but at much lower amounts.

The amount of chemotherapy and/or radiation given weakens your immune system. When you receive the donor’s stem cells, the donor’s immune system will kill the cancer cells in your body.

To decide if you want a non-myeloablative transplant is not an easy decision. You need to discuss the possible benefits and risks with your doctor.

What are the differences between a non-myeloablative transplant and a traditional transplant?
With non-myeloablative transplant:

- You may be admitted for a few days to the hospital, if you have several side effects
- More outpatient hospital visits care needed — may be several times a week during the first month
- You will need to buy certain drugs
- Less amounts of chemotherapy are used
- Older or very sick patients may have the option of a transplant
- There are fewer immediate side effects and is better tolerated
- Donor’s stem cells from blood (not from bone marrow) are used

Some side effects can last a long time, so follow-up care with clinic and doctor’s visits are usually needed for a while after the transplant.

After the transplant – follow-up care
After your transplant, we carefully watch your health and the success of the treatment. Sometimes problems or complications happen. The complications may include infections and graft-versus-host diseases (often called GVHD). GVHD is a complication that the donor’s immune system (the graft) reacts against the body of the transplant patient (the host).

Here is a general outline of follow-up care:

- Your first follow-up appointment is the day after the transplant
- The first month, you will be seen several times a week to check your blood count and see how you are feeling. Also, we will watch closely for signs of GVHD that may need treatment. Your drugs will be adjusted quite often. And you may have long days in the clinic for Intravenous fluids (IV).
- The second month and months after, your drugs may be reduced.
- In general, you will be checked closely for a year.
- For long-term follow up, depending on where you live, we may also provide shared-care with your doctor and clinic.

Your follow-up schedule is based on how you are doing. We want to see how the transplant worked, and prevent and treat any problems that may happen. Follow-up care generally lasts about 2 to 3 years, and sometimes even longer.

In case of complications
In our experience, nearly half of the patients need to be re-admitted to hospital to treat complications like GVHD and sometimes infections. These can usually be managed with medications.
Before your transplant, you will receive special medications to weaken your immune system. This lets your body accept the donor’s immune system more easily. It is important for you to take care of yourself and stay as healthy as you can by:

- Eating a healthy balanced diet
- Being physically active
- Getting enough rest
- Managing your stress. Talk to your social worker if you need help with stress management.

Day of transplant
The transplant itself is just like a blood transfusion. It takes about 2 hours. The stem cells are put through the tunnelled catheter in your chest. The stem cells find their own way to your bone marrow.

You do not need to fast or restrict your diet or any activity the day of transplant. Take your regular medications and follow the schedule given to you.

Drugs
Having non-myeloablative transplant is complex. You will need to take several drugs. They can help control the growth of the immune system and prevent infections. They may be needed for months or years. Please see information on Drug Coverage.

Who can have a non-myeloablative transplant?
A non-myeloablative transplant may be done to treat several types of cancer of the blood cells. It does not work for fast growing cancers. This is because of the way a non-myeloablative transplant works – it works by using the donor’s immune system; it usually works more slowly than standard chemotherapy.

The donor stem cells take time to get used to your body while they learn to attack your cancer cells. It is also important that the cancer is slowly growing and not highly resistant to treatment. A non-myeloablative transplant is not done as a first treatment. It is used for patients who did not respond to previous treatments, or not as well as expected.

Do stem cell donors need to be related?
– How do I find a match?
Stem cell donors may be related or unrelated to you.

- Related donors must be full siblings – brother or sister with both the same mother and same father. The chance of a matching related donor is 1 in 4 for each brother and sister tested, no matter how many are tested.
- If no siblings are a match, an International Donor Registry can be searched for an unrelated donor. The registry contains over 29 million donors. The chance of finding an unrelated matching donor depends on your ethnic origin. A match is not always found.

Is there research being done?
Non-myeloablative transplant method of treatment is always being researched. This type of research, called clinical trials, involves many different aspects of a non-myeloablative transplant. Hamilton Health Sciences is a part of many Canadian and international clinical trials. Depending on currently available trials and your personal situation, your physician may discuss your suitability and interest in being part of a trial with you.
Non-myeloblastic transplant (mini-transplant)

What to expect at the Transplant Clinic
It is not easy to have a non-myeloablative transplant. Being well prepared helps.
The information in this section will help you understand what you can expect:
✓ Before the transplant
✓ Day of the transplant
✓ After the transplant – follow-up care

Finding a matching donor
Your referring doctor may have asked you if you have any full brothers or sisters and if they are interested in being tested as a donor. A transplant nurse coordinator will arrange for a special blood test to check for a donor match. Your transplant doctor will let you know the test results when they are ready. It could take a few weeks.

If a matching related donor is not found, the coordinator searches an International Donor Registry for a match. If a donor match is found, it will take at least 2 months to do the special blood test and to confirm the match. Depending on the donor’s availability, sometimes it takes 3 to 4 months to get the transplant arranged.

Please do not call for the blood test results. These will be discussed at your next clinic visit after the results are available.
Canadian privacy legislation does not allow us to give out this information over the phone.

Your appointment
The clinic at Hamilton Health Sciences is a busy place. We see patients from all over the region. You may have to wait a few weeks for your first appointment. The visit can take up to a whole day if you need blood work and transfusions.

What to bring
✓ Information on your drug coverage
✓ Book or magazine to read while waiting
✓ Lunch or snacks
✓ Medications you need and a list of the medications that you are currently taking.

Preparing for the transplant
To decide if you are a candidate for a non-myeloablative transplant, several tests may be needed:
✓ a bone marrow test
✓ an ultrasound and CAT scan
✓ heart and lungs test

To start the transplant, a tunnelled catheter is inserted.
A tunnelled catheter is a long thin tube that goes under the skin in your chest area into large vein. This is done in the X-ray Department.

Any other chemo lines or ports must be removed before the transplant.
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 ✓ For long-term follow up, depending on where you live, we may also provide shared-care with your doctor and clinic.

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In case of complications
In our experience, nearly half of the patients need to be re-admitted to hospital to treat complications like GVHD and sometimes infections. These can usually be managed with medications.
Questions often asked by patients and families

This section provides answers to some common questions about non-myeloablative transplant. If you would like more information, write your questions down and discuss them with your doctor or clinic nurse.

1. How long do I have to wait to get an appointment at the clinic?
   The clinic at Hamilton Health Sciences is busy place. We see patients from all over the region. You may have to wait a few weeks for your first appointment.

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   A clinic visit can take up to a whole day. Review the checklist in the "before coming to your appointment section of this booklet.

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   We recommend you come with a family member or a friend.
   The non-myeloablative transplant treatment is long and complex you may need to be at Hamilton Health Sciences for 4 to 6 weeks.
   The whole course of treatment requires a great deal of support.
   Therefore, it is always helpful to have a family member or a friend come with you.

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   It is more convenient to stay close to Hamilton Health Sciences for your appointments. If needed, ask the nurse or social worker for some information about places to stay.

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Places to stay

You will have many hospital appointments for about 4 to 6 weeks at the time of your non-myeloablative transplant. During this time, staying close to Hamilton Health Sciences will make it easier to get to your appointments. Ask the nurse or social worker for the information about places to stay. Please keep in mind that this information provides options on where to stay. It is your responsibility to find, make arrangements and pay for where you stay.

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Questions for my transplant doctor and clinic nurse
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My health care team

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Non-myeloablative transplant
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