For out-patients (staying at home) with multiple myeloma, lymphoma, and other disorders

Read this guide to learn:

- What an autologous stem cell transplant is
- If an autologous stem cell transplant is right for you
- How an autologous stem cell transplant works
- How to prepare for your stay in hospital
- What to expect during your autologous stem cell transplant
- What to expect during your recovery

For more information on how to get to the hospital, services and resources, and places for your family and friends to stay near the hospital, visit:

- [www.theprincessmargaret.ca](http://www.theprincessmargaret.ca) for the Princess Margaret Cancer Centre
  Click on “Patients & Families”, then click on “Guide to Princess Margaret”.

- [wwwuhn.ca](http://wwwuhn.ca) for Toronto General Hospital
  Click on “Maps & Directions” at the top of the page for directions to the hospital.
  Click on “Patients & Families” for hospital services, resources and places to stay.
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Important phone numbers

**Transplant Coordinators**
Available Monday to Friday, 9:00 am – 5:00 pm

Myeloma, Amyloidosis, and other Plasma Cell Disorders
Andrew Winter
Phone: 416-946-4583

Myeloma, Amyloidosis, and other Plasma Cell Disorders
Allyson Mayo
Phone: 416-946-2985

Lymphoma, Germ Cell Cancer, and Acute Leukemia
Denise Turvey
Phone: 416-946-4689

**Transplant Office**
Location: The Princess Margaret Cancer Centre, 5th Floor
Phone: 416-946-4501, extension 5082

**Out-patient Transplant Day Hospital**
Location: The Princess Margaret Cancer Centre, 14th Floor, Room 627
Phone: 416-946-6555

**In-patient Transplant Ward**
Location: The Princess Margaret Cancer Centre, 14th Floor (14C)
Phone: 416-946-2011

Apheresis Unit
Location: Toronto General Hospital, Gerrard Wing 2nd Floor
Phone: 416-340-399

Write down and keep track of all your appointment dates and times in:
“Princess Margaret BMT Program Pre-Transplant Guide”
For urgent questions or problems for patients followed in the Out-patient Transplant Day Hospital only:

- During the day (7:30 am – 7:30 pm, every day) call: 416-946-6555
- During the night (7:30 pm – 7:30 am, every day) call: 416-946-2011
Understand what an autologous stem cell transplant is

What are stem cells?

Stem cells are found in your bone marrow (spongy tissue inside your bones). Stem cells can form different blood cells, like:

- red blood cells
- white blood cells
- platelets
- and make more stem cells

What are autologous stem cells?

Autologous stem cells are your own healthy stem cells that have been collected and cryopreserved (frozen).

What is an autologous stem cell transplant?

Autologous stem cell transplant is used to treat people who have different cancers, such as Multiple Myeloma and Lymphoma. Other non-cancer diseases such as Amyloidosis may also benefit from transplant.

- In order to destroy as much of your cancer as possible, a very high dose of chemotherapy treatment called “high-dose chemotherapy” is given.

- This chemotherapy will also destroy your bone marrow where you make blood cells.

- Since you cannot live without blood cells, the high-dose chemotherapy must be followed by an infusion (giving you back through an intravenous, also known as “IV”) of your own stem cells.

- This infusion of your stem cells is called an “autologous stem cell transplant”. This will allow your bone marrow to grow back, and start making blood cells again.

- The infusion of stem cells is called a stem cell “rescue”, since it is rescuing your normal bone marrow from dying. Without the autologous stem cell transplant, patients would not be able to get high-dose chemotherapy to treat their cancer.
How an autologous stem cell transplant works

There are 9 major steps involved in getting a transplant. More details about each step will be given in the rest of this booklet.

Step 1: Know if a transplant is right for you, and plan for the transplant.

Your cancer and overall health are checked to see if an autologous stem cell transplant is the right treatment for you. You will need to do some basic tests and procedures as part of this assessment. Your health care team needs to know if your cancer is under control, how much of it is still there, and if your body can handle the transplant.

Your health care team at the Princess Margaret includes:

- your transplant doctor (hematologist)
- nurse practitioners
- specialized transplant clinic and in-patient nurses
- transplant coordinators
- administrative assistants
- training doctors (called residents or fellows)

Your health care team will also assess if you should stay in hospital during the transplant (in-patient transplant), or if you can stay at home and visit the Out-patient Day Hospital daily after the transplant (out-patient transplant).

This information booklet will discuss the steps for an in-patient transplant.

Step 2: Stem Cell Mobilization

Moving your stem cells into your bloodstream is called “mobilization”.

- Your healthy stem cells need to be collected and cryopreserved (frozen) before you can get high-dose chemotherapy.

- Since stem cells live in your bone marrow and they are collected from your bloodstream, you will need treatment to move your stem cells from your bone marrow into your bloodstream. This process of “stem cell mobilization” uses a drug called Filgrastim (Neupogen®), with or without chemotherapy.
• The chemotherapy works together with the Neupogen® to make stem cells move into your bloodstream. For most patients, both chemotherapy and Filgrastim (Neupogen®) are used for mobilization. In a few cases Neupogen® alone is used.

• Your health care team will let you know what will be used in your case.

Step 3: Collect your stem cells

Your stem cells will be collected by a process called “apheresis”. During this process:

• Your blood is run through an intravenous (IV) line into the apheresis machine where the stem cells are removed from your blood and collected. The rest of your blood is then returned to your bloodstream.

• The apheresis machine is similar to the machine used by patients with kidney disease who have their blood cleaned by dialysis. Once the stem cells are collected by apheresis, they are cryopreserved (frozen) until you are ready for the transplant.

Step 4: Get a Hickman line put in

When you are ready to have your transplant, you will need a Hickman line. This is a special intravenous (IV) line that is put into one of the large veins under the collar bone or in your neck.

The Hickman line is used by the nurses to:

• take blood samples during your transplant.
• give you high-dose chemotherapy and infuse your stem cells.
• give you transfusions of blood and platelets, extra fluid and supplements, and antibiotics (medicine that fights infection).

Step 5: Start your transplant

After the Hickman line is put in, you will be registered with the Out-patient Transplant Day Hospital to start your transplant. This is where you will be seen for daily assessments during your transplant. You will start off with a visit to the Day Hospital where the transplant nurses or doctors will give you a tour and orient you to the day by day steps involved in an Out-patient Transplant.
Step 6: During your transplant

Every day during your transplant, you will be assessed by the nurses, nurse practitioners, and doctors. They will assess your blood levels, what side effects you may be feeling, and whether you need any:

- transfusions
- replacement of any fluids and electrolytes (minerals) your body needs
- antibiotics (medicine that fights infection)
- tests to check for infections

Otherwise, you can rest or sleep, have visitors, and even go out for walks and other activities.

Step 7: Get your high-dose chemotherapy

Once you start your daily visits to the Out-patient Day Hospital, you will be scheduled to get high-dose chemotherapy to destroy your cancer and bone marrow. This chemotherapy will be given in the Out-patient Day Hospital.

The chemotherapy you get may be given in one dose or in many doses over several days, depending on what your health care team decides. You will get extra medications to help prevent nausea and vomiting from chemotherapy and intravenous (IV) fluids to help flush the chemotherapy out of your system.

Step 8: Infuse stem cells (get your stem cell transplant)

After getting your high-dose chemotherapy, you will need to wait 1-2 days before having your stem cells infused into your bloodstream. This stem cell infusion is the actual “stem cell transplant” part of your treatment and will be booked on a separate visit.

By waiting at least 1-2 days after the chemotherapy, your body will have time to flush out the chemotherapy drugs before infusing the stem cells into the bloodstream.

The stem cells are infused through your Hickman line, very much like a blood transfusion.
Step 9: Follow up

You will be seen in the Day Hospital for about 16-20 days. After your transplant is done and your blood counts are better, you will continue to be seen in the Out-patient Transplant Day Hospital but you will not need to be seen daily.

The same doctors and nurses who were taking care of you during the transplant will be seeing you, but they will now see you in the “Post-transplant clinic.”

During the first few weeks, your health care team is still concerned with your blood counts getting better. They want to make sure that you get enough fluid, and can help stop any side effects you may still have from the transplant.

Once these early issues are taken care of, you will be seen back in your usual clinic. You and your transplant doctor will talk about plans for your ongoing care.
Know if a transplant is right for you

You will do an assessment to help you and your health care team to decide if an autologous stem cell transplant is right for you. Your visit to get assessed can last a long time, so be prepared.

What should you bring with you to your assessment?

- Health card (OHIP card)
- All the medications you are taking at the moment, including:
  - prescribed medications
  - over-the-counter medications
  - alternative medications and supplements
  - bring any medications you may need to take that day
- A pen and paper, or a notebook to take notes with
- Snacks and drinks
- A family member or friend for support

What will happen during the assessment?

During your assessment, your health care team will:

- Review your health history and medications.

- Give you a survey that helps them assess how well you are dealing with the stress and symptoms (signs) of your cancer.

- Assess whether an in-patient or out-patient transplant is best for you.

- Plan for you to do some tests or procedures. You may need more tests and procedures, or to repeat some to make sure a transplant is right for you.
Tell you about medications you will need later on. Some of these medications can cost a lot of money. If you have private insurance, you can check to see if they are covered. These medications can include:

- anti-nausea medication to prevent throwing up
  (Ondansetron or Zofran®, Dexamethasone or Decadron®, Aprepitant or Emend®, Prochlorperazine or Stemetil®)
- antibiotic medication to prevent infection
- growth factors to stimulate your stem cells (Filgrastim or Neupogen®)

**Will all your tests and procedures be at the Princess Margaret?**

Not all of your tests and procedures will be at the Princess Margaret. Your health care team will let you know where each test and procedure will be done.

- Many of the tests may be done at Toronto General or Toronto Western hospitals. All 3 hospitals are part of the University Health Network.
- Some tests will also be done at Mount Sinai Hospital, which is next door to the Princess Margaret.

Information shared between hospitals and clinics can move slowly. Your health care team at the Princess Margaret will try its best to stay up-to-date with your overall care. You can help them by keeping notes of the tests, procedures and care you may get at other hospitals.

Write down information like:

- Chemotherapy drug names and treatment dates
- Any imaging you get done (x-rays, MRIs and other scans)
- Names and amounts of any medication you are taking (such as prescribed, over-the-counter and alternative medicine)

Bring your notes with you to all clinic appointments because this information is very useful to your health care team.

**What are some tests and procedures you may have to do?**

Below are some common tests and procedures patients are asked to do. Your health care team will tell you which ones you may need to do, and book the appointments for you. We will notify you by phone, mail or both. Write down the dates and times in your Pre-Transplant guide, “Tests and Procedures” section on page.
Heart scan (MUGA or Multi-Gated Acquisition scan) also called an “RNA test”

A MUGA (Multi-Gated Acquisition) scan is used to look at how well your heart is working:

- The scan will take 90 minutes and involves getting a small amount of radioactive tracer put into a vein.
- The tracer is picked up by an x-ray camera and creates a recording of your heart beating.
- You may be asked to do light exercises during the scan.

To prepare for the test:

- Avoid food and drinks with caffeine in them for 24 hours before the scan.
- Do not eat or drink at all for 2 hours before the scan.
- Wear comfortable clothes and shoes.

Lung tests (pulmonary function tests)

A pulmonary function test is used to:

- Look at how well your lungs are working. Smoking and some chemotherapy drugs can affect your lungs.

- The test will take one hour and involves having you take deep breaths and blowing into tubes for different periods of time.

- This will measure how well your lungs work and how well they take in oxygen.

- If your lungs do not work well, you may be at a higher risk for complications from high-dose chemotherapy or infection during the transplant, which your health care team can then plan for.

- You can eat and drink normally before this test.

Echocardiogram

An echocardiogram is an ultrasound of your heart and is used to:

- Look at how your heart is beating by looking at the different parts of your heart.

- Tests to assess the response of your cancer before stem cell transplant.

- This test will take 40 to 60 minutes and involves a gel being spread over your chest. You may feel a slight pressure as the ultrasound tool is rubbed over the gel.

- Not everyone needs this test. Your doctor may suggest you take it.
• The response of your cancer to treatment before the transplant is very important in helping predict how well the transplant will work and how much you will benefit from it.

• Test to assess response may include CT scans, magnetic resonance scans (MRI), PET (positron emission tomography) scan, special blood and urine tests, and a bone marrow biopsy. The choice of these tests will depend on where your cancer was before starting treatment.

Transmissible disease testing

All transplant patients are checked for transmissible infectious diseases (infections that can be passed to other people through contact with blood). You will have these tests done within 30 days of your stem cell collection. There are 2 reasons for this testing:

1) Even if you got it a long time ago, infectious diseases (such as hepatitis) can cause problems during the transplant while your immune system is weakened.
2) Stem cells from patients with transmissible diseases have special storage needs.

You can still have your transplant even if these tests show you have a transmissible disease. But, your transplant may be delayed if the disease(s) need treatment, or if you need to see a specialist. By law, we also need to report some of these positive tests to the Public Health department.

Some of the diseases we test for are:
• Hepatitis B
• Hepatitis C
• Human immunodeficiency virus (HIV)
• Syphilis
• West Nile Virus

Mouth and dental care

Proper mouth and dental care can help prevent any infection that may delay your transplant or cause problems during your transplant. Some important dental care includes:

• Teeth cleaning
• Cavity fillings if needed
• Review of your mouth and dental cleaning habits
• Removal of infected or damaged teeth—this may be needed before your transplant if the dentist thinks there is a high risk of infection
Every transplant patient must be checked by the Dental Clinic at the Princess Margaret. If dental work is needed before your transplant, you have some choices:

- The dental specialist at the Princess Margaret can do the dental work. The Dental Clinic at the Princess Margaret knows the long-term effects of your cancer and treatment on your teeth. You must have at least one dental check at the Princess Margaret.

- You can choose to have the dental check done by your own dentist, if you prefer. The Dental Clinic at the Princess Margaret can advise your dentist on the work you need.

- OHIP (Government of Ontario) only pays for dental extractions (pulling teeth). You will have to pay for the dental assessment, and other dental work that needs to be done. If you have any concerns about the cost of dental work, make sure you discuss it with the Dental Clinic when you arrive.
Make a decision about the transplant

After your first visit and after any tests, your health care team will help you decide if an autologous stem cell transplant is the right treatment for you.

If you and your health care team agree that a transplant is right for you:

• Your transplant coordinator will plan an Orientation for you. It may be on the same day as one of your visits with your transplant physician, or it may be on a different day.

If you and your health care team do not think an autologous stem cell transplant is right for you:

• Your Princess Margaret doctor will discuss other treatment options with you.

What will happen during your Orientation Appointment?

Your transplant coordinator will:

• Explain the full stem cell mobilization and collection process in detail. This includes what to expect and what you need to do to prepare. The details are also described in this guide.

• Ask you to sign consent forms showing that you agree to have the transplant and get blood transfusions, if needed. The consent forms will also show that someone talked to you about the risks and benefits of transplant.

• Explain any other tests and procedures you need to do to get ready for the transplant. Most of these tests will be at a University Health Network hospital.

• Assess whether an in-patient (staying in the hospital) or out-patient (staying at home) transplant is best for you.

Why is an Out-patient Transplant best for you?

Getting your transplant as an out-patient allows you to:

• stay in the comfort of your own home,
• sleep in your own bed,
• eat your usual foods,
• and have your loved ones close by during this stressful time.

Patients at home are less likely to develop infections related to the hospital and do not have to wait for a hospital bed to open to start the transplant.
To have your transplant from home (out-patient), you must:

- Not have serious medical problems (such as being on dialysis) that may need for you to be in hospital during your transplant.
- Have a 24-hour caregiver. This is someone or many people, usually family or friends, who can stay with you overnight and for most of the day to help you with things like making dinner and buying groceries.
- Have someone to drive you in every day to the Out-patient Transplant Day Hospital at the Princess Margaret. Ask your transplant coordinator for information about caregiver responsibilities.
- Live close enough to the Princess Margaret to drive in about 45 minutes or less. If you live farther away but do not want to stay in hospital, we can arrange for you to stay at the Princess Margaret Lodge. Please ask your transplant coordinator about this.

What other information does your Princess Margaret health care team need to know?

- Any issues or problems during treatment, like treatment delays or if you get admitted to another hospital.
- Big personal events (like family weddings or trips) that might happen at the same time as any tests, procedures or the transplant.
- Any other issues that may affect your care, such as:
  - money
  - housing
  - drug coverage issues
  - family matters

Let your health care team know of any changes, or of any information that can affect your treatment during the transplant process. This will let you be more involved in your care and will help your health care team better understand your needs.
Once you and your Princess Margaret doctor have decided that an out-patient autologous stem cell transplant is the best choice for your treatment, some planning and preparation are needed.

Ask yourself some questions, and if you are not sure of the answers, speak with your transplant coordinator (contact information is on page 11).

Some questions to ask yourself include:

1. Do I know how my prescriptions are paid for, and if all my drugs are covered?
2. If I cannot work for a long period of time, how will I deal with financial issues?
3. If I have people dependent on me (children, pets, parents, and other family), what support can I get to help care for them while I am going through my transplant?

Planning for these concerns, sooner instead of later, can help reduce stress levels. The solutions to some of these concerns take time to organize, and are best not left to the last minute.
Get your stem cells mobilized

To prepare for your autologous stem cell transplant, you will need to get your stem cells mobilized. Stem cell mobilization moves your stem cells from your bone marrow into your bloodstream so they can be collected from your vein and be used for your autologous stem cell transplant. Your stem cells will be given back after getting high-dose chemotherapy to speed the recovery of your blood counts.

Stem cell mobilization will involve:

- Getting mobilization chemotherapy, if needed.
- Taking Neupogen® injections.
- Taking other medications to prevent nausea, vomiting, and to reduce the risk of infection.

During stem cell mobilization and collection, you will keep taking your normal medications to deal with other health issues, such as medications for:

- high blood pressure
- diabetes
- cholesterol
- pain

You will need to stop medications that are treating your cancer (such as chemotherapy) during this process. But, you may be asked to continue with medications to prevent infection with viruses or bacteria (antivirals and antibiotics) that you were taking during chemotherapy.

Your Princess Margaret health care team will tell you if and when you need to restart any medications. They will also let your community health care team know about this.

**Stem cell mobilization chemotherapy**

This is a chemotherapy treatment that most patients will need before starting Neupogen®.

- Some patients (like those with Myeloma) will get one chemotherapy drug called Cyclophosphamide.
- Some patients (like those with Lymphoma, testicular cancer) will get one or more different chemotherapy drugs for mobilization.
- Some patients (like those with Amyloidosis) will not get any chemotherapy at all, and will use only Neupogen® for mobilization.

Your health care team will let you know if you need mobilization chemotherapy or just Neupogen®.
**Neupogen® (also called Filgrastim or G-CSF)**

This is a medication that helps move stem cells out of the bone marrow and into the bloodstream. Neupogen® is injected (given by a needle) under the skin. You can give yourself the needle, or a family member, friend or homecare nurse can give you the needle.

Your transplant coordinator will talk to you about these options. You will need to get the needle every day until your stem cell collection is done. Your transplant team will let you know when to start getting the needles and when to stop.

**Getting your mobilization chemotherapy**

If you do not need mobilization chemotherapy, you can skip to “Take Neupogen® injections” on page 30.

**What are the possible side effects of mobilization chemotherapy?**

- Nausea and vomiting (remember to take your anti-nausea medication)
- Fatigue (feeling tired)
- Hair loss (prepare for this well in advance, see page 49 for more information)
- Low number of blood cells (blood cell count)
- Urine that is dark or the wrong colour
- Pain or burning when you urinate

**What happens during mobilization chemotherapy?**

You will need to come into the Princess Margaret to get your mobilization chemotherapy. Some patients may be able to get the chemo at the cancer centre that referred you to Princess Margaret...

**Day 1 (Chemo Day)**

What to bring with you:

- Health card
- Any medicines you may need to take during that day (like pain medication). You should also take your other, regular medications (like blood pressure, cholesterol pills).
- Your transplant schedule booklet
- A pen and paper or notebook for note taking
- Snacks and drinks
- A family member or friend for support
When and where to arrive:

See your Pre-Transplant Guide, “Mobilization chemotherapy” section. If you are getting this chemotherapy at the Princess Margaret you will be given a schedule with those appointment dates and times that you need to check in at the Systemic Therapy Unit on the 4th floor of the Princess Margaret.

You will be prescribed medication to be taken by mouth to prevent nausea and vomiting from the mobilization chemotherapy: these medications need to be taken one hour before your chemotherapy is scheduled to start.

During your mobilization chemotherapy:

• When your treatment is ready, a nurse will bring you back into the treatment area.

• The nurse will insert an intravenous (IV) line (given to you by a needle in your arm). You will get the mobilization chemotherapy through this line.

• You may get intravenous (IV) fluids for hydration.

• You may get medications to help with side effects through the intravenous (IV) line before and after the chemotherapy. The mobilization treatment can take from one to 4 hours, depending on the chemotherapy your cancer doctor decides to use.

• The chemotherapy may be given over one, 2 or 3 days.

• The details about how long each day will be, and the number of days, will be in the mobilization schedule.

• Some people feel light-headed or dizzy during mobilization chemotherapy. If this happens, let the nurse who is giving you the chemotherapy know. This feeling may last for the rest of the day.

For some patients, a medication called “Mesna” may be used after mobilization chemotherapy. Because some chemotherapy drugs pass out of the body in the urine, this medication will protect your bladder from the effects of chemotherapy. The nurse will give you Mesna to drink at home with orange juice or cola according to instructions.

What should I eat and drink during my mobilization chemotherapy?

• Drink lots of fluids and go to the bathroom often so your body can flush out the chemotherapy drug when its work is done. Aim for 8 cups or 2 litres a day (4 water bottles). Water, soup, ice cream, sherbet, puddings, milk, jello, popsicles, ginger ale, and juice are some examples of the fluids you can drink.
• Be careful with any alcohol intake. Alcohol and most drugs are removed from the body by the liver. Drinking alcohol while you are getting chemotherapy may affect your ability to produce blood cells and affect how your liver disposes of chemotherapy drugs.

• If you wish to have alcohol during mobilization, or before your transplant, talk to your transplant coordinator (contact information is on page 11).

**Taking Neupogen® injections**

Once you start taking your Neupogen® injections, you will need to take them every day until you finish your stem cell collection. Your health care team will let you know when to start and stop.

See your mobilization schedule, “Your Neupogen® injections” section for the start date. Your first injection will be given by a nurse at the Princess Margaret or your local cancer clinic, or your family doctor.

If you choose, you will be shown how to take Neupogen® injections yourself. A family member can also be shown how to give you the injections.

**What are the side effects of taking Neupogen injections?**

• Bone pain, especially in the lower back, legs, or even the breast bone
• Headaches
• Fatigue (feeling tired)
• Flu-like symptoms, like muscle aches or soreness or mild fever up to 38 °C or 101 °F
• Red or irritated skin where the needle was injected

Your health care team can prescribe pain-relief medication, if you are not already taking some.

**Do not take:** Tylenol® or any medication that contains aspirin (acetylsalicylic acid or ASA) or ibuprofen until a doctor or nurse says it is safe. Tylenol can cover up a fever which may be an early sign of infection, and aspirin can raise your risk of bleeding and bruising, especially if your platelets are low. You may take Tylenol for pain if your transplant team says it is OK.

If you are having trouble with any side effects, contact your transplant coordinator (contact information is on page 11).

These side effects should stop a few days after you stop taking Neupogen® injections. If you still have side effects a week or more after you stop taking the injections, tell your transplant coordinator.
**Where should I keep my Neupogen® injections?**
Always store your Neupogen® injections in the fridge until just before you use them.

**What if I am not comfortable giving the injections to myself, and my family is not comfortable giving me the injections?**
There are community health care programs in some areas that can send a nurse to your home every day to give you Neupogen® injections. Ask your transplant coordinator if this is an option where you live.

To get your injections, you can also:
- Go to a community clinic every day.
- Ask your family doctor to inject you.
- Ask a friend, family member, or a neighbour if they have experience, or if they are willing to be trained.

**I have to start taking Neupogen® injections soon, but the community health care provider has not contacted me yet. What should I do?**
- Community health care programs may not contact you until shortly before you start Neupogen®.

- If it is the day before your Neupogen® start date and you do not hear from the community health care provider by 2:00 pm, call the Princess Margaret Transplant Office at 416-946-4501, extension 5082, and leave a message.

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**While you are getting your mobilization, go to the nearest hospital Emergency Department if you have:**
- Shortness of breath that starts suddenly
- Blood in your urine Pain or burning when you pass urine after mobilization chemotherapy
- Fever of 38.5 ° C of higher, within 2 weeks of your mobilization chemotherapy
- Chills or shakes
- Yellow or green mucous after you cough
- Severe bone pain that your pain medication doesn’t help.

These symptoms may mean a possible infection or side effect from the mobilization therapy that should be treated as an emergency.
Get your stem cells collected

After you have taken 5-7 Neupogen® injections, you will need to come into the Toronto General Hospital for stem cell collection. Your health care team will let you know when your collection starts.

See your Pre-transplant Guide, “Your stem cell collection” section.

It usually takes one to 5 days to collect enough stem cells. This depends on:

- how many stem cells are needed,
- the number of these cells that can be counted in your blood on the day of collection.

You need to make sure you can come for all the possible collection days. Each day, the nurses in the Apheresis Unit will let you know if you need to come back for more collection, or if the collection is completed.

Your health care team may adjust your medications during stem cell collection. This includes adjusting blood thinner medications (such as Warfarin® or Coumadin and Fragmin) that help prevent bleeding issues during stem cell collection.

What to bring with you

- Any Neupogen® injections you still may have. Your health care team will keep your injections for you
- Health card
- Any medications you need to take that day
- Your Pre-transplant Guide
- Snacks and drinks
- Family member or friend for support

Get your stem cells collected

1. Get your blood work done – you will be checked for the number of stem cells in your blood. This will let your health care team know if you are ready to start the collection.
   
   Time: 7:00 am
   
   Go to: Diagnostic Test Centre, Eaton Building, Ground floor, Room G-406
   Toronto General Hospital (200 Elizabeth Street, Toronto, ON M5G 2C4)
2. Go to the Apheresis Unit

Time: 8:30 am

Go to: Apheresis Unit, Gerrard Building, 2nd floor, Room 2-539

Toronto General Hospital (200 Elizabeth Street, Toronto, ON M5G 2C4)

Check-in at the reception desk. The Apheresis nurses will look at your blood test results with you.

If your blood counts are not high enough in your blood:
  • You will not have your stem cells collected that day.
  • You will be given a Neupogen® injection and then you will go home.
  • You will need to return the next day to the Diagnostic Test Centre at 7:00 am for a blood test.
  • You will need to return to the Apheresis Unit at 8:30 am to look at your blood test results again.

If your blood counts are high enough in your blood:
  • Stem cell collection can begin.

3. Getting your stem cells collected

  • You will be hooked up to an Apheresis machine by an intravenous (IV) line in each arm.
  • Your blood will be drawn into the machine through one intravenous (IV) line.
  • The machine will collect the stem cells from your blood and return the rest back to your body, through the other intravenous (IV) line.
  • Patients with veins in their arms that are not large enough for the Apheresis will have a Quinton Line (special intravenous (IV) put in a large vein, usually in the upper chest or neck area). This will be decided by an experienced nurse in the stem cell collection unit.
  • The Quinton Line has 2 channels that allow blood to enter through one channel and return through the other.
• The Quinton Line is put in by a doctor using a special type of x-ray machine to see the vein clearly. It usually takes 30 minutes to insert.

• The Quinton Line will stay in for each day collection is needed and will be removed when collection is done. You do not need to stay in the hospital with this line and can go home with it in place.

• The process of stem cell collection will take 5 to 6 hours each day.

**Are there any side effects to stem cell collection?**

During the collection, you may feel:

• **Light-headed or dizzy** – This is due to your blood going through the machine. Let the nurse know if you feel this side effect.

• **Cold** – This is due to your blood going through the machine. It is normal and will stop when the collection is done. Ask the nurse for a blanket, or dress warmly the day of your stem cell collection.

• **Tingling in your lips, fingers and toes, and cramping in your hands and feet** – This is due to low calcium from the anticoagulants medication used to prevent blood clotting inside the collection machine. Tell the nurse if you feel any of these side effects. Calcium will be added to your intravenous (IV) and the symptoms should fade.

**Are there any risks to doing the stem cell collection?**

There is some risk of bleeding when an intravenous (IV) needle is put into your veins. There is also a small risk of an infection where the needle is put in. Always contact your transplant coordinator if the skin where the intravenous (IV) was put in gets:

• Red
• Swollen
• Warm or tender to the touch

**What if there are not enough stem cells?**

Sometimes not enough stem cells can be collected. Your doctor will let you know if this happens and what your options are.
Prepare for your transplant

Get your Hickman line

Closer to the start of your transplant, you will need a Hickman line to be put in. A Hickman line (also called Central Venous Catheter or central line) is a special tube that is put into a large vein in your chest. It is put in near your collarbone and comes out a few inches below your collar bone. It is used to:

- Give you high-dose chemotherapy and other medicine
- Give you intravenous (IV) fluids to help keep you hydrated
- Draw your blood for tests
- Give back your stem cells during the transplant
- Give you blood transfusions and antibiotics (medicine that fights infection), if needed

You will need a Hickman line even if you have a PICC line or Port-a-Cath. If you have a dialysis line, your health care team will use that line for the transplant, and you will not need a Hickman line.

Some patients experience pain or discomfort in the neck and shoulder area for a day or two after the Hickman line is inserted; your doctor can prescribe pain killers if this happens to you.

Your first visit to the Out-patient Transplant Day Hospital

Go to: Princess Margaret Cancer Centre 14th Floor, Room 627

What to bring with you:

- [ ] Your health card
- [ ] Any medications you are currently taking
- [ ] Your 24-hour caregiver

This first visit will provide you with an orientation to what will happen on each daily visit and what you will be expected to do at home during your transplant. You will meet the Out-patient transplant nurse practitioners or doctors who will be seeing you every day and they will give you a tour of the Out-patient Transplant Day Hospital.
On this Orientation Visit, you will get your own Transplant Binder with:

- Your schedule of visits
- A transplant guide
- A thermometer for taking your temperature at home
- A transplant calendar with the schedule of your transplant
- A list of medications that you will be taking
- An appointment for your start of the transplant to get high-dose chemotherapy in the Outpatient Transplant Day Hospital
- Teaching about what to do at home, how you will feel on each day of the transplant, and how to take care of your Hickman line
- A Daily Patient Record for you to track important measurements each day

**What is the Daily Patient Record?**

The Daily Patient Record is a form that you will be asked to fill out every day. You will be asked to write down important measurements of things that you do during the day at home. You will discuss the Daily Patient Record every day with your transplant team to help them know how you are doing.

The Daily Patient Record will ask you to record:

- Your temperature 4 times a day.
- How much fluid you drink (including water, juice, popsicles, jello)
- How often you had a bowel movement and whether it was watery or loose – this will help the transplant team decide whether you need extra fluid through your intravenous.
- What medications you took and when you took them.
- Any other problems you may have had at home, like problems with nausea or sleeping, that the transplant team can help with.
During your transplant

Get high-dose chemotherapy

One or 2 days after your Orientation Visit, you will come back to the Out-patient Transplant Day Hospital to get your high-dose chemotherapy. You will spend at least 6 hours at the Day Hospital on this day so remember to bring your lunch, snacks, something to read, or your iPod to listen to music.

The high-dose chemotherapy is used to treat your cancer. The chemotherapy drug that is used is called “Melphalan” but you may also get a second chemotherapy drug called “Etoposide”; other drugs or combinations are also sometimes used. The exact amount and how long you will get these chemotherapy drugs depends on your cancer.

When you arrive at the Day Hospital for your high-dose chemotherapy, the nurses will:

- Take your blood tests
- Give you intravenous (IV) fluids for a few hours, along with some medications that prevent nausea (feeling of having to throw up) and vomiting.
- Give you the high-dose chemotherapy through the intravenous (IV). This will take about 30 minutes. You will be asked to suck and chew on crushed ice while you receive your chemotherapy. This will help lessen the chances of the mouth sores happening.
- You may receive more fluids after the chemotherapy

Although you may feel nausea and the medications you get to prevent nausea can make you sleepy, you will probably feel fine during the chemotherapy. The transplant team will check how you are doing and decide when you are ready to go home.

It is common to feel tired after you get home so rest and relax for the rest of the day. Keep your medications to help with nausea handy as you might feel like throwing up.

The day after your chemotherapy is a day of rest at home. There is no need to come into the hospital or get bloodwork done.
What are the possible side effects from high-dose chemotherapy?

There are many possible side effects that can be split into short-term and long-term.

Short-term side effects (those that you can expect in the first 1-2 weeks after):
  o low white blood count which increases your risk of infection
  o low platelet count which can increase your risk of bleeding. This will be monitored and platelet transfusions given as needed
  o fever, chills and infections
  o nausea and vomiting
  o hair loss
  o loss of appetite (do not feel like eating)
  o mouth sores and sore throat which may make it hard for you to eat or drink.
  o diarrhea
  o skin rashes (from the chemotherapy drugs or occasionally from antibiotics given to treat infection)

Later side effects (those that might continue longer than 2 weeks):
  o fatigue
  o shortness of breath with physical activity—this will improve with gradual increases in simple exercise such as walking or stationary bike
  o loss of taste for food
  o nausea, diarrhea

Long-term side effects (can last longer than 6 months)
  o fatigue (feeling tired)
  o changes in your ability to concentrate, and short-term memory problems (this has been called “chemo brain”)
  o infertility (not being able to have children)
  o low levels in some hormones in your body (thyroid hormone, testosterone in men, estrogen in women)

See page 49 for more information on each side effect.
Infuse your stem cells
(get your autologous stem cell transplant)

Two days after your high-dose chemotherapy, you will come back to the Out-patient Transplant Day Hospital to get your stem cells back. Your stem cells are given back at least 1 to 2 days after you finish your high-dose chemotherapy treatment to give your body time to flush out the chemotherapy drug before your stem cells enter your blood.

The day of your autologous stem cell transplant is called “Day 0”. From “Day 0” onward, your health care team will count each day as “Day 1”, “Day 2”, “Day 3”, and so on.

What to do on the morning of your Stem Cell Infusion before you come in:

- Do not eat a full breakfast. You should just drink clear fluids (like water, juice, broth or jello) in case you feel like throwing up later
- If you are taking high blood pressure medications, do not take them that morning. If you are not sure what to do with your medications, ask your transplant team
- Bring your lunch, snacks, and something to read or your iPod to listen to music. You will probably be at the Day Hospital for at least 4 hours on this day

What will happen when you arrive at the Day Hospital:

- You will be seen by the nurse who will check how you are doing, measure your weight and blood pressure, and take your blood test from the Hickman line.
- You will get intravenous (IV) fluids for 1-2 hours and also get medications to reduce any side effects before you get your stem cells back.
- Your preserved (frozen) stem cells will be thawed (unfrozen) in a warm water bath in your room.
- A nurse will be by your side during the infusion of your stem cells to monitor and help you, if needed. A doctor or nurse practitioner will be close by during the transplant.
- When your stem cells are thawed, the bag will be hooked up to your Hickman line and given back to you like a transfusion.
- To give you back the stem cells it will take 5 to 10 minutes per bag.
While your stem cells are being given to you (during your transplant)

You may:

- Feel nauseated (feeling of having to throw up).
- Have some discomfort (feeling dizzy, nervous).
- A cold feeling in your chest because the thawed stem cells are colder than your body temperature.
- Have an odd taste or smell like canned corn or garlic. This is due to a drug called dimethylsulfoxide (DMSO) which is added to the stem cell bag to protect your stem cells when they are frozen. You can suck on a hard candy during the transplant to help get rid of this odd taste.

After your stem cells have been given back (after the transplant)

- Your urine may be red for a few hours after the transplant and should stop after 24 hours.
- The canned corn taste and smell from the DMSO will stay in your breath and sweat for 24 to 48 hours after the transplant.
Recovering from the transplant

Your blood count recovery

A blood count is a test that is done by a nurse or a doctor to get information about the cells in your blood. The parts of your blood count include:

- **Red blood cells**
  - carry oxygen from your lungs to different parts of your body
  - give you energy
  - are measured as your hemoglobin level
  - a low hemoglobin level can cause you to be tired and weak

- **White blood cells**
  - help fight infection
  - neutrophils (a type of white blood cell) are very helpful at fighting infections due to bacteria (“germs” that live on your skin, in your mouth and in your intestines that can cause high fevers and make you very ill)
  - low white blood cells can put you at risk of infections during the time of transplant

- **Platelets**
  - help your blood form clots so that your body can stop bleeding
  - low platelet levels can lead to bruising, bleeding (such as nosebleeds) and petechiae (small bleeding spots on your skin)

As a result of the high-dose chemotherapy, your white blood cells, red blood cells, and platelets will be very low for 7 to 10 days. You are at the greatest risk for an infection and bleeding at this time. Once your stem cells are put back into your blood stream, they begin to move back into your bone marrow where they will grow and start to make new blood cells. The new stem cells will help replace the bone marrow destroyed by the chemotherapy.

During your transplant recovery, you will need to wait for your transplanted stem cells to move into your bones and start replacing the bone marrow that was destroyed by the high-dose chemotherapy. This often takes 12 to 14 days, but sometimes longer.
What happens during your transplant recovery

During your transplant recovery, you will be seen every day in the Out-patient Transplant Day Hospital and you will be asked to keep track of how you are doing during the day and night at home.

What will happen at your daily visits to the Out-patient Transplant Day Hospital?

Each daily visit may be a bit different, depending on whether you need special tests or medications. You may have a short visit of 2 hours or you may need to stay all day.

Things to bring to the Day Hospital:

- Your health card
- Your Transplant Binder with the Patient Daily Record from the previous day
- Any medications you may need to take during that day (e.g. pain medication). You should also take your other, regular medications (e.g. blood pressure or cholesterol pills).
- Your 24-hour caregiver
- Lunch, snacks, and drinks
- Something to read, iPod to listen to music, or a notebook to write in

When you arrive at the Day Hospital, you will be seen first by a transplant nurse who will:

- Take your blood tests from the Hickman line
- Take your temperature, blood pressure, heart and breathing rate
- Take your weight
- Ask how you are doing at home and what side effects you may have
- Check your body for any signs of bleeding or bruising or infection.
- Give you 1 bag (1 litre) of fluid through your intravenous (IV)

Let your nurse know if you:

- See any bruising or little red spots on your body
- Have blood in your stool or urine
- Have a nose bleed
- Have a fever, chills or a cough
- Have skin redness, tenderness and swelling around the Hickman line
After the nurse sees you and you get your intravenous (IV) fluids, a specialized transplant nurse practitioner or doctor will examine you and review your blood test results.

Depending on your tests and how you are feeling, you may need:

- A transfusion of red cells or platelets if your counts are low.
- Antibiotics (medication to fight infection) through the intravenous.
- Extra intravenous fluids to help you stay hydrated. A homecare nurse can be arranged to give you fluids at home as well.
- Other tests, such as a chest x-ray, ultrasound, urine tests. Often these are done to look for signs of infection.

If you need any of these special tests, your visit on that day may be longer than usual.

**What should you do at home?**

- If you feel like it, you can do many of your usual home activities like going for walks, reading, listening to music, visiting with family and friends. You may have side effects from the high-dose chemotherapy (see page 49 on how to manage them) so do not try to do too much. On some days, you may feel tired and want to spend the day resting in bed.
- Take your medications – you will be given a list of medications and when to take them.
- Fill out your Patient Daily Record – it is a good idea to hang this on your fridge or wall so it is easy to fill it out. Remember to take it down every morning to bring with you to your daily visits.
- Your 24-hour caregiver can help you prepare your meals, keep track of how much you are drinking, take your temperature, and anything else you need help with.

**What should you drink and eat at home during your transplant?**

- Try to drink at least 2 litres of fluid every day. Water, juice, soups, and even jello, are all good fluids to drink. Some patients find it hard to drink this much fluid but most manage by drinking small amounts (½ cup or even just sips) throughout the day. Acidic juices (like orange or tomato juice) may bother your stomach, and caffeinated drinks (tea, coffee, and cola) should not be taken in large amounts.
- You will receive fluids every day during your visits to the Day Hospital, but a homecare nurse can be arranged to give you intravenous fluids at home as well.
- Eat your usual foods, but if your mouth becomes sore from the chemotherapy side effects (see page 51), then bland (dull tasting) foods are best.
- Eating small amounts of food often is better than trying to eat big amounts of food less often.
Children, pets, and other people living in your home

- Children are often not careful with their hand-washing and may have infections that could make you ill. Although we do not want to prevent you from spending time with children, you should try not to touch or kiss them if they have a runny nose or cough.

- Pets who have been vaccinated (got shots) are fine to have at home. But, it is suggested that you do not change litter boxes or scoop the poop of pets during your transplant to avoid getting an infection.

- Other people living in your home should try to stay away from you if they are sick with an infection. As well, they should stay away from you if they have been vaccinated recently with a live virus vaccine, such as the chicken pox (varicella) vaccine that is given to children or the shingles (herpes zoster) vaccine that is given to older adults.

What can you do to avoid getting an infection while your counts are low?

- Wash your hands often.

- Tell all your visitors to wash their hands.

- Tell any sick visitors to not visit you.

- Make sure family and friends who bring you food follow the instructions in the “Food Safety for Patients with Weakened Immune Systems” pamphlet. This pamphlet will teach them how to prepare food safely, and the safer food choices to eat during this time.

- Tell visitors not to use your bathroom.

- Do not bring cut flowers or potted plants into your room – these can sometimes carry bacteria that can cause infections.

- You should also try to reduce your risk of getting cut and bleeding since that can lead to an infection.

- To help reduce your risk of bleeding, you can avoid shaving with a blade razor while your platelet count is low. (There will be hair loss from the chemotherapy, so you may not need to shave).

- Avoid using a toothpick and flossing your teeth. Brush your teeth gently with a soft brush.
What should you do if you have problems or questions while at home?

If are having problems such as diarrhea or sore mouth at home, you can call the hospital to speak directly to a transplant nurse.

- During the day (7:30 am to 7:30 pm Monday to Friday) – Call 416-946-6555
- During the night (7:30 pm to 7:30 am Monday to Friday, or anytime on weekends) – Call 416-946-2011

The transplant nurse can give you advice over the phone and can arrange for you to get a medication prescription to pick up for home to help with your symptoms. If needed, the transplant nurse can also arrange for you to be seen in the Out-patient Transplant Day Hospital or have the transplant doctor call you directly.

Here are some things that you should call the transplant nurse about:

- Fever greater than 38.3 °C
- Chills or shakes
- Severe (very bad) nausea that prevents you from drinking or taking your pills
- Severe diarrhea (more than 4 bowel movements in a day)
- Yellow or green mucus when you cough
- Pain or burning when you pass urine (pee)

Go to the nearest hospital Emergency Department if you have:

- Severe shortness of breath that starts suddenly
- Severe chest pain
- Blackouts

These symptoms are rare but if they occur, they may mean a severe side effect and cannot be handled by the transplant nurse on the phone. These should be treated as an emergency.
Manage your high-dose chemotherapy side effects

As your bone marrow recovers, you may feel some side effects from the high-dose chemotherapy. The side effects may be stronger than what you may have felt before. Some days, you may feel very uncomfortable and want to stay in bed.

Below is a list of common side effects and what you can do to manage them.

Nausea (feeling of having to throw up) and vomiting (throwing up)

Nausea and vomiting are common side effects of high-dose chemotherapy. Your health care team will give you medication before these treatments to help prevent and reduce nausea and vomiting. You will be given anti-nausea medication for home and can be taken any time during the day if you feel nauseated.

Sometimes you might not feel like eating, but this is temporary and improves as your recover from your transplant. For helpful dietary tips, read the “Nausea” pamphlet at Princess Margaret Patient & Family Education Library located on the Main floor.

Hair loss

You will probably lose some hair during your stem cell mobilization. More hair loss is expected during the transplant. Hair loss often starts within a few days after you finish high-dose chemotherapy, but it is short-term and your hair will grow back.

You may also lose hair on areas of your body other than your head. Your hair will start to grow back one to 2 months later.

Some patients like to wear a wig or headwear (e.g. hat, scarf) during their hair loss. Here are some ways to prepare for hair loss:

- Consider cutting your hair short, before the chemotherapy. Longer hair comes out easier and makes hair loss more noticeable.
- Wearing a wig or headwear will keep you warm after your hair comes out.
- If you go outside in the sun, wear a hat and use sunscreen.
- Read the “Prepare for and cope with hair loss due to cancer treatment” pamphlet at the: Princess Margaret’s Patient & Family Library Location: Main Floor, near the atrium Phone: 416-946-4501, extension 5383
To get a wig that is right for you, you can:

- Contact or visit the Princess Margaret’s Wig Salon & Accessories Boutique
  Location: 3rd Floor, Room 3-642
  Phone: 416-946-6596
- If you think you want to use a wig, plan this well in advance since it takes time to get one fitted and styled.
- If you have private insurance, some plans will pay the cost of a wig for hair loss caused by chemotherapy. If your plan does cover it, ask your transplant doctor for a prescription for a wig.

**Fatigue or feeling tired**

- You will feel very tired and low on energy after your high-dose chemotherapy. While you are recovering from your transplant, you should plan on taking walks around the house or outside at least 2 or 3 times a day, and should spend as much time out of bed as you can. This will help your energy level. Your energy level will get better from week to week and should be much better by 2-3 months after the transplant.

**Loss of appetite (do not feel like eating)**

You may have loss of appetite after high-dose chemotherapy because:

- Food will taste different. Chemotherapy may affect your taste. It can take a few weeks for your sense of taste to return to normal.
- Nausea can reduce your desire to eat.
- Mouth sores and sore throat can make it hard to eat.

You should try to eat healthy foods because they provide nutrients your body needs to build itself up after the transplant. For other helpful dietary tips read the “Increasing Calories and Protein in Your Diet” and “Eating Tips for Sore Mouth and Throat” pamphlets found in the Princess Margaret Patient & Family Library.

Fluids help to keep your body working. Bland foods, such as bread, bananas, and soda crackers may be easier to eat. Drinking a lot of fluids is even more important than eating healthy foods.

If it is hard for you to eat and maintain your weight, ask your health care team to refer you to our Registered Dietitian (someone who helps you to plan what you eat and drink).

For more nutrition information, visit the Princess Margaret’s Patient & Family Library (main floor, near the atrium).
**Diarrhea** (watery, or loose bowel movements)

Diarrhea often happens a few days after you finish high-dose chemotherapy and can last for a week or more. It can be severe and occur many times a day and wake you up at night. Diarrhea may also be a sign of infection, so if it is very watery, a sample of your stools will be taken and sent for testing.

If no infection found, medications can be given to help slow or stop the diarrhea.

When you have diarrhea, it may help to:

- switch to Lactose Free milk e.g. Lacteeze, Almond or Soy Beverages,
- avoid spicy foods,
- avoid foods with high fibre, like crunchy vegetables or seeds that may be hard to digest.

For more helpful dietary tips, read “Eating Hints for People with Diarrhea” pamphlet found in the Princess Margaret Patient & Family Library.

**Brain fog or chemo brain**

It is common for some things to change due to high-dose chemotherapy treatment, and it can also be due to other drugs you have been on. This can include changes to your:

- memory,
- concentration (focus),
- attention span

These changes are short-term and will start to get better in the months following your transplant. Get plenty of rest and make sure your doctor reviews your medications. Lack of sleep and some medications, like sleeping pills, can make your memory and concentration worse.

**Mouth Sores and Sore Throat**

The high-dose chemotherapy can also damage the lining of your gastrointestinal system (gut). The tissue underneath gets irritated easily and this causes sores and pain in the mouth and throat.
While you are getting your transplant:

- You will be asked to suck and chew on crushed ice while you receive your chemotherapy. This will help lessen the chances of the mouth sores happening.
- When you notice any pain swallowing, or your mouth feels sore, make sure you tell the nurses or doctor.
- You will be asked if you feel any pain every day.

You will be prescribed pain medication, often liquid or in a patch on the skin to make it easier to swallow if your mouth or throat pain makes it very hard for you to swallow your medications.

- When your mouth is very sore, it may be hard to eat solid foods. Soft or mashed foods like applesauce, jello, soups, and ice cream can be soothing.
- For more helpful dietary tips read the “Eating Tips for Sore Mouth and Throat” pamphlet.

**Infertility**

Your ability to have children of your own is also affected by the high-dose chemotherapy, as well as by age, and overall health. In the weeks to months after the transplant, women will not have periods and men will not make sperm.

Younger patients (in their 20s and 30s) can regain their fertility over time, but for older patients, infertility is often permanent.

If having children that come from you, and not adoption, is important to you:
- Discuss this with your health care team as soon as possible
- Do not wait until treatment starts

**How to cope emotionally during and after your transplant**

Getting an autologous stem cell transplant can have a big effect on your body and your emotions. It can also have an effect on those around you, like your family and friends.

Below are some concerns you may have after the transplant, including what you can do and what resources can help you.
Your emotions

You can feel different emotions after the transplant, and they can change day to day. You may feel emotions like hope, fear, anger, sadness, stress or worry and loneliness. This is why patients have described going through a transplant to be an “emotional roller coaster” that includes ups (better days) and downs (more difficult days).

Each person has strengths and skills that they use to cope with difficult emotions. Below are some tips that can help you:

- **Let feelings out.** Share your feelings with those you feel close to, such as your family and friends or your health care team member. It is often helpful to talk about your feelings with someone and to know that you are being listened to. You can get help from a social worker if you need more support.

- **Get information.** Ask the staff questions, so you will know what to expect. This will help you feel more involved and in control of your care.

- **Get peer support.** Ask to speak to other patients who have had a transplant. There are many peer support programs available through community cancer organizations which can be really helpful. Your health care team members can give you information on these resources.

- **Use relaxation exercises.** Practice relaxation exercises such as meditation or deep breathing. These exercises can be really helpful in reducing feelings of stress.

- **Do activities you enjoy.** Distract yourself by focusing on or doing an activity. This will give you some relief from your thoughts and feelings. This may include things like:
  - reading,
  - listening to music or an audiobook,
  - watching a TV show or favorite movie,
  - painting, sketching, knitting,
  - playing a game,
  - doing a puzzle,
  - spending time with family and friends.

- **Keep physically active.** This is a great way to reduce stress. Being active can improve your mood and keep you healthy:
  - Take short walks for 10 to 15 minutes if you feel alone, bored or restless.
  - Check with your health care team about your level of physical activity. You may also need to do certain things to stay safe.
• **Make sleep a priority.** Make sure you are getting enough sleep and that you are sleeping well. If you have trouble sleeping, speak to your doctor or nurse.

• **Set realistic small goals —“Taking it one day at a time”**. When you find yourself feeling overwhelmed or you feel what lays ahead to be too long or tiring, try taking it one day or even one hour at a time. This helps focus you on the here and now and see your progress one step at a time.

**Your family**

Your family is also affected by the transplant treatment and you may be worried about your family’s well-being. It may be hard to cope with all of these feelings when you are tired from your treatment. Some of your family’s feelings and worries may be like yours, but they can also have different reactions and concerns.

• Family members may have to take on more responsibilities and may be unsure about how to cope with your illness.

• Stresses related to work, money, childcare, eldercare or other issues can become a problem.

• For those from out of town, there can be the added stress of being away from familiar surroundings and the support of friends, neighbours and family.

• Children too may have their own worries. You may also see some changes in your children’s behavior.

It is important for you and your family to share your feelings and any concerns with your health care team, so that the team can offer you support and assistance. Here are some suggestions that you and your family may find helpful:

• **Talk and share feelings.** As a family, try to openly share your feelings and work together to solve your problems. This can be difficult at times when you and your family may be feeling overwhelmed, tired or stressed. The social worker can help if this is hard to do.

• **Prepare and talk to your children.** Prepare your children by talking with them and giving them information suited to their age and level of understanding.

There is a Parent Child Information Package available to help guide you and your family.
This package is available at the Patient & Family Library at Princess Margaret, or ask your health care team members about how to get this package. The social worker can help if you or your family need more help with this.

- **Get information.** Ask the staff questions, so you know what to expect.
- **Seek support.** Ask family and friends for extra help at this time with car rides, meals, childcare, and daily routines.
- **Caregiver support.** Encourage family members to take care of themselves by getting enough sleep, eating well, exercising and finding time alone. Encourage them to ask for help and seek support from others including family, friends or a professional counsellor. The social worker can help you with this.

- **Tell family members and friends how they can best help you.** They want to be there to love and support you, but need to know what is most helpful.

**Princess Margaret Psychosocial Oncology Clinic**

The Psychosocial Oncology Clinic at Princess Margaret has a specialized team of occupational therapists, psychiatrists, psychologists, and social workers. This team offers counselling and therapies to help you and your family cope with the diagnosis of cancer, reduce stress and improve your emotional well-being. Although it is normal to worry about different concerns related to your illness, treatment and your future after treatment, speaking with a Psychosocial Oncology professional can be helpful.

Let your health care team know about your concerns and tell them if you want to speak with a:

- **Psychiatrist** is specially trained to help you and your family learn how to cope with the emotional stress of a cancer diagnosis and treatment. They offer consultations, counselling, and medications if needed for patients and family members.

- **Psychologist** is an expert in assessing, diagnosing and treating mental health conditions, such as problems with thinking and memory (neurocognitive disorders), emotional disturbances and behavioral disorders. They can help you and your family improve and maintain the best possible quality of life and well-being.

- **Social Worker** can help you and your family with the emotional and practical aspects of coping with the diagnosis and treatment of cancer. They provide counselling and can help with:
  - Emotional matters, such as dealing with fear, anxiety, sadness, anger and a sense of loss
Financial matters, such as income support, drug costs and disability pensions
Practical matters, such as transportation, home support and referrals to community resources

- **Occupational Therapist** can help you learn relaxation techniques to help you deal with your feelings of anxiety or feeling overwhelmed which may help reduce the effects of stress on your body and mind.

Ask your health care team for a referral or you can contact the Psychosocial Oncology directly for more information at 416-946-4525. These professionals can help you when you are an in-patient or an out-patient.

**Psychosocial Oncology Clinic:** 416-946-4525
Open Monday – Friday, 9:00 am – 5:00 pm
Princess Margaret Cancer Centre, 16th Floor

**The Princess Margaret’s Healing Beyond the Body (HBB) – Psychosocial Volunteers**

Healing Beyond the Body (HBB) is a special type of volunteer service. Volunteers are trained to give support to you and your family in order to help make the hospital experience less stressful, confusing and overwhelming.

Volunteers can also offer assistance with resources and help you learn about the different services and programs available to you. HBB volunteers visit the nursing unit while you are in the hospital and also offer in-patients the use of the activities from their “Diversion Cart” - which includes DVDs, crafts, games and reading material.

You can also find HBB volunteers throughout the hospital including the transplant out-patient clinics.

**Princess Margaret Spiritual Care**

Spiritual Care can help you maintain your health and cope with hard experiences. It can help you find meaning, value and connection, especially during difficult times. Spiritual care professionals can help you express your feelings and concerns in a way that honours your values and beliefs.

Ask your health care provider to contact a spiritual care professional for you, or call the number listed below.

**Phone:** 416-946-4501, extension 5652
After your autologous stem cell transplant

Usually at about 12 to 13 days after your stem cell transplant, your blood counts will have recovered to a safe level. Your health care team will assess you to see if no longer need to be seen daily in the Day Hospital.

You will be given an appointment to return to the Out-patient Transplant Day Hospital for a check-up in the post-transplant (“after transplant”) clinic. At first, you may be seen 2 to 3 times per week, depending on how you are doing.

How will you feel after the transplant and your blood counts have recovered?

Even after your blood counts recover, you will still have fatigue (feel tired). The best way to fight fatigue and low energy is to slowly increase the amount of activity you do every day.

Feeling tired can persist for many months after the transplant. Regular exercise, like walking, is the best remedy.

You may also have other symptoms, such as:

- nausea and sometimes vomiting
- diarrhea
- poor appetite
- changes in taste
- hard time sleeping

These symptoms are very common and improve slowly, likely over the first month.

You can get medications that may help settle uncomfortable symptoms. Ask your nurse or doctor about this at your clinic visits. You may need to keep taking medications to control your symptoms (such as nausea) until your symptoms get better.

What to expect during post-transplant clinic visits

After your blood counts have recovered and you do not need to be seen every day, you will return to the Day Hospital as part of the post-transplant clinic. At each visit, you will have a blood test to follow your blood count recovery and to see how well your kidneys are working.
A doctor, clinic nurse or nurse practitioner will:

- Check your blood pressure, heart rate, temperature and weight.
- Keep track of your medications.
- Review new or ongoing symptoms or concerns.

If needed, you can get extra fluid infusions or blood transfusions during these visits.

A doctor or nurse practitioner will decide:

- When you are ready to have your Hickman line removed. It can be removed in the Day Hospital or in the Out-patient Procedure Clinic.
- When home fluids or intravenous (IV) medications are no longer needed.

Ongoing medications given to you by your family doctor or other specialists may have been stopped during your transplant, or the dose may be changed until you have recovered after the transplant. This includes medications for diabetes or high blood pressure that you were taking before transplant. A clinic doctor will decide when it is time to restart these medications and any others that were started in hospital.

Once you get better and your symptoms from the transplant are gone, you can resume check-ups with any cancer doctors you may have. You will have a check-up with your transplant doctor at the Princess Margaret about 2 to 3 months after your stem cell transplant. This check-up is to see if your cancer is under control or has responded to the high-dose chemotherapy.

If you need any tests (CT scans, blood work) before this check-up, your regular cancer doctor will arrange them at your local cancer centre.

**Vaccinations (shots) after your transplant**

After your transplant, your immune system may be weakened from the chemotherapy. Vaccinations after transplant are recommended to defend your immune system against common infections.

These vaccinations are given as injections (shots). They will be given:

- About 3 months after your transplant, you will be given a handout with a suggested vaccination (shots) schedule.
• Some of the vaccinations can be given at the Princess Margaret, but most will be given by your family doctor. You should give the vaccination handout to your family doctor.

• There may be a cost to you for some of them.

Manage long-term

Changes to your sexual health and intimacy

Having a transplant can affect your sexual health and intimacy with others. This includes concerns about:

• self-image,
• sexual and intimate acts or performances,
• infertility,

Your health care team can answer any questions or concerns you may have, or give you information and direction.

Here are some suggestions which may be helpful:

• **Get information.** You may be worried that sexual activity may be unsafe for yourself or your partner. Ask your doctor or nurse for guidance and information.

• **Communication.** Share your feelings, desires and worries with the people who care for you and to the person who you are intimate with. They cannot help unless they understand your needs and know how you feel.

  No one can read your mind – not even someone you have lived with for years.

• **Explore new forms of affection.** Sexuality and intimacy can be expressed in many ways, such as:
  - holding hands,
  - cuddling,
  - dancing,
  - taking a walk,
  - and watching a movie or even sitting on a park bench enjoying your surroundings.

Try to remember you are not alone as many other transplant patients have found ways of coping with their sexuality. If you are having a hard time, ask your health care team such as your doctor, nurse or a social worker.
Fear of recurrence

Many transplant patients are concerned about their cancer coming back or not being controlled.

- This is a very common fear. The risk of recurrence is different for each person.

- It depends on many factors, such as your type of cancer, the treatment you had, and how long it has been since your treatment.

- If you find yourself worried by questions about recurrence, ask your doctor to talk directly about the chances of the cancer coming back.

If you have a fear of cancer coming back, here are some things you can try:

- **Keep a record of your appointments.** Go to all your medical follow-up appointments. At these visits, your doctor will look for side effects from treatment and check if your cancer has come back.

  It is important for your long-term health to go to all these appointments, even if the hospital brings back unpleasant memories. Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions.

- **Be informed.** Learn about your cancer. Know what symptoms of recurrence to look out for. Talk to your doctor and ask any questions you may have about your cancer experience. Having more knowledge may give you with a greater sense of control over your life.

- **Share your feelings.** People often find that when they share strong feelings like fear, anger or sadness, they are better able to let go of them. Some people talk to:
  - friends or family,
  - other cancer survivors,
  - or a counsellor.

There are organizations in your community which offer support for those affected by cancer. In Toronto, there are 2 organizations called Wellspring and Gilda’s Club which offer programs that can help you connect with other cancer survivors.

Even if you prefer not to talk to others, you can still sort out your feelings by thinking about them or writing them down. If you are having a hard time, talk to your doctor, nurse or a social worker.

- **Focus on wellness.** Try to be hopeful. Sometimes this means looking for the good even during a bad time. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible. Eat healthy and avoid alcohol and other sedatives (unhealthy things you may feel dependent on).
Returning to work

Returning to work is a common source of stress for people coping after their transplant. Many people think that others have no problem with it, but it is a big adjustment for everyone. When you feel ready to return to work, it is best to do it slowly and over time.

Going back to work helps to get you get back into a more “normal” routine, but you may still be thinking about your transplant experience and will need to balance your work schedule with your post-transplant medical visits. You may also be dealing with side effects, such as:

- low energy,
- feeling anxious or worried about returning to work,
- or you may have troubling thoughts about family, relationship issues or financial concerns.

These side effects can affect your ability to focus concentrate.

Here are some tips to help you return to work:

- **Talk to your doctor.** It is important to talk to your doctor about your return to work plans so you get medical support and guidance.

  Your doctor can give you advice on when you can consider returning to work. They can also give you and/or your workplace tips on what needs to be considered given your physical needs.

- **Be patient with yourself.** It is important to pay attention to your body. Each person is different and each person’s return to work plan will look different. It is important to accept that.

  Forcing yourself to move ahead before you are ready may result in needing to take even more time off from work.

- **Before you return to work, make a plan.** Consider if you want to share information about your illness with your coworkers. How much and how you share this information is fully up to you. Do not feel that your coworkers need to know everything. You have a right to keep your personal situation private.

  Wellspring offers 2 programs called “Return to Work” and “Back to Work” which are led by professionals who assist people with this issue. You can also connect with other cancer survivors going through the same experience. If you are having a hard time, talk to your doctor, nurse or a social worker.