Your Autologous Stem Cell Transplant

Information for Patients and Families

South East
Regional Cancer Program
in partnership with Cancer Care Ontario

About this booklet

This booklet is about autologous stem cell transplants for adults. The purpose of the booklet is to prepare you and your family for transplant.

The amount of information about your stem cell transplant can be overwhelming. To help ease your stress, this booklet provides written information to go along with the education you receive from your health care team.

You can read each section when you are ready. While reading this booklet you may come up with questions. Write your questions down and bring this book along with you to your appointments and during your hospital stay. We encourage you to ask questions or for more information.

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Introduction

What is an autologous stem cell transplant?

An autologous stem cell transplant is a treatment for certain types of cancer. It involves removing some of your blood stem cells, getting a high dose of chemotherapy, and then re-infusing your stem cells back afterwards.

This treatment allows you to have much higher doses of chemotherapy than usual. Your re-infused stem cells act as a rescue and help re-grow your blood cells after the high dose of chemotherapy.

You will need to stay in the hospital for a total of 3-4 weeks to receive the stem cell reinfusion and for your blood counts to recover.

Other transplants use stem cells from someone else (a donor) and are called a donor stem cell transplant, or an allogeneic transplant. An autologous stem cell transplant is different because you are both the donor and the recipient of the stem cells.

The bone marrow and stem cells

To understand a stem cell transplant, it helps to know about stem cells and the bone marrow.

Stem cells are blood cells at their earliest stage of development. All blood cells develop from stem cells. The full name for stem cells in the blood and bone marrow is haematopoietic stem cells, but in this booklet we call them stem cells.

Bone marrow is a spongy material inside the bones. The bone marrow is where stem cells are made. Stem cells stay in the bone marrow while they develop into blood cells. Then, once they are fully mature, the blood cells are released into the bloodstream.

High-dose chemotherapy will destroy the stem cells in your bone marrow as well as the cancer cells. Therefore, your healthy stem cells are taken and stored before your high-dose chemotherapy. Afterwards, the stored stem cells are given back to you through a drip (infusion) into one of your veins. The stem cells go to your bone marrow and start to make blood cells again. Without stem cells, your blood counts could not get back to normal after such high doses of chemotherapy.

What types of cancer are treated with an autologous stem cell transplant?

At Kingston General Hospital, the types of cancer treated with an autologous stem cell transplant are:

- Relapsed Hodgkin's disease
- Relapsed or Aggressive Lymphoma
- Multiple myeloma or plasma cell disorders
- Testicular cancer and germ cell tumours

With lymphomas, the purpose of the transplant may be to cure the disease or control the disease symptoms and improve your quality of life.

With myeloma, there is no known cure at this time. The purpose of the transplant is to control the disease symptoms and improve your quality of life.

Your stem cell transplant doctor and nurse will explain why you are being recommended for a stem cell transplant. They will also tell you about the possible benefits and risks.

Pictured to the right

The stem cell transplant nurses with a patient undergoing transplant. The stem cell transplant nurses are one of the first team members you will meet. They will care for you before, during and after your stem cell transplant.

The stem cell transplant team

The **Stem Cell Transplant Unit** is located within the hospital setting near the inpatient unit at Kingston General Hospital (KGH).

Your **stem cell transplant team** at KGH is specially trained to care for patients undergoing a stem cell transplant.

You and your family are very important members of the team. You know best about your body, your health and your needs. Your health care team counts on you to let them know how you are doing.

The team also includes:

- Doctors (stem cell transplant doctor, infection specialists, residents, medical students, and more)
- Nurses (stem cell transplant unit nurses, inpatient oncology (Kidd 9) nurses, Oncology/Hematology clinical nurse specialist)
- Social workers
- Dietitians and dietary assistants
- Physiotherapists and physiotherapist assistants
- Pharmacists
- Chaplain/Spiritual care provider
- Occupational therapist
- Environmental aids
- Unit clerks (secretaries)

You will meet some or most of these team members throughout your stem cell transplant process.

Kingston General Hospital is a teaching hospital. During your transplant process, you will meet students in addition to your regular health care team. These students may change during your treatment, but your stem cell transplant doctors will remain the same and continue to oversee your care.

Pictured to the left

Members of the stem cell transplant team include registered dietitians, social workers, physiotherapists and a clinical nurse specialist.

Steps of the stem cell transplant (overview)

This is an overview of the steps you will go through during your stem cell transplant. The stem cell transplant is a step-by-step process. The team does not move ahead with the next step unless it is safe to do so.

Step 1 Preparing for treatment	Preparing for your treatment involves meeting some members of the stem cell transplant team and getting the proper tests and procedures done beforehand. These activities are done as an outpatient.
Step 2 Mobilizing your stem cells	Mobilizing your stem cells usually involves getting chemotherapy and growth factor injections to help increase the number of stem cells in your blood stream before your stem cell collection. This step is done as an outpatient. Another injection may be used to release more stem cells if required.
Step 3 Collecting your stem cells (harvest)	Collecting your stem cells is done as an outpatient in the stem cell transplant unit using a machine that collects the stem cells from your blood. It returns all the other blood components back to you.
Step 4 Getting high-dose chemotherapy	Your high-dose chemotherapy is given 2-3 days before your stem cell transplant to destroy your cancer cells. You will be admitted to the hospital beforehand to receive this chemotherapy - the average length of stay is 3-4 weeks.
Step 5 Re-infusing your stem cells (transplant)	Your stem cells are re-infused through an intravenous (IV). This happens during your hospital stay in the stem cell transplant unit.
Step 6 Waiting for your blood counts to recover (engraftment)	The high-dose chemotherapy will cause your blood cells to fall to very low levels for at least 14 to 21 days. You will stay in hospital during this time.
Step 7 Recover after transplant	Once your blood cells have recovered after the transplant and you are feeling well, you will be discharged home from the hospital. During this step it will take time to resume a normal life and you will have follow-up visits with your health care team.

Steps of the stem cell transplant (detailed)

This section of the booklet gives detailed information about each step of your stem cell transplant.

Remember, the stem cell transplant is a step-by-step process. The team does not move ahead with the next step unless it is safe to do so.

Steps as an outpatient

The following steps, from Step 1 to 3, will happen as an outpatient. You will come to the hospital on specific days for care or treatment.

Step 1

Preparing for treatment

Preparing for your treatment involves meeting some members of the stem cell transplant team and getting the proper tests and procedures done beforehand. These activities are done as an outpatient.

Your first appointment with the stem cell transplant team is a called a consult. During this appointment, you will be given this guide. You will also be asked to sign consent forms. Signing consent forms means that you agree to the different steps in the transplant process.

The stem cell transplant team will explain and coordinate the tests and procedures that must be done before the transplant process starts. These tests and procedures usually include:

- A MUGA scan to check your heart functioning.
- A Pulmonary Function Test (PFT) to check your lung functioning.
- A dentist appointment for a check-up and x-rays (You will need to book an appointment with your dentist).

Throughout the transplant process, we may need to share information with other members of your healthcare team, such as your family physician, social workers, oncologist, etc.

Pre-mobilization chemotherapy appointment

One week before your mobilization chemotherapy, you will come back to the Stem Cell Transplant Unit at Kingston General Hospital (KGH) for an appointment with one of the nurses. The purpose of this visit is to have:

- An assessment done to make sure you are well for the mobilization chemotherapy.
- Blood work taken.
- A PICC line (Peripherally Inserted Central Catheter- a type of long-term intravenous [IV]) inserted. The PICC line will be used to give your mobilization chemotherapy.

Step 2

Mobilizing your stem cells

Mobilizing your stem cells involves getting chemotherapy and growth factor injections to help increase the number of stem cells in your blood stream before your stem cell collection. This step is done as an outpatient.

Mobilization chemotherapy

- Your mobilization chemotherapy is given in the Stem Cell Unit. Please arrive at the appointment time given to you. **Please bring your binder with you to your appointments.**
- The first day of mobilization chemotherapy is a long day. Expect to be here for 6 hours.
- Arrange for someone to drive you home after this first day. You will be feeling drowsy from the medication. Family members and caregivers are welcome in the Stem Cell Unit.
- Wear comfortable clothing.
- Bring items that help you pass the time (book, tablet, laptop).
- You will be given IV fluids and medication to prevent nausea.
- You will be given a prescription for medication that prevents nausea at home after chemotherapy.
- Once you have received your mobilization chemotherapy, you will go home with growth factor injections (Neupogen) and the supplies needed to give the injections (see below).

Refer to drug-specific Patient Information Sheets for more information on your chemotherapy and anti-nausea medications.

After your mobilization chemotherapy

There are some important things you must do on the days after your mobilization chemotherapy and before your stem cell collection. These include:

- Growth factor injections (Neupogen)
- Protect your bladder
- Prevent infection

Growth factor injections (Neupogen)

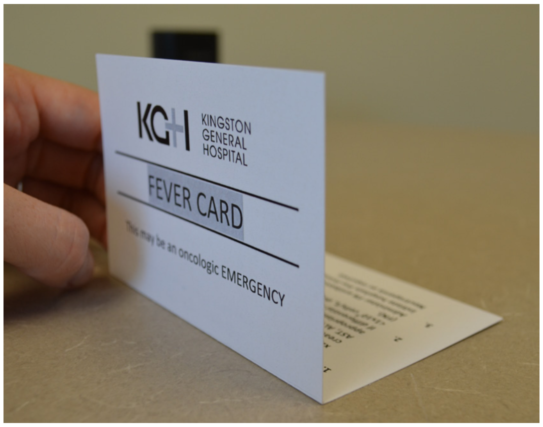
- You will receive a daily injection (needle) under your skin of a growth factor called Neupogen for 8-10 days after mobilization chemotherapy. Neupogen increases the production of stem cells so there are enough cells in the blood stream for collection.
- The injections start 4-5 days after your mobilization chemotherapy, and they should be given early in the morning.
- The first day, a nurse will come to your home to give you the injection in your arm or abdomen and teach you or a family member how to give the injections.
- Keep the Neupogen in the refrigerator. Bring the vial to room temperature before each injection.
- You may feel bone pain from the injections. Take Tylenol to help relieve bone pain. If the pain continues, call your doctor. Due to risk of bleeding, avoid taking anti-inflammatory medications such as Aspirin, Ibuprofen or Naproxen.
  Note: When you take Tylenol for pain, take your temperature first (Tylenol can 'hide' an infection by reducing fever).

Protect your bladder

- The mobilization chemotherapy contains Cyclophosphamide, a chemotherapy drug that can harm your bladder.
- To help prevent harm to your bladder, drink plenty of clear fluids and urinate every 2 hours throughout the day and night. Set an alarm clock to get up to urinate at night.
- If you have multiple myeloma, you will receive a higher dose of cyclophosphamide so a prescription for medication to protect your bladder will be provided.

Prevent infection

- When your white blood cells are low, you are at risk for developing an infection
- Monitor your temperature every 4-6 hours starting 5 days after your mobilization chemotherapy.
- **IMPORTANT: If you develop a fever, go to the closest Emergency Department with your FEVER CARD (pictured below) and the Information Sheet to Healthcare Providers (located in the front of your binder- this sheet will be completed and reviewed with you on the day of your mobilization chemotherapy). You may need to be admitted to the hospital to receive antibiotics through an IV. Bring a packed overnight bag just in case, including your Neupogen (to give if you are admitted).**



- Always check your temperature before taking Tylenol. Call your doctor if your pain is not managed by Tylenol, or go to the Emergency Department if your temperature is 38.0 degrees Celsius or higher.

Managing hair loss from your mobilization chemotherapy

- You will experience hair loss 2-3 weeks after your mobilization chemotherapy.
- Your nurses can provide information and support to manage the impact of hair loss on your life.
- An information sheet is available that lists services nearby selling wigs and hair alternatives.

The Stem Cell Unit nurses will call you on the Thursday after your mobilization chemotherapy to check-in and assess how you are feeling.

Step 3

Collecting your stem cells (harvest)

Collecting your stem cells is done as an outpatient in the stem cell transplant unit using an apheresis machine that collects the stem cells from your blood. On the first day of your stem cell collection, you will come to the Stem Cell Unit at 7:30 a.m. for blood work and a temporary central line insertion.

Temporary central line

- The temporary central line will be inserted to collect your stem cells. Your PICC line is too small for this procedure.
- Wear a shirt with a loose neck line for comfort. Please leave all jewellery at home on the collection days.
- **If you think that you may need a mild sedative for the insertion of the central line, do not eat breakfast before arriving.**
- The central line will need to stay in for a couple of days until the team has collected enough stem cells for your transplant.
- Leave the central line lying in the direction that it exits your skin. Do not twist or bend it. You may have pain at the place where the line enters your skin, but it is usually mild. Bring Tylenol with you to manage the pain.

A temporary central line will be inserted to collect your stem cells (pictured to the right).

Stem cell collection

Once the team gets the results back of your blood work, a decision is made to collect the stem cells that day, or give Mozobil. Mozobil is an injection that will release more stem cells into your blood stream (see note below about Mozobil).

Your stem cell collection will involve the following:

- A nurse will be with you during the collection monitoring your care.
- You will be directly connected to the apheresis machine for about 6 hours.
- During the collection, your blood is pulled from your body using one line, the stem cells are separated in the apheresis machine, and the remaining blood is returned to you using another line.
- There is only a small amount of your blood circulating in the apheresis machine at any one time. Your blood is returned to you when the collection is finished.
- You should not feel any pain during the collection.
- To prevent your blood from clotting while it circulates in the apheresis machine, a blood thinner is used. A side effect of this drug is low calcium, which may cause a tingling feeling around your mouth or in your arms or legs. Your nurse will be monitoring you for this side effect. Please let your nurse know as soon as the tingling starts.
- Once your stem cell collection is complete, the temporary central line will be removed by your nurse.
- You will need someone to drive you home after the removal of the central line.

During the stem cell collection, you will be directly connected to the apheresis machine for about 6 hours (pictured to the left). Patients find that the collection day(s) are long. It helps to bring things to pass the time.

Key Points

- Collection days are long days. You will be required to lie on a hospital bed for the entire stem cell collection (except for when you need to use the washroom).
- Bring things to help you pass the time. Wi-Fi is available and there is a television in the room. Family members and friends are always welcome.
- Bring your supply of Neupogen to the hospital on the stem cell collection days so the nurse can give your injection.

Mozobil

- Not all patients need Mozobil.
- Mozobil is an injection given to help the bone marrow release more stem cells. On the day of your planned stem cell collection, Mozobil will be given to you if your blood work shows that there aren't enough stem cells in your blood yet.
- Mozobil must be given 10 hours before the next expected collection. This means you will need to return to the hospital (Kidd 9) at 10 p.m. to receive it. Your nurse will give you further instructions.

What happens to my stem cells once they are collected?

- At the end of the collection day, the bag of collected stem cells will be sent to the lab in Ottawa where the cells (called 'CD 34') are counted.
- Your cells are then frozen so they can be returned to you later. A preservative called 'DMSO' is added to your cells to prevent damage during freezing and thawing.

Steps of the stem cell transplant as an inpatient

The following steps, from Step 4 to 6, will happen as an inpatient. You will be admitted to the hospital to receive high-dose chemotherapy, re-infuse your stem cells, and recover your blood counts. The total length of hospital stay is usually 3-4 weeks.

Preparing for your hospital stay

Admission to hospital

- You will be admitted to the hospital on Kidd 9 (the 9th floor) the day before your high-dose chemotherapy. The team will complete a baseline assessment (blood work and chest x-ray) before you receive the chemotherapy.
- Our Admitting Department will call you on the day of your hospital admission with information on when to come to the hospital (likely between 10 a.m. - 10 p.m.). If you are planning to be out on this day, please call the Admitting Department at 613-549-6666 extension 1221 and provide a phone number where you can be reached.
- The first 1-2 days in hospital you may be required to share a room with another patient. You will be moved to a private room once your stem cells have been returned to you, or possibly sooner.
- There are no restrictions on visiting hours. Family members are welcome at all times.

Packing for the hospital

Bring items to help you feel at home during your hospital stay. Make sure you read the recommended packing list below when you are preparing for your hospital stay. **See our recommended packing list on the next page.**

Recommended packing list for your hospital stay

- Soft toilet tissue
- Unscented Baby Wipes
- Unscented Body Lotion
- Soft toothbrush
- Soft Snacks such as pudding, instant breakfast, apple sauce, yogurt, soups etc.
- Club soda (similar to a mouth rinse you will be given to prevent mouth sores)
- Plug-in cooler/bar fridge to keep your own supplies in your room
- Reading lights
- Tablet/laptop (Wi-Fi available)
- IPod for music
- Whatever you do at home that fills your time (hobbies, puzzles, etc.)
- Your own comforter, blanket and pillows (the hospital supplies bed linens and pillows but you can bring your own in for comfort)
- Walking shoes and outdoor clothing (coats, hat, etc.). We will encourage you to be active.
- Comfy clothes to wear during the day
- Clothes to sleep in
- Shower shoes

Hospital Routines

Daily routines

- Your vitals (temperature, heart rate, blood pressure) will be monitored every 4 hours, day and night.
- Each morning around 5:00 - 6:00 a.m., your nurse will come to your room to draw your bloodwork. This is necessary so that any required infusions can be planned for the day.
- If you wake up or go to the washroom in the middle of the night, ring your call bell so the nurse can come check your vitals or do blood work while you are awake.
- The Hematology Oncology team will come to assess you daily.

Meals

- You will receive a menu with a variety of choices. A staff member will come around to take your selection before each meal.
- There is a kitchen with a microwave and fridge available on the unit. Some food items are available in the kitchen for patients. You can bring a plug-in cooler to keep food and drinks cold in your own room.
- You can bring food from home.
- You will meet a registered dietitian at the beginning of your hospital stay. The registered dietitian will help you manage your nutrition throughout treatment.

Staying active in the hospital

We encourage you to be as active as you can during your hospital stay. Being active will help prevent your body from becoming deconditioned. It can also prevent some complications from treatment, like a lung infection. Here are some key things to keep in mind:

- It is expected that you set a routine of getting out of bed in the morning, dressing in your own clothes, and doing activities you would normally do at home.
- Go outside and use the walking path by Lake Ontario, or walk around the hospital unit.
- Sit up in a chair for all your meals

Step 4

Getting high-dose chemotherapy

- Your high-dose chemotherapy is given on the day(s) following your admission to the hospital and 2-3 days before your stem cell transplant.
- The high-dose chemotherapy is much stronger than any of your previous chemotherapies. This is why you need your stem cells to help your bone marrow recover. Without your stem cells as a "rescue", your bone marrow would take months to recover. During this time you would be at very high risk of a serious life threatening complication.
- The type of chemotherapy you will get depends on your type of cancer. Refer to drug-specific Patient Information Sheets for more information on your chemotherapy and anti-nausea medications given on these days.
- On the day(s) of your chemotherapy, you will be connected to an IV before, during, and after for hydration.

Key points about side effects from high-dose chemotherapy

Go to the section 'Managing side effects' on page 24 to learn more about managing side effects of high-dose chemotherapy.

- Do not take your side effects lightly. They will likely be more intense than what you have previously experienced. However, every patient is different- some experience more side effects than others.
- Report any side effects as soon as they start. When you identify a side effect early, it can often be managed better and there is less chance of complications.
- Your health care team will provide you with special care to prevent and manage side effects while you recover in hospital.
- Your high-dose chemotherapy will cause your blood counts (red blood cells, white blood cells and platelets) to fall to a very low level for at least 14 to 21 days. This is the time that you are at the greatest risk for infection and bleeding.
- Painful mouth changes/sores (called 'mucositis') are another common side effect and can be severe. To manage mouth changes, you will be provided with several mouth rinses. Your nurse will teach you how to use the mouth rinses regularly. Maintaining good, regular mouth care is also important.

Key points about side effects from high-dose chemotherapy (continued)

- If you receive Melphalan (a type of chemotherapy), you will be given ice to suck on starting 30 minutes before the chemotherapy to reduce mouth changes. You will continue to suck on ice during the infusion and for 30 minutes after. For more information, read the provided cryotherapy handout
- Other possible side effects include: nausea, vomiting, diarrhea, hair loss, lack of energy and appetite.

Step 5

Re-infusing your stem cells (transplant)

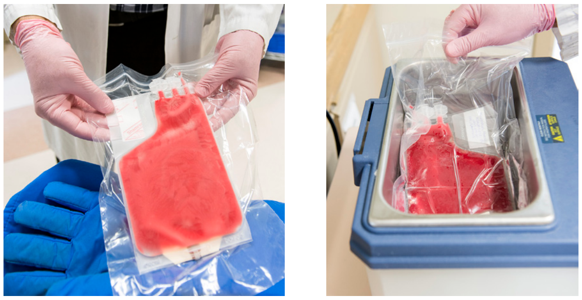
Your stem cells are given back to you (re-infused) 2-3 days after your high dose chemotherapy.

- Your stem cell reinfusion will occur in the Stem Cell Transplant Unit. The reinfusion happens in the mid-afternoon and takes about 2 hours total. Once your reinfusion is complete you will return to the inpatient unit.

Pictured to the right

Your stem cell re-infusion will occur in the Stem Cell Transplant Unit using your PICC line.

- Your PICC line will be used.
- A family member is welcome.
- Your frozen stem cells are thawed in a tub of warm water. They are then infused like a unit of blood. Each bag of cells is infused over 30 minutes.



Pictured to the right

Frozen stem cells being thawed in a tub of warm water.

There are some minor effects from the reinfusion that last about 24 hours. These include:

- An unusual taste in your mouth. To lessen this side effect, hard candy will be provided to suck on during the reinfusion.
- Some pain in your lower back.
- An unusual smell from your skin. Some people say it smells like ‘creamed corn’. It is caused by a preservative that is cleared through pores in your skin. Patients do not smell it but family members or visitors may.

Step 6

Waiting for your blood counts to recover (engraftment)

The high-dose chemotherapy will cause your blood counts (white blood cells, platelets and red blood cells) to fall to a very low level. You will stay in the hospital until your blood counts recover.

The medical term for when your blood cells recover is called 'engraftment'. Engraftment is when your stem cells go back to your bone marrow and begin to make new blood cells. Engraftment usually starts 10-12 days after your stem cell reinfusion.

What treatment to expect while you stay in the hospital after your stem cell reinfusion:

- The Hematology/Oncology team will come to assess you daily.
- Your blood work will be taken daily to check your blood counts and other important blood work results.
- You will receive transfusions and fluid replacements as needed.
- You will be started on several new oral medications to prevent infection. Some patients will still develop an infection and need to start on IV antibiotics.
- On the 5th day after your stem cell reinfusion, you will start daily injections of Neupogen again. Your Neupogen injections will continue until your white blood count has recovered.

Pictured to the right

Patient undergoing stem cell transplant in her hospital room.

You play a very important role while your blood counts recover in the hospital. Key things that you can do to help in your recovery:

- Tell your healthcare team about any concerns or questions you have. Your team counts on you to let them know how you are feeling and what your needs are.
- Stay active as possible. Being active will help prevent your body from becoming deconditioned. It can also help to prevent some complications from treatment, like a lung infection. Walk around the unit as much as you can, at least 3 times a day.

Step 7

Recovery after stem cell transplant

Once your blood counts have recovered and you are feeling well, you will be discharged home from the hospital.

Pictured to the right

A stem cell patient "ringing the bell" before leaving the hospital. "Ringing the bell" is a way to mark the end of your hospital stay after the stem cell transplant.

Long term side effects

Many patients have questions about how they will feel once they go home. There are some common side effects that last longer, such as:

- Feeling tired. This can last for several months.
- Appetite and taste changes. These changes usually last for 1-3 months.

Go to the section 'Managing side effects' on page 24 to learn more about managing side effects of high-dose chemotherapy, including fatigue, appetite and taste changes.

Resuming life

It will take time to resume a normal life. Here are some common questions from patients after their stem cell transplant:

- **When can I return to work?** Everyone is different, but some people find they are able to return to work about 6 months after their transplant.
- **When can I have sex?** Check with your nurse or doctor about resuming sexual activity while your blood counts are recovering.
- **Can I exercise?** Being physically active, as you are able, will help you manage fatigue, feel better and build strength. However, you may have to modify your old activities. Ask your nurse or doctor if there are any restrictions on your physical activity.
- **Can I drink alcohol?** Talk to your doctor about recommendations for if/ when you can drink alcohol after a stem cell transplant.

Follow-up appointments

You will have regular follow-up appointments with your health care teams during your recovery after stem cell transplant. Follow-up appointments will be scheduled for you with:

- Your primary hematologist within 1 month of your hospital discharge
- The stem cell transplant team at 100 days after your stem cell reinfusion

You are still a patient at the Cancer Centre. To manage long-term changes, registered dietitians and social workers in the Cancer Centre are available to help you.

You will be scheduled to return to the hospital for a follow-up appointment with the stem cell transplant team100 days after your transplant. This visit will include seeing the doctor (pictured to the left).

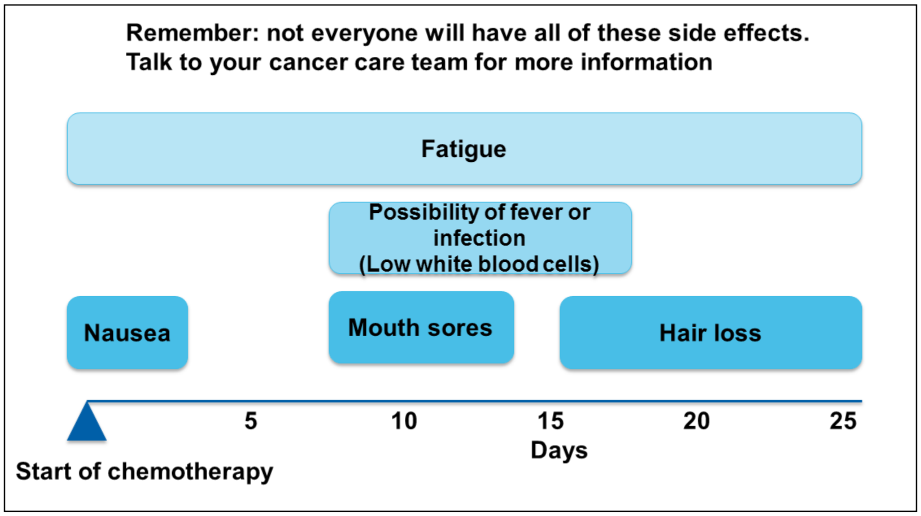
Managing side effects

There are side effects from high-dose chemotherapy, which can last for days to months after receiving the chemotherapy. You may experience some or all of these side effects:

- Mouth sores
- Diarrhea and rectal pain
- Constipation
- Bleeding easily
- Risk of infection
- Lack of energy (fatigue)
- Hair loss
- Loss of appetite
- Taste changes
- Nausea and vomiting
- Weight loss

You can expect some of these side effects to get better by the time you leave the hospital. The others can take longer to resolve.

The following chart gives you an idea of when to expect certain side effects after your chemotherapy.



Remember: not everyone will have all of these side effects.
Talk to your cancer care team for more information

Mouth sores

It is common to develop a sore or painful mouth several days after chemotherapy. The medical term for this is 'mucositis'. The first sign of 'mucositis' is a dry, irritated or burning feeling in your tongue or mouth. This can progress to small sores on the inside of your cheeks and lips. While you are in hospital, members of your health care team will inspect your mouth daily.

Keeping up good mouth care can help with the pain caused by mouth sores and also prevent infection from starting.

Things for you to do:

- Tell your nurse if you have trouble swallowing or notice pain or sores in your mouth or throat.
- Clean your mouth after every meal and at bedtime.
- Brush your teeth with a soft toothbrush. The hospital has touthette sponges if it is too painful for you to use a toothbrush.
- Try not to use anything that could cause irritation to your mouth. This includes: commercial mouthwashes, alcohol, hot or spicy foods, tobacco and poorly fitting dentures.
- To rinse your mouth when you are at home, use a baking soda mouth rinse 3-4 times a day (¼ tsp baking soda and 1/8 tsp salt in 1 cup of warm water). Use this mouth rinse up to 1 month after your stem cell transplant.
- Try the following eating suggestions:
  - Try soft, non-irritating foods such as eggs, cream soups, ice cream, and ground meats.
  - Gravies, sauces and soups can help soften foods.
  - Limit foods that may irritate a sore mouth such as hard or crunchy foods, very hot or very cold foods, and acidic, spicy or salty foods.

While you are in the hospital, your nurse will instruct you in more detail on how to take good care of your mouth and will give you special mouth rinses to use. Pain medications may also be ordered for your mouth pain or sores.

Diarrhea and rectal pain

You may develop diarrhea after you have received chemotherapy.

Things for you to do:

- Tell your nurse if you develop diarrhea. While you are in the hospital, a sample will be taken to test for any infection. While the test is being performed, you will be placed on isolation precautions. These precautions will be removed when the test is confirmed negative.
- Clean your outer rectal area with mild soap and water after each episode of diarrhea then rinse well and pat dry with a soft towel. Cleaning will help to lessen your risk of infection and skin irritation. Avoid inserting anything in your rectum (anus), such as rectal suppositories or enemas, when your white blood cells are low.
- Tell your nurse if you start to have any pain or bleeding in your rectal area.
- Ask your nurse about using a sitz bath (a warm, shallow bath for your genital and rectal area) to clean and relieve pain.
- Try the following eating suggestions:
  - Drink plenty of fluids to replace losses, at least 8 to 10 large glasses per day. Try water, broth, fruit juices, Jell-O and Gatorade.
  - Eat high potassium foods such as bananas, apricot and peach nectars, meat and potatoes.
  - Limit the use of bowel stimulants such as coffee, chocolate and prune juice.
- Check with your doctor before taking any over-the-counter (not prescribed by a doctor) medications for diarrhea.

Constipation

While you recover, you may develop constipation from changes in what you are eating, medication and being less active.

Things for you to do:

- Tell your nurse if you feel constipated or if you have not had a bowel movement in 3 days.
- Avoid straining to have a bowel movement.
- When your blood counts are low, do not use suppositories or enemas to relieve constipation. This may cause infection or bleeding.
- Try the following eating suggestions:
  - Drink at least 8 to 10 large glasses of fluid each day.
  - Try gradually increasing high fiber foods such as bran and whole wheat breads and cereals.
  - Try natural laxative foods such as prunes, prune juice or rhubarb.
- Check with your doctor before taking any over-the-counter (not prescribed by a doctor) medications for constipation.

Bleeding easily

Chemotherapy will cause your platelets to become low for a short period of time. This usually occurs 1 to 2 weeks after chemotherapy and lasts for 2 to 3 weeks. Low platelets put you at a greater risk for bleeding. For this reason, steps need to be taken to prevent bleeding.

While you are in hospital:

- Blood tests are done every day to check your platelet count.
- You will get platelet transfusions if your platelet count becomes too low.
- Your healthcare team will examine you for signs of bleeding.

Things for you to do:

- Report any signs of bleeding to your healthcare team. Signs of bleeding include:
  - Bruising
  - Vomit that looks like coffee grounds
  - Black, tarry bowel movements
  - Bright red blood in your urine or bowel movements
  - Nose bleeds
  - Heavy or long menstrual periods
- Use an electric razor, instead of a blade, to prevent cuts.
- Do not take medications that thin your blood without first speaking to your cancer care team. Medications that thin your blood include anti-inflammatories (Aspirin (ASA), Ibuprofen or Naproxen); anti-platelets (Plavix); and anticoagulants.

Risk of infection

As mentioned earlier, your white blood cells are affected by chemotherapy. After chemotherapy, you will be at a greater risk of infections because of your lowered immune system. Your care after transplant is focused on preventing infection.

While you are in hospital:

- You will stay in a private room after your transplant to lessen the chances of catching an infection from others.
- Your nurse will check your temperature every 4 hours during the day and night and watch for signs of infection, such as a new cough or redness, tenderness and swelling at your PICC line site.
- If you develop an infection, your team will treat you with antibiotics and monitor you carefully. A doctor who specializes in infectious disease will also come to see you.

Things for you to do:

- Washing your hands is the best thing you can do. Wash your hands often with soap and water or hand sanitizer, especially before eating and after using the toilet.
- Tell anyone who enters your room, including visitors and hospital staff, to wash their hands.
- People who are sick should not visit you when your white blood cells are low.
- The first sign of infection is usually a fever. Tell your nurse right away if you feel like you have a fever or are chilled.
- Check with your nurse to see if you can leave the unit, as you may need to wear a mask when your white blood cell counts are low.
- While your blood counts are low (neutrophils under 0.5), wear a face mask (hospital will provide you one) when you leave your room.
- Avoid common areas on the unit, such as the kitchen and sun room.

Fatigue (lack of energy)

A stem cell transplant and its side effects will reduce your energy level, especially 2-3 weeks after chemotherapy. You will likely still feel very tired when you are discharged from the hospital, but you will improve gradually over the next few weeks and months.

'Fatigue' is the term used to describe lack of energy, feeling weak and tired, and having trouble concentrating or finishing small tasks.

Fatigue is often caused by many factors such as low blood counts, infections, eating less food and being less active.

Things for you to do and be aware of:

- Balance your rest and activity. Take opportunities to rest throughout the day.
- Chemotherapy affects your red blood cells. You may need transfusions to increase your red blood cells and give you more energy.
- Try to limit the length of visits with family and friends.
- Light exercise such as walking will help with your energy.
- Plan activities that need concentration or energy when you are more rested.
- Ask your team for patient education material on managing fatigue.
- Fatigue can make it difficult to prepare healthy meals and snacks. If fatigue is a problem, try the following:
    - When you feel well, prepare meals ahead of time and freeze individual servings.
    - Keep easy to prepare foods on hand, such as frozen dinners, canned foods, eggs, tuna and noodles.
    - Eat small, frequent meals.
    - Try take-out food restaurants.
    - Use home delivery services.

Hair loss

- You will experience hair loss 2-3 weeks after your mobilization chemotherapy. Hair loss is temporary. Your hair will grow back 3-6 months after your treatment.
- Your nurses can provide information and support to manage the impact of hair loss on your life.
- An information sheet is available that lists services nearby selling wigs and hair alternatives.

Side effects related to your nutrition

You may experience side effects that affect your eating habits or ability to eat. These side effects are especially concerning if they prevent you from eating well.

During your treatment, your body will need enough energy and protein to heal and repair tissue. Being well nourished can help you cope with your disease and treatment. It will also keep your energy level up and help you recover. Poor nutrition can decrease your immune function and slow bone marrow response.

Maintaining a healthy weight is important. Find out from your doctor or registered dietitian if your weight is within the healthy range. Being underweight can weaken your ability to fight infection. If you are underweight, try to gain some weight before your treatment.

A registered dietitian will be consulted during your hospital stay to help you eat well. The registered dietitian can help you learn about nutrition and provide suggestions on how to eat as well as you can during your treatment.

Poor appetite

When you have a poor appetite, it is important to make every bite count. Try the following ideas to increase your food intake:

- Eat frequent meals during the day.
- Have a meal or snack every one to two hours.
- Choose snacks that are higher in protein and calories, such as eggs, cheese, and higher fat milk.
- Choose fluids that are higher in nutrients, such as milk, smoothies, Ensure, cream soups, or hot chocolate made with milk and cream.

Upset stomach

- Try cold foods such as meat, tuna or egg salad sandwiches and creamed cottage cheese with fruit.
- Eat bland foods that are easier on your stomach, such as soda crackers, rice, soft cooked eggs, apple juice and custards.

Change in taste

Each person’s taste may be affected differently. Here are some tips to help your food taste better:

- If red meat is unappealing, try dairy products, eggs and fish.
- Tart foods may help to overcome a metallic taste. Try citrus juices, pickles and mints.
- Add extra sugar to mask the flavor of salty foods.
- Add salt to decrease the sweetness of sugary foods.

Dry mouth

Some treatments can reduce the flow of saliva and cause a dry mouth or thick saliva. If this is a problem, try these suggestions:

- Sip liquids often.
- Try soft, moist foods.
- Eat less dry foods such as crackers.
- Avoid thick syrups.

Other Important Nutrition Points

Drink plenty of fluids

- You need to try to drink at least 8 to 10 glasses of fluid a day to prevent dehydration.
- Water, tea, juice, popsicles, Jell-O and Gatorade Recover are excellent fluid choices. Ice cream, milk and pop are higher in calories.

Commercial nutrition supplements

- Supplements that are high in protein and calories are available. Your registered dietitian will be able to recommend a supplement that is best suited for you.

Vitamin and mineral supplements

- Vitamins and minerals are an important part of a healthy diet. Following "Eating Well with Canada's Food Guide" will help you receive all your vitamins and minerals in the correct amounts. Find Canada's Food Guide online at: www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php.
- Cancer treatment can affect your ability to eat a healthy diet, so a multivitamin may be recommended. Check with your doctor before taking any vitamin or mineral supplements.
- You may read articles or books that recommend high doses of vitamins or minerals to prevent or treat cancer. Most nutrition and medical experts agree that high doses of vitamins or minerals are not effective in preventing or treating cancer. In fact, taking too much of one vitamin or mineral can be harmful.
- Discuss any concerns with your dietitian or doctor.

Herbal teas

- Check with your health care team about whether there are any herbal teas to avoid while receiving treatment.

Coping with the emotional impact

Undergoing a stem cell transplant can affect every part of your life, including your body, feelings, relationships, self-image and sexuality. Some patients say that the emotional impact of a transplant can be harder to manage than the physical changes.

Your emotions can change from day to day, or minute to minute. Your emotions may also change because of the step of the transplant process you are in.

Your emotions

Some of your feelings may include:

- Hope, anxiety, helplessness, uncertainty, impatience, isolation
- Being out of control and overwhelmed
- Fear of sickness, death or the unknown

All of these feelings are normal.

Taking care of your emotional wellbeing during your stem cell transplant is very important. Here are some things you can try that other patients have found helpful:

- Share your feelings with those who are close to you, such as your family and friends.
- Ask your health care team questions, so you will know what to expect.
- Ask to speak to other patients who have had a transplant.
- Practice relaxation techniques, such as meditation and listening to music.
- Manage your energy before, during and after the transplant by eating well and being active.
- Bring your own belongings to the hospital, like family pictures, books, movies, crafts and your own clothes.
- Set small daily goals for yourself.
- Take one day at a time.

Your family

Family members are also affected by a stem cell transplant. Your family members may share the same feelings and worries that you do. Role changes are common and family members may take on more responsibilities. Financial or legal problems are also common concerns.

Here are some things to try:

- As a family, try to openly share your feelings and work together to solve your problems. A social worker can help with this.
- Prepare family members, such as children and grandchildren, by talking with them and giving them information suited to their age and level of understanding.
- As a family member and caregiver, you need to take care of yourself too. Get enough sleep, eat well, be active and find time to do things you enjoy.
- Let extended family members know how they can best help you. Family and friends want to be there for you, but need to know what is most helpful. Practical things include help with car rides, meals, child care/pet care, household chores and daily activities.
- Take care of any financial or legal problems such as Power of Attorney, wills, sick benefits and disability pensions. A social worker can help you with this.

Self-image and sexuality

Side effects of treatment (such as hair loss, weight changes, fatigue and emotional changes) can affect your sexuality. Common sexual changes include body image concerns, low sexual desire, difficulties with erections, pain during sexual activity, and relationship changes.

It is safe to have sex once your blood cell counts and immediate treatment side effects have recovered.

Here are some things to remember:

- Talk openly about your feelings with your partner.
- Being physically active improves self-image and energy.
- There are many ways to express your affection and be intimate with your partner. Long walks, good conversation, hugging, kissing and touching are important aspects of intimacy.
- Talk with your health care team if you have questions or concerns about sexual or body changes, birth control, periods (menstruation) or fertility
- There is support available to help you.

Going home and recovery

Patients often have mixed feelings about leaving the hospital, feeling relieved and frightened at the same time. You may feel worried or uncertain about what's next. Once your follow up visits become less frequent, you may also feel out of touch with your health care team.

Adjusting to life after your stem cell transplant will take time. You will likely have good days and bad days. It will take time for you to step back into your roles, such as being a parent, spouse, employee and friend again. Be patient with yourself as you adjust and recover.

Here are some things you can try that other patients have found helpful:

- Gradually return to a routine.
- Talk with your health care team about any questions, such as when you can return to work.
- Ask to speak with a cancer care social worker if you are having trouble adjusting.
- Try to find small pleasures in each day. Do things that you enjoy, things that boost your mood and things that are relaxing to you.

Pictured to the right

A stem cell transplant patient at her 100 day follow-up appointment. Ask your healthcare team if you have questions about adjusting to life after your stem cell transplant.

Community Resources and Websites

Here are a list of resources to help you look for information and support.

Cancer Chat Canada

www.cancerchatcanada.ca

- An online support group for people with cancer.

Canadian Cancer Society

www.cancer.ca

- A database of easy-to-read information on diagnosis, pathology and staging, treatment, supportive care, research and development, Canadian statistics, prognosis and survival.

Cancer Information Service (Canadian Cancer Society)

Phone 1-888-939-3333

- An information specialist will answer your questions and give you information about cancer-related topics and services. Service is available Monday to Friday from 9 a.m. to 6 p.m. in English and French. For other languages, an interpreter service is available.

Lymphoma Canada

www.lymphoma.ca

- Lymphoma Canada offers information about the different types of lymphoma, including a comprehensive section for the newly diagnosed patient.

Leukemia & Lymphoma Society of Canada

www.llscanada.org

- Leukemia & Lymphoma Society of Canada funds blood cancer research and provides free information and support services to patients and family members.

Myeloma Canada

www.myelomacanada.ca

- Canadian support organization for patients diagnosed with multiple myeloma.

Community Resources and Websites (continued)

Look Good, Feel Better®

- A free, 2 hour hands-on workshop for women to help you manage the appearance-related effects of cancer and its treatment.
- Workshops are offered monthly in Kingston. To register call 613-549-6666 extension 7480. Workshops are offered 5 times a year in Belleville. To register call 613-962-0686. For more information visit Look Good, Feel Better® website at www.lgfb.ca

Peer Support Service (Canadian Cancer Society)

Phone 1-888-939-3333

- Telephone support program that connects you with a trained volunteer who has had a similar cancer experience.

Explanation of blood counts

Your bone marrow is the “factory” where blood cells are made. Bone marrow is found in the skull, breast bone (sternum), ribs, back bone (spine) and pelvis. Chemotherapy affects the growth of cancer cells and some normal cells, especially blood cells (temporarily).

The most common blood cells you will hear about are red blood cells, white blood cells and platelets.

You will get a tracking sheet from your team to help you keep track of your blood count levels each day you are in hospital.

White blood cells (WBC)

- The normal range is between 4.5 and 10.5.
- White blood cells are made in the bone marrow and their purpose is to fight infection.
- When your white blood cells are low, you have a lowered immune system and are at higher risk of infection.
- After high dose chemotherapy your WBC will be very low for several days.
- Transplanting your own stem cells will help these blood cell counts to return to safe levels. This usually occurs about 14 to 21 days after high dose chemotherapy.

Neutrophils

- The normal range is between 2.0 -7.5. This is called the Absolute Neutrophil Count (ANC).
- Neutrophils a type of white blood cell important in fighting infections. These cells are measured separately as part of the white blood count. After high dose chemotherapy, your neutrophils will be very low for several days to weeks.
- Your ANC needs to be at an adequate amount before you leave the hospital (equal or exceeding 0.5). When your neutrophil count reaches this level it means your stem cells have ‘engrafted’ and are making new blood cells.

Explanation of blood counts (continued)

Red blood cells (RBC)

- The normal range for women is 120 to 160 g/L.
- The normal range for men is 140 to 170 g/L.
- These cells carry oxygen to all cells in the body. Our bodies need oxygen in order to work properly.
- A blood test called a CBC will measure the red blood cells.
- When your RBC is low, or these cells do not contain enough hemoglobin, you have anemia. This may occur temporarily after chemotherapy.

Following high dose chemotherapy, your hemoglobin is likely to be very low. You may need a blood transfusion to increase your hemoglobin.

Platelets

- The normal range is between 150 and 450.
- Platelets are cells in the body that make your blood clot. When the platelet count is lower, you may bleed more easily and for a longer time.
- A lower platelet count occurs after chemotherapy because the bone marrow is temporarily damaged.
- If your platelet count is quite low and not expected to return to a safe level for a few days you may need a platelet transfusion.
- A platelet transfusion is given through your IV to increase your platelet count until your blood cells recover and you are making enough platelets on your own.

Glossary

Anemia: A condition in which the blood contains less hemoglobin than normal.

Antibiotics: Medications used to fight bacterial infections.

Apheresis: A painless procedure by which your blood is withdrawn and circulated through a machine that removes the stem cells and then returns remaining cells back to your bloodstream.

Aspiration: To draw out the marrow by suction using a syringe.

Autologous Transplantation: A transplant in which the tissue infused comes from the individual receiving it.

Biopsy: Removal of small piece of tissue for microscopic examination.

Bone Marrow: Spongy tissue inside the bones where the blood cells are produced.

Chemotherapy: Anticancer drugs or combination of drugs designed to kill cancer cells.

Clinical trial: A carefully controlled and monitored research to test a new drug or therapy, involving human patients.

DMSO (dimethyl sulfoxide): A substance used to keep stem cells alive during the freezing process.

Engraftment: When the re-infused stem cells start making blood cells. Its onset is defined as the day when the neutrophil count equals or exceeds 0.5.

Growth Factors: hormones that stimulate cells to divide and grow.

Hematologic: Relating to blood and blood forming tissues.

Heparin: A drug used to thin the blood and keep it from clotting.

High-dose Chemotherapy: Higher than standard doses of anticancer drugs given to destroy as many remaining tumor cells as possible.

Immunosuppression: Suppression of the immune system.

Infusion: The introduction of a liquid into the body through a vein.

Mobilization: The process of treating patients to move stem cells from the bone marrow into the bloodstream for apheresis.

Neupogen (Filgrastim): A hormone given by injection which mobilizes stem cells from bone marrow into the bloodstream.

Peripheral Blood Stem Cell: A stem cell that has left the bone marrow and is circulating in the blood stream.

Glossary (continued)

Platelets: Cells that are needed for blood to clot.

Red Blood Cells: Cells that pick up oxygen from the lungs and take it to tissues throughout the body.

Regimen: A defined system of treatments.

Reinfusion: The return of your stem cells to your bloodstream.

Remission: Complete or partial disappearance of symptoms of a disease in response to treatment.

Re-staging: The process of evaluating how well your cancer is responding to treatment.

Stem cells: “Parent” cells in bone marrow from which all blood cells develop; also known as progenitor cells.

Stem cell collection (Harvest): The process of taking stem cells out of the blood; see apheresis.

Subcutaneous Injection: Injection into the fatty layer under the skin.

White Blood cells (WBC): The blood cells that fight infection.

We hope you found this resource helpful.

This resource has been developed by members of the Oncology Program at the Kingston General Hospital.

We welcome your feedback on how we can improve this resource for future patients. Contact Patient Education at (613) 549-6666 extension 7987 with your feedback.

Patient Education, Oncology Program
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