



Myeloma Canada

InfoGuide Series

High-dose Therapy and Autologous Stem Cell Transplantation



**MYELOMA
CANADA**

MAKING MYELOMA MATTER

www.myeloma.ca

Disclaimer

The information in this InfoGuide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your specific diagnosis, treatment and medical or social situation.

Although this InfoGuide briefly discusses allogeneic stem cell transplantation, its main focus is on high-dose therapy followed by stem cell “rescue”.

The procedure is commonly referred to as an autologous stem cell transplant and will be referred to as such. Autologous stem cell transplantation is the standard of care and most commonly used therapeutic approach for newly diagnosed transplant-eligible patients with myeloma.

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Centre universitaire
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McGill University
Health Centre

Office d'éducation des patients
Patient Education Office

Reviewers

Healthcare Professionals

Richard LeBlanc
MD, FRCPC, CSPQ
Hematologist/Oncologist
Maisonneuve-Rosemont Hospital
Clinical Assistant Professor of Medicine
University of Montreal
Montreal, QC

Yvonne Gulliver
RN, BN, CONC
Stem Cell Transplant Coordinator
Eastern Health
St John's, NL

Karen MacCurdy Thompson
BSc Pharm, BCOP
Oncology Pharmacist
The Moncton Hospital
Moncton, NB

Patients and Caregivers

Myeloma Canada Patient Advisory Council

Lorelei Dalrymple
Chair
Edmonton, AB

Hervé Benoît
Quebec Representative
Montreal, QC

David McConkey
Atlantic Canada Representative
St John's, NL

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Co-chair
Halifax, NS

Julie Gibbons
Ontario Representative
Toronto, ON

Keith Taylor
Western Canada Representative
Vancouver, BC

Additional Reviewers

Susan Collins
Saint John, NB

Editors

Gabriele Colasurdo, MSc
Manager, Education and Patient Services
Myeloma Canada
Montreal, QC

Aldo Del Col, BScPhm
Co-founder
Myeloma Canada
Montreal, QC



Introduction

This InfoGuide is intended for patients with myeloma, their families and friends. It provides information about **high-dose therapy** and autologous stem cell transplantation and aims to clarify and explain the process and what to expect. Some of the more technical or unusual words **appear in bold** the first time they are used and are explained in the glossary on page 31.

This InfoGuide aims to be informative, practical and easy-to-read.
You will find information on:

- Autologous stem cell transplantation and its potential advantages and disadvantages
- Each step of the procedure and what is involved
- What to expect before, during and after this treatment
- Helpful tips for you to make informed decisions about your treatment and care

Furthermore, this InfoGuide will explain how you can play an active part during the recovery process. You can help prevent some complications and increase your chances of a faster recovery if you follow the instructions that we have included for you here.

Once you and your doctor agree that an autologous stem cell transplant is the best option to help control your myeloma and possibly get it into **remission**, an extensive process that takes place over several weeks will begin. You will meet the stem cell transplant team who will provide you with a lot of information about your care. Depending on your hospital, the team may include: doctors, nurses, a stem cell transplant program coordinator and quality officer, pharmacists, social workers, nutritionists, physiotherapists, occupational therapists, psychiatrists and stem cell lab technologists. As experts in their respective areas, they will all be available to support you.



About Myeloma Canada

Myeloma Canada is a registered non-profit organization created by, and for, people impacted by multiple myeloma. As the only national organization exclusively devoted to the Canadian myeloma community, Myeloma Canada has been making myeloma matter since its founding in 2005.

Working with leading myeloma researchers and clinicians as well as other cancer organizations and local support groups across Canada and internationally, Myeloma Canada seeks to strengthen the voice of the Canadian myeloma community and improve the quality of life of myeloma patients, their caregivers and families through education, awareness, advocacy, clinical research and community engagement.

Myeloma Canada's goals are to:

- Empower patients and caregivers through community engagement
- Provide educational resources to patients, families and caregivers
- Increase awareness of the disease and its effects on the lives of patients and their families
- Facilitate access to new therapies, treatment options and healthcare resources
- Advance clinical research and promote access to new drug trials in Canada

This InfoGuide is intended to help patients and families who are living with myeloma better understand autologous stem cell transplantation and help them prepare for the procedure.

For more detailed information about myeloma and living with the disease, you can refer to Myeloma Canada's educational publications:

- *Multiple Myeloma Patient Handbook*
- *Myeloma Bone Disease InfoGuide*
- *Understanding Your Blood and Blood Tests InfoGuide*
- *Myeloma and the Kidney InfoGuide*
- *Clinical Trials as a Treatment Option InfoGuide*

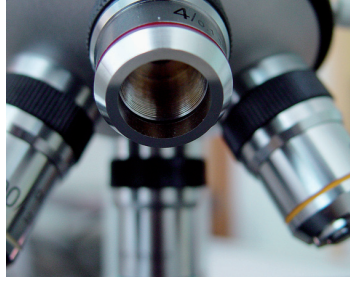
To order free copies, send an e-mail to contact@myeloma.ca or call 1-888-798-5771 toll free.

Visit www.myeloma.ca to download Myeloma Canada's educational publications or to find a support group in your area.



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About Bone Marrow, Stem Cells, Plasma Cells and Myeloma

Definition of Bone Marrow and Stem Cells

Bone marrow is the spongy tissue that is found inside your bones (Figure 1). It is soft, fatty and full of blood vessels. Your bone marrow is where most of the blood cells in your body are made.



Did You Know?

Cells are the building blocks that make up the tissues and organs (eg, heart, stomach, liver) of your body. When a cell (eg, blood cell) gets old or is damaged, your body repairs it or clears it away. A brand-new cell then grows and takes its place. There are billions of cells in your body and these cells are constantly growing and being replaced by new cells.

Stem cells (also referred to as progenitor or master cells) are found in many of your body's organs, such as the bone marrow. When compared to other kinds of cells (eg, muscle, nerve or blood), stem cells are unique because they are capable of long-term self-renewal (Figure 2).

Figure 1: Bone marrow

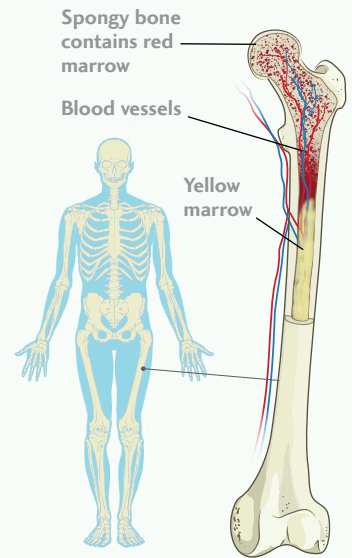
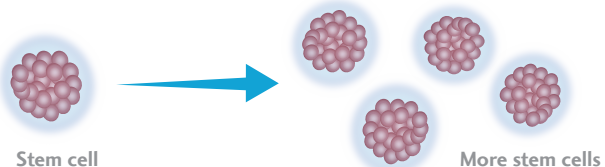
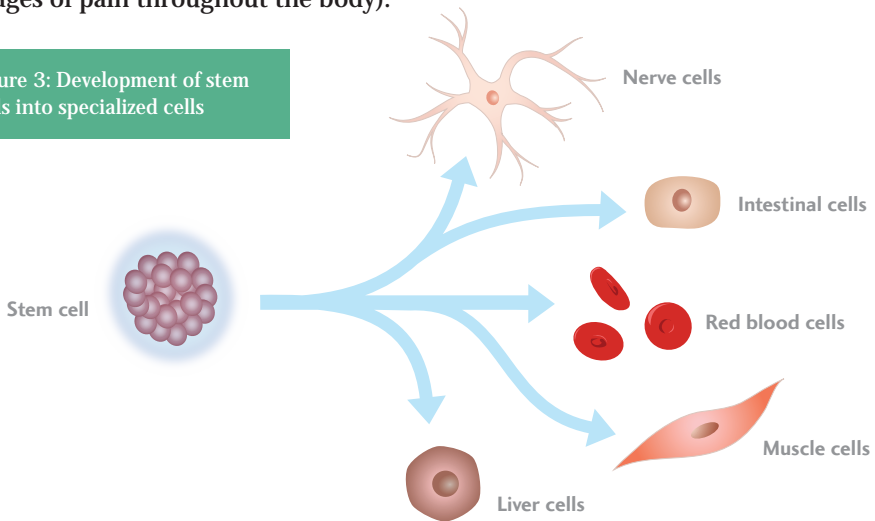


Figure 2: Self-renewal of stem cells



Stem cells are also unique because they are only partially developed (unspecialized) cells that can develop (or differentiate) into over 200 different types of specialized cells (Figure 3) with useful bodily functions (eg, nerve cells in the brain being able to send messages of pain throughout the body).

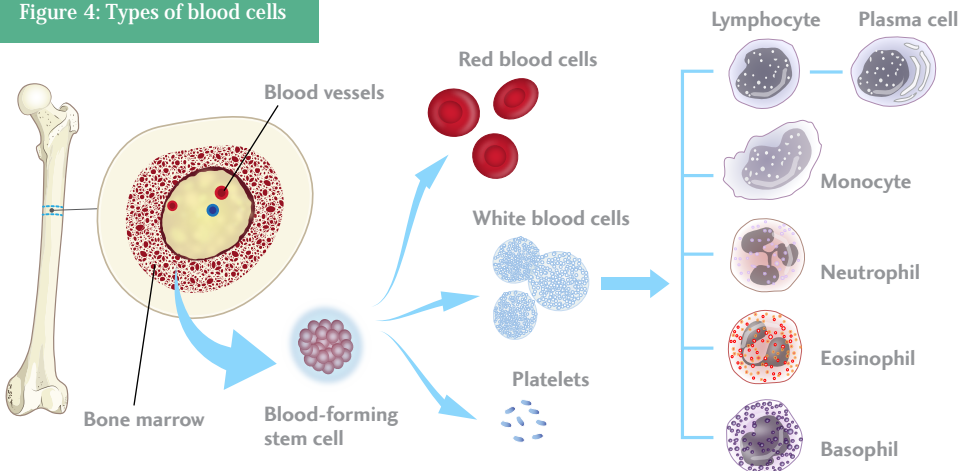
Figure 3: Development of stem cells into specialized cells



One type of blood-forming stem cell found in the bone marrow (also called a hematopoietic stem cell) grows into each of the different types of blood cells (Figure 4) in your body before moving into your blood:

- White blood cells – help fight infection (eg, plasma cells; neutrophils)
- Red blood cells – help carry oxygen to all the organs in your body
- Platelets – help the blood to form clots (eg, to stop bleeding)

Figure 4: Types of blood cells



Plasma Cells and Myeloma

A plasma cell is a type of white blood cell that is made in the bone marrow by “blood-forming” or hematopoietic stem cells. Plasma cells produce **antibodies (immunoglobulins)** that fight infection (Figure 5). They are therefore an important component of the body’s immune system. The production of normal, healthy plasma cells is a controlled process. When plasma cells age or become damaged, they normally die and new plasma cells take their place.

Myeloma is a cancer associated with the abnormal behaviour of plasma cells. In someone with myeloma, this normal process “breaks down” resulting in the uncontrolled growth of abnormal plasma cells, also known as myeloma cells. Myeloma cells can have a negative effect on different parts of the body and interfere with the production of other types of blood cells by “crowding out” the bone marrow. Furthermore, myeloma cells overproduce one type of antibody, known as an **M-protein** (also referred to as monoclonal protein, paraprotein, myeloma protein or M-spike). Due to the overproduction of myeloma cells and M-protein, several related health problems can occur (among others):

- Elevated blood calcium (hypercalcemia)
- Kidney damage
- Low hemoglobin (anemia)
- Bone pain and/or fractures (lesions)
- Frequent or recurring infections
- Fatigue/weakness

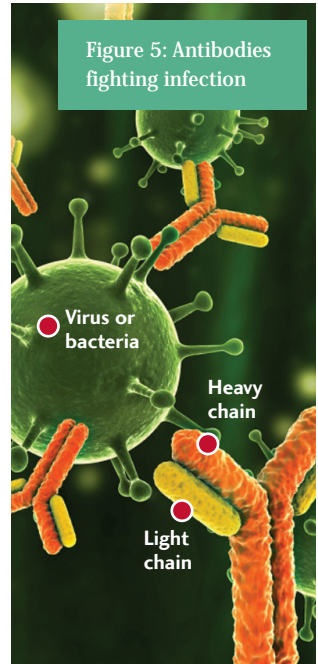


Figure 5: Antibodies fighting infection

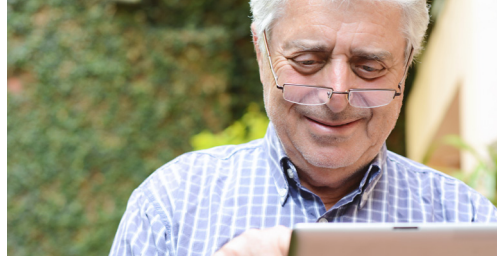
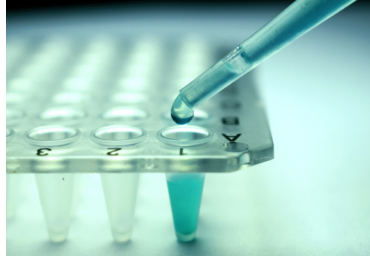
Immunoglobulins (antibodies) are Y-shaped molecules. The heavy and light chains of the antibody contain specific binding sites that attach to bacteria or viruses, ultimately leading to their destruction thereby protecting against disease.



Did You Know?

Based on your specific diagnosis and situation, participating in a clinical trial (research study) may be a treatment option to consider. Whether you are newly diagnosed or have exhausted some or all available treatment options, clinical trials can provide you with access to new drugs or combinations of treatments that are not yet approved by Health Canada and, therefore, unavailable to patients, except through a clinical trial. Clinical trials may also provide access to drugs or combinations of treatments that are approved by Health Canada but not covered by government drug plans.

For more details about clinical trials and for answers to frequently asked questions, please refer to Myeloma Canada’s *Clinical Trials as a Treatment Option InfoGuide* by visiting www.myeloma.ca. To order free copies, send an e-mail to contact@myeloma.ca or call 1-888-798-5771 toll free.



Stem Cell Transplantation

Overview

Before deciding to undergo a stem cell transplant, you should find out as much as you can about the procedure. If you decide that this treatment is not right for you, you should still consider collecting and storing your stem cells for a future transplant because some therapies used to treat myeloma may reduce the chances of a successful stem cell collection in the future. Once the stem cells are collected, a transplant can be performed either as **first-line treatment** or at the time of **relapse**, if eligible.

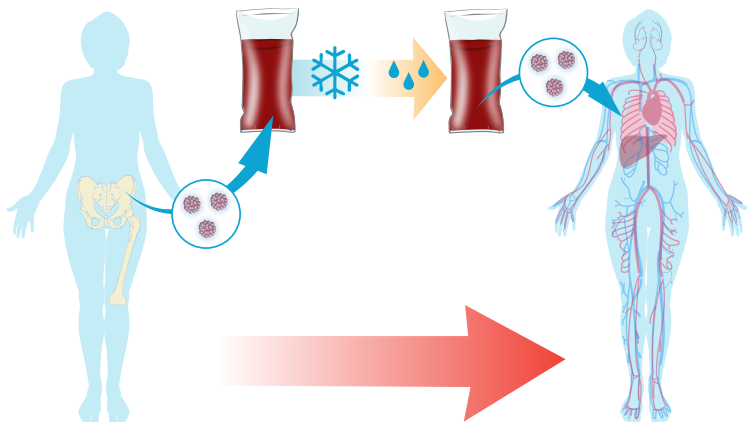
Eligibility for first-line transplant does not guarantee eligibility for a transplant at the time of relapse. This is the main reason why stem cell transplantation is often proposed as a first-line treatment for eligible newly-diagnosed myeloma patients. Your doctor will speak to you about your options and the best transplant plan for you. Your transplant team will support and guide you throughout the process (before, during and after the procedure).

There are two main types of stem cell transplant approaches:

- **Autologous stem cell transplant (Figure 6):**

The stem cells come from you. An autologous transplant is the **standard of care** for treating newly diagnosed myeloma.

Figure 6: Autologous stem cell transplant

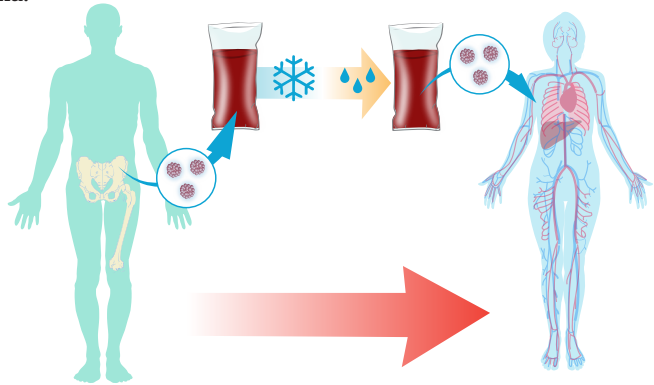


■ **Allogeneic (donor) stem cell transplant (Figure 7):**

The stem cells come from a matching donor such as a relative (usually a sibling), or a matched unrelated donor (MUD). Allogeneic transplant is not the standard of care for treating myeloma.

This approach is generally undertaken under the supervision of a clinical trial setting.

Figure 7: Allogeneic (donor) stem cell transplant



In some cases, tandem (double) transplant approaches can prolong the response of the first transplant.

- **Two (double/tandem) autologous transplants:** May be beneficial depending on the treatment response achieved after the first transplant or if the myeloma is considered to be “high-risk”. The transplants are usually planned within six months of each other.
- **Autologous transplant followed by a reduced-intensity allogeneic (donor) transplant:** This is an experimental approach where high-dose therapy with an autologous transplant is followed by reduced-intensity allogeneic transplant.

A second autologous transplant after relapse may be considered if the clinical benefit of the first transplant was sufficiently significant, usually determined by when the relapse occurs more than 18-24 months after the first transplant.

NOTE: From this point onwards, the focus of this InfoGuide will be exclusively on autologous stem cell transplantation.

? **Did You Know?**

Although called a stem cell “transplant”, there is no actual organ removed from a donor to a recipient. As stem cells were traditionally collected directly from the bone marrow rather than from the circulating blood, the procedure was originally referred to as a bone marrow “transplant”.

The 7 Steps of an Autologous Stem Cell Transplant

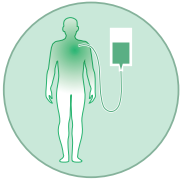
The goal of an autologous stem cell transplant is to help you achieve a deeper, more durable response and ultimately improve your quality of life and **overall survival**. When considering any treatment, however, it is important to think about the potential advantages and evaluate if they outweigh the potential disadvantages, risks and side effects. An autologous stem cell transplant will likely be the most intensive myeloma treatment you will receive; therefore, it is important that you are well-informed. To help you better understand and assess whether an autologous stem cell transplant is right for you, the following section will clearly outline the 7 steps involved, before, during and after the procedure.



1. EVALUATION

Not every newly-diagnosed patient is eligible for an autologous stem cell transplant.

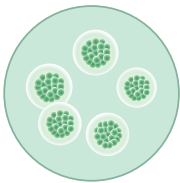
The high-dose therapy step (step 5 – **conditioning**) is very intensive and generally limited to people that are strong enough to tolerate the treatment.



2. INDUCTION

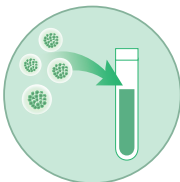
You will receive a chemotherapy regimen to kill as many myeloma cells as possible with the aim of reducing symptoms and lessening **end-organ damage**.

This step also prepares for the mobilization and collection of your stem cells.



3. MOBILIZATION

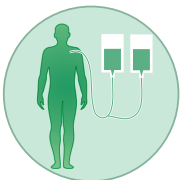
To enable stem cell collection, you will be given medication to mobilize (release) some stem cells from your bone marrow to your blood.



4. COLLECTION

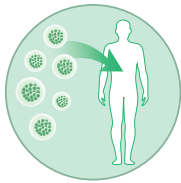
Stem cells will be collected from your blood.

This step is also referred to as stem cell harvest.



5. CONDITIONING

You will receive a high-dose chemotherapy to kill as many of the remaining myeloma cells in your body and bone marrow as possible.



6. RESCUE

This step involves the thawing and infusion of your collected stem cells back into your body to “rescue” the bone marrow. These stem cells contain healthy blood-forming cells that will make new blood cells to replace the cells destroyed by the high-dose therapy through a process known as **engraftment**. A successful engraftment enables the bone marrow to recover and re-establish blood cell production.



7. RECOVERY

Depending on the person, the recovery period can vary widely from a few months to a year. During this time, you will be followed closely by your healthcare team.

? Did You Know?

The induction and conditioning steps of an autologous stem cell transplant involve treatments that can lower the amount of myeloma cells in your bone marrow and body. Specifically, the conditioning step (high-dose therapy) is the most important therapeutic step, along with the rescue step (stem cell transplant) providing the support necessary for recovery.

Evaluation: Assessing Eligibility

To determine whether you are eligible for an autologous stem cell transplant, overall health, fitness, age, previous treatments and the presence of other diseases or conditions (co-morbidities) are considered. Many hospitals have a general rule that an autologous stem cell transplant is not routinely offered to people above a certain age, such as 65 or 70 years; however, these are not “hard-and-fast” rules. The important thing is not your chronological age – how old you are, but rather your biological age – how generally healthy you are.

Age cut-offs vary between hospitals and can be somewhat flexible depending on the case and the hospital. For example, a “fit” 71-year-old person could be considered for an autologous stem cell transplant while a “frail” 64-year-old person may not be eligible. In other words, someone who is deemed not healthy enough to withstand the high-dose therapy (conditioning step) of the procedure will not be eligible for an autologous stem cell transplant. Moreover, a person considered ineligible can become eligible for a transplant if the reason for their ineligibility changes. There are, however, several effective treatment options for people who are deemed ineligible for a transplant. Speak to your doctor about what options may be best suited to your specific situation.

Induction: Reducing the Number of Myeloma Cells

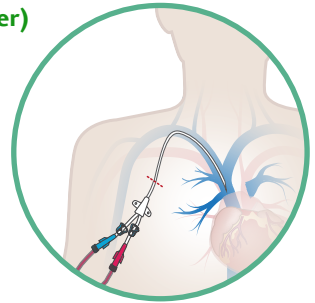
The goal of the induction step of an autologous stem cell transplant is to reduce the amount of myeloma cells in your body in order to diminish symptoms and lessen end-organ damage. This step is done before your stem cells are mobilized from your bone marrow to your blood, collected and frozen. Induction treatment is given in cycles for approximately four to six months depending on:

- Type of induction treatment
- Response to the induction treatment
- Time delay until transplant

The combination referred to as CyBorD (cyclophosphamide [Cytoxan], bortezomib [Velcade], dexamethasone) is commonly used. Other combinations such as RVd (lenalidomide [Revlimid], bortezomib, dexamethasone) are sometimes used under certain clinical circumstances. Ask your doctor which induction treatments are available at your hospital and which would be the best suited for you. Your medical team will explain the medications that you will receive before the induction treatment.

If vein access is difficult, a **central line (central venous catheter)** may be inserted in your upper chest (Figure 8) to administer the induction treatment. The central line can also be used for some of the remaining treatments and tests of the stem cell transplant procedure.

Figure 8: Central line in upper chest



Induction Side Effects

Depending on the regimen used, myeloma induction treatments can cause varying **side effects** such as fatigue, mouth sores, nausea, diarrhea, clotting, anemia and an increased risk of infection. “Supportive” treatments can help prevent, treat or manage side effects or reduce the risk of getting them. All side effects must be immediately reported to your doctor or nurse to prevent them from becoming worse.

Side effects can often be reduced by a lower dose or change in treatment schedule.

Response to Induction Treatment

Before proceeding to the collection of your stem cells, your myeloma should ideally respond to the induction treatment. This generally means that there is a 50% or more reduction in your monoclonal protein (also referred to as M-protein, paraprotein, myeloma protein or M-spike) blood levels. If this response is not achieved after a few cycles of induction treatment, you may be switched to another induction treatment. If the response is not achieved following the second induction treatment, you might still be able receive a stem cell transplant depending on whether enough stem cells can be mobilized and collected.

? Did You Know?

“Chemo Brain” is Real

Throughout the various steps of an autologous stem cell transplant, you will be exposed to chemotherapy treatments that may have an impact on mental functions such as memory and thought processing. Patients have termed this feeling of their brain “not being the same” as chemo brain or chemo fog. Although the effects that are felt and their extent can vary from person to person, the most commonly reported effects are general “fogginess”, slowed thinking, forgetfulness, periods of confusion and difficulty concentrating.

Chemo brain symptoms generally improve over time and full cognitive function can take a year (or more) to be reestablished. Others may continue to experience symptoms long after their treatment has ended and never fully regain that “normal” mental feeling.

There are no established treatments for chemo brain. Coping strategies such as memory aids, mild to moderate exercise and minimizing distractions (ie, avoiding loud places to improve concentration) can also help minimize the effects of chemo brain. Untreated depression, anxiety and sleep disorders (ie, apnea) may also worsen chemo brain symptoms.

Collection: Harvesting and Storing the Stem Cells

Prior to the collection of your stem cells, be sure to talk to your doctor about the number of stem cells that will be collected. By making sure that enough stem cells are harvested and frozen to support two or more transplants, you can increase your treatment options for the future.

The stem cells can be obtained either through circulating blood (more common) with a process called **leukapheresis** (Figure 9) or from bone marrow (very rarely used) using a special needle and syringe that draws out bone marrow cells from the pelvic bones (Figure 10).

When stem cells are collected through circulating blood, the first step is to increase the number of stem cells in the blood with drugs that stimulate the bone marrow to release more stem cells into the bloodstream. This treatment is referred to as **mobilization**.

Figure 9: Leukapheresis machine

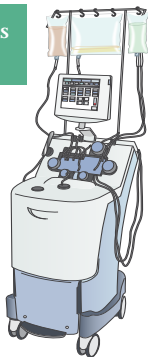
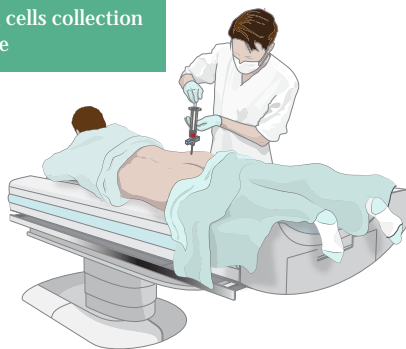


Figure 10: Stem cells collection from pelvic bone



Stem Cell Mobilization

The two most common methods of stem cell mobilization use a growth factor called granulocyte-colony stimulating factor (G-CSF) such as filgrastim (Neupogen; Grastofil) with or without cyclophosphamide (Cytoxan). G-CSF stimulates the bone marrow to release stem cells into the bloodstream and is given as a daily subcutaneous injection (under the skin) around the same time each day for 5–7 days prior to the collection of stem cells. Cyclophosphamide is given as a single dose prior to the first dose of G-CSF as it is useful for stem cell mobilization and also has an anti-myeloma effect. In situations where there is difficulty in collecting the required number of stem cells, another drug called plerixafor (Mozobil) may be added to improve the release of stem cells and is administered as a daily subcutaneous injection for up to 4 consecutive days. Towards the end of mobilization, a **CD34+** blood count is done to check if there are enough stem cells in the blood for collection to take place.

? Did You Know?

CD34+ is the technical name given to a protein found on stem cells. Measuring CD34+ provides a useful way of ‘tagging’ and counting the number of stem cells in the blood.

Unfortunately, for a very small number of people, even after additional mobilization treatments, enough stem cells cannot be collected for a safe transplant. In that case, alternative treatment options would be discussed.

Mobilization Side Effects

G-CSF injections can cause temporary side effects such as fever, aches and bone or joint pain that should disappear when the injections stop. Pain medications may be necessary during this time.

Regarding cyclophosphamide, the most common side effects include nausea, general weakness, loss of appetite, rash and hair loss.

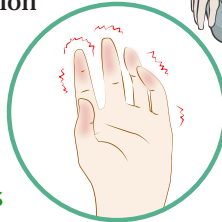
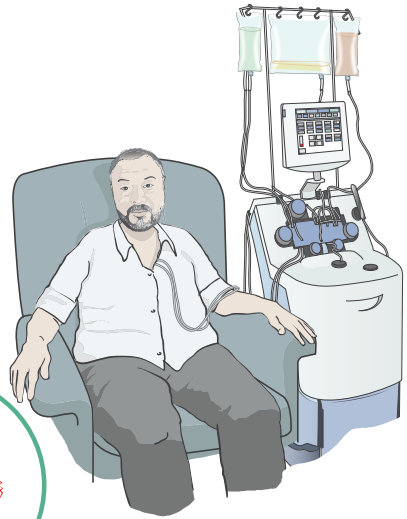
The most common temporary side effects associated with plerixafor include headache, nausea, dizziness, diarrhea, bone or joint pain and redness and irritation at the injection site. These are temporary and should disappear when the injections stop.

Stem Cell Collection from Circulating Blood

Stem cell collection from circulating blood is a simple procedure that involves inserting a line into a vein in each arm. Blood is taken by a leukapheresis machine that separates the stem cells from the rest of the blood. The remaining blood is then returned to the body. If vein access is difficult, some people may need to have a central line installed in their upper chest (Figure 11).

The procedure usually takes about 3-4 hours and may be done over a period of a few days to collect enough stem cells. A minimum of two million stem cells per kilogram of body weight is required for one successful transplant. It is common practice to collect enough stem cells for two transplants, regardless whether only one transplant is planned. This ensures that people have the option of having a future second transplant.

Figure 11: Stem cell collection from central line with leukapheresis machine



Stem Cell Collection Side Effects

During the collection process, you may feel cramping or tingling sensations in the hands, feet and/or mouth. This side effect is felt because your blood is mixed with an anticoagulant to stop it from clotting in the leukapheresis machine, leading to a drop in your body's calcium levels when the blood is returned to your body.

Stem Cell Freezing (Cryopreservation)

Your collected stem cells will be frozen through a process called **cryopreservation** and stored until they are needed. This ensures that the stem cells are not damaged by high-dose therapy (next step) and survive while outside of your body.

The stem cells are mixed with a chemical called dimethyl sulfoxide (DMSO) and placed in special labelled bags before being frozen and stored. DMSO is used to prevent the water in the cells from forming ice and permanently damaging them. Stem cells can be stored for many years depending on the hospital or storage facility. Your transplant team should be able to provide you with details regarding their storage policy.

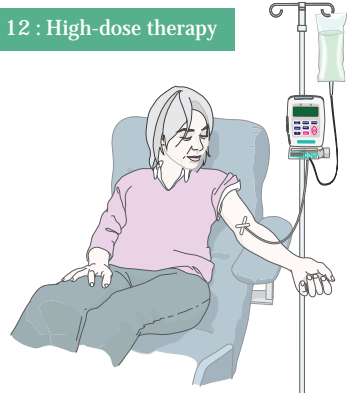
Conditioning: High-dose Therapy

The next step in the stem cell transplant process is a conditioning treatment: high-dose therapy (Figure 12), generally with melphalan (Alkeran), given **intravenously**. High-dose therapy may be the strongest treatment you will ever receive. The goal of the treatment is to kill as many of the remaining myeloma cells in your bone marrow and your body as possible. Higher doses can kill more myeloma cells than standard doses.

High-dose therapy is an important therapeutic step. Research shows a link between a lower amount of residual myeloma cells remaining in your bone marrow and your body (response to the stem cell transplant) and longer periods of possible remission with better outcomes.

Prior to receiving melphalan, you will be given fluid intravenously to prevent dehydration and possible kidney damage. If you have poor kidney function, the dose of melphalan may be adjusted.

Figure 12 : High-dose therapy



Side effects of Conditioning (High-dose Therapy)

The common side effects of high-dose therapy are:

- **Nausea and vomiting:**

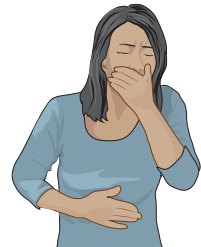
Prior to high-dose therapy, an anti-nausea (anti-emetic) drug is given to prevent nausea and vomiting. If nausea and/or vomiting occurs despite this prevention, your prescription will be modified to better control it.

- **Mouth sores and/or dry mouth:**

Mouth sores (oral mucositis) can occur for a short time after receiving therapy. Sucking on ice chips during the infusion may help prevent mouth sores. Medicines or a special mouthwash can also help to prevent or treat mouth ulcers. Keep your teeth clean by regularly using a soft toothbrush and try to avoid things that might irritate your mouth, such as spicy, salty or tangy foods. If you have a sore or dry mouth, avoid foods that stick to the roof of your mouth (eg, peanut butter or chocolate) and mouthwashes that contain alcohol. Moisten your food with gravy or sauces and try drinking through a straw or sucking ice cubes or frozen treats.

- **Altered taste, smell and loss of appetite:**

With some time, your sense of smell and taste will return to normal, along with your appetite. Try eating small amounts of food frequently throughout the day. If you feel hungry at some parts of the day and not at others, eat your larger meal when you are hungry. It is also important to stay hydrated and drink plenty of fluids.



- **Fatigue:**

Feeling very tired, being sluggish and unable to concentrate or sleeping longer than usual is normal. As you recover, you will slowly regain your energy levels.

- **Hair loss (alopecia):**

This is common 2–3 weeks after high-dose therapy. If it occurs, remember that your hair will grow back after 3–6 months. Hair loss may begin sooner based on exposure to cyclophosphamide during the induction treatment phase.



Potential Long-term Effects of High-dose Therapy

Unfortunately, high-dose therapy also damages your healthy blood-forming cells. Furthermore, with new myeloma treatments and improved supportive care, people are living longer than ever before. Thus, there may be an increased risk for long-term effects associated with high-dose therapy. Although rare, some long-term effects include:

- **Second cancers:** When high doses of melphalan damage normal cells, some are not able to recover and may become cancerous.
- **Organ damage:** High-dose therapy can damage organs, particularly the lungs (interstitial lung disease). Following the transplant, recurring chest infections can also damage the lungs.
- **Infertility:** High-dose therapy can lower your fertility or trigger premature menopause. You may be offered the choice of having your eggs or sperm stored.

Speak to your healthcare team about all of the possible long-term effects and what you can do to minimize the risks.



Rescue: The “Transplant” – Infusion of Your Collected Stem Cells

Since high-dose therapy also destroys healthy blood and stem cells in your bone marrow, the bone marrow needs to be “rescued” or “re-seeded” with your previously collected stem cells. A few days following the conditioning step (high-dose therapy), your stored stem cells are thawed and intravenously infused back into your body over approximately one hour. The infused stem cells will help “jump start” or rebuild your bone marrow by producing new blood cells. This step is sometimes also referred to as engraftment.

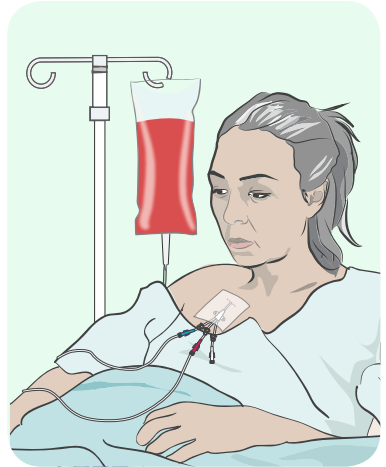
Side Effects of Stem Cell Infusion

Temporary side effects related to the agent (DMSO) added to the stem cells prior to freezing include: nausea, vomiting, coughing, shortness of breath, abdominal/stomach cramping, headache, chills, and facial flushing. During the infusion, you may taste or smell garlic or corn. Your urine can be red for a few hours after the infusion.

DMSO completely leaves your body through the lungs (as you breathe) in 24-48 hours. Slow, deep breaths during the infusion can help push the DMSO out of your body faster and help control side effects.

A rare side effect of the infusion is low blood pressure and/or a fast heart rate. Medications are given before the infusion to prevent or minimize these effects.

It is important that you share any new symptoms or side effects with your nurse or doctor.



Engraftment

Within the first few days after infusion, the “transplanted” stem cells make their way through the bloodstream and into the bone marrow, where they start to produce new blood cells and begin to “rescue” or re-populate your bone marrow. This process takes approximately 14-21 days and, until then, your immune system is very fragile and you are susceptible to infection. Thus, you must maintain your personal cleanliness and you may be required to stay in a clean room until engraftment is established and the new cells start to grow. For many people, this is the toughest part of the transplant process. In some cases, high-dose therapy followed by stem cell rescue can be done at the outpatient clinic with frequent visits. You can speak to your doctor about this possibility.

During this time, you are also at risk of bleeding, infection and anemia, therefore you will be monitored with regular blood tests to check your blood counts. If necessary, blood transfusions can help increase the levels of your red blood cells and platelets.

In rare cases, the stem cells do not engraft well and injections with a G-CSF such as filgrastim (Neupogen; Grastofil) is required to stimulate the growth of **neutrophils**. Sometimes, more stem cells, if available, can also be infused.



Recovery: Supportive Care and Maintenance

Inpatient or Outpatient?

Depending on the hospital, you may either begin your recovery at the hospital (inpatient) or from home (outpatient). As an outpatient you will be required to have a 24-hour caregiver, keep a daily record and visit the hospital's outpatient transplant day hospital regularly to track your recovery. You will also need to go over your home care instructions with your nurse, review your medication list and schedule with your pharmacist and discuss your nutrition plan with the nutritionist. As an inpatient, the average hospital stay is 4 weeks for an autologous stem cell transplant.

Inpatient: Recovering at the Hospital

At the hospital, you should expect the following daily routine. Please note that protocols will vary from centre to centre.

- Your vital signs will be monitored closely and your doctor will come see you daily.
- Your blood will be drawn daily for tests. If you have a central line, it will be checked every 3 days, or as per your treatment centre protocol.
- You will have a complete daily physical check-up and you will be weighed at least once a day.
- You may meet regularly with a nutritionist and a physiotherapist. You may also request to meet other members of the transplant team (social worker, psychiatrist, etc).
- You may be given daily breathing exercises to perform.
- You may be asked to save all of your urine, vomit and stool in the appropriate containers for monitoring purposes.

A lack of concentration is common during this time, so it is important to stay relaxed and do things that are not too mentally challenging or demanding. Your floor or room will most likely have a television and a phone, and you will be allowed to bring things to help keep you busy (books, magazines, DVDs, etc).

It is also important to eat and stay active during your recovery:

- If you don't have an appetite and/or can't keep food down, the nutritionist can help.
- Get out of bed at least three times a day for at least 30 minutes each time.
- Walk around in your room or unit a few times each day.

Outpatient: Recovering at Home

For a patient recovering at home, each visit at the outpatient day clinic may be slightly different based on whether you need special tests or medications. Your visits can be short (a few hours) or last the entire day.

Here is a list of items you should take with you to each visit:

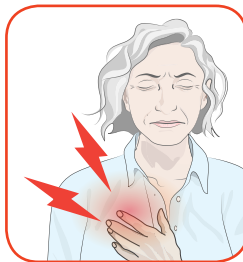
- Both your hospital and provincial healthcare cards
- Your daily record from the previous day(s)
- Any medications you may need to take that day (eg, pain medication)
- Your regular medications (eg, blood pressure)
- Your 24-hour caregiver
- Lunch, snacks and drinks
- A pen and notebook
- Entertainment (books, magazines, DVDs, etc).

Your transplant nurse will (this may vary depending on where you are being treated):

- Ask about how you are feeling and any side effects you may be experiencing
- Take your blood tests
- Take your weight, temperature and blood pressure
- Measure your heart and breathing rate
- Give you 1 litre of saline (intravenously) to keep you hydrated
- Check your body for signs of bruising, bleeding or infection

Be sure to let your transplant nurse know if you have had:

- Blood in your stool or urine
- Nose bleed(s)
- Fever, chills or a cough
- Tenderness and swelling around your central line



Depending on your blood test results and how you are feeling, you may need:

- A blood transfusion (red blood cells and/or platelets)
- Additional saline to prevent dehydration
- Additional tests (eg, urine, X-ray, ultrasound) to look for signs of infection
- Intravenous antibiotics to fight an infection

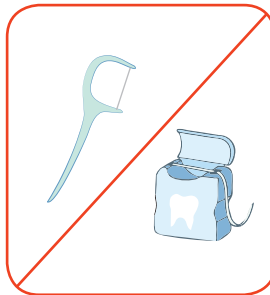
In the majority of cases, a short-term hospitalization will be eventually needed, mostly because of fever and infection.

Special Precautions (Inpatient and Outpatient)

As stated in the previous chapter, you will have an increased risk of infection, anemia and bleeding. To help prevent fungal and viral infections, you may be prescribed antibiotics as well as other drugs. An infection such as **shingles** can sometimes originate from your own body due to the re-emergence of the chickenpox virus over your weakened immune system. Infections can occasionally be very serious and life-threatening; therefore, they are usually treated in the hospital with intravenous medications.

Special Precautions

- Keep your hands clean by washing them with soap and water after going to the bathroom and before eating. Only use an alcohol-based sanitizer if a sink is not available.
- Visitors and hospital staff should always wash their hands before they make contact with you or with your body fluids, blood, bed linen and clothing.
- Shower every day and dry with clean towels. Wear clean clothes.
- Your bed linen should be changed every day.
- Avoid flossing. Use a soft-bristle toothbrush when brushing your teeth after all meals and at bedtime. Use any special mouthwashes provided to you.
- Avoid using razors or scissors as they can lead to bleeding and infections.
- Follow the diet recommendations set by the transplant centre to avoid foods that may cause a stomach bug. Speak with your centre's dietician.



Leaving the Hospital

After being in the hospital as an inpatient for a few weeks, it is normal to feel many different emotions. Although you are excited to go home and relieved that the transplant is over, you may feel nervous and anxious about leaving the safety of the hospital and wonder how successful the treatment was. Thus, it is important to share your concerns with your transplant team so that they can help you (and your caregiver) plan for your recovery at home.

You will be allowed to leave the hospital when you are feeling better and your blood counts have increased. Note that it may be normal for your blood counts to be lower than what they were prior to the stem cell transplant. The minimum requirements to be discharged from the hospital are as follows (the criteria may vary from centre to centre):

- Your neutrophil count must be above $0.5 \times 10^9/L$
- You must not have had a fever (sign of infection) for at least 24 hours
- You only need a maximum of two blood transfusions per week

Note: Many patients do not require transfusions.

You must also be able to:

- Properly take your oral medications
- Eat and keep the food down
- Drink enough fluid each day



Before leaving, you will:

- Go over your home care instructions with your nurse
- Review your medication list and schedule with the pharmacist
- Discuss your nutrition plan with the nutritionist

If you need help with making arrangements for transportation and/or where you will be staying after leaving the hospital, speak to a member of your healthcare team (social worker or discharge nurse).

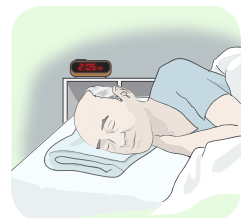
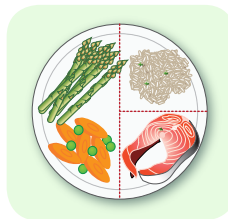


At Home

The full recovery period can last a few months but can vary greatly from person to person; the first few months at home are generally the most difficult as you may continue to feel weak and extremely tired.

There are a number of things you can do to stay healthy and help in your recovery:

- Take your prescribed medications as directed. Speak to your doctor before taking anything that was not prescribed (eg, vitamins, herbal supplements, over-the-counter medications) to you.
- Drink at least 1.5 litres of fluids (no alcohol) each day to stay hydrated and to help reduce the side effects of your prescribed medications.
- Eat well and follow the food safety instructions provided to you by the transplant centre for at least six months after your transplant. If you have trouble eating large meals, eat several small meals throughout the day. You may also speak with your centre's dietician.
- Take extra care of your mouth and teeth to decrease the risks of dental infection by brushing with a soft-bristle toothbrush after all meals and at bedtime. Do not floss.
- Take care of your skin by washing with gentle soaps and moisturizing with cream.
- Apply sunscreen whenever you plan on being outdoors.
- Stay active and exercise each day to maintain your muscle strength. Light exercises such as short walks or yoga are sufficient. Always check with your doctor before engaging in any, more strenuous, activities such as riding a bicycle (your platelet counts must be high enough).
- See your family and friends but be sure to avoid anyone who is sick.
- Find a good balance between resting and being active.



There are a few things that you should avoid while recovering:

- Smoking and drinking alcohol and beer (eg, homemade or microbrew).
- Products that contain alcohol (eg, perfumes and some creams).
- Eating raw foods such as (among others):
 - Seafood/fish (eg, sushi, sashimi, oysters, clams) or meat (eg, steak tartare)
 - Nuts, honey, grains, rough-textured fruits (eg, raspberries) and sprouts (eg, bean, alfalfa).
 - Cured, smoked or pickled deli meats and fish
- Eating uncooked or undercooked foods such as (among others):
 - Eggs or foods that might contain them (eg, some salad dressings)
 - Non-refrigerated cream and mayonnaise-based foods (eg, tuna/macaroni salad, pudding, custard)
 - Cultured foods (eg, yogurt, kimchi, sauerkraut, tempeh, miso)
- Eating unpasteurized foods, drinks and cheeses such as (among others):
 - Milk, eggs, honey, juices or teas (eg, kombucha)
 - Soft cheeses (eg, brie or feta), cheeses with mold (eg, blue cheese) or fresh cheeses (eg, queso fresco/blanco)
- Drinking water from a well or swimming in a lake.
- Large crowds (eg, parade, party, busy mall).
- Eating at restaurants for the first six months after your transplant.
- Cleaning litter boxes, bird cages or fish tanks for one year after your transplant.
- Gardening (eg, mowing, raking) for one year after your transplant.

Call your nurse if you notice the following:

- New cough or skin rash
- New pain
- Sore throat and/or trouble swallowing
- Mouth sores
- Nausea or vomiting that does not go away
- Changes in your urine or bowel habits
- Shortness of breath when you are resting or after mild exercise
- Problems with your central line
- You are unable to take your medication
- Changes to your appetite or any other changes that concern you



Go to the hospital's emergency department immediately if you have:

- High fever (38.3°C or more) or if your temperature is higher than 38.0°C for more than one hour
- Chest pain and/or trouble breathing
- More than three liquid stools per day
- Severe nausea or vomiting



Travelling

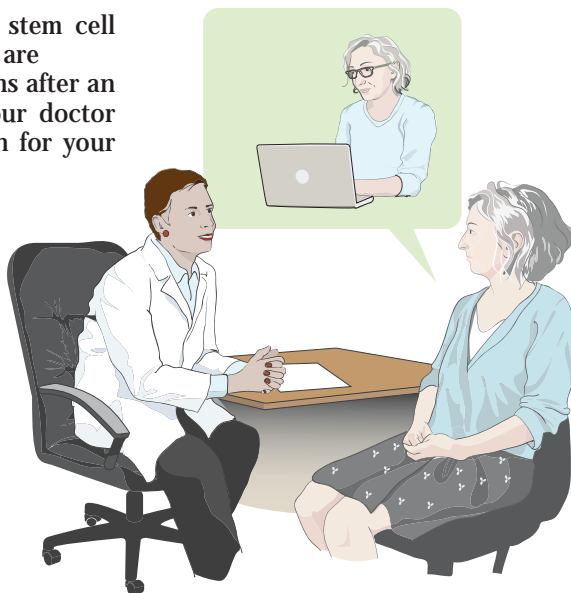
Travelling should be avoided for 6 months after an autologous stem cell transplant.

Returning to Work

Everyone recovers differently from a stem cell transplant. Generally speaking, people are usually able to return to work 6 months after an autologous transplant. Speak with your doctor about how you are feeling and a plan for your return to work.

It is recommended to go back to work part-time at first, until you have your strength back. Talk to your employer about this.

You may want to consider whether you would like your colleagues to know about your cancer and treatment. This is a very personal decision that you should think about before returning to work.



Treatment Follow-up and Response

Following an autologous transplant, you will have frequent visits to the hospital clinic for the first 100 days. If you need blood transfusions, then you may need to visit the clinic more often. Note that you should only receive irradiated blood products.

Blood tests with or without urine and imaging tests (eg, **CT** scan, **PET** scan, **MRI**, X-rays) will be done to see how your body is responding to the transplant and to the disease. Approximately three months after your transplant or if you have achieved an apparent complete response you may have a bone marrow biopsy. After 100 days, depending on your hospital, you will visit your regular hematologist, an oncologist or a nurse practitioner.

You may have heard terms such as complete response (CR) or partial response (PR) used to describe a person's response to treatment and to accurately evaluate its efficacy. Although some hospitals may use different definitions, the most commonly-used response criteria for myeloma were developed by the *International Myeloma Working Group (IMWG)*:

- **sCR (Stringent Complete Response):** Complete Response (see description below) plus a normal **free light chain** ratio and an absence of myeloma plasma cells in the bone marrow.
- **CR (Complete Response):** No detectable monoclonal protein (M-protein or M-spike) in the blood or urine, disappearance of any **soft tissue plasmacytomas (extramedullary tumours)** and less than 5% of myeloma plasma cells in the bone marrow.
- **VGPR (Very Good Partial Response):** Detectable blood and urine M-protein by **immunofixation** (but not on **electrophoresis**) or 90% or greater reduction in blood M-protein plus urine M-protein less than 100 mg per 24 hours.
- **PR (Partial Response):** 50% or greater reduction in blood M-protein and a 90% or greater reduction in 24-hour urine M-protein (or less than 200 mg per 24 hours). If blood and urine M-protein are not measurable, PR is defined by additional criteria (ask your healthcare team). If soft tissue plasmacytomas (extramedullary tumours) were present, a 50% or greater reduction in their size is also required.
- **MR (Minimal Response):** A reduction between 25-49% of blood M-protein and reduction in 24-hour urine M-protein by 50–89%. If soft tissue plasmacytomas (extramedullary tumours) were present, a 50% or greater reduction in their size is also required.
- **SD (Stable Disease):** Not meeting the above criteria or progressive disease (see below). SD is not recommended for use as an indicator of response, as the stability of disease is best described by estimating the time-to-progression (see below).
- **PD (Progressive Disease):** Generally speaking, a 25% or greater increase in one or more of the several features of myeloma (serum and urine M-protein, free light chain ratio, myeloma plasma cells) or the appearance of a new bone lesion (other criteria apply for existing lesions; ask your healthcare team). PD can also be defined as an increase of 50% or greater in circulating plasma cells if it is the only measure of disease.

Additional common criteria that may be used include:

- **MRD (Minimal Residual Disease):** A very sensitive test that can measure minute levels of myeloma plasma cells in the bone marrow during and/or after treatment. Presently, this test is not considered “standard of care” and is only used in the context of a clinical trial.
- **OS (Overall Survival):** Length of time from either the date of diagnosis or the start of treatment when the patient is still alive.
- **PFS (Progression-free Survival):** Time from the start of treatment to progressive disease or death from any cause.
- **TTP (Time to Progression):** Time from the start of treatment to progressive disease.

Consolidation and Maintenance Therapy

Consolidation

Consolidation therapy involves short course of treatment with the goal of deepening the treatment response following a stem cell transplant. It is often done with the same drug regimen used during the induction treatment phase (see page 8), but only for a few cycles (ie, two to four cycles). Clinical trials have shown that people who receive consolidation therapy after a stem cell transplant can have a longer median progression-free survival than those who did not receive consolidation; however, consolidation therapy has not shown a benefit in overall survival and is not routinely used in Canada. Talk to your doctor about consolidation therapy.

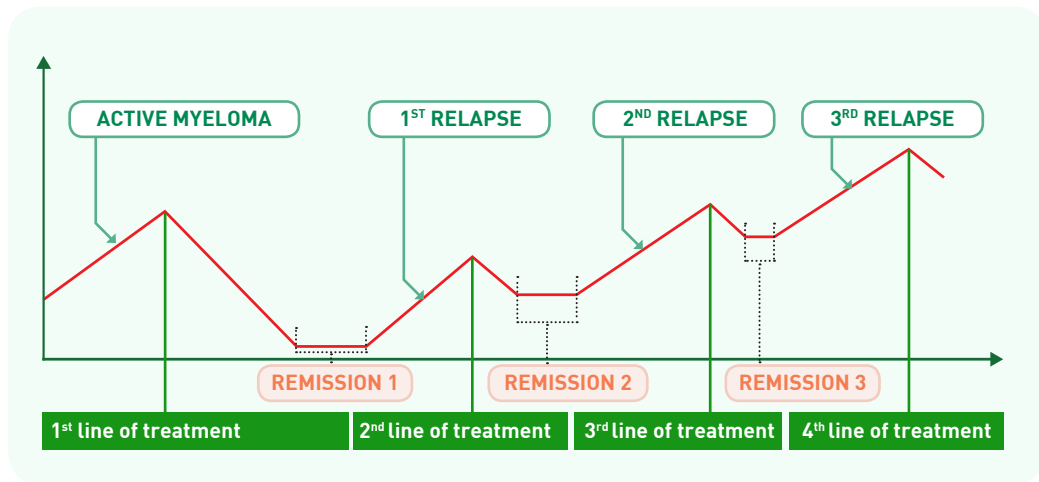
Maintenance

Maintenance therapy is a prolonged, low-dose, form of treatment given to myeloma patients after an autologous stem cell transplant. The goal of maintenance therapy is to prevent or delay disease progression for as long as possible while maintaining a favourable quality of life. Data from clinical trials have shown that lenalidomide (Revlimid), taken continuously as a single agent starting 90 -100 days after an autologous stem cell transplant improves both progression-free survival and overall survival. Maintenance therapy is not a new concept; however, it is being increasingly used because of the availability of newer myeloma drugs with fewer side effects. At the time that this InfoGuide was developed, additional drugs were being investigated as maintenance therapy.

There are, however, some disadvantages associated with maintenance therapy, such as potential side effects, treatment costs and increased frequency of doctor visits. Although the clinical evidence suggests that the benefits outweigh the risks, maintenance therapy can also increase your chances of developing a secondary cancer. Talk to your doctor about the potential risks associated with maintenance therapy.

Understanding Relapse

It is important to understand that high-dose therapy followed by a stem cell transplant is not a cure for myeloma. Although the procedure is able to kill most myeloma cells, it is not able to kill them all. With time, these residual myeloma cells will start multiplying, leading to relapse.



Once relapse occurs, treatment options may include:

- A myeloma drug, usually in combination with a steroid such as dexamethasone
- Second transplant (see page 5)
- New treatments through clinical trials

Your doctor will take into consideration the amount of time you were in remission and past treatments before recommending future treatment options.

For information on the various drugs used to treat myeloma and on how clinical trials work, refer to Myeloma Canada's Multiple Myeloma Patient Handbook and Clinical Trials as a Treatment Option InfoGuide, respectively.

You may order free copies by sending an e-mail to contact@myeloma.ca or calling 1-888-798-5771 toll free. This information and other educational resources are also available for download at www.myeloma.ca.



Preparing for Your Transplant

Overview

Many weeks or months may go by between your first visit with the stem cell transplant team and the day of your transplant. Thus, there are many things you can do to plan and prepare for the transplant.

Meet the Transplant Team

During this visit, your transplant doctor will explain the:

- Type of transplant that is best for you
- Induction therapy that you will receive
- Possible health problems (complications) and side effects that you may experience
- Probability that your treatment will work for you

? Did You Know?

You will receive a lot of information during your visit and it is nearly impossible for anyone to remember all of the important details. Here are some suggestions:

- Take notes during your visit
- Invite 1 or 2 family members or a significant other to all appointments
- Bring a recording device, and with your doctor's or nurse's permission, record what is said during the appointment

You will also be expected to answer any questions regarding your health history such as any illnesses, medications, surgeries and treatments you are receiving or have had in the past.

Finally, remember that the transplant team is there to help you. You will be given an opportunity to ask questions and voice any of your fears and/or concerns. Be sure to write down any questions you may have ahead of time.

Pre-transplant Tests

After your first visit, you will undergo some tests that will give the transplant team more information about your general health and your myeloma. They may include any of the following:

- Imaging tests: CT scan, PET scan, MRI, X-rays
- Blood, urine, lung and heart tests
- Bone marrow evaluation

Important Check-ups and Appointments

The following check-ups and appointments are important before the transplant team can plan your stem cell transplant:

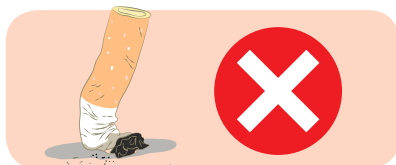
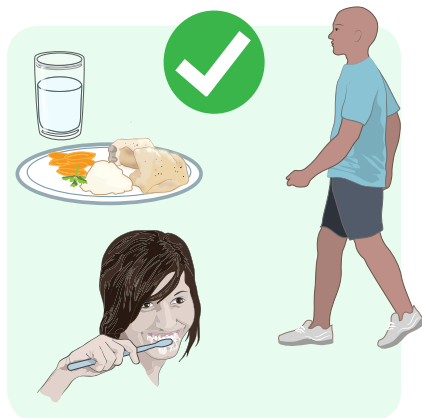
- **Dentist:** It is very important to carry out all your dental work before the transplant to lower your chances of having infections.
- **Vaccinations:** Be sure to discuss, with your hematologist, the need for any vaccinations prior to or following the procedure.
- **Social situation and support network:** If necessary, you will meet a psychiatrist or social worker from the transplant team. They will work with you to address your readiness and address any social issues before your transplant.

Getting Ready for Your Transplant

Practice Healthy Living

Having a stem cell transplant when you are in good physical condition will help reduce the chances of having complications.

- **Be active:** Taking a short walk every day can build your muscle strength and increase your energy bank. Speak to your doctor, nurse or physiotherapist about other appropriate exercises you can do.
- **Eat well:** Keep a balanced diet and refer to the Canadian food guide or the nutritionist for advice.
- **Take care of your teeth:** Brush after each meal and at bedtime with a soft-bristle toothbrush. Do not floss if your platelet count is low.
- **Stop smoking:** Smoking increases the risk of lung (pulmonary) complications during and following a stem cell transplant. If you need help with this, ask about your hospital's smoking cessation program.



Plan Ahead

You will not be able to do some things during your hospital stay and for a few weeks after you have returned home. Do not hesitate to ask family, friends or your caregiver for help with:

- Pet care
- Paying your bills
- Taking care of your home (eg, snow removal, mowing the lawn)

It is also important that you plan for your return home to help with your recovery and to reduce the risk of infections.

- **Plan your meals:** Ask to meet with a nutritionist before your hospital stay for meal and snack ideas. The nutritionist will also be able to inform you of any food restrictions.
- **Clean your home:** Wash your bed linens and disinfect the kitchen and bathrooms. Vacuum the floors, carpets and furniture to remove dust and allergens.
- **Remove all natural plants:** Plants and flowers can carry microbes such as bacteria and/or fungi.

Pack Your Bag

Depending on hospital policy, you may be able to bring some personal items with you for the stay:

- Pyjamas or night gowns
- Comfortable clothes, scarves or head covers
- Blanket or quilt
(it is important to arrange for it to be washed weekly)
- Shoes that are not slippery
- Soft-bristle toothbrush and toothpaste
- Soap, shampoo, deodorant and tissues
- Electronics such as a laptop, tablet and mobile phone
- Books, magazines, pen and paper
- Pictures of your loved ones
- A lock to secure your most important items safely when you are not in your room and avoid bringing the following items:

- Valuables (eg, jewellery, money, bank cards)
- Stuffed animals (they can carry microbes)



Hospitals are not responsible for lost or stolen items.





Life After a Stem Cell Transplant

Emotions and Support

Emotions

Dealing with your emotions during the entire stem cell transplant process can be difficult and you may sometimes feel like that you have lost control. You may also find it hard to remain positive and hopeful during this time. Speak to your doctor about any medications or support that may help with your situation.

Adjusting to life after having a stem cell transplant is also not always easy. The potentially enormous physical, emotional and financial strain on you and your family can result in many feelings of anger, resentment, depression and anxiety. Furthermore, these feelings can be magnified when support and care is reduced and you are recovering. These feelings are normal, so remember to be patient with yourself and others. Sharing your feelings with the transplant team may help.

For some people, the recovery period is an opportunity to make positive changes to your life as you work towards regaining a “normal” life.

Support

If you feel that you need it, you may be able to turn to your family and friends for support with your practical and financial problems. You may also find it useful to seek help from healthcare professionals and support organizations.

Support groups can help patients and caregivers that are living with myeloma cope by providing important information about the disease and its treatment and by allowing them to connect with members of the myeloma community and their supporters. These groups can give you the opportunity to share your perspective and learn from the experiences of others. There are over 30 myeloma support groups in all 10 provinces across Canada. To find a myeloma support group in your area, visit www.myeloma.ca.



Sexuality

Practicing Safe Sex

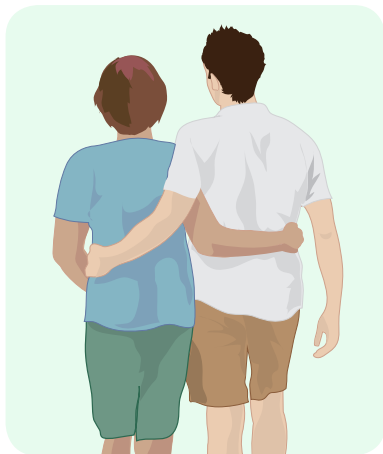
Sexual activity can be an important part of your recovery. If you are ready to be sexually active, keep in mind that it is recommended that your platelet count is over $50 \times 10^9/L$ ($50,000 \times 10^6/L$) and that your neutrophil count is above $0.5 \times 10^9/L$ ($500 \times 10^6/L$) to lower your risk of bleeding and infection. Also keep the following in mind:

- It is recommended that you use a condom during intercourse
- Oral sex and anal intercourse may increase your chances of infection

Questions or Concerns

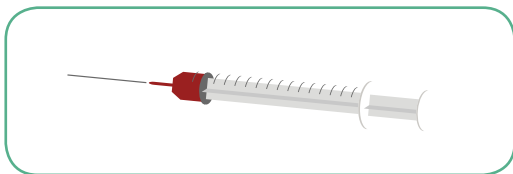
Speak to your nurse or doctor if you have any questions or concerns about your sexual health following the transplant.

- Women often report vaginal dryness, irritation or tightness. A water-based lubricant can help.
- Men often report difficulty in maintaining an erection (erectile dysfunction).



Vaccination

The stem cell transplant process can erase your body's memory of any previous vaccinations you may have had. To keep yourself protected against infection, your doctor may recommend having your first set of vaccinations 6 months after your transplant (can be completed in approximately 2 years). Speak to your doctor about re-vaccination and inquire if it is right for your specific situation.





Finding the Right Health Information

Myeloma is a very individual disease and not all patients experience the same symptoms and response to treatment. Be cautious of the information that comes your way. Myeloma Canada's website (www.myeloma.ca) is an excellent source for accurate information.

- The internet offers a wealth of information; however, not all of it is correct. Moreover, the information you read may not apply to your unique situation.
- Some people may try to give you health advice without knowing the details of your illness and treatments.
- Although online support groups may be helpful, be wary of possible misinformation.
- Information published online or in books can be confusing or misleading.

Write down your questions or bring any information you have to share with your stem cell transplant team. They can help you make sense of the information you have found and learn how it may apply to your health and your stem cell transplant plan.



Glossary

Antibodies (immunoglobulins): Protein that are produced by certain white blood cells (plasma cells) to fight infection and disease in the form of antigens such as bacteria, viruses, toxins or tumours. Each antibody can bind only to a specific antigen. The purpose of this binding is to help destroy the antigen. Antibodies can work in several ways, depending on the nature of the antigen. Some antibodies disable antigens directly. Others make the antigen more vulnerable to destruction by other white blood cells. Antibodies are Y-shaped molecules that have heavy and light chains (portions). These portions contain specific binding sites that attach to bacteria or viruses, ultimately leading to their destruction thereby protecting against disease.

Bone marrow: The spongy tissue that is found inside your bones. It is soft, fatty and full of blood vessels. Your bone marrow is where most of the blood cells in your body are made.

CD34+: CD34+ is a protein found on stem cells. Measuring CD34+ is a useful way of counting the number of stem cells in the blood.

Central venous catheter/line: A tube that is placed in a blood vessel (usually in the upper chest) to provide a pathway for drugs or nutrients. The catheter allows medications, fluids, or blood products to be given and blood samples to be taken.

Conditioning: Treatments used to prepare a patient for stem cell transplant that may include chemotherapy, immunotherapy and radiation to the entire body. Conditioning regimens help make room in the patient's bone marrow for new stem cells to grow and help kill cancer cells that are in the body.

Cryopreservation: Cooling (freezing) and storing living cells, tissues, or organs at extremely low temperatures (often -196 degrees Celsius) so that they can survive after thawing.

CT or CAT (Computerized axial tomography) scan: A test using computerized X-rays to create three-dimensional images of organs and structures inside the body, used to detect small areas of bone damage or soft tissue involvement.

Cycles: A course of treatment that is repeated on a regular schedule with periods of rest in between (eg, one week of treatment followed by three weeks of rest is one treatment cycle).

Disease progression: When a disease or physical ailment's course worsens, grows or spreads.

Electrophoresis: A laboratory test in which a person's serum (blood) or urine molecules are subjected to separation according to their size and electrical charge. For people with myeloma, electrophoresis of the blood or urine allows both the calculation of the amount of myeloma protein (M-protein) as well as the identification of the specific M-spike characteristic for each patient. Electrophoresis is used as a tool both for diagnosis and for monitoring. There are two types of electrophoresis:

- Serum protein electrophoresis (SPE or SPEP)
- Urine electrophoresis (UPE or UPEP)

End-organ damage: Refers to damage occurring in major organs due to uncontrolled disease. In myeloma, end-organ damage is defined as any one or more of the following CRAB features: elevated blood calcium (hyperCalcemia), kidney (Renal) failure, low hemoglobin (Anemia) and Bone pain and/or fractures (lesions).

Engraftment: When blood-forming stem cells start to grow and make new blood cells.

First-line treatment: Therapy that is used on people who have not had any previous treatment for their myeloma. If the myeloma does not respond (the disease is said to be refractory) or if it progresses after the first-line therapy has been completed (ie, there is a relapse), the subsequent therapy is referred to as second-line treatment.

Free light chain: The light chain portion of an M-protein (monoclonal protein, paraprotein, M-spike) that is circulating in the blood in a free (unbound) state. Free light chains can be measured with a sensitive test, the Freelite assay.

High-dose therapy: An intensive chemotherapy drug treatment that kills cancer cells, as well as the bone marrow, causing severe side effects. High-dose therapy is usually followed by bone marrow or stem cell transplantation to rebuild the bone marrow. High-dose therapy is a type of conditioning treatment/regimen.

Immunofixation: A specialized type of electrophoresis that can identify the type of monoclonal paraprotein or M-protein that makes up an M-spike (ie, whether it is IgG, IgA, kappa [κ] or lambda [λ]). This immunoelectrophoresis test can be conducted on the blood (serum) or the urine.

Indication: The basis for initiation of a treatment for a disease or of a diagnostic test that is warranted by knowledge of the cause, symptoms that are present or the nature of the disease. The opposite of an indication is a contraindication (a reason to withhold a certain treatment because it could be harmful).

Intravenously: Into/within a vein. Medications (solution) is administered directly into the venous circulation via an intravenous (IV) drip, syringe or catheter (central line).

Leukapheresis: A process that separates the stem cells from the rest of the blood and returns the remaining blood to the body.

MRI (Magnetic Resonance Imaging): A diagnostic test that uses magnetic energy, rather than X-ray energy, to produce detailed two- or three-dimensional images of organs and structures inside the body. Gives very fine resolution of soft tissues, especially encroachments on the spinal cord, but is less accurate for bone lesions.

M-protein (monoclonal protein, paraprotein, or M-spike): Also known as myeloma protein. These are antibodies or parts of antibodies found in unusually large amounts in the blood or urine of myeloma patients. M-spike refers to the sharp pattern that occurs on protein electrophoresis when an M-protein is present.

Mobilization treatment: Prior to stem cells being harvested from peripheral blood, granulocyte-colony stimulating factor (G-CSF) drugs (eg, Neupogen; Grastofil) are used with or without chemotherapy to “coax” or mobilize stem cells out of the bone marrow and into the blood.

Neutrophil: A variety of white blood cell that plays an important role in defending/protecting against bacterial infection and other very small inflammatory processes. Neutrophils are usually the first responders to a bacterial infection. Low neutrophil levels make you more susceptible to infection.

Overall survival: Length of time from either the date of diagnosis or the start of treatment when the patient is still alive.

PET (Positron Emission Tomography) scan: A diagnostic test that uses a sophisticated camera and computer to produce images of the body. PET scans show the difference between healthy and abnormally functioning tissues.

Relapse: The reappearance of signs and symptoms of a disease after a period of improvement or remission.

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

Shingles: An acute, painful inflammation of the nerve ganglia that results in a localized skin rash, usually with blisters (fluid-filled sacs). It is caused by the reactivation of a previous infection with the herpes zoster virus (also named varicella-zoster or chickenpox virus).

Side effects (adverse events): Problems that occur due to drugs used for disease treatment. Common side effects of cancer therapy are fatigue, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.

Soft tissue plasmacytomas (extramedullary tumours): A collection of plasma cells found in a single location rather than diffusely throughout the bone marrow, soft tissue, or bone.

Standard of care: A treatment (medicine or procedure) that is accepted and widely used by doctors as an appropriate therapeutic approach for a certain type of disease or condition.



Make Myeloma Matter

Every year, Myeloma Canada provides information to thousands of people with myeloma and their families and caregivers, and helps many more by providing programs and services such as the annual Myeloma Canada National Conference, Patient and Family InfoSessions, the *Myeloma Matters* newsletter and webinars.

That is why we need your help. We depend on support and generous donations from people like you to provide support to myeloma patients, their families and their caregivers. All donations are greatly appreciated and allow us to continue our vital work.

Ways You Can Help

Donate

You can make your donation online at www.myeloma.ca, over the phone by calling toll-free at 1-888-798-5771, or by mailing a cheque payable to Myeloma Canada to:

Myeloma Canada
1255 Trans-Canada, Suite 160
Dorval (Quebec) H9P 2V4

Fundraise

There are other ways you can support Myeloma Canada, such as taking part in the annual Multiple Myeloma March held in cities across Canada, or by fundraising for Myeloma Canada in your local community. When so much about myeloma is beyond the control of the people that it affects and those who care for them, fundraising can be a rewarding and fun way of doing something positive for yourself and for others affected by myeloma.

Contact the fundraising team toll-free at 1-888-798-5771 for more information, or visit www.myeloma.ca.



Myeloma Canada Scientific Advisory Board

Nizar J Bahlis, MD

Tom Baker Cancer Center
Assistant Professor
University of Calgary
Foothills Medical Center
Calgary, AB

Andrew R Belch, MD

Division of Medical
Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB

Christine Chen, MD

Assistant Professor
Department of Medical
Oncology and Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON

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Assistant Professor
Integrated Cancer
Genomics Division
Translational Genomics
Research Institute
Phoenix, AZ

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Maisonneuve-Rosemont
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Clinical Assistant Professor
of Medicine
University of Montreal
Montreal, QC

Paola Neri, MD, PhD

Clinical Associate Professor
Arnie Charbonneau Cancer
Institute
University of Calgary
Calgary, AB

Linda Pilarski, PhD

Division of Experimental
Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB
*Member, IMF Scientific
Advisory Board*

Donna E Reece, MD

Professor of Medicine
Director, Program for
Multiple Myeloma and
Related Diseases
Department of Medical
Oncology and Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON
*Member, IMF Scientific
Advisory Board*

Tony Reiman, MD

Medical Oncologist
Saint John Regional
Hospital
Assistant Dean of Research
Dalhousie Medicine
New Brunswick
Saint John, NB

Jean Roy, MD

Maisonneuve-Rosemont
Hospital
University of Montreal
Montreal, QC

Michael Sebag, MD, PhD

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of Medicine
McGill University Health
Centre
Montreal, QC

Chaim Shustik, MD

Associate Professor of
Medicine & Oncology
McGill University Faculty
of Medicine
Royal Victoria Hospital
Montreal, QC
*Member, IMF Scientific
Advisory Board*

Kevin J Song, MD

BC Cancer Research Centre
Vancouver General Hospital
Vancouver, BC

Rodger Tiedemann, PhD, ChB, MB

Scientist, Ontario
Cancer Institute
Staff Hematologist
Division of Medical
Oncology & Hematology
Princess Margaret Hospital
Assistant Professor
of Medicine
University of Toronto
Toronto, ON

Suzanne Trudel, MD

Assistant Professor
Clinician/Research Scientist
Department of Medical
Oncology and Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON

Darrell White, MD

Nova Scotia Cancer Centre
Queen Elizabeth II Health
Services Centre
Dalhousie University
Halifax, NS





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Myeloma Canada

Mailing Address:

Myeloma Canada
1255 TransCanada, Suite 160
Dorval QC H9P 2V4

Telephone:

Toll-free: 1-888-798-5771

E-mail:

contact@myeloma.ca

Website:

www.myeloma.ca

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