

Myeloma Post-Transplant Patient Information

For patients who have had an autologous stem cell transplant (ASCT) following a Multiple Myeloma diagnosis



In this booklet you will find information about what to expect after your ASCT for lymphoma:

- How often will I need to come to the hospital?
- How will I feel?
- What kind of medication will I be taking and why?
- What should I eat and drink at home?
- When does my Hickman line come out?
- How will I know if the transplant worked?
- What happens next?
- How do I stay healthy going forward?

After my transplant, how often will I need to come to the hospital?

- You will have an appointment scheduled in the cancer program within 1 week from when you are sent home from the hospital (discharged).
- Each patient is different. Some patients will have an appointment to see their healthcare team 1 time per week while other patients might need to visit the hospital 2-3 times each week.
- Your healthcare team will tell you how often they need to see you

After my transplant, what will happen at my hospital visits?

- You will have a blood test at each visit. This will help your healthcare team to track the number of blood cells your body is making and how your kidneys are working.
- A doctor or specialized nurse will check your blood pressure, heart rate and temperature. They will talk to you about your medications and will ask you questions about your symptoms and concerns
- Sometimes people will need to be given some extra fluid or blood (called infusions or transfusions) to help them feel better. This could happen during one of your hospital visits.
- If you need nursing care in between hospital visits, your healthcare team will arrange for a nurse come to your home (called home care). For example, home care could be arranged if you need to have hydration (fluid) at home.

How will I feel after my transplant?

- You might feel:
 - Really tired (fatigue)
 - Sick to your stomach (nauseous)
- You may experience:
 - A decrease in your appetite (not hungry)
 - Taste changes
 - Watery poop (diarrhea)
 - Trouble sleeping
- There might be some medication that your healthcare team can give you to control these symptoms
- If you are not drinking very much water and are having diarrhea, this can make you dehydrated (not enough water in your body). This can make you feel weak and tired
- Your symptoms will get better about one month after your transplant.
- You may try to increase your energy by slowly increasing the amount of activity that you do each day. The fatigue can last for a number of months. Many patients have found that walking a little bit each day really helps to improve their level of energy. It is important to listen to your body and rest when needed.

What kind of medicine will I be taking and why?

- Often, you will be asked to stop taking medication that was given to you by your family doctor or another specialist before you had the transplant. For example, medication for diabetes, high blood pressure or cholesterol. This is to allow your body time to recover from the transplant. A member of your transplant team will tell you when you can start taking these medications again.
- You will be told how to taper (slowly stop taking) medications for any post-transplant symptoms, such as anti-nausea medicine (like ondansetron) and stomach protectors (like ranitidine).
- Before your transplant, you might have been taking medicine like Pamidronate or Zoledronate (drugs to prevent bone loss). You will be told to start taking these medications again 1-2 months after your transplant. You will be asked to keep taking these medications for at least 2 years after your transplant and will be given to your local oncologist (cancer doctor).
- After transplant, your body's ability to fight infection (called immunity) will be decreased. This makes you at-risk for getting shingles (chicken pox in the nerves). You might be given an anti-viral medication (like acyclovir or famcyclovir) that you will take for 1 year after your transplant to prevent infection.

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- Maintenance drugs (like Lenalidomide) might be given to you to start taking 2-3 months after your transplant. Sometimes there are forms that need to be filled out for you to get these drugs so you will want to prepare them in advance to avoid delays. The oncologist (cancer doctor) in your community will monitor you.
- Some of the drugs you were given (like chemotherapy) can take away your body's ability to fight infection (called immunity). This is why you will be encouraged to get vaccinations after your transplant. A vaccination schedule will be sent to your family doctor and, before you are discharged from the hospital, a member of your healthcare team will give you a copy of that vaccination schedule. You may need to pay for some of the vaccinations but they are very important to keep you healthy.
- If you were taking blood thinners (like heparin) before the transplant, your healthcare team will tell you when it is okay to start taking them again. This usually happens when your platelets (cells that help your blood to clot) are greater than 50.

When I go home after my transplant, what should I eat or drink?

- You will want to read that handout in your package called “Food Safety” for more information.
- It is important for you to stay hydrated (lots of water in your body). You should try to drink 2 litres of fluid every day. Fluid can include things like soup and jello. At first, you will need to avoid drinking anything acidic (like juice and pop) or drinks that have caffeine in them like coffee or non-herbal tea. Sometimes it can be hard to drink this much fluid. Many patients find it easier to drink small amounts more often through the day.
- After your transplant, you might have an upset stomach (feel nauseous) and bland food might be easier to tolerate. Bland foods have mild flavor and are not spicy. They also tend to have a less strong smell.
- You may also want to eat smaller portions more frequently. This will also make it easier to eat when you feel sick to your stomach (nauseous).
- You will need to start rebuilding your muscle strength. You can do this by eating foods that are high in protein (like meat, cheese and nuts).

When does my Hickman line come out?

- If you are scheduled for a second transplant, your Hickman line will need to stay in place.
- A doctor or nurse with special training (called a nurse practitioner) will decide when you are ready to have your Hickman line taken out. This will only happen when you don't need home fluid or intravenous medication anymore.
- Before your Hickman line can be taken out, you will be asked to stop taking your blood thinners to stop you from bleeding a lot when they take your Hickman line out.
- You will not need to be admitted to the hospital for the Hickman line to be taken out. This procedure will be scheduled as an outpatient visit.

How will I know if the transplant worked?

- It is going to take time for your body to recover from the transplant. Until your body has a chance to recover, your healthcare team cannot tell you if the transplant was successful.
- Around 2-3 months after your transplant, the status of your myeloma will be re-evaluated.
- You will need to go for some testing including myeloma protein testing, skeletal survey and, maybe, a bone marrow examination (not done all the time).
- At this visit, the cancer doctor will decide what maintenance or other myeloma medicine is needed.

Note: It is important to remember that, at this time, myeloma is not curable but can be brought to a stable level after treatment.

After I recover from my transplant, what happens next?

- A follow-up appointment will be scheduled with the Oncologist (cancer doctor) and/or the Nurse Practitioner (nurse with special training) who work at the Simcoe Muskoka Regional Cancer Program (SMRCP) at the Royal Victoria Regional Health Centre. Your appointment will usually be scheduled within 1 week after you have been discharged from the hospital.
- The healthcare team at SMRCP will share your care with Princess Margaret Hospital and will give you any other treatment or medication that you might need, such as maintenance therapy or pamidronate (a drug that prevents bone loss).
- You will usually be seen by your local doctor every 2-3 months but this depends on whether or not you are still taking medicine.
- At each hospital visit, myeloma proteins and basic blood work will need to be completed.
- You will need to get a skeletal survey once a year.
- Patients with amyloidosis might be asked to follow-up with other specialist doctors, like a nephrologist (kidney doctor) or a cardiologist (heart doctor).

What should I do to stay healthy going forward?

- You should:
 - ⇒ Eat well. This will help your body to stay strong and will give it all the building blocks it needs to repair itself
 - ⇒ Drink 2 litres of fluid a day. This will keep your body hydrated (full of water).
 - ⇒ Stay active. This will help to keep your bones and muscles strong.
- Myeloma can make your bones more weak so you will need to be careful when doing activities that put stress on your bones (like weightlifting).
- Chemotherapy can make your skin more sensitive to the sun so you will need to wear sunscreen to protect yourself when you are outside.



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