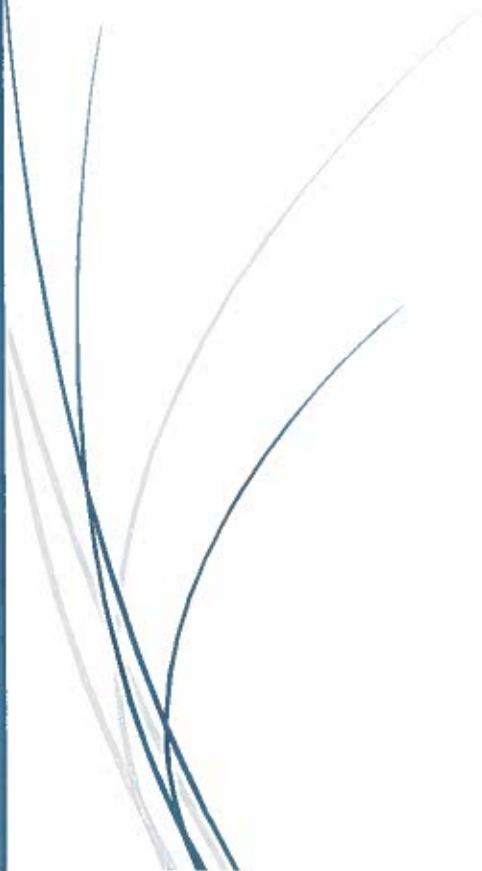




# Preparing for an Autologous Stem Cell Transplant

A Patient Guide



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## Overview

### About This Guide

The information in this guide goes along with the information that your transplant team members will share with you. It will help you learn how to prepare for a stem cell transplant.

You should read this guide at least one time. It is also helpful to refer to this information again as you go through the pre-transplant process.

As you and your family read this information, write down your questions on page 25 of the guide. Call your nurse coordinator to talk about your questions. You should also bring your list of questions with you during visits with your transplant doctor or nurse.

### What Can You Do?

- ✓ Read this guide at least one time.
- ✓ Take notes and write your questions on page 25.
- ✓ Call your transplant nurse to discuss your questions.



Discuss your questions with your doctor and nurse.

## The Basics of Bone Marrow

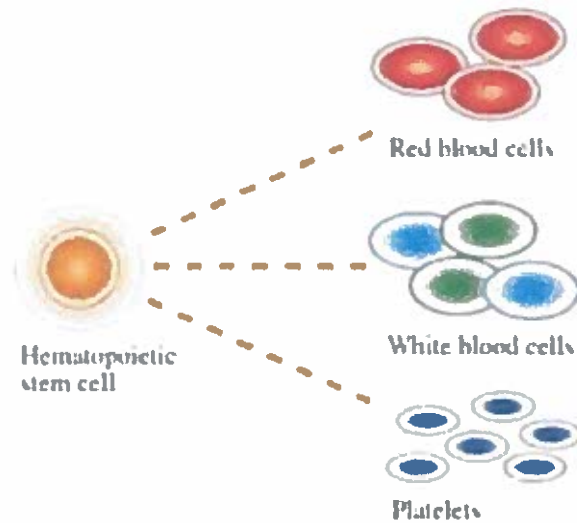
Bone marrow is a spongy material found in the center of the large bones in your body.

Bone marrow contains many stem cells. Stem cells are mother cells that make all of the blood cells that you need to live:

- White blood cells – Fight infection
- Red blood cells – Carry oxygen
- Platelets – Stop you from bleeding

### Key Points

- ✓ Stem cells are made in your bone marrow.
- ✓ Stem cells grow and change to become your white blood cells, red blood cells, and platelets.
- ✓ These cells are needed for you to live.



Stem cells grow and change into your blood cells.

Your stem cells are always growing and changing into white blood cells, red blood cells, and platelets. They replace the old cells when they die. Some stem cells also float in your blood.

You might hear your doctor or nurse refer to your transplant as a "bone marrow transplant." It is also called a "stem cell transplant." Since the stem cells come from the bone marrow, both names are correct.

## Autologous Stem Cell Transplant

Your doctor would like for you to learn about an autologous stem cell transplant as a possible treatment option for your disease.

Autologous means “from yourself.” When you have this kind of transplant, your stem cells are collected from your blood and frozen to keep them safe. Your doctor will then give you a very high dose of chemotherapy to kill any cancer cells that are still in your body. The chemotherapy will also kill most of the blood cells that are in your bone marrow and blood.

By collecting and keeping your stem cells safe first, your doctor is able to give you the chemotherapy safely. Your stem cells will then be given back to you through a line placed in your vein. The stem cells will slowly start to make new blood cells that you need to live.

### Key Points

- ✓ An autologous stem cell transplant means that you use your own stem cells.
- ✓ Your stem cells are collected and frozen.
- ✓ Chemotherapy kills the cancer cells in your body.
- ✓ Your stem cells are given back to you to create new blood cells.

## **The Five Stages of Transplant**

A stem cell transplant is a major treatment and can cause many changes in your life. There are five stages in the transplant process. Each stage is important for safety and success.

### **Stage 1: Pre-Transplant Evaluation**

Your doctor will order tests to see how healthy you are and to be sure that transplant is right for you.

### **Stage 2: Stem Cell Mobilization and Collection**

You will receive a medication to create extra stem cells in your bone marrow. Your cells will be collected from your blood.

### **Stage 3: Chemotherapy**

You will receive chemotherapy that will kill the cancer cells in your body.

### **Stage 4: Stem Cell Transplant**

Your stem cells will be given back to you.

### **Stage 5: Recovery**

You will work closely with your transplant team to ensure that you recover safely.

## **Key Points**

- ✓ There are five stages of transplant.
- ✓ Each stage is important for safety and success.

This guide will help you learn about Stages 1 and 2 only. You will be given other material to help you learn about Stages 3, 4, and 5.

## What Can You Do?

- ✓ Call your transplant nurse coordinator with questions as you prepare for transplant.

My Transplant Nurse  
Coordinator is:

.....

Phone number:

.....

## The Transplant Team

The transplant team is made up of many people that help you through the transplant process.

**Doctor** – The doctor is in charge of your care during your transplant. You will have one doctor that helps you prepare for the transplant. Once you are in the hospital, you will work with several transplant doctors.

**Nurse Practitioners (NPs)** – These are nurses that have a high level of training. They have a license to provide medical care and prescribe medications. NPs work with your doctor to provide care for you in the hospital and clinic.

**Physician Assistants (PAs)** – These are health care professionals that have a high level of training. They have a license to provide medical care and prescribe medications under a doctor's supervision. PAs work with your doctor to provide care for you in the hospital and clinic.

**Pharmacists** – These are health care professionals that help manage your medications when you are in the hospital for the transplant.

**Psychologist** – This is a doctor that can help you and your family manage the emotional and mental stresses that you might feel during transplant. The doctor is there to listen to your concerns and offer counseling.

**Transplant Nurse Coordinator** – This is a registered nurse that specializes in helping you and your family prepare for the transplant. Your nurse coordinator will work with your doctor to organize and schedule your tests before your transplant.

**Clinic Nurse Coordinator** – This is a registered nurse that will assist in your care during your clinic visits after transplant.

**Unit Nurses** – These are registered nurses that provide your day-to-day care on the transplant unit. They are specially trained to care for transplant patients.

**Social Worker** – This professional will help you and your family arrange for services that might be needed when you go home from the hospital.

**Dietitian** – This food and nutrition expert will assess your nutritional status and provide dietary assistance to you and your caregiver during and after the transplant.

**Chaplain** – This is a spiritual advisor who is available to listen to your concerns and provide spiritual support during your hospital stay if you so choose.

**Financial Coordinator** – This is a financial specialist that helps you understand and manage your health insurance before, during, and after the transplant.

## Key Point

- ✓ There are many people on the team that will help you through your transplant.



Many people are a part of your care during transplant.



## Before Your Transplant

### Introduction

There are many things to think about before you have a transplant. It is important to talk to your doctor and nurse to decide if a transplant is right for you.

- Do you have a caregiver that can help you through the process?
- Is your disease under good control?
- Are you healthy enough to go through a transplant?
- What will your insurance cover?

These are just some of the questions that you will talk about.

### Key Point

- ✓ Talk to your doctor and nurse to decide if transplant is the right treatment for you.



Talk to your doctor to decide if transplant is for you.

## What Can You Do?

- ✓ Identify a caregiver who can help you during your transplant and recovery.

My main caregiver will be:

.....

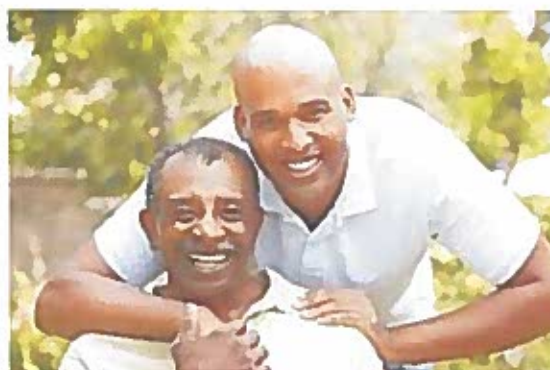
## Identifying a Caregiver

The transplant process is a busy time for you. It can be very stressful. It is important that you have a caregiver that can help you through the process.

Your doctor will ask you to identify a person that can be your caregiver during and after transplant. This can be a family member or a close friend who is willing and able to help you. If there is not one single person that can help you as often as you need, it may be possible for you to have different caregivers help you at different times.

Your caregiver will need to help you with:

- Taking your medications
- Getting to your clinic visits
- Grocery shopping
- Preparing meals
- Cleaning your home
- Caring for your pet
- Managing your visitors
- Noticing changes in your health
- Calling for help in an emergency
- Emotional support



Having a caregiver is an important part of transplant.

## Talking about Your Fertility

The chemotherapy that you get with your transplant is given at a very high dose. The chemotherapy helps kill cancer, but it can also cause harm to your eggs or sperm. It will likely affect your fertility. Most men and women who have a transplant are not able to conceive a child anymore.

### Men

The chemotherapy that you get with your transplant may cause your sperm production to slow down or even stop permanently.

### Women

The chemotherapy that you get with your transplant may permanently damage your egg supply.

It is hard for your doctor to know how your fertility will be affected. Every patient is different. It is still important to use a form of birth control after your transplant.

Sometimes, it is possible to preserve your eggs or sperm before the transplant. Insurance usually does not cover the cost of egg or sperm preservation or storage. There are financial assistance programs that may help you pay for this if you are eligible.

Talk to your doctor or nurse to learn more.

## What Can You Do?

- ✓ Talk to your doctor or nurse if you would like to preserve your eggs or sperm before the transplant.

### For Menstruating Women

If you are a woman who menstruates, or has your period, your doctor may ask you to take a hormone shot called Lupron. This shot will stop your menstruation for a few months during the transplant process. This is to keep you safe from heavy bleeding until your new platelets begin to grow again. If you are a woman who is post-menopausal, you will not need this shot.

## Local Housing

When you go home from the hospital after your transplant, your doctor will ask you to come to the clinic at least two times a week for check-ups. It can be difficult to make these trips if you live far away. There also may be times when you need to see the doctor quickly if you feel sick.

The transplant department works closely with a guest housing facility that is 1/3 mile from the hospital. This housing is for patients who need to stay close to the hospital for a short period of time after transplant. You must have a family member stay with you as well. There is a small fee to stay in the guest housing.

### What Can You Do?

- ✓ Talk to your nurse about living close to the hospital for a short time after your transplant.



Talk to your nurse about staying close to the hospital.

Your doctor may ask you to stay in the guest housing for a short time after you leave the hospital. Talk to your nurse if you think this will be a good option for you.

## Working with Your Insurance

Early in the transplant process, you will meet with the Financial Coordinator to talk about your health insurance.

The Financial Coordinator will talk to you about what tests and medications your insurance will pay for. You will also learn about out-of-pocket costs that you will be responsible for. This specialist will be able to answer your questions about your personal costs throughout the transplant process.

Stem cell transplants are expensive. The Financial Coordinator will work with your insurance to get approval for pre-transplant tests, the cell collection, chemotherapy, stem cell infusion, and medications.

Your insurance company must give the doctor approval before you can have the transplant.

### What Can You Do?

- ✓ Talk to your Financial Coordinator about your health insurance and transplant costs.

My Financial Coordinator is:

.....

Phone number:

.....



Learn about your transplant costs early.

## Key Points

- ✓ Your doctor will order tests to determine if the disease is under control.
- ✓ You will have:
  - A bone marrow biopsy
  - One or more scans

## Assessing the Disease

Before you can have a transplant, your doctor must know if your disease is under control. Your doctor will order tests for this.

**Bone Marrow Biopsy** – A needle will be used to collect liquid and a small bone chip from your hip bone. This will tell your doctor if your bone marrow is healthy enough for the transplant.

**Scan(s)** – Pictures will be taken of the inside of your body so your doctor can look at areas that normally cannot be seen.

One or more of these scans may be needed based on the disease.

- **Skeletal Survey (Bone scan)** – This is an x-ray that takes pictures of your bones.
- **CT scan** – This is an x-ray that takes pictures of the tissue and bones inside your body. Tell your doctor ahead of time if you have an allergy to contrast dye, seafood, or iodine. The scan may need to be changed or you may need to take an extra medication to keep you safe.
- **PET scan** – This is a scan that takes pictures of the organs inside your body.
- **MRI** – This is a scan that takes pictures of the tissues, organs, and bones in your body.

## What Can You Do?

- ✓ Carefully review the work-up schedule from your nurse.
- ✓ Bring a copy of your schedule to all visits.
- ✓ Ask for time off from work.
- ✓ Ask your caregiver to be with you for visits when needed.

## Stage 1: Pre-Transplant Evaluation

Transplant can cause stress for both your body and your mind. If the disease is under control, your doctor will order tests to determine if you are healthy enough to go through the stress of a transplant.

You may hear your nurse refer to this time as “work-up.” This time period is very busy. There are many tests to complete. Your nurse will help you schedule tests that are needed.

If you are working, you will need to have time off to come to the clinic for tests. Your caregiver will need to be with you for some of these visits.

### Work-Up Tests

During your work-up, you will need to have some or all of the following tests:

- **Blood tests** – These are done to assess how well the organs in your body are working. Blood will also be tested to see if you have ever been exposed to viruses that could be dangerous during the transplant.
- **Urine and Stool tests** – Urine may be tested to look for protein or bacteria. Stool may be tested to look for blood.
- **Chest X-ray** – This is done to be sure that your lungs are clear of infection.
- **Vein Evaluation** – A team member from the blood center will look at your arms to see how healthy your veins are.
- **Vascular Ultrasound** – This is a test that takes pictures of the vessels in your arms and chest. Your surgeon will use these pictures to safely insert your central venous catheter (CVC), if you need one.



- **Electrocardiogram (EKG)** – This is done to test the electrical activity of your heart.
- **Echocardiogram** – This is a test that looks at how your heart pumps.
- **Cardiac Stress Test** – This is an extra heart test that measures how your body reacts to stress. Your doctor will only ask you to take this test if you have had heart problems.
- **Pulmonary function tests (PFTs)** – These are breathing tests that measure how well your lungs work.
- **Lumbar Puncture** – This is a procedure that uses a needle to collect fluid from around your spine. The fluid is tested for disease. You only need this test done if you have disease that could spread to your nervous system.
- **Dental Exam** – You must have a full dental exam before the transplant. Your dentist will work with you to fix any problems with your teeth or gums. Your dentist will need to sign a note that says your dental problems are fixed.

## What Can You Do?

- ✓ Make a dental appointment. Ask your dentist to fix any problems with your teeth or gums before the transplant.



See your dentist for an exam before the transplant.



• **Routine Health Screening** – You should have routine health exams completed before your transplant. These include:

- Mammogram
- Pelvic Exam
- Colonoscopy

• **Psychology Assessment** – You will meet with the transplant psychologist to talk about how you are dealing with your stress. The psychologist will give you advice on how to cope during the transplant.

• **Surgical Assessment** – You will meet with a surgeon to discuss the procedure of inserting your CVC, if you need one. The surgeon will give you instructions to follow for the day of your surgery. Tell your surgeon ahead of time if you are taking any medications that thin your blood.

• **Specialty Doctor Visits** – Your transplant doctor may ask you to see a specialist if you have other health problems.

## What Can You Do?

- ✓ Make appointments for your routine health screening:
  - Mammogram
  - Pelvic Exam
  - Colonoscopy
- ✓ Tell your surgeon and nurse if you are taking any medications that thin your blood.

Once your workup tests are done, your doctor will see you in the clinic to talk about the results. Your doctor will tell you if it is safe for you to have the transplant.

## Key Points

- ✓ Mobilization is the process of making extra stem cells in your bone marrow.
- ✓ Your nurse will teach you how to give yourself an injection called Neupogen.
- ✓ Neupogen causes your bone marrow to make lots of stem cells.

## Stage 2, Part 1: Stem Cell Mobilization

### What is mobilization?

Mobilization is the process of making a lot of stem cells in your bone marrow. The stem cells are released into your blood so that it is easier to collect them.

In an autologous transplant, your stem cells are mobilized before they are collected from your blood. This is done before you go to the hospital for chemotherapy.

### How are my stem cells made?

Normally, your body makes just enough stem cells for your body to be healthy. The stem cells are made in your bone marrow and move into your blood when they are needed.

In order to make extra stem cells for your transplant, you will take injections of a medication called Neupogen. The Neupogen causes your bone marrow to make lots of stem cells. A nurse will give you the first injection of Neupogen in the clinic. The nurse will teach you how to give the rest of the injections to yourself. A family member or friend can help you if you would like.



Your nurse will teach you how to give yourself an injection.

Usually, you take the rest of the Neupogen home with you after the first injection in the clinic. You should keep the Neupogen in your refrigerator. The nurse will teach you to give yourself a shot of the medication in your belly or your arm at the same time each day for 5 to 7 days.

#### **How do the stem cells move into the blood?**

Once the extra stem cells are made, your nurse may give you another injection of a medication called Mozabil. This medication will push the extra stem cells from your bone marrow into your blood. The stem cells can then be collected from your blood.

#### **How will I feel during mobilization?**

Most patients feel some body and muscle aches while they are taking Neupogen. You may also feel tired. These feelings go away one or two days after you stop taking the medication.

Your doctor and nurse will talk to you about other side effects that you might have. They will also talk to you about when you should call the doctor for side effects.

### **What Can You Do?**

- ✓ Keep your Neupogen in the refrigerator.
- ✓ Take your Neupogen injection each day as your nurse taught you.
- ✓ Talk to your doctor and nurse about possible side effects from Neupogen.

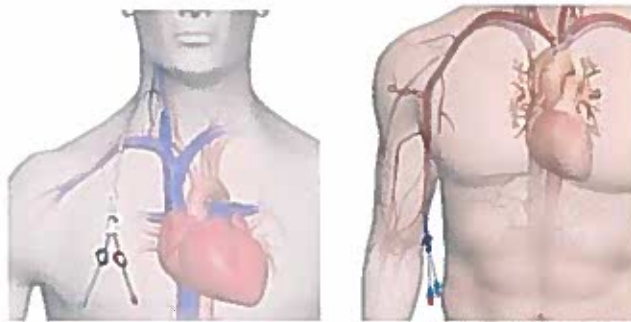
## Central Line Insertion

A central line is a tube that a surgeon puts into a large vein in your chest or your arm. Half of the tube stays inside your body. The other half is on the outside of your body. There will be 2 or 3 smaller tubes hanging off of the end that are called lumens.

There are two kinds of central lines. A central venous catheter (CVC) is put in your chest. A peripherally inserted central catheter (PICC) is put in your arm. Your doctor and nurse will talk to you about which type of line you will need for the transplant.

### Key Points

- ✓ A central line is a tube that a surgeon puts into a vein in your chest or arm.
- ✓ The central line may be used to collect your stem cells and to give you fluids and medication.



A surgeon will put a CVC or a PICC into a vein in your chest or arm.

The CVC or PICC will stay in place for several weeks or months and will be used for many things during the transplant process. The tube may be needed to collect your stem cells safely. It will be used to give you your cells back and to give you fluids, blood, and some medications. It will also be used to draw your blood.

Your doctor will talk to you about when it is safe to have the central line removed from your chest or arm.

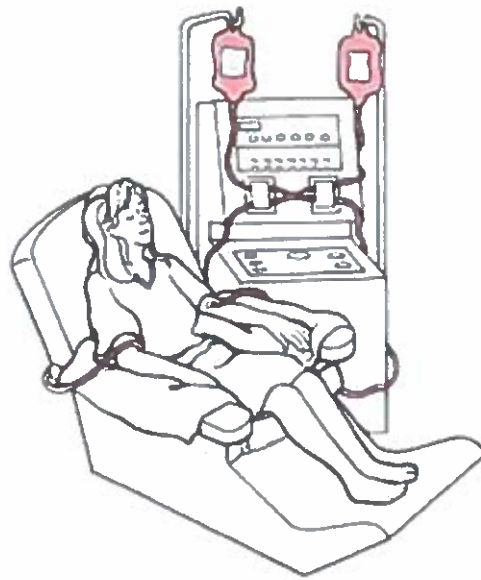
## Stage 2, Part 2: Stem Cell Collection

After your stem cells have been mobilized, it is time to collect them from your blood. You might hear your nurse or doctor call this “apheresis.”

During apheresis, you sit or lie comfortably in a reclining chair. You are connected to a machine through an IV tube in your arm or a CVC in your chest. Blood is pulled out of your body. The blood goes through a machine that pulls out the stem cells. The rest of your blood is returned to your body through the IV or CVC. You may have up to 4 sessions total. Each session will last 6 to 8 hours.

### Key Points

- ✓ Apheresis is the process of collecting your stem cells from the blood.
- ✓ Your blood goes through a machine that pulls the stem cells out.
- ✓ The rest of your blood is returned to your body through the IV or CVC.



Your blood goes through a machine that pulls the stem cells out. The rest of your blood is returned to your body through the IV or CVC.

## What Can You Do?

- ✓ Drink extra water, juice, or milk for 2 days before your cells are collected.
- ✓ Talk to your nurse about ways to add calcium to your diet.
- ✓ Wear comfortable clothing.

It is good for you to drink extra liquids such as water, milk, or juice for 2 days before your cells are collected. Your nurse will also ask you to add extra calcium to your diet for several days.



Drink extra water, juice, or milk for 2 days before your stem cells are collected.

You should wear comfortable clothing while your cells are being collected. You can have a visitor with you for company, or you may choose to read a book or watch TV. You can even take a nap while your cells are collected.

Once the collection is finished, your stem cells will be frozen in the lab until you are ready to get them back during the transplant.

## Summary

Preparing for an autologous stem cell transplant is an important and busy time. You will have many tests to be sure that a transplant is safe for you. You will take medication to make extra stem cells in your bone marrow. You will take another medication to push the cells into your blood. The cells are then collected from your blood through an apheresis machine. The cells are frozen until it is time for you to get them back.

Once your doctor clears you for transplant and your stem cells have been collected, your nurse will schedule a day for you to come to the hospital. You will get chemotherapy in the hospital. Your stem cells will be given back to you through the central line and your recovery period will begin.

The transplant team understands that this process is new for you. We will work very closely with you to help you learn everything that you need to know about a stem cell transplant.

## Key Points

- ✓ Preparing for a stem cell transplant is an important and busy time.
- ✓ Your transplant team will work with you to help you learn everything that you need to know.



Your transplant team will work closely with you during the transplant process.

## Resources

National Marrow Donor Program

Be the Match

<https://bethematch.org/>

National Bone Marrow Transplant Link

<http://www.nbmtlink.org/>

The Leukemia and Lymphoma Society

<http://www.lls.org/>

National Cancer Institute

<http://www.cancer.gov/publications/patient-education/takingtime.pdf>

Illinois Medical District Guest House

1933 W. Polk Street, #214 (SSR Building)

Chicago, IL 60612

312-996-1167

<http://www.imdguesthouse.org/>

American Cancer Society

Mary Herbert – Rush University Medical Center ACS Navigator

312-563-2409

<http://www.cancer.org/>



## Notes and Questions

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