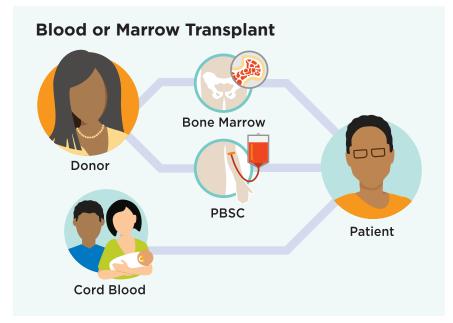


## Transplant Basics

- Your bone marrow is where your body makes all your blood cells.
- BMT replaces your unhealthy blood-making cells (stem cells) in the bone marrow with healthy ones.
- The healthy cells come from a donor or umbilical cord blood.
- A donor can give stem cells from the bone marrow (inside the bone), or the bloodstream. Cells from the bloodstream are called peripheral blood stem cells (PBSC).



Bone Marrow Transplant (BMT) is not surgery.

### Finding a donor

- Your doctor looks for a donor or cord blood unit who matches you.
- Doctors will look for a donor in your family first.
- If you do not have a matched donor in your family, they will look on the Be The Match Registry<sup>®</sup>.
  They can search the registry for a volunteer donor or donated umbilical cord blood.



If you're having a BMT, your doctor will typically look for a matching donor in your family first

# Transplant is a long process

### The transplant timeline



Every patient's experience is unique. Your path may be different.

### What to expect before BMT

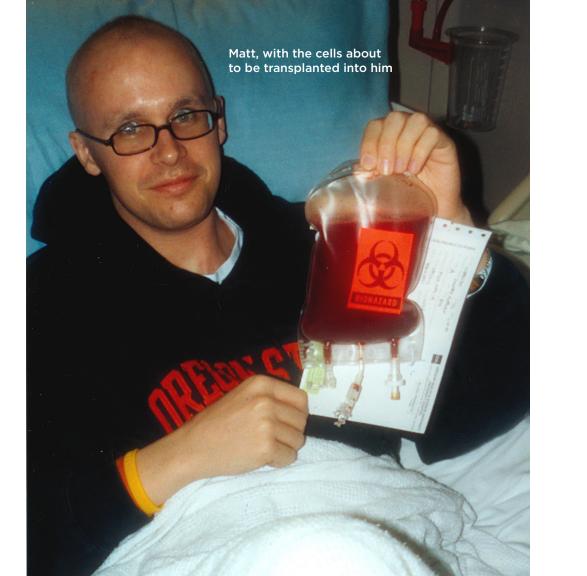
- First you'll have tests and checkups to make sure your body is healthy enough for transplant.
- You will get a central line, also called a central venous catheter. This makes it easier to give blood and get medicines.
- A few days before transplant you get chemotherapy and maybe radiation. This prepares your body for the donated cells.

Transplant is doable, but not easy. This is more of a marathon than a sprint. Your life will be affected forever in both positive and negative ways.

Evelyn, transplant recipient

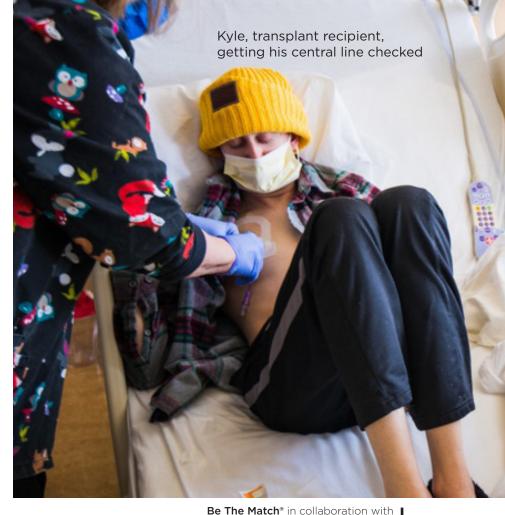
# What to expect on transplant day

- The donated cells are given to you through your IV just like a blood transfusion.
- The infusion can take a few minutes to a few hours.
- You will be awake but you may feel tired.
- Your loved ones can be in the room with you.
- You may want to do something to celebrate or remember the transplant day.
  Some people have a prayer or blessing. Others may celebrate like it's a new birthday.



# Recovery after transplant takes time

- You may stay in the hospital or have checkups every day.
- Your central line will be used to get blood samples and give you medicines.
- If you're in the hospital, nurses will measure everything you eat and drink. They will also check your temperature often.



### Side effects are common



Becky, transplant recipient

### Coping with side effects **Diarrhea -** Tell your doctor if you're having diarrhea. Use lukewarm water and soft wipes to keep your anal area clean and dry. **Hair loss -** Your hair will grow back in a few months. Until then, wear hats, wigs or scarves to keep your head warm. ☐ **Infection -** To lower your risk of infection, wash your hands, wear your mask, and avoid ill people. Mouth sores - Eat soft foods. Suck on ice chips. Avoid foods that can hurt your mouth, such as spicy foods, tomatoes, or orange juice. ☐ **Nausea or low appetite -** Eat small meals more often. Take anti-nausea medicines before you eat. Avoid foods that have strong smells. ☐ **Stress -** Talk with family and friends about how you are feeling. Write in a journal. Take a short walk.

Take a few deep breaths. Watch a funny video

and laugh.

### Tips for coping with other side effects

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Some people find complementary therapies, like yoga or meditation, helpful to cope with side effects. Some complementary therapies are safe. But others can be dangerous. It is important to talk to your doctor about it before you start any other therapies. They can tell you which complementary therapies are the safest and best for you.



Tom, transplant recipient, getting an after-transplant checkup

### **Going home**

- It takes time to recover from transplant. Most people have to go back to the hospital at some point during the first 3-6 months after transplant.
- You will have to take many medicines. These medicines help prevent or treat side effects like infection and graft-versus-host disease (GVHD). Tell your doctor if you cannot take your medicines for any reason.
- GVHD happens when the donated cells attack your body.
- Watch for early signs of GVHD, such as changes to your skin, mouth or eyes. Tell your doctor right away if you notice these signs.
- Set a goal to walk a little bit more each week. This will help you get your energy and strength back.
- Talk to someone, like a close friend or a counselor about what you are going through. This may help you and your caregiver feel better during the ups and downs of your recovery.

Recovery will probably be a permanent process. What I'm battling now is graftversus-host disease, as a result of having someone else's immune system."

> - Tom, transplant recipient (pictured on left)

### **GVHD early warning signs\***

\*symptoms are in alphabetical order

Not everyone experiences all of these warning signs, but many transplant recipients experience some of them.

### Acute

### Intestines

- Diarrhea
- Belly pain that does not go away
- Feeling bloated, or full of gas
- Blood in your stool

#### Liver

- Jaundice (your skin or eyes look yellow)
- Dark (tea-colored) urine
- Pain in the upper part of your belly
- Swelling in your legs or belly

### Skin

- Sunburn-like rashes
- Blisters

#### Stomach

- Nausea that does not go away
- Loss of appetite
- Vomiting
- Feeling full after eating very little

### Chronic

### Eyes

- Dry eyes
- Irritation that does not go away
- Blurred vision
- Teary eyes

#### Genitals

- Irritation or dryness
- Rash
- Painful intercourse

### Joints and muscles

- Arthritis-like symptoms (pain and stiffness)
- Muscle pain, cramps or weakness

### Lungs

- Cough that does not go away
- Shortness of breath
- Trouble breathing

### Mouth

- Trouble opening your mouth
- Sores
- Irritation that does not go away
- Chapped lips
- Pain

### Skin and nails

- Skin texture changes (thickening)
- Nail changes
- Rash
- Unusual hair loss or thinning
- Itchy skin

#### Stomach and intestines

- Nausea or vomiting
- Diarrhea
- Stomach pain or cramping

### **NOTES:**

# Checklists to help you get ready for transplant

The advice I would give is just to take it one step at a time.

Rachel, BSN,
Transplant Nurse Coordinator

### General

- Ask someone to look after your home or apartment (and any pets) while you are away.
- ☐ Have your mail forwarded or have someone collect it for you.
- ☐ Make a list of tasks you need help with. Share this with family and friends. Your list might include: cook meals or drive kids to school.
- ☐ Make plans with your employer for being away from work. Ask someone in your human resources (HR) department about programs to help you and your family.
- Ask your doctor about steps to prepare your home for life after transplant, such as recommended cleaning. Then, ask a family member, neighbor, or friend to help get your home ready.

### **Financial**

- ☐ Talk to the financial coordinator at your transplant center to find out what costs you may have.
- ☐ Call a fundraising organization to get help raising money for out-of-pocket costs.

### **Bone Marrow Foundation**

Phone: 1 (800) 365-1336, Website: BoneMarrow.org

### **Children's Organ Transplant Association** (COTA)

Phone: 1 (800) 366-2682, Website: cota.org

### **HelpHOPELive**

Phone: 1 (800) 642-8399, Website: helphopelive.org

### **National Foundation for Transplants**

Phone: 1 (800) 489-3863, Website: transplants.org

- ☐ Ask your transplant center social worker about local resources for financial help.
- Ask your health insurance case manager if you have any benefits related to transplant, like for housing or travel.

### Other:

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# Checklists to help you get ready for transplant (continued)

**NOTES:** 

### Caregivers

- ☐ Keep a notebook to write down information about treatments and checkups.
- ☐ Ask the doctor or nurse for written information about:
  - Treatments
  - Who to call after hours: Phone:
  - Care instructions
- ☐ Take care of yourself each day. For example,
  - Go for a walk
  - Talk to a close friend or family member
  - Take a few deep breaths
  - Watch a funny video

### **Parents and guardians**

- ☐ Talk with your child's teachers and principals about the plan for schoolwork and staying connected with friends while your child is away.
- ☐ Help your child make a list of items they want to bring to the hospital.
- ☐ Ask the social worker for tips to keep your child connected with school and friends.
- ☐ Talk with your other children about the plan for when their sibling gets a transplant.



Jade, transplant recipient, with her mom and brother

# Resources for you and your family

The **Be The Match®** Patient Support Center provides free support and resources for you and your family.

Contact a BMT Patient Navigator:

CALL: 1 (888) 999-6743

Monday through Friday, 8 a.m. - 5 p.m. Central Time

**EMAIL:** patientinfo@nmdp.org

The **Leukemia & Lymphoma Society** (LLS) is the leading source of free blood cancer information, education and support.

Contact an Information Specialist:

CALL: 1 (800) 955-4572

Monday through Friday. 9 a.m. - 9 p.m. Eastern Time

EMAIL: infocenter@lls.org

My doctor: Phone: Email: After hours phone number: My financial coordinator: Email: Mv nurse: Email: My social worker: Email:

### Word list

### Allogeneic transplant

A type of BMT where a patient receives healthy blood-forming cells. The healthy cells can come from a family member, unrelated donor or umbilical cord blood unit.

### Be The Match Registry®

A list of potential volunteer marrow donors and cord blood units established and maintained by the National Marrow Donor Program® (NMDP).

Blood-making cells (also called blood stem cells) Cells that grow into blood cells.

### **Blood and marrow** transplant (BMT)

A process to replace unhealthy bone marrow with healthy bone marrow. Also called bone marrow transplant, stem cell transplant or BMT.

### **Blood transfusion**

A procedure where donated blood is given to you through a narrow tube placed in a vein.

#### **Bone marrow**

A spongy tissue inside of bones.

### **Central venous line**

A long, thin tube that is put into a large vein in the chest or neck. It is used to give medicines, fluids and blood. Also called a central venous catheter.

#### Cord blood

The blood collected from the umbilical cord and placenta after a baby is born.

### Engraftment

When the blood-forming cells start to grow and make healthy blood cells that show up in your blood.

### **Graft-versus-host disease** (GVHD)

A common side effect of an allogeneic transplant. This happens when the donated cells attack your body.

### Peripheral blood stem cells (PBSC)

Blood-making cells in the bloodstream.

# WHEN YOU HAVE QUESTIONS ABOUT TRANSPLANT, **WE'RE HERE TO HELP**

**GET SUPPORT: BeTheMatch.org/one-on-one** 

EMAIL: patientinfo@nmdp.org

**ORDER:** BeTheMatch.org/request

CALL: 1 (888) 999-6743

TRANSLATED RESOURCES: BeTheMatch.org/translations

Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judament or advice.

### **About Be The Match®**

For people with life-threatening blood cancers—like leukemia and lymphoma—or other diseases, a cure exists. Be The Match connects patients with their donor match for a life-saving blood or marrow transplant. People can be someone's cure as a member of the Be The Match Registry\*, financial contributor or volunteer. Be The Match provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

Be The Match is operated by the National Marrow Donor Program' (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved.

Learn more at **BeTheMatch.org/patient** or call **1 (888) 999-6743**.



SPEAK ONE-ON-ONE with an Information Specialist from the Leukemia and Lymphoma Society who can who can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are master's level oncology social workers, nurses and health educators.

CALL: 1 (800) 955-4572

**EMAIL:** infocenter@LLS.org

**VISIT: LLS.org/patientsupport** 

About The Leukemia & Lymphoma Society®

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to funding research, finding cures and ensuring access to treatments for blood cancer patients.

LLS is the leading source of free blood cancer information, education and support.

Speak to an Information Specialist at 1 (800) 955-4572 or visit: LLS.org/patientsupport

