

TRANSPLANT BASICS Understanding transplant and how it works



AT EVERY STEP, WE ARE HERE TO HELP

As you journey through transplant, you're not alone. Be The Match® is ready to help.

The Be The Match Patient Support Center offers many free programs and resources to support you and your loved ones before, during and after transplant.

Our certified oncology patient navigators and licensed social workers provide:

- Guidance and information throughout the transplant process
- Emotional support, including counseling and support groups
- Help accessing financial grants and insurance resources, including Be The Match grants
- Connections with others who've been through transplant
- Information about clinical trials and personalized clinical trial searches. Learn more at CTSearchSupport.org.

Connect with us:

CALL OR TEXT: 1 (888) 999-6743

EMAIL: patientinfo@nmdp.org

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

REQUEST INFO: BeTheMatch.org/request

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There are risks and benefits to having a transplant. This booklet can help you learn about them so you can make informed decisions about your treatment.

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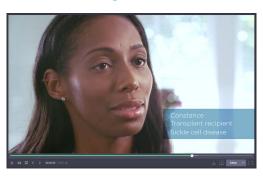
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To learn about transplant from doctors and health professionals, and hear from patients and caregivers who've been through it, watch short videos at:

BeTheMatch.org/LearnTheBasics.



INTRODUCTION

Transplant Basics is written for you—someone who is learning about or planning for a blood or marrow transplant (BMT). Your family and friends might want to read this too.

This booklet will help you and your loved ones:

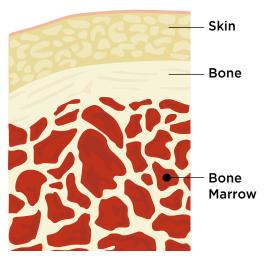
- Learn about BMT, also called a bone marrow transplant or stem cell transplant
- Think of questions to ask your doctor
- Prepare for transplant
- Access free resources through Be The Match and other organizations

Every patient's situation is unique, so it's important to talk about all your treatment options with your doctor.



UNDERSTANDING BLOOD AND MARROW TRANSPLANT

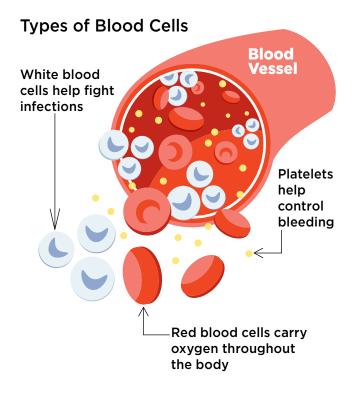
Bone Marrow



WHAT IS **BONE MARROW**?

Bone marrow is the soft tissue inside your bones that makes blood-forming cells. Blood-forming cells are immature cells (also called blood stem cells) that grow into red blood cells, white blood cells and platelets. Once they're mature, the cells and platelets leave the marrow and enter the bloodstream.

Healthy marrow and blood cells are needed to live. Different diseases can make the marrow not work well. When this happens, a transplant may be needed. For some diseases, transplant is the only possible cure.



BMT, also called a bone marrow transplant, replaces your unhealthy cells with healthy ones. Before your transplant, you get chemotherapy with or without radiation to kill your unhealthy cells.

WHAT IS A BLOOD OR MARROW **TRANSPLANT** (BMT)?

Then, the healthy cells are given to you. **A transplant is not surgery.** It's just like getting a blood transfusion. The new cells are given to you through an intravenous (IV) catheter, or tube. From there, the cells find their way into your marrow. There, they grow and start to make healthy red blood cells, white blood cells and platelets.

The blood-forming cells for transplant come from one of the following sources:

- 1. Bone marrow: The soft, spongy tissue inside of bones
- **2. Peripheral blood stem cells (PBSC):** Blood-forming cells from the bloodstream
- **3. Umbilical cord blood:** The blood collected from the umbilical cord and placenta after a baby is born



DISEASES MORE COMMONLY TREATED WITH BMT

Leukemia

- Acute lymphoblastic leukemia (ALL)
- Acute myeloid leukemia (AML)
- Chronic lymphocytic leukemia (CLL)
- Chronic myelogenous leukemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- Non-Hodgkin lymphoma (NHL)

Fanconi anemia
Multiple myeloma
Myelodysplastic syndromes (MDS)
Myeloproliferative disorders
Severe aplastic anemia
Sickle cell disease (SCD)

Children Only

Inherited Immune System Diseases

- Severe combined immunodeficiency (SCID)
- Wiskott-Aldrich syndrome (WAS)

Inherited Metabolic Disorders

- Adrenoleukodystrophy (ALD)
- Hurler syndrome
- Krabbe disease (GLD)
- Metachromatic leukodystrophy (MLD)

There are over 75 diseases for which transplant may be an option. Talk to your doctor to find out if transplant might be right for you.

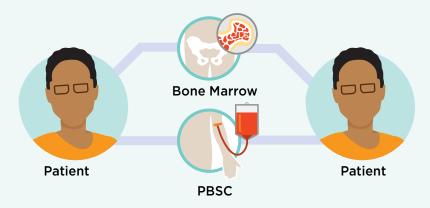


You can learn more about these diseases and when transplant may be a treatment option at **BeTheMatch.org/Diseases**.

WHAT ARE THE **TYPES OF TRANSPLANT**?

There are 2 main types of transplant:

1. Autologous Transplant



An autologous transplant uses your own blood-forming cells. The cells are collected from your bloodstream (a process called apheresis) or marrow (a procedure called a harvest) and safely stored until your transplant.

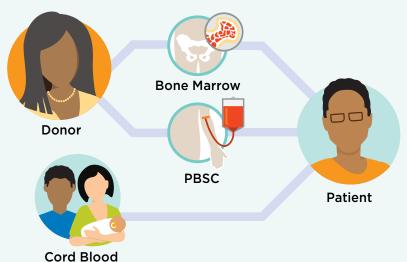


You may hear your health care team say "auto" and "allo." Auto means autologous transplant. Allo means allogeneic transplant.



To learn more about the steps before, during and after transplant, see The Transplant Process section starting on page 12.

2. Allogeneic Transplant



An allogeneic transplant uses blood-forming cells donated by someone else. This can be a family member or a person unrelated to you. If cord blood is used, this is most often from a public cord blood bank (from a baby unrelated to you), but can sometimes come from a baby in your family.

Allogeneic transplants require donors and patients to have closely matched **human leukocyte antigen** (HLA) markers. If you don't have a matching donor in your family, your doctor can search the Be The Match Registry® for a matched unrelated donor or cord blood unit. For more information, see **Steps to search the registry** (page 14).



Be The Match Registry®

If you need an allogeneic transplant, you won't have to find your own donor. Your doctor will test family members to try to find a matching donor first. If a matched donor is not found in your family, your doctor can search our registry.





There are many different terms that all mean blood or marrow transplant. Your doctor might say:

- Allo transplant (allogeneic transplant)
- Auto transplant (autologous transplant)
- BMT (blood and marrow transplant, or bone marrow transplant)
- HCT (hematopoietic cell transplant)
- Matched unrelated donor (MUD) transplant
- Mismatched unrelated donor (MMUD) transplant
- Related donor transplant
- Stem cell transplant

Your transplant doctor will recommend which type of transplant is best for you. This decision is based on:

- What disease you have—some diseases can only be treated with allogeneic transplant and some are best treated with autologous transplant.
- What stage your disease is in.
- Your overall health.



QUESTIONS TO ASK YOUR DOCTOR

- What are the risks and benefits of each type of transplant for my disease?
- Do you recommend an autologous or allogeneic transplant for me? Why?
- If an allogeneic transplant is recommended:
 - Which family members will you test as possible donors?
 - If a matched family member is not available, how will you find an unrelated donor for me?

WHEN IS **THE BEST TIME**TO HAVE A TRANSPLANT?

In most cases, the earlier you meet with a transplant doctor after your diagnosis, the better. It takes time to plan for a transplant, so it's important for your doctor to start the process early—even if you're still considering other treatment options.

A transplant doctor can talk with you about the best time for a transplant. In general, transplants work best if:

- The disease is in an early stage
- There are no signs of disease (remission), or there is very little disease in your body
- The disease has gotten better after chemotherapy
- You are in good overall health



Ask all the questions that you feel you want answers to, whatever that is. Everybody is different.

 Bob, transplant recipient, pictured above, with his wife and caregiver, Karen



QUESTIONS TO ASK YOUR DOCTOR

- Will a transplant be an option at some point in my treatment? If so, when?
- Should I see a transplant doctor now? If not now, when will you refer me to a transplant doctor?
- Is there a risk or benefit of waiting until later to meet with a transplant doctor?

WHICH **CELL SOURCE** IS BEST FOR ME?

Autologous transplants are mostly done with peripheral blood stem cells (PBSCs). Allogeneic transplants may use any of the 3 sources – marrow, PBSC or umbilical cord blood.

Your doctor will recommend which cells are best for you based on:

- Your overall health
- Your disease status or stage, including how quickly you need a transplant
- Your weight, because the number of blood-forming cells you need is based on your weight

OTHER TREATMENT OPTIONS

Transplant is one treatment option for blood or marrow diseases. Other options may include:

- CAR T cell therapy—Treated immune cells help your own immune system find and destroy cancer cells.
- Chemotherapy—Medicines that destroy cancer cells or stop them from growing. The goal may be to slow down the disease or kill the disease so there are no more signs of it (remission).
- Immunotherapy—Special proteins that attach to the outside of cancer cells to mark them so the immune system can destroy the cancer cells.
- Radiation therapy—Beams of energy to stop cancer cells from growing and multiplying.
- Blood transfusions—Intravenous (IV) infusions of red blood cells or platelets to ease the symptoms of many blood or marrow diseases.

Even if you get a transplant, you may still have one or more of these treatments as part of your overall treatment plan.



THE TRANSPLANT PROCESS



See a detailed, interactive timeline of an allogeneic unrelated transplant at: BeTheMatch.org/Timeline

The transplant process is different for everyone. Your path will depend on many factors including type of transplant, your overall health and your disease status. Your transplant team will be there the whole time to guide and support you.

The diagram below* shows the phases for both an allogeneic transplant (using cells from a donor) and an autologous transplant (using your own cells).

Transplant Phases*

Before transp	olant Day 0	After transplant	
CHEMOTHERAPY OR RADIATION	0	RECOVERY	
TREATMENT	TRANSPLANT DAY	*Every patient's experience is unique. Your path may be different.	

Learn more about the preparative regimen on page 17 and engraftment on page 19.



The days you receive the preparative regimen (the process to prepare your body for receiving the cells) are minus days (or -days). The number of days will vary, depending on your regimen. For example, you may receive the preparative regimen on day -8 through day -1. Someone else may receive it on day -6 through day -2. This part of the transplant process is the countdown to transplant day, or "**Day Zero**." The days after transplant day are called positive days (or +days).

The number of days for engraftment and recovery will be different for each patient.

BEFORE YOUR TRANSPLANT

If I need an allogeneic transplant, what happens first?

The first step is to find a donor who is the best match for you. Your doctor will use human leukocyte antigens (HLA) to match you with your donor or cord blood unit. HLA are proteins—or markers—found on most cells in your body. Your immune system uses HLA markers to know which cells belong in your body and which don't. Matching HLA markers is much more complex than matching blood type.

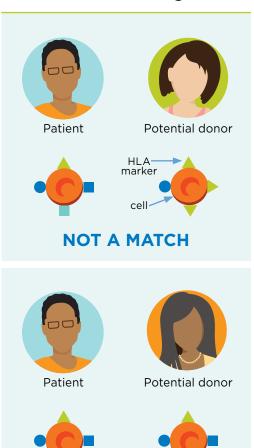
Typically, your doctor will first look for a matched donor in your family—usually a brother or sister. Each brother and sister has a 25% (1 out of 4) chance of matching you, if you have the same mother and father.

Most patients don't have a close match in their family. If you don't have a match in your family, your doctor will search the Be The Match Registry. This can take as little as a few weeks and sometimes many months. Depending on your ethnic background, the chance of having a matched, available donor is between 29% to 79%.

After deciding to move ahead with an allogeneic unrelated donor transplant, I didn't know what to expect. The search moved quickly, but for me it seemed like an eternity. To this day I am amazed and in awe of someone who would donate their cells to save the life of a complete stranger. I will forever be grateful for this selfless act.

-Michael, transplant recipient

HLA Matching



This is a simplified picture of a very complex process.

MATCH

Our Related Donor Services program can help if your donor is a family member.

Learn more at BeTheMatch.org/Related.

STEPS TO SEARCH THE REGISTRY



Your doctor requests a free search of the Be The Match Registry. This search shows the potential donors and cord blood units on the registry that could match your HLA markers.





Your doctor reviews the results. If you're not already seeing a transplant doctor, your doctor may refer you to one.



Your transplant doctor starts a more **detailed, formal search** of the registry when it's clear you'll need an unrelated donor or cord blood unit. This will tell you if a potential donor or cord blood unit is truly the best match for you. This costs money. If your health insurance doesn't pay for this, Be The Match grants may be able to help. Learn more at BeTheMatch.org/PatientAssistance





While your treatment continues, your transplant doctor chooses the best donor or cord blood unit for you. The chosen donor will have more blood tests and checkups to make sure they're healthy enough to donate.





Read more about the search process and HLA matching at **BeTheMatch.org/DonorSearch**.

Haploidentical and mismatched transplants

For some patients, doctors will look for a donor who matches half of your HLA markers. This is called a haploidentical, or half-matched, transplant. In these transplants, donors and patients share half of the HLA markers. Parents are always a half-match for their children and vice versa. Brothers and sisters have a 50% (1 out of 2) chance of being a half-match for each other.

For other patients, doctors will look for a donor who matches most of vour HLA markers. This is called a mismatched transplant.

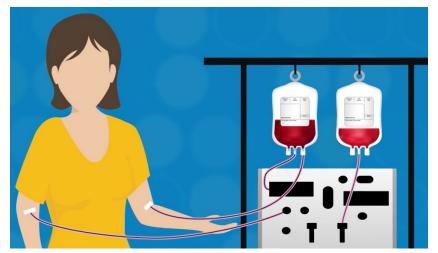
Not all transplant centers do haploidentical transplants or mismatched transplants. But it may be an option for you if your doctor can't find a closely matched family member, unrelated donor or cord blood unit.



Remember, your doctor-not youis the one who finds a matched donor or cord blood unit for your allogeneic transplant.

If I need an autologous transplant, what happens first?

When planning for an autologous transplant, your doctor won't need to find a donor. That's because you will be supplying your own blood-forming cells. Your doctor may collect PBSC or marrow. Most patients use PBSC. Your doctor will decide which is best for you.



Collecting PBSC through apheresis

PBSC COLLECTION: Blood-forming cells are collected from the bloodstream. This process is called apheresis. Before apheresis you receive shots to increase the number of blood-forming cells in your bloodstream. During apheresis, blood is removed through an IV line, passed through a machine, and put back into your bloodstream. The machine takes out the blood-forming cells that will be used for your transplant.

MARROW COLLECTION: Blood-forming cells are collected from the pelvic bone (hip bone) though surgery. You receive anesthesia so you are comfortable during the process. A doctor uses a special needle to remove the blood-forming cells from your bone marrow.

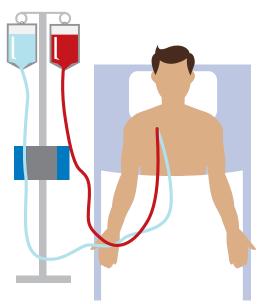
After they are collected, the cells can be frozen for months, or years, until you need them for your transplant.



Learn more about insurance coverage, financial assistance programs and how we can help at BeTheMatch.org/PatientAssistance.



Penny, transplant recipient with her doctor



A central line is used throughout treatment for many reasons, such as getting IV medicines and blood transfusions.

WHAT IS THE TREATMENT BEFORE TRANSPLANT?

In the weeks before your allogeneic or autologous transplant, you will meet with your doctor and other members of your transplant team.

Tests before transplant

You will have a checkup before you start the transplant process. This is to make sure that your body is healthy enough to have a transplant.

The checkups and tests you need will depend on your disease and health history. They also may vary from hospital to hospital. Typically, the tests include:

- Heart tests
- Blood tests
- Lung function tests
- Bone marrow biopsy This is where a needle is put into your hip bone to take out a small sample of bone marrow. A doctor studies the marrow under a microscope.

Ask your doctor about any tests you don't understand and make sure you are comfortable with your treatment plan.

Getting a central line

Whether you have an allogeneic or autologous transplant, you will give blood samples, get IV medicines and likely get blood transfusions often. If you don't already have one, you will have a central venous catheter, or central line, put in. This is a thin tube that's put into your arm or chest. It makes it easier to take blood and give you medicines without so many needle pokes.

Preparative or conditioning regimen

Before you get your cells, your doctors need to prepare your body to receive them. This process is called the preparative regimen, or conditioning regimen.

The preparative regimen is the chemotherapy and radiation you get in the days right before your transplant. Your doctor will choose the type of preparative regimen for you based on your disease and overall health.

It's a long process and it's intense. It's going to be rough at first, but you can do it. Just stick with it.

-Constance, transplant recipient



There are 2 main types of preparative regimens:

- **1. Standard-intensity regimen** This is also called a myeloablative regimen. This regimen uses high doses of chemotherapy, and possibly radiation. The high dose treatment helps to destroy diseased cells in your body. But it also weakens your immune system. Weakening your immune system helps your body accept the donated cells.
- 2. Reduced-intensity regimen This is also called a nonmyeloablative regimen. This regimen uses a lower dose of chemotherapy, and possibly radiation.

Autologous preparative regimens

Doses of chemotherapy and radiation are higher than what would be used to treat the same disease if you weren't getting a transplant. The higher doses may cause more severe side effects, but they also destroy more diseased cells. TRANSPLANT DAY: "DAY ZERO"

What happens on transplant day?

The day you receive your new cells is often called "Day Zero." It usually comes 1 or 2 days after you finish your preparative regimen.

You may have mixed feelings about transplant day. You may feel nervous. It may be a time of celebration. These feelings are normal. Your health care team will be with you to support you and address any concerns you may have.

On the day of my transplant, they came in to tell us how long it would be before the cells arrived, and I was so excited. It was like, 'Okay, this is it. We're moving on and I'm going to get better.'

-Patsy, transplant recipient

Receiving your cells

The transplant is **not** surgery. Instead, the healthy cells are given to you through your central line. The cells arrive in blood bags, similar to the ones used for blood transfusions.

You will be in your hospital room and awake when the new cells are given to you. The cells are put into your body like a blood transfusion. The whole process could be short (1 hour or less) or long (many hours) depending on how you feel and the number of cells being infused.

Some patients and family members like to do something special on transplant day to honor the milestone, like have a small gathering, play music or say a prayer. You may want to ask your transplant center for ideas on how you can honor and remember the day.

ENGRAFTMENT

The cells know where they belong in the body. They move through your bloodstream to settle into your bone marrow. There, the cells will begin to grow and make new red blood cells, white blood cells and platelets. When this happens, it's called engraftment. It can take days to weeks for engraftment to happen.

Engraftment is an important medical milestone after your transplant. It tells your doctors that the cells are working properly. With these cells, your immune system is now beginning to recover, and you are better able to fight infections on your own. This time also marks the beginning of your recovery process.

AFTER YOUR TRANSPLANT

How long does it take to recover from transplant?

Recovering from transplant takes time, and complications are common. Your doctor can tell you what complications you could have and how to help reduce them.

Early recovery

In the first few months after transplant you'll stay in or near the hospital. Focus on your recovery by:

- Eating well
- · Washing your hands often to prevent infections
- Taking your medicines
- Going to all of your doctor's appointments
- · Doing everything your transplant team tells you



Life after transplant is a different challenge than treatment. Paving the road to your new normal has its emotional ups and downs. However, if you lean on your support system and listen to your doctors, your road will be much smoother.

-Matt, transplant recipient, pictured above



Find tips on how to lower your risk of infections and stay healthy after transplant at BeTheMatch.org/AfterTransplant

Even after engraftment, you will still be weaker than normal for many months. The risk for complications from a transplant is highest during the first 100 days after a transplant. This is because your immune system needs time to grow stronger. Your transplant team will watch you closely for infections and other problems.

You may be able to leave the hospital when:

- Your cells have engrafted, and
- You have no sign of infection, and
- You're able to take all your medicines by mouth

This usually happens some time during the first 100 days, but may take longer. However, you will likely still need to visit the hospital or clinic regularly.

Some hospitals have programs for outpatient transplant. If you are having an outpatient transplant, you will still need to make frequent, often daily, visits to the outpatient clinic.



GRAFT-VERSUS-HOST DISEASE (GVHD)

Graft-versus-host disease (GVHD) is a common complication of an allogeneic transplant. GVHD can affect many different parts of the body including the skin, eyes, mouth, stomach and intestines.

GVHD happens because of differences between the donated cells (graft) and your body's cells (host). Your new cells from your donor might see your body's cells as different and attack them.

Types of GVHD:

- Acute GVHD: Typically develops in the early weeks and months after transplant. It's called Late Acute GVHD when it develops 3 or more months after transplant.
- Chronic GVHD: Typically develops within 1 year of transplant. It's called Overlap Chronic GVHD when signs and symptoms of chronic and acute GVHD appear together.

Acute and chronic GVHD can range from mild to severe.

If your allogeneic transplant is treating a blood cancer, your doctor may see mild GVHD as a good thing. It is a sign that the donor's immune system is working to destroy any remaining cancer cells. Patients who have some GVHD may have a lower risk of the cancer returning after transplant than patients who don't develop GVHD. However, if your allogeneic transplant is treating a disease other than cancer, like aplastic anemia. then your doctor may want to treat even mild GVHD.

GVHD is serious, but there are several treatment options.



Tom, transplant recipient, with his doctor



More information on GVHD, including prevention, signs and symptoms, and treatment, can be found at BeTheMatch.org/patientGVHD

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. Surround yourself
with friends and have a committed
caregiver who will be your advocate
as well. Focus on the things you can
do instead of your limitations.

-Evelyn, transplant recipient

Long-term recovery

When you leave the hospital, you will need to:

- Follow guidelines to reduce the risk of serious infections and other complications.
- Take all of your medicines exactly as your doctors tell you.
- Follow your transplant team's advice for eating and safe handling of food. Eating healthy foods will help you get your strength back and reduce your infection risk.
- Call your doctor right away if you have any symptoms or signs of infection, like a fever. They'll give you a detailed list of what to watch for.

Everyone has a different experience after transplant. It's common to re-enter the hospital to be treated for complications after transplant.

In your first weeks or months after you leave the hospital, you will see your transplant team often, even daily. If you travel to a transplant center far from home, expect to stay near your transplant center for treatment for at least the first 100 days.

You will continue to see your doctor in the months and years after your transplant. Regular doctor visits are important to protect your health. Your doctors will watch for problems related to the transplant or past treatment.

When symptoms are found and treated early, there may be more options for treatment, and those treatments can be more effective. See text at right for information about after-transplant care guides for both allogeneic and autologous transplant recipients.

Each patient's recovery is different. It is possible to have a short recovery, but for some patients, recovery can last for years.





The medicines you will take after transplant are very important to your health and recovery. If you have trouble paying for any of them, let your doctor know right away. Be The Match, and other organizations, have financial aid available to help cover the costs of medicine and co-pays.



POST-TRANSPLANT CARE GUIDES

(available in English and Spanish)

We provide free after-transplant care guides for you and your doctor. They'll help you and your doctor quickly find and treat problems that can occur after transplant. They are available in print and online.

Visit: BeTheMatch.org/CareGuide.



After transplant, our survivorship team is available to answer questions, connect you to resources and offer free telehealth appointments with our medical staff. Learn more at

BeTheMatch.org/Survivorship

BEING A CAREGIVER



A transplant caregiver is anyone who provides direct support or care to someone who has received a blood or marrow transplant. This support may be medical, financial or emotional.

A caregiver can be:

- A spouse or partner
- Adult children
- Brothers or sisters
- Parents
- Friends or co-workers

WHO IS A CAREGIVER?

A caregiver is someone who will be there to provide support and care throughout the transplant process. Your caregiver will play an important role in your health care and recovery. In fact, most transplant centers require you to choose a caregiver before you can get a transplant.

The doctors, nurses and social workers at the transplant center will help your caregiver learn about their role. We also support caregivers with programs and resources, including one-on-one support.

WHAT DOES A CAREGIVER DO **BEFORE TRANSPLANT**?

Even before your transplant, you might need some extra help and support. Your caregiver can help you and advocate for you.

For the **medical** areas of transplant, your caregiver can:

- Be with you in the hospital or clinic during doctor's visits to listen and ask questions
- Ask your doctors to explain treatment choices, test results and medicines
- Keep track of all your treatments in a notebook
- Talk with you to understand your treatment goals



For the **cost** of transplant, your caregiver can:

- Find out what insurance will pay and what you will need to pay
- Ask your social worker or financial coordinator about other financial help
- Help you plan how to pay for transplant
- Make sure household bills are paid on time
- Help you keep your health insurance and other benefits active
- Ask about taking an extended leave from work (Family Medical Leave Act) for both you and your caregiver

Your emotional care before transplant is important, too. Your caregiver can:

- Be there to listen, talk or simply be by your side
- Show support for your feelings
- Spend time with you doing things you both like to do
- Help communicate with your support system

(From left to right) Johnnie and Frances, parents and caregivers for their daughters, Samantha, sister and donor, and **Constance**, transplant recipient

WHAT DOES A CAREGIVER DO

AFTER TRANSPLANT?

Your caregiver's role will change when you're ready to leave the hospital. You will need to have a caregiver available at all times, especially when you first leave the hospital.

Before leaving the hospital, your health care team will teach your caregiver:

- How to care for you at home
- What to do if there is an emergency
- Who to contact with questions

Once you get home from the hospital, one of your caregiver's most important tasks is to watch for new symptoms or problems and report them to your doctor right away. That's because waiting to report symptoms could cause serious complications.

Your caregiver may also need to:

- Help you take the right medicines at the right times
- Change dressings on your central line, if it's still in place
- Take you to appointments at the hospital or clinic sometimes on short notice
- Protect you from infections by cleaning your home and caring for children and pets
- Cook food safely and help you follow any rules about what is safe for you to eat

Remember, your caregiver will need to be available all of the time, in case you need medical help right away.

Your caregiver may also continue to offer financial and emotional support.



Looking for effective ways to care for yourself while caring for your loved one? Go to

BeTheMatch.org/Caregiver for easy tools that can help.

IS THERE SUPPORT AVAILABLE

FOR MY CAREGIVER?

Yes! In addition to resources for patients, the Be The Match Patient Support Center offers information and support for BMT caregivers and parents. We can help them cope with the challenges that come with caring for a BMT recipient during the transplant journey. All of our programs and resources are free. Caregivers and parents can:

- Chat with a BMT Patient Navigator to get information, support and resources
- Get one-on-one emotional support from licensed social workers
- Register for webinars and telephone support groups
- Sign up for *Peer Connect* to talk with a caregiver or parent who's been there

CALL OR TEXT: 1 (888) 999-6743

EMAIL: patientinfo@nmdp.org

LEARN MORE: BeTheMatch.org/Caregiver

One of the most important things a caregiver can do is take care of themselves. The stress of transplant affects them, too.



As you go into this and you know you're going to be the primary caregiver, you probably need to get a caregiver, too.



-Steve, caregiver and husband to Patsy, transplant recipient, pictured above

It was very hard to walk away,
but it needs to be done so you
are refreshed and ready to care
for your child. Whether it's going to eat
or taking a walk, leaving the room
a couple of times a day really does help
with caring for yourself. Making sure
you are taken care of helps you take
better care of your child.

—Dan, father of 3-month-old transplant recipient

HOW DO I CARE FOR A CHILD

WHO NEEDS A TRANSPLANT?

When your child needs a transplant, the lives, roles and responsibilities of the whole family often change. Many times, at least one parent will stay with your child throughout the transplant process, including staying in the hospital. You know your child best, and you can be your child's best advocate.

Remember, the transplant process is more like a marathon than a sprint. As you go through the transplant journey with your child, it's important that you take care of yourself so you can stay healthy and be there to care for your child. Reach out to other family members, friends and neighbors who can support you.



PREPARING FOR TRANSPLANT

Contact Us

Our BMT Patient Navigators can answer your questions and provide support and education to help you and your family navigate your transplant journey. Contact us at 1 (888) 999-6743 or

patientinfo@nmdp.org with your questions. Support is available in many languages.



Maria MacWilliams, OPN-CG, Principal BMT Patient Navigator, Bilingual

If you and your doctor decide to move forward with transplant, you may have many questions. Your transplant center's social worker is a good place to start. Your social worker can help you prepare by listening to your concerns and answering your questions about what you'll need to do. Your social worker can also tell you about support resources available to you and your family.

HOW CAN I PREPARE EMOTIONALLY?

Going through a major illness and treatment is stressful. Talking to someone about what you're going through may help.

You may want to:

- Tell your family and friends how you're feeling and how they can support you.
- Let your children know what to expect during and after your treatment.
- Talk to other people who are going through a transplant or who have already had a transplant.



Blood & Marrow Transplant Journeys: Ordinary people with extraordinary stories.

Stories of isolation, illness, healing, faith and resilience will offer you hope and comfort during your transplant journey.

Order your free copy:
BeTheMatch.org/BMTJourneys



HOW CAN I HELP MY CHILD

PREPARE EMOTIONALLY?

Children express their emotions in different ways. If you are concerned about your child's emotional health during your transplant and recovery, there are things you can do to help, depending on your child's age.

- Explain to your child what they can expect during your treatment process and encourage them to ask questions.
- Encourage your child to express their feelings such as through talking, journaling or drawing.
- Tell stories of how you have felt during stressful situations, how you handled it (good or bad) and how it turned out.
- Share feelings and solve problems together. You may want to try creative ways to express feelings like drawing pictures or writing a story.
- All of the ways you normally comfort your child are more important than ever right now. Hold them, give hugs, or offer a hand massage or gentle back rub.
- Tell them how much you love them.

Early on in our journey, a friend told me, 'No emotion is bad. All feelings are good. Just go with it.' Through all the emotions, I always reminded myself of this.

-Sherri, mother of TJ, age 18 at transplant



Our **Peer Connect** program can connect you or your caregiver with someone who's been through the transplant journey. Our trained peer volunteers are available to talk by phone, or connect through email. Request a connection by visiting BeTheMatch.org/PeerConnect.

You can also connect with other transplant patients and caregivers:

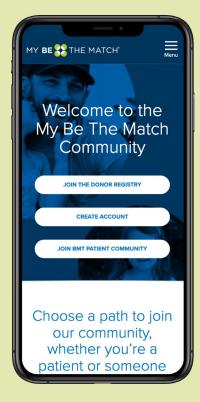
f Facebook.com/ BeTheMatchPatient.



MY BE THE MATCH APP

A free, secure tool to help you and your caregiver manage your health.

Join at: my.BeTheMatch.org



FOR TRANSPLANT: Make a list of important phone numbers. Share the list with the entire family. Include names and numbers of your health care team and caregivers. Write down important information about finances.

THINGS TO DO AS YOU'RE PLANNING

Tell your caregiver where you'll keep this information
Ask your bank what you need to do so your

caregiver	can handle	certain	transactions	for you	

ш	Plan how your bills will be paid while you're in the
	hospital and during recovery.

Ask for help with household chores and other
duties in your absence.

If you have children, set up schedules and make
plans for how they'll be cared for while you're away
Tell your children and others involved about the
plans vou make.

If you're the only one who can allow medical care
for your children, provide a medical release that
gives permission to your caregiver or another
person you trust. Ask your children's doctor to give
you a medical release form

Family and friends will want to know how they can
help. Make a list of tasks they can do.

HOW CAN I PREPARE FINANCIALLY?

Even if you have insurance, some costs may not be paid by your insurance. These may include deductibles, copayments and housing.

Here are 6 things you can do to prepare financially:

- 1. List your income and expenses. It can help you organize your money and prepare for unexpected costs.
- **2. Learn about your benefits.** The financial coordinator at your transplant center can tell you about your benefits and talk with your insurance company to learn more about your coverage.
- **3. Apply for financial grants.** The social worker at your transplant center can help you apply for grants through Be The Match and other financial aid programs.
- **4. Raise money.** Fundraising is usually the best way to meet ongoing financial needs. But, it takes time and energy, so consider asking a close family member or friend to help you. See page 45 for organizations that can help you raise money and make sure your taxes and other benefits aren't affected.
- **5. Explore ways to keep some of your income.** There may be disability insurance options that will pay some of your income if you're unable to work. This may include short-term and long-term disability insurance and Social Security Disability Insurance.
- **6. Lower your monthly costs.** Call your creditors (the people you owe money) and explain your situation. Many creditors will understand and work with you to find a lower monthly payment.



If coverage is denied ...

You have the right to ask your health insurance plan to pay for a particular treatment or service even if they have already denied you coverage. This is called an appeal. The financial coordinator at your transplant center can help with this process.



The finance and insurance series of short, easy-to-read fact sheets has information and resources for things like:

- Financial planning
- Health insurance
- The Affordable Care Act
- Raising money to pay for transplant

You can download or order the fact sheets at

BeTheMatch.org/Request.



Learn more about fertility preservation options at **BeTheMatch.org/Fertility**.

WHAT ELSE SHOULD I THINK ABOUT?

Transplant and fertility

If you want to have children in the future, tell your doctor, nurse or social worker right away. Chemotherapy and radiation can lower your fertility (ability to have children). But there may be ways for you to keep, or preserve, your fertility. Ask your doctor about your fertility preservation options.

Preparing a living will

Make sure your health care team and your family understand your treatment wishes. This may help you be more in control of your own health care.

You may want to prepare an advance directive, commonly called a living will. In a living will, you can:

- Say what kind of care you would or would not want if you aren't able to speak for yourself
- Share your preferences about treatments to prolong your life if some of your organs stop working (for example, a breathing machine if you can no longer breathe on your own)
- Choose someone who can make medical decisions for you

Living wills can be helpful throughout your treatment. For example, if you are really sick during a temporary complication, there could be a short amount of time when you can't tell your doctors what you want. Your health care team can turn to your appointed person during these short amounts of time.

Having a living will means your family and medical team aren't left wondering what kind of care you would or would not want to have.



QUESTIONS TO ASK YOUR DOCTOR



Get help finding clinical trials at CTSearchSupport.org



Before you meet with your doctor, make a list of questions you would like to ask. You can use the following list of questions to get started.

- What are my treatment options?
- What treatment do you recommend? Why?
- What is the goal of this treatment?
 - To control symptoms?
 - To have a long-term remission—if so, for how long?
 - To cure my disease?
- How many patients have you treated who have the same disease?
- What are the chances that this treatment will get rid of the disease? For how long?
- What are the chances that I could get rid of the disease without this treatment?
- What are the possible risks and side effects of the treatment?
 - First few months?
 - First year?
 - Long term?
- What can be done to lower my risk of side effects?
- Is it possible to continue work or school during treatment?
- What can you tell me about my quality of life after this treatment?
- How long will the treatment take?
- How will we know whether the treatment is working?
- What other choices do we have if the treatment does not work?
- Do you know of any clinical trials that might be appropriate for me?



If a transplant is recommended:

- •When should I have the transplant?
- What are the risks of waiting or trying other treatments first?
- How long will I be in the hospital for my transplant?
- How long do I have to stay near the hospital before I can return home?
- What can I do to take care of myself and get better after transplant?
- Do I need a caregiver throughout the process?
- What does a caregiver do while I'm in the hospital? What about when I go back home?
- What kind of care might I need after I return home?



If an allogeneic transplant is recommended:

- Which family members will you test as possible donors?
- If a family member is chosen as a donor, what would he or she have to do?
- What happens if I don't have a match in my family?
- Is a haploidentical (half-matched) transplant an option for me?
- Is a reduced-intensity transplant an option? Why or why not?



If an autologous transplant is recommended:

- •How will you decide the best time to collect my cells?
- How will you decide the best timing for transplant?
- If the disease relapses (comes back), will I be eligible for an allogeneic transplant?



Learn more about the basics of transplant in our easy-tounderstand videos:

BeTheMatch.org/ LearnTheBasics.



You can find a list of transplant centers in the United States and information on choosing a transplant center at

BeTheMatch.org/Access.



Ines, transplant recipient

QUESTIONS TO ASK WHEN CHOOSING

A TRANSPLANT CENTER

You may be comparing 2 or more transplant centers (a hospital that does transplants). Or you may have already chosen one.

Ask the transplant doctor:

- How much experience does this transplant center have with allogeneic or autologous transplants?
- How many transplants has this center done for this disease?
- Does this transplant center have experience with patients who are my age?
- Does this center have experience with cord blood transplants?
- Does this center have experience with haploidentical transplants?
- What are the typical transplant outcomes (results) for patients like me at this center?
- What resources (for example, emotional or financial) are available at this center?
- If I am having an unrelated donor transplant, how will I learn about the progress of the donor search? Will the center call me or should I call them? How often can I expect to get progress reports?



If the transplant center is far from your home, you may want to ask these questions:

- Will the transplant center help make arrangements for my family or caregiver to stay close by?
- Is there housing near the transplant center?
- Is there help to pay for the cost of this housing?

Here are some questions you can ask yourself after visiting a transplant center:

- What do I think after talking with or visiting the transplant center?
- Did they answer my questions in a way that helped me understand the process?
- Did they seem willing to help me solve any problems I might have?
- Did they return my phone calls within a reasonable amount of time?
- Did I feel like they would take good care of me?



Other important things to consider:

- How important is the location to me? To my family?
- Is it important for me to be close to family and friends? Or, would I rather go to the transplant center with the most experience, even if it is far from home?

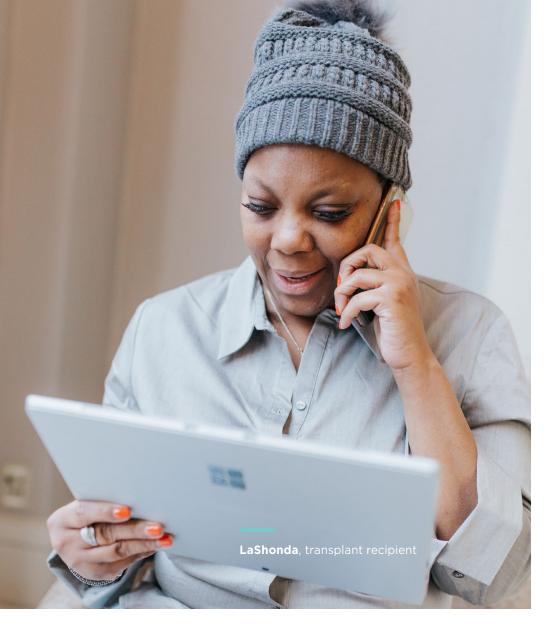
QUESTIONS TO ASK ABOUT INSURANCE AND PAYING FOR TRANSPLANT

Insurance companies or government programs (such as Medicaid or Medicare) have different ways to pay for treatment and transplant costs. Some pay all costs, others pay for some, and still others don't pay for any costs. It is very important to find out what costs are covered (paid for), and if the transplant center where you will be seen is covered.



Here are some important questions to ask the transplant center's financial coordinator or your insurance representative:

- Does my insurance cover transplant for my disease?
- Does it cover the type of transplant my doctor has recommended (autologous, allogeneic, etc.)?
- Does it cover the cost of testing my family members?
 Or testing to find an unrelated donor?
- Does it cover the collection of marrow from the donor or cord blood units? Are there any limits to what it will pay? If so, what are they?
- What kind of costs won't it pay for?
- Does it cover any costs such as travel or lodging for me? For my caregiver? For my relative if my relative is my donor?
- Does it cover prescription medicines before and after a transplant? How much will I have to pay? (Your doctor or transplant center pharmacist can give you a list of common medicines after transplant.)
- Are there any limits to what my insurance will pay, such as how many people can be tested to see who is a possible match? (If so, what will I have to pay?)





If you have not chosen a transplant center yet, here are some more questions to ask your insurance representative:

- Which transplant centers will my insurance cover?
- Can I choose which transplant center I go to? What happens to my coverage if I choose a transplant center that is not on the list?
- Does my insurance company ever make exceptions? For example, could I go to a transplant center with the most experience treating a rare disease, even if it is not on the list?



Talking about finances can feel like a very personal topic, but our confidential one-on-one support is available to help you. We can help you learn more about transplant costs, insurance coverage and financial resources. Contact us at 1 (888) 999-6743 or patientinfo@nmdp.org.

More information about insurance and transplant coverage, financial planning resources and financial assistance resources is available at

BeTheMatch.org/ PatientAssistance.

RESOURCES FOR YOU

I was diagnosed with acute myeloid leukemia (AML) in 2011, and had a BMT in 2012.

Be The Match has been with me every step of the way, supporting me, counseling me, and providing information.

-Lorayne, transplant recipient

AT EVERY STEP, WE'RE HERE TO HELP

We are here to help you get reliable, easy-to-understand information from diagnosis through recovery. Call or email us for confidential, one-on-one support from caring experts. We'll listen and help you find answers. All of our programs and resources are free.

Our Patient Support Center team can help you:

- Learn about transplant
- Understand the donor search process
- Find a transplant center
- Get answers to your financial or insurance questions
- Connect with other transplant patients and caregivers through our *Peer Connect* program
- Find clinical trials
- Prepare for and cope with life after transplant

Our services include:

- Telephone counseling and one-on-one support
- Financial grants for patients
- Support groups and telephone webinars
- Caregiver support
- Survivorship support
- Tips for talking with your healthcare team
- Educational books, DVDs, newsletters and fact sheets
- Information and support in many languages

Contact us:

CALL OR TEXT: 1 (888) 999-6743

Monday-Friday, 8:00 a.m.-5:00 p.m. Central Time

EMAIL: patientinfo@nmdp.org

VISIT: **BeTheMatch.org/one-on-one**

The following list can help you find resources and information. Be The Match is not endorsing these organizations. The choice to work with these groups is solely that of the patient and his or her representative.

TRANSPLANT ORGANIZATIONS

(S) BLOOD & MARROW TRANSPLANT INFORMATION NETWORK (BMT InfoNet) (888) 597-7674 bmtinfonet.org help@bmtinfonet.org

(S) NATIONAL BONE MARROW TRANSPLANT LINK (NBMTLINK) (800) 546-5268 nbmtlink.org info@nbmtlink.org

(S) THE BONE MARROW **FOUNDATION** (800) 365-1336 bonemarrow.org TheBMF@BoneMarrow.org

SOCIAL SUPPORT

BMT SUPPORT bmtsupport.org

BMT-TALK listserv.acor.org

CARINGBRIDGE® (651) 789-2300 caringbridge.org

(S) = Spanish language support

LOTSA HELPING HANDS lotsahelpinghands.com info+contactus@lotsahelpinghands. com

GENERAL CANCER **RESOURCES**

(S) AMERICAN CANCER SOCIETY® (800) 227-2345 cancer.org

(S) CANCERCARE® (800) 813-HOPE (4673) cancercare.org info@cancercare.org

CANCER HOPE NETWORK® (877) 467-3638 (HOPENET) cancerhopenetwork.org info@cancerhopenetwork.org

CANCER SUPPORT COMMUNITY (888) 793-9355 cancersupportcommunity.org

(S) LIVESTRONG® **SURVIVORCARE** (855) 220-7777 livestrong.org/cancersupport cancersupport@livestrong.org

(S) NATIONAL CANCER INSTITUTE'S (NCI'S) CANCER INFORMATION SERVICE (CIS) (800) 422-6237

cancer.gov

(S) NATIONAL COALITION FOR CANCER SURVIVORSHIP (877) 622-7937 canceradvocacy.org info@canceradvocacy.org

DISEASE ORGANIZATIONS

(S) APLASTIC ANEMIA AND MDS INTERNATIONAL FOUNDATION (AAMDSIF) (800) 747-2820 aamds.org help@aamds.org

(S) FANCONI ANEMIA **RESEARCH FUND** (888) 326-2664 fanconi.org info@fanconi.org

(S) IMMUNE DEFICIENCY **FOUNDATION** (800) 296-4433 primaryimmune.org

(S) INTERNATIONAL MYELOMA **FOUNDATION** (800) 452-CURE (2873) myeloma.org

(S) THE LEUKEMIA & LYMPHOMA SOCIETY® (LLS) (800) 955-4572 lls.org

RESOURCES FOR YOU (continued)

LEUKEMIA RESEARCH FOUNDATION (888) 558-5385 allbloodcancers.org

LYMPHOMA RESEARCH FOUNDATION (800) 500-9976 lymphoma.org helpline@lymphoma.org

MULTIPLE MYELOMA RESEARCH FOUNDATION (866) 603-6628 themmrf.org patientnavigator@themmrf.org

(S) NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD®) (800) 999-6673 English (844) 259-7178 Spanish rarediseases.org

SICKLE CELL DISEASE
ASSOCIATION OF AMERICA, INC.
(SCDAA®)
(800) 421-8453
sicklecelldisease.org
admin@sicklecelldisease.org

FOR CHILDREN

(S) AMERICAN CHILDHOOD CANCER ORGANIZATION (855) 858-2226 acco.org

CHAI LIFELINE (877) 242-4543 (CHAI LIFE) chailifeline.org info@chailifeline.org KIDS KONNECTED (949) 484-9092 kidskonnected.org info@KidsKonnected.org

(S) THE NATIONAL CHILDREN'S CANCER SOCIETY (800) 532-6459 thenccs.org

THE NEUROBLASTOMA
CHILDREN'S CANCER SOCIETY
(800) 532-5162
neuroblastomacancer.org

CHILDREN'S HEALTH INSURANCE PROGRAM (877) 267-2323 medicaid.gov/CHIP

FOR TEENS & YOUNG ADULTS

THE ULMAN FUND (888) 393-3863 (FUND) ulmanfund.org info@ulmanfoundation.org

STUPID CANCER (877) 735-4673 stupidcancer.org contact@stupidcancer.org

CLINICAL TRIALS

CLINICAL TRIALS SEARCH AND SUPPORT (888) 814-8610 CTSearchSupport.org Contact@CTSearchSupport.org

FERTILITY

(S) FERTILE HOPE (855) 220-7777 fertilehope.org

SAVE MY FERTILITY (312) 503-2504 savemyfertility.org

FINANCIAL

CANCER FINANCIAL ASSISTANCE COALITION (CFAC) cancerfac.org

HEALTHCARE HOSPITALITY NETWORK, INC. (800) 542-9730 hhnetwork.org

(S) NEEDYMEDS (800) 503-6897 needymeds.org info@needymeds.org

(S) = Spanish language support

FUNDRAISING

CHILDREN'S ORGAN TRANSPLANT ASSOCIATION® (COTA) (800) 366-2682 cota.org cota@cota.org

HELPHOPELIVE (800) 642-8399 helphopelive.org

NATIONAL FOUNDATION FOR TRANSPLANTS (NFT) (800) 489-3863 transplants.org info@transplants.org

INSURANCE

(S) MEDICARE (800) 633-4227 medicare.gov

(S) HEALTH INSURANCE MARKETPLACE (800) 318-2596 healthcare.gov

(S) PATIENT ADVOCATE **FOUNDATION** (800) 532-5274 patientadvocate.org help@patientadvocate.org

(S) SOCIAL SECURITY **ADMINISTRATION** (800) 772-1213 ssa.gov

LEGAL & EMPLOYMENT

(S) CANCER AND CAREERS (646) 929-8032 cancerandcareers.org cancerandcareers@cew.org

(S) CANCER LEGAL RESOURCE CENTER (866) 843-2572 thedrlc.org/cancer CLRC@drlcenter.org

CANCER FINANCIAL ASSISTANCE COALITION (CFAC) cancerfac.org

TRANSPORTATION

AIR CARE ALLIANCE aircarealliance.org mail@aircarealliance.org

MIRACLE FLIGHTS (800) 359-1711 miracleflights.org info@miracleflights.org

NATIONAL PATIENT TRAVEL HELPLINE (800) 296-1217 patienttravel.org

WORD LIST

ALLOGENEIC TRANSPLANT

A type of transplant where a patient receives healthy blood-forming cells from a donor or umbilical cord blood unit.

APHERESIS

A process to collect blood-forming cells from the bloodstream.

AUTOLOGOUS TRANSPLANT

A type of transplant where a patient's own blood-forming cells are collected, stored and given back after chemotherapy, and sometimes radiation.

BLOOD-FORMING CELLS

Cells that grow into red blood cells, white blood cells or platelets. Also called blood stem cells.

BLOOD OR MARROW TRANSPLANT (BMT)

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

BONE MARROW

The soft, spongy tissue inside of bones.

CELL SOURCES

The 3 places where blood-forming cells are found:

- Bone marrow
- Peripheral blood (circulating blood or bloodstream)
- Umbilical cord blood

CENTRAL VENOUS CATHETER

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 line.

CHEMOTHERAPY

Medicines that destroy cancer cells or stop them from growing. Also called "chemo".

CLINICAL TRIAL

A way to gather information about how well a particular treatment for a disease works and what the side effects may be.

CORD BLOOD

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

DISEASE-FREE SURVIVAL (DFS)

The number of patients who are alive at a certain time after treatment without any signs of the disease.

DONOR

A person who volunteers to give blood-forming cells. A donor can be a family member or an unrelated donor.

ENGRAFTMENT

When the donated blood-forming cells start to grow and make healthy blood cells in your blood.

FORMAL SEARCH

A detailed search of the Be The Match Registry. This search shows whether a potential donor or cord blood unit is truly the best match for you. There is a cost for this service. Your insurance may or may not pay for these costs.

GRAFT FAILURE

When the donated new cells do not make the white blood cells, red blood cells and platelets you need.

GRAFT-VERSUS-HOST DISEASE (GVHD)

A common side effect of an allogeneic transplant. GVHD happens because your new cells from your donor (graft) might see your body's cells (host) as different and attack them.

HAPLOIDENTICAL TRANSPLANT

A type of transplant where your donor matches half of your HLA markers. Also called a half-matched transplant. Biological parents and their children are always a half-match.

HARVEST

A way to collect blood-forming cells from the bone marrow before transplant.

HLA (HUMAN LEUKOCYTE ANTIGEN) MARKERS

Proteins, or markers, found on most cells in your body. There are certain HLA markers your doctor looks at for transplant. You get half of your HLA from your mother and half from your father.

NOTES:

IMMUNE SYSTEM	
The parts of your body (blood cells and organs) that fight infections.	
INFORMED CONSENT	
When you have been given	
information including the possible risks and benefits before agreeing	
to a treatment or clinical trial.	
PERIPHERAL BLOOD STEM	
CELLS (PBSC) Blood-forming cells from the	
bloodstream.	
PLATELETS	
Parts of the blood that help the blood clot.	
PRELIMINARY SEARCH	
A free search of the Be The Match	
Registry. This search shows the potential donors and cord blood	
units that could match your HLA	
markers.	
PREPARATIVE REGIMEN	
The process of preparing your	
body to receive the new blood- forming cells. Also called a	
conditioning regimen.	
RED BLOOD CELLS	
Blood cells that carry oxygen	
throughout the body.	
REDUCED INTENSITY	
TRANSPLANT Preparative regimen that uses	
lower doses of chemotherapy with or without radiation.	
or without radiation.	
WHITE BLOOD CELLS	
Blood cells that fight infections.	

NOTES	

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 judgment 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.