Rhiannon,
transplant recipient

Allogeneic Transplant

How to plan and what to expect

nmdp℠
FIND CURES. SAVE LIVES.

At Every Step, We Are Here to Help

As you journey through transplant, you're not alone. NMDP$^{\text{SM}}$ is ready to help.

We offer many **free** programs and resources to support you and your loved ones from diagnosis through survivorship. Help is only a click or a call away.

Need to talk?

Our BMT patient navigators are available to listen, answer questions and find resources. Our BMT social workers provide free one-on-one counseling support to help you cope with the transplant process.

Looking for resources?

Our free print, video and online resources can help you throughout the transplant process.

Want to connect with someone who's been there?

Our NMDP Peer Connect Program will put you in touch with a trained volunteer who's been through transplant.

Our programs and resources offer support in 11 languages, including Spanish bilingual staff, and interpreter services are available in over 100 languages.

Connect with us in the way that works best for you.

- **GET SUPPORT:** nmdp.org/one-on-one
- **REQUEST INFO:** nmdp.org/request
- **EMAIL:** patientinfo@nmdp.org
- **CALL:** 1 (888) 999-6743
- **FACEBOOK:** facebook.com/nmdpPatient

Table of Contents

Understanding Allogeneic Transplant

Matching Patients and Donors

Getting Ready for Transplant

The Transplant Experience

Graft-Versus-Host Disease (GVHD)

Introduction

As you're preparing for your blood or marrow transplant, you may have a lot of questions. Maybe you're wondering how your doctor will find a donor for you. Maybe you're wondering how you can get ready for your transplant. Or maybe you're already thinking about what you need to do when you return home after your transplant.

This booklet will:

- Help you understand what to expect before, during and after your transplant
- Provide tips on how to prepare for transplant
- Help you find free support and resources for you and your caregiver
- Share helpful advice from other patients and caregivers who've been through transplant

Remember, this booklet should not replace medical advice from your doctors. Your transplant team knows you best, so follow their recommendations.

Wherever you are in your transplant journey, know this: you are not alone. We are here to help. We offer free support and resources for you and your loved ones throughout your transplant journey.

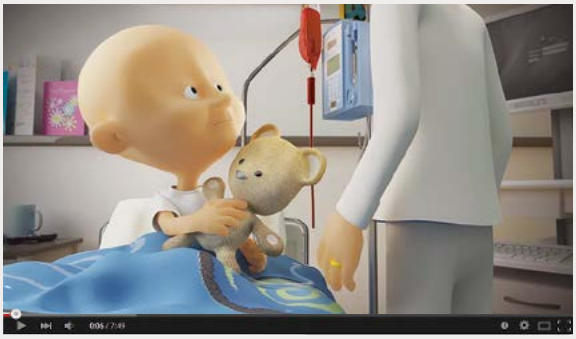
> "The way that we got through really tough times was just to take it one step at a time. So just saying, "What can we do between today and tomorrow?" Just taking each challenge as it came and not getting too far ahead of ourselves, was a part of keeping it manageable."
>
> —**KAREN, TRANSPLANT CAREGIVER**

Deegan, (third from left),
transplant recipient, with his family

When your child needs a transplant

When your child needs a transplant, the entire family will need to prepare and adjust. We offer information and resources specifically for young transplant patients and their families.

Super Sam versus the Marrow Monsters is an animated video about transplant. It features Sam, a young boy making an epic movie about his own transplant experience, as well as the stories of other young transplant patients.



Visit **nmdp.org/SuperSam** to view Super Sam online or order this free DVD (also available in Spanish).

Understanding Allogeneic Transplant

What is an allogeneic transplant?

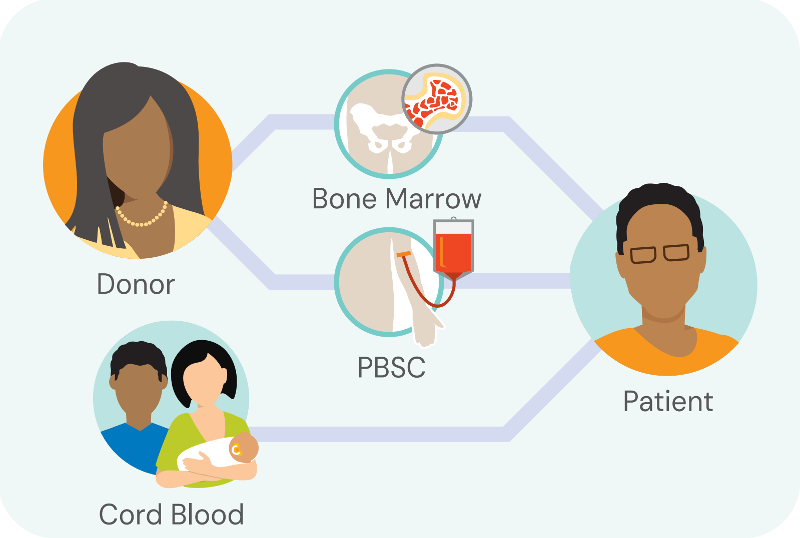
An allogeneic transplant uses healthy blood-forming cells donated by someone else to replace your unhealthy blood-forming cells. First, you receive chemotherapy with or without radiation to kill diseased cells in your body. This treatment also destroys your marrow, which may be making the diseased cells. Then, the healthy donated cells are put into your bloodstream through an intravenous (IV) infusion. They travel to the inside of your bones and begin to make healthy red blood cells, white blood cells and platelets.

Recovery from transplant takes time, and complications are common. But, your transplant team will be there to support you throughout the transplant process and your recovery.

Learn more about preparing for your transplant, transplant day and recovery after transplant starting on page 10.

> 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. Throughout your journey, focus on the things you can do.
>
> **—EVELYN, TRANSPLANT RECIPIENT**

Allogeneic Transplant



Learn more about the allogeneic transplant process at **nmdp.org/patient** in the About Transplant section.

Where will my healthy blood-forming cells come from?

When you get your allogeneic transplant, your healthy blood-forming cells will come from either:

A donor, who is:

- A person in your family, most likely a brother or sister, or
- An adult who is unrelated to you and has volunteered to be a donor for anyone in need

- **Cord blood**, which is the blood collected from the umbilical cord and placenta after a baby is born. These cells most often come from a public cord blood bank (from a baby unrelated to you), but can sometimes come from a baby in your family.

If your cells come from a donor, your doctor may ask the person to donate either:

- **Bone marrow:** The soft, spongy tissue inside of bones
- **Peripheral blood stem cells (PBSC):** Blood-forming cells from the bloodstream

Marrow, PBSC and cord blood are often called the cell source. Your doctor will choose the cell source that's best for you, based on:

- The best available match (read more about matching on page 6)
- Your overall health
- Your disease status or stage, including how quickly you need a transplant
- Your weight—the number of blood-forming cells you need is based on your weight

You can find more information about the types of cell sources at **nmdp.org/patient-allogeneic**.

Many different words are used to describe the allogeneic transplant process. Your doctor might talk about:

- Allo transplant (allogeneic transplant)
- BMT (blood or marrow transplant, or bone marrow transplant)
- Haploidentical (half-matched) transplant
- HCT (hematopoietic cell transplant)
- Marrow or cord blood transplant
- Matched unrelated donor (MUD) transplant
- Related donor transplant
- Stem cell transplant

No matter where your donor cells come from, you and your donor must have very closely matched human leukocyte antigens (HLA). HLA are proteins, or markers, found on most cells in your body. You can find information on HLA matching starting on page 6. Information is also available at **nmdp.org/patient** in the Before Transplant section.

Matching Patients and Donors

What is HLA matching?

HLA matching is used to match patients and donors for blood and marrow transplants. HLA (human leukocyte antigens) are proteins—or markers—on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which don't.

HLA matching is much more complicated than blood typing. To have HLA matching done:

- You and any potential donors will have blood drawn
- The blood is tested in a lab to determine HLA type
- Your HLA is compared to that of any potential donors to see if there is a match

HLA types are inherited, so you're more likely to match someone from a similar ethnic background. Sometimes doctors have a hard time finding a match because some HLA types are less common than others.

Once a match is found, the donor will have medical tests to make sure they're healthy and can donate safely. Umbilical cord is also tested for safety.

To learn more about HLA matching, watch the video series at **nmdp.org/LearnTheBasics**.

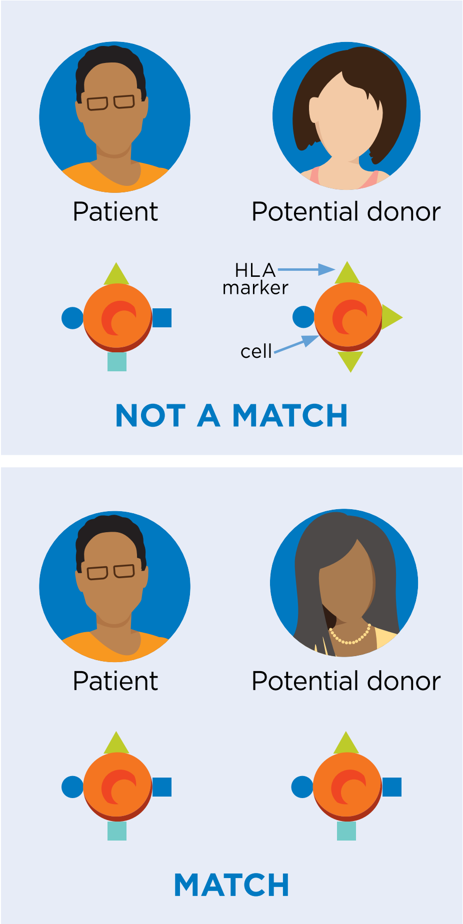
HLA MATCHING IS COMPLEX

Starts with a blood test.

More complex than blood type testing.

Many more HLA markers than blood type markers.

HLA Matching



THIS IS A SIMPLIFIED PICTURE OF A VERY COMPLEX PROCESS.

How do doctors find donors?

Finding a donor is not your responsibility. Your doctor will find the best donor for you within your family or on the NMDP Registry^{SM}.

Look in your family

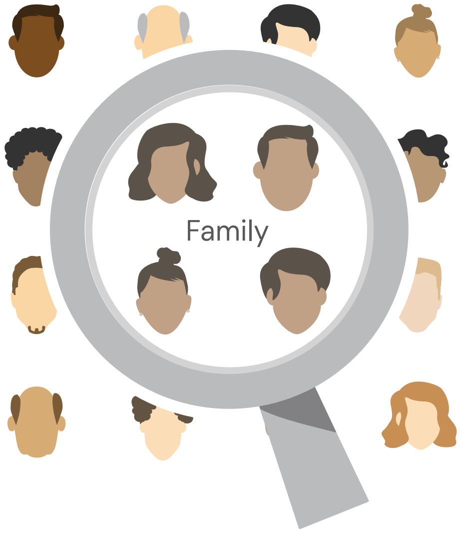
HLA identical transplant

If you have a brother or sister who is willing and able to be your donor, your transplant doctor will test each of them to see if they match you. Each brother and sister who has the same parents as you has a 25% chance (1 in 4) of matching you. Aunts, uncles and cousins are rarely a match so it's unlikely they will be tested.

HLA haploidentical (half-matched) transplant

This is a type of transplant where the donor matches exactly half of your HLA markers. Biological parents and their children are always a half-match for each other. Brothers and sisters have a 50% (1 out of 2) chance of being a half-match for each other.

Even though haploidentical transplant is starting to be used more often, it is a newer type of transplant. Not all hospitals offer it. Also, doctors don't know yet how the long-term results with haploidentical donors compare to fully matched donors.



If you're having an allogeneic transplant, your doctor will typically first look for a matching donor in your family.

How does HLA matching work?

There are many HLA markers. Each HLA marker has a name. The names are letters or combinations of letters and numbers.

There are rules for the minimum, or lowest, HLA match needed between a donor and patient. These rules are based on research that shows patients have better results with a closely matched donor.

Different transplant centers may have different matching rules.

After these minimum matching rules are met, your doctor will request more tests to see if the donor match is suitable for you. A suitable match is one that matches you at a detailed level. Sometimes a patient and donor seem to have matching markers at first, but more testing shows that they don't match at a detailed level.

Latrall, transplant recipient (left), with Raykell, her donor

How long will it take to find a donor for me?

It can take as little as a few weeks and sometimes many months to find the right match for you. Typically, it takes a few months from the beginning of the search process to the day of transplant. When umbilical cord blood is used, it may take just a few weeks because the cord blood units have already been collected and stored.

While your transplant doctor searches for your donor or cord blood unit, you will continue to be treated for your disease. It's important that you and your family focus your energy on caring for yourself instead of finding a donor. The search process for a donor can be complicated. But your transplant team will take care of it, and keep you up-to-date on its progress.

For some patients, no suitable donor or cord blood unit can be found. If that happens, your doctor will look at other treatment options.

Search the NMDP Registry

About 70% (7 out of 10) of patients who need a transplant do not have a match in their family. If you don't have a match in your family, your doctor will search the registry to find an unrelated donor or cord blood unit(s) for you. Similar to a haploidentical transplant, cord blood does not need to be HLA identical to you to be used for a transplant.

When doctors search our registry, they search more than 41 million potential adult donors and nearly 800,000 cord blood units on U.S. and global registries. Thousands of new donors are added to the registry each month.

Doctors searching the registry receive daily updates on the progress of searches. Your doctors are notified if a new donor or cord blood unit is added that matches you. Our goal is to help your doctor find you the best match in the shortest amount of time.

Questions to ask your doctor

As you prepare for your allogeneic transplant and learn more about donor matching, you may want to ask your doctor:

- ☐ Which family members will you test as possible donors?
- ☐ If my donor is a family member, what will they have to do?
- ☐ If I don't have a matched donor in my family, will you look for an adult volunteer donor or a cord blood unit?
- ☐ Which is the best cell source (marrow, PBSC, cord blood) for me?
- ☐ If a matched donor or cord blood unit cannot be found, what are my options?
- ☐ Does this transplant center allow partially matched donors or cord blood units?
- ☐ How frequently will I get updates about my donor search? Who should I call if I have questions about my donor search?
- ☐ Is a haploidentical, or half-matched, transplant an option for me?
- ☐ What are the risks and benefits of transplant from a haploidentical donor?
- ☐ Are there any clinical trials that may be an option for me?

> 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.
>
> **—MICHAEL,**
> **TRANSPLANT RECIPIENT**

To learn more about a caregiver's role and find support resources to help caregivers, visit **nmdp.org/caregiver**.

More information on being a caregiver is also available in our Transplant Basics booklet. You can view or order the booklet online at **nmdp.org/request**.

Getting Ready for Transplant

There are steps you can take to prepare yourself and your family for the process ahead. You are not alone. If you're feeling overwhelmed, ask your transplant team for help. They can help you prepare for transplant with emotional and practical support for you and your family.

This section will help you:

- Choose a caregiver
- Prepare financially
- Think about fertility preservation
- Prepare an advance directive (will)

How should I choose my caregiver?

Your caregiver will play an important role in your transplant and recovery. In fact, most transplant centers require that you have a caregiver—someone who will provide support and help care for you before, during and after your transplant.

A parent, spouse, partner, adult child or other close family member is often a natural choice to serve as a caregiver.

Sometimes the person who seems like the natural choice to be your caregiver won't be able to provide the support you need. Perhaps the person may not be physically able to care for you. Or maybe you have family members at home and someone must be there to care for them.

When you're choosing your caregiver, make sure that person is able to provide the ongoing support you will need.

Here are some questions you may want to discuss with a potential caregiver before you decide:

- I might have to be at the hospital for long periods of time. Are you comfortable spending time in the hospital?
- Do you have the flexibility to be at the hospital for long periods of time?
- Will you be able to go to my medical appointments with me?
- Can you manage stressful situations?
- Will you support my health care choices?
- Will you be a strong advocate for me?

Support for your caregiver

It can be easy for caregivers to forget about their own needs. But one of the most important things caregivers can do is take care of themselves, which will help them take better care of you.

There are many resources available to help caregivers take care of their health:

- Our **Caregiver's Companion book** and our Patient Support Center staff can help caregivers manage the emotional and physical stress they may experience. To learn more, visit **nmdp.org/companion**.
- Our **NMDP Peer Connect program** puts caregivers in touch with other caregivers who have been through the process. They can connect with you over the phone or by email to help answer your questions and share their own transplant experiences. To request a connection, visit **nmdp.org/PeerConnect**.

You can learn more about these programs or get more information by calling **1 (888) 999-6743** or emailing **patientinfo@nmdp.org**.

LaShonda, transplant recipient

How can I prepare financially for transplant?

There's a lot to think about when planning for the cost of a transplant. Some health insurance plans will cover the transplant, but may not cover all the services you need before or after transplant. Some insurance plans don't cover transplants at all. By planning now, you can know ahead of time what your insurance will cover and what you may have to pay yourself.

Your transplant center's financial coordinator may help you:

- Understand what your insurance policy does and does not cover
- Plan for your expenses and arrange payments
- Find other financial resources that might be available to you
- Talk with your insurance company and ask them questions

?

Questions you may want to ask your health insurance company:

- Does my insurance pay for the donor search and collection costs?
- Does my insurance pay for finding and shipping cord blood?
- Does my insurance cover all parts of the transplant process? If not, what doesn't it cover?
- Does my insurance pay for all of the prescription medicines I will need before and after a transplant? (Your doctor or transplant center pharmacist can give you a list of common medicines after transplant.)
- What is the maximum amount I would have to pay out-of-pocket? Does this include prescription medicines?
- Does my insurance provide travel or lodging benefits for me or for my caregiver?

You may want your caregiver, or another trusted family member or friend, to learn about your insurance coverage and transplant costs so you can focus on your health. Ask your insurance company what you need to do to have someone speak to them on your behalf. Most likely you'll have to give your permission in writing.

Your caregiver may also be able to help you keep your medical bills organized and keep track of what you've paid and what your insurance company has paid for your treatment.

Help With Transplant Costs

Even if you have insurance, you will be responsible to pay for some costs. Examples of these costs include:

- Deductibles: The dollar amount you pay for health care services or treatments before health insurance coverage begins. For example, if you have a $1,000 deductible, you owe the first $1,000 of covered health care services.
- Co-pays: A fixed amount that you are responsible for paying for a covered health care service ($20, for example). Your co-pay amount may be different depending on the health care service you receive.
- Co-insurance: The percent of health care costs you are responsible for paying (20%, for example).

Financial help for some of these costs may be available. Your transplant center social worker can help you find financial help and apply for grants offered through NMDP or other financial aid programs. Our financial grants can help pay for donor HLA testing and costs after transplant. Some patients fundraise to help pay for the costs. Find resources to help you fundraise on page 43.

Resources for You

NMDP offers resources to help you understand and plan for the financial aspects of transplant:

- Short, easy-to-read fact sheets have information on financial planning, health insurance, and raising money to pay for transplant.
- Worksheets to help you plan for and keep track of the out-of-pocket costs related to your transplant can be found in the financial planning fact sheet.

You can download or order the fact sheets at **nmdp.org/request**.

There are many other resources available to help you understand insurance. Here are just a few you might find helpful:

- PatientAdvocate.org: Helps patients resolve insurance, employment and debt crisis disputes related to their diagnosis.
- Healthcare.gov: Has information on government and individual health insurance.
- CMS.gov: Offers a glossary of commonly used health insurance terms. Enter the search term “uniform glossary.”

For additional transplant resources from organizations you can trust, visit nmdp.org/helpful-organizations.

Talking about money matters can feel like a very personal topic, but 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**.

What should I know about fertility after transplant?

To learn more about fertility after transplant, visit **nmdp.org/fertility**

If you think you may want to have children in the future, tell your doctor, nurse or social worker before you start your treatment. Chemotherapy and radiation can lower your fertility (your ability to have children). But even if you've already had some treatment, there may still be ways for you to keep your fertility.

Some transplant patients consider freezing sperm, eggs or embryos. Because it can take time to plan for this process, talk to your doctor as soon as possible. Some couples are able to have a baby using donated sperm or eggs, and others may choose to adopt. Ask your doctor what is best for your situation.

Not all transplant recipients become infertile. Some transplant recipients have gone on to have children. If you and your partner do not want to have a child, use an effective form of birth control, such as birth control pills, condoms, hormone shots or other methods.

Questions to ask your doctor about fertility

Doctors and nurses are used to answering questions about fertility. But, they may think you've had your questions answered already. So don't be afraid to ask.

Questions you may want to ask include:

- With my treatment, what are my chances of being able to have children in the future?
- Can you refer me to a fertility doctor to talk about freezing sperm, eggs or embryos?
- Can you refer me to a sperm bank near my home?

Questions to ask your insurance company

Egg or embryo freezing and storage and sperm banking can be expensive. Your insurance policy may pay for all, some or none of the process. You may want to ask if your insurance policy pays for:

- Collection of eggs or sperm
- Fertilization of eggs
- Storage of eggs, embryos or sperm

If your insurance doesn't pay for all of the process, there are other resources that may be able to help with the costs. Talk with your transplant center social worker or your fertility doctor to learn more.

Do I need an advance directive?

Making sure your transplant team and your family know your treatment goals and wishes can help you be more in control of your care.

If you haven't done so already, you should prepare an advance directive. There are 2 parts in an advance directive:

1. **Living will:** You say what kind of care you would or would not want if you're not able to speak for yourself.
2. **Durable power of attorney for health care:** You say who can make medical decisions for you if you're not able to make medical decisions for yourself. This person may also be called a health care agent, proxy or surrogate.

Having an advance directive isn't enough. Talking with your family and transplant team about it is just as important. When your family and transplant team know your treatment goals and wishes, they aren't left wondering what kind of care you would or would not want to have.

Advance directives can be helpful throughout your treatment. For example, if you are really sick during a complication, there could be a short amount of time when you can't tell your doctors what you want. Your transplant team can turn to your appointed person and your advance directive during these short amounts of time.

> When I got sick, I looked at my will again, including my advance directive, and made some changes. Then, I sat down with my sons and my husband and shared my wishes with them. Knowing they understood my wishes relieved some stress during a very difficult time.
>
> **—DEBI, TRANSPLANT RECIPIENT**

Here are some steps you can take before your transplant to make sure your health care wishes are followed:

- Ask your nurse or social worker to help you prepare an advance directive.
- Make copies of your advance directive, and share it with your family and all your doctors.
- Talk to your family and doctors about your wishes.
- Keep your advance directive in a safe place.
- Check with your hospital and clinic to see if your advance directive can be added to your medical record.

An advance directive can be changed at any time and for any reason. As you go through treatment, your goals and wishes may change. If they do, go back and update your advance directive. Be sure to talk with your family and doctors about how your wishes have changed.

The Transplant Experience

As you go through transplant, remember no two patients will follow the same path. Your overall health, disease status and other factors can all impact your experience. Your path may be very different from someone else's.

Your transplant team will be with you every step of the way.

This section will help you learn about:

- Medical treatments before transplant
- What happens on transplant day
- Recovery after transplant

What is the treatment before transplant?

Leading up to the day of your transplant, you will meet with your transplant doctor and other members of your transplant team.

This section will explain:

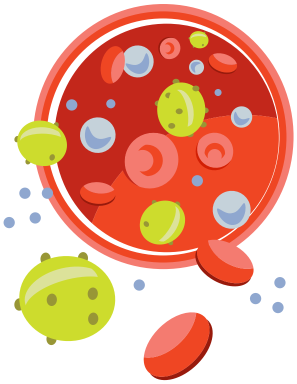
- Checkups and tests before transplant
- Getting a central line
- The preparative regimen before transplant

Checkup before transplant

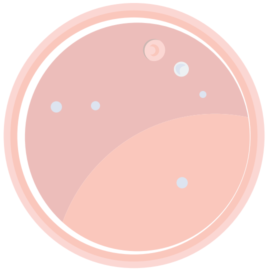
You will have a checkup before starting the transplant process. The checkup will include:

- A physical exam and tests to see how your organs and body systems are working
- Questions about your past and current health

BEFORE TRANSPLANT



TRANSPLANT DAY



ENGRAFTMENT

● Red blood cells carry oxygen throughout the body

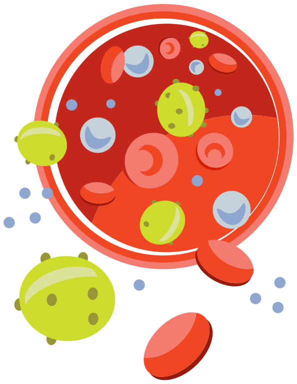
● White blood cells help fight infections

● Platelets help control bleeding

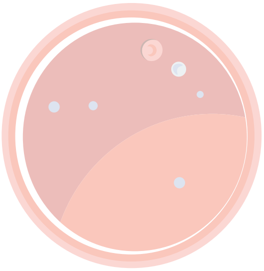
● Diseased cells

Desiree, transplant recipient, with her doctor

BEFORE TRANSPLANT



TRANSPLANT DAY



ENGRAFTMENT

This checkup helps your doctor make sure that transplant is still the best treatment for you, and is as safe as possible. Your doctor will also be better prepared to prevent or treat complications.

Checkups and tests before transplant vary from hospital to hospital. They also depend on your disease and health history. Ask your doctor about any test you don't understand.

Some of the tests you might have include:

- Heart tests
- Blood tests
- Pulmonary (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.
- Lumbar puncture (LP), or spinal tap—This is where a needle is put into your back bone or spine to take out a small sample of fluid. A doctor studies the fluid under a microscope.

NMDP is here to support you before, during and after transplant. Our **free** services for you and your loved ones include:

- One-on-one, confidential support from our team of BMT patient navigators and BMT social workers
- Talking with someone who's been there through our NMDP Peer Connect program
- Educational resources such as booklets, DVDs, e-newsletters and webinars

CALL: **1 (888) 999-6743**

EMAIL: **patientinfo@nmdp.org**

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

Looking for more information about the transplant process? Learn more at **nmdp.org/patient**

Getting a central line

Throughout the transplant process, you will have blood tests, get IV medicines and likely get blood transfusions often.

If you don't already have one, you will have a central venous catheter (central line) put in before your transplant to ease this process. A central line is a tube that is put into a large vein in the chest.

Some patients may already have an implanted port. This is a type of central line where the catheter is completely under the skin. A nurse pokes a needle through your skin to connect to the implanted port. Your doctor will tell you if the port is okay for your transplant, or if a central line is also needed.

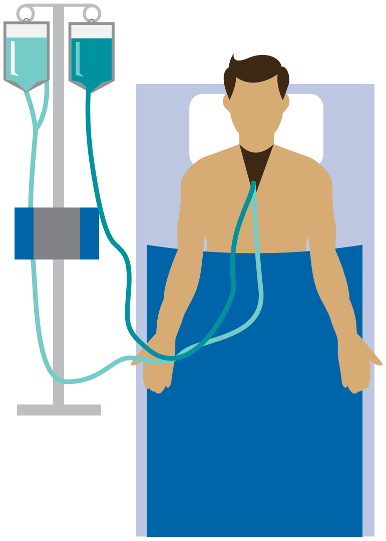
It's important to keep your central line and the skin around it clean and dry to prevent infections. Your transplant team will teach you and your caregiver how to keep your central line clean when you're at home. They will also teach you how to protect the central line when you shower or bathe. It's also important that you never use scissors near your central line.

Tell your doctor if you see any signs of infection around your central line.

Some signs of infection include:

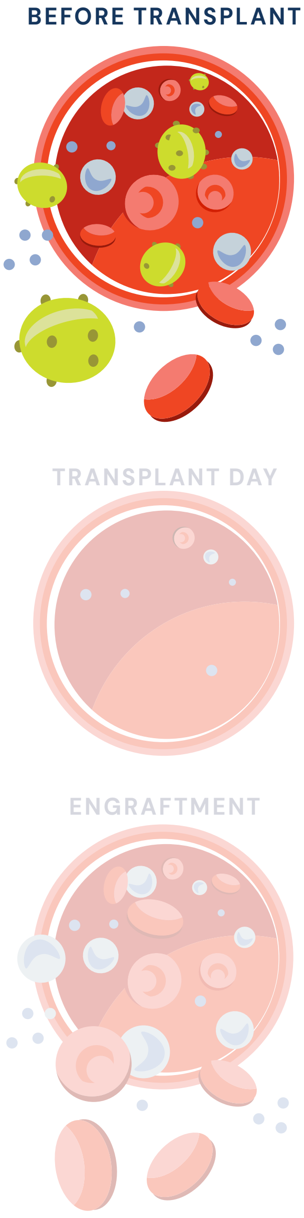
- Fluid draining around where the tube enters your body
- Pain, redness or swelling along the tube under your skin
- Chills after flushing the line
- Fever

More information on central lines can be found at **nmdp.org/patient** in the Before Transplant section.



A central line will be used throughout the treatment process for many reasons, such as getting IV medicines and blood transfusions.

A central line has many names. Your doctors or nurses may call it a central venous catheter (or CVC), a Hickman catheter or a Broviac catheter.



● Red blood cells carry oxygen throughout the body

● White blood cells help fight infections

● Platelets help control bleeding

● Diseased cells

Preparing your body for transplant

Before giving you the new cells from your donor, your doctors will prepare your body to receive them. This process is called the preparative regimen or conditioning regimen.

The preparative regimen includes different types of chemotherapy. You may get the chemotherapy through your central line for 1 day or over a few days. Sometimes the preparative regimen includes radiation therapy.

There are 2 main types of preparative regimens:

- Standard-intensity regimen — Uses high doses of chemotherapy, with or without radiation.
- Reduced-intensity regimen — Uses lower doses of chemotherapy, with or without radiation.

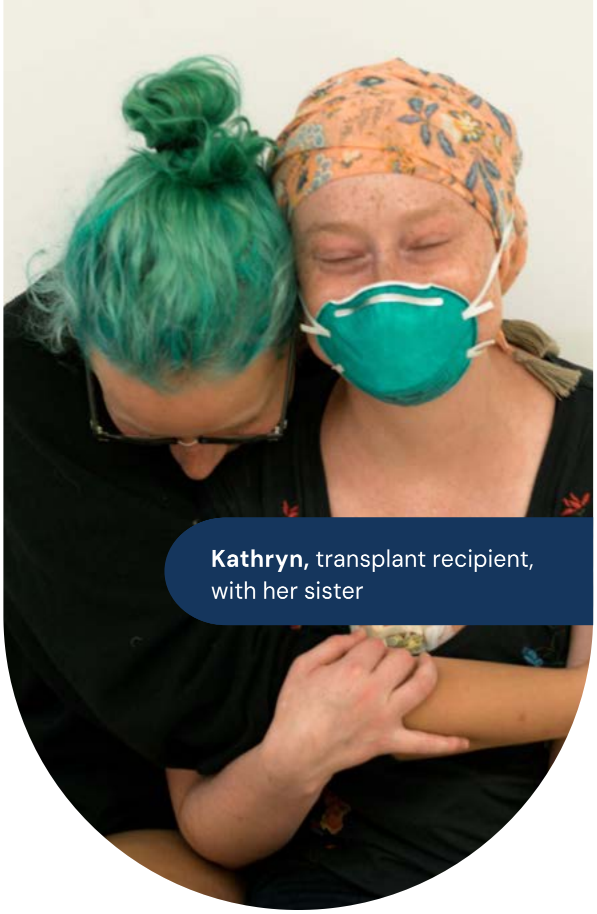
Your doctor will choose the type of preparative regimen for you based on your disease and your overall health.

The preparative regimen will:

- Destroy as many of the diseased cells that are left in your body as possible
- Weaken your immune system to help keep your body from rejecting the donated cells after transplant

The days leading up to your transplant are called “minus” days (-days). The days after your transplant are called “plus” days (+days). The day of your transplant or the day you receive the new cells is often called “Day Zero”.

You will likely have some side effects from your preparative regimen. Some may last a few days. Others can last longer. Your transplant team will treat your side effects and help keep you comfortable.



Kathryn, transplant recipient, with her sister

Some common side effects are:

- Fatigue (feeling tired)
- Nausea
- Vomiting
- Diarrhea
- Lack of appetite
- Mouth sores
- Hair loss
- Skin rash

You may have other side effects in the first month after the preparative regimen. Your transplant team will care for you to prevent or treat these side effects.

Participating in a clinical trial

Some patients who receive transplant may be offered the option to join a clinical trial, also known as a research study. Clinical trials have led to improved results for transplant patients. They help doctors make important discoveries for future patients.

If you're asked to join a clinical trial, your doctors should tell you about:

- What they are trying to learn
- What the treatment and tests are
- Your rights as a patient

If you join a clinical trial, your doctor or research nurse will go through a consent process with you. This means they will tell you more about the purpose of the study, the risks and benefits, other options available to you, and your rights as a participant in the study.

Make sure you ask questions so you understand the clinical trial process. Then, if you decide to join, you will get a consent form to sign.

Learn more about clinical trials

Jason Carter Clinical Trials Program makes it easier for patients and families to find and join clinical trials to treat blood cancers and blood disorders.

Visit JCCTP.org

What happens on the day of my transplant?

Usually 1 or 2 days after you finish your preparative regimen, you will receive your new cells. The day of transplant is often called "day 0." When day 0 arrives, it is normal to have many emotions. You may feel nervous, wondering how your recovery will go. At the same time, you may want to celebrate the day has come and your new cells have arrived. You may wish to have a blessing service, dedicate a time for reflection or write about your experience and feelings in a journal. Your hospital chaplain or social worker can be a source of support for you.

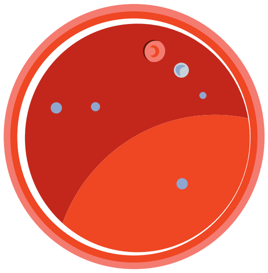
A transplant is not surgery. Instead, the healthy cells from your donor are put into your body just like a blood transfusion using your central catheter or port.

You will be in your hospital room and awake during the transplant. Your transplant team will watch you closely while you are getting your new cells. They'll also explain what to expect, how long the infusion might take and how you might feel.

The whole process could take less than an hour, but sometimes many hours depending on how you feel and the number of cells being infused.

BEFORE TRANSPLANT

TRANSPLANT DAY



ENGRAFTMENT

Watch the What is transplant day like? video to hear patients, caregivers, and transplant experts describe what happens on transplant day.
Visit nmdp.org/LearnTheBasics

> Just knowing that there are a lot of other people going through the process is very comforting. This is a standard treatment that can really work for many people.
>
> **—KAREN,**
> **TRANSPLANT CAREGIVER**

How Your Donated Cells Get to You

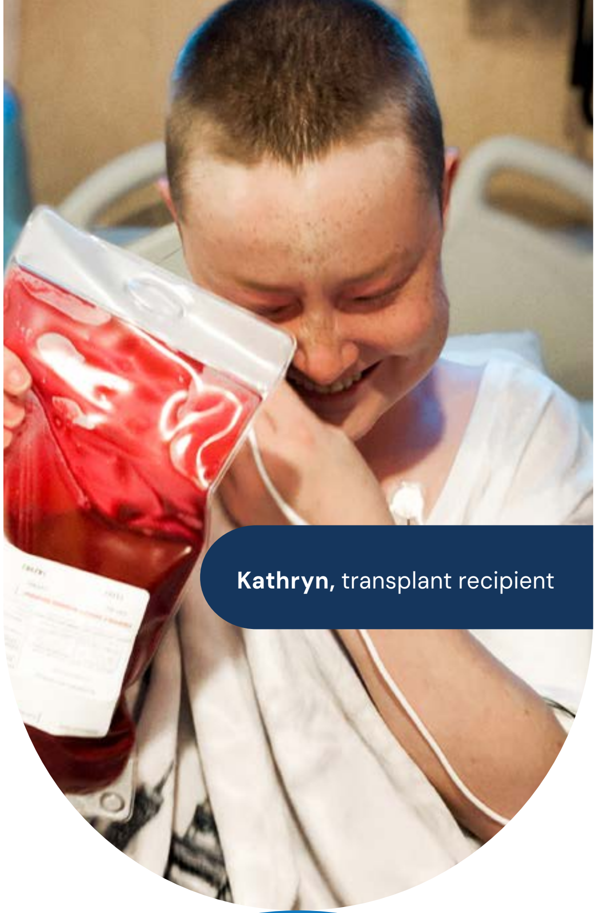
Typically, cells from your donor arrive in 1 or 2 bags, similar to the ones used for blood transfusions.

If your cells come from an unrelated donor, they'll be delivered to your transplant center by a trained courier. The courier picks up the cells at the hospital or clinic where your donor donated his or her cells and brings them to your transplant center. Your cells may come from somewhere in the United States or a different country. Experienced staff at NMDP coordinate the delivery of your donated cells and make sure they get to you exactly when you need them.

If your cells come from a family member, they may donate at the same hospital where you are getting your transplant. However, if your family member doesn't live nearby, a courier may deliver your cells.

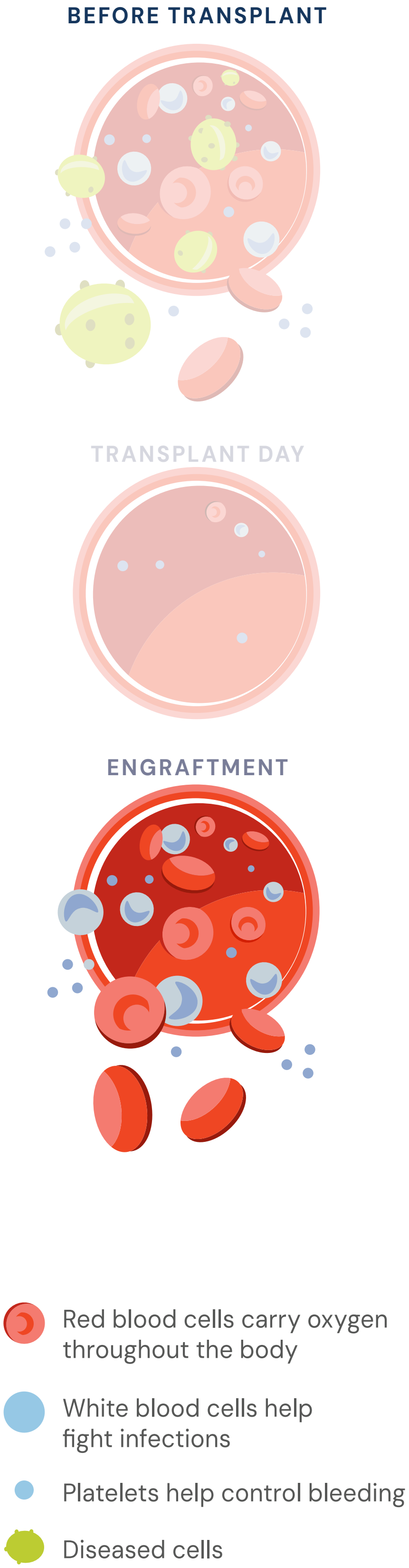
If you are receiving cord blood cells, the cells are sent from a cord blood bank to your transplant center.

You may want to do something special on transplant day to honor the milestone, like have a small gathering, play music or say a prayer. Your transplant team may be able to help you come up with ideas on how you can honor and remember the day.



Kathryn, transplant recipient

> Getting a transplant isn't like what you see on TV when a person is getting an organ transplant and someone is rushing in with a cooler from the airport. My cells came in a bag and they got hooked up, and then I just waited. It's a lot like getting a blood transfusion.
>
> —MATT,
> TRANSPLANT RECIPIENT



What is recovery like after transplant?

Many transplant patients are in the hospital for several weeks or months after transplant. The length of your hospital stay will depend on your transplant center, your treatment plan and how quickly you recover after transplant.

Some hospitals have programs for "outpatient" transplant. As long as the patient is well enough (for example, there are no signs of infection, like a fever) the patient will not have to stay overnight in the hospital. Patients having an outpatient transplant will still need to make frequent, often daily, visits to the clinic.

This section will help you learn about:

- Engraftment after transplant
- What to expect during early recovery
- Long-term recovery after transplant

Engraftment

Your donated cells will "know" where they belong in your body. They'll move through your bloodstream to settle in your bone marrow. There, the cells will begin to grow and make new blood cells. This is called engraftment.

Your doctors and nurses will watch for engraftment by monitoring your lab reports. They may write your blood counts on a white board in your hospital room. Or, if you are an outpatient, they may write your blood counts in a notebook for you.

> There are many twists and turns. I had good news, then bad news, then good news. It can change many times. So stick with your doctor, do what he or she says. Many people get through this and come out on the other side.
>
> **—LINDA, TRANSPLANT RECIPIENT**

Your doctors and nurses will check the following blood counts:

- White blood cells (WBCs)
- Absolute Neutrophil Count (ANC)—This is a special type of white blood cell that helps fight infections
- Hemoglobin (Hgb) — This is a protein in red blood cells that helps to carry oxygen from your lungs to all parts of your body
- Platelets (Plts)

Engraftment usually happens within the first 30 days after your transplant. Engraftment tells your doctors your new cells are working properly and starting to rebuild your immune system. Engraftment is an important milestone and marks the start of your recovery process. White blood cells are the first cells to engraft, followed by red blood cells and platelets.

Early recovery

Even though your cells have engrafted, your immune system will still be weaker than normal for many months. The risk for complications is highest during the first 100 days after your transplant. This is because your immune system needs time to grow stronger. Even though you may have the right number of white blood cells, the cells may not be working as well as they should be because your immune system is still suppressed.

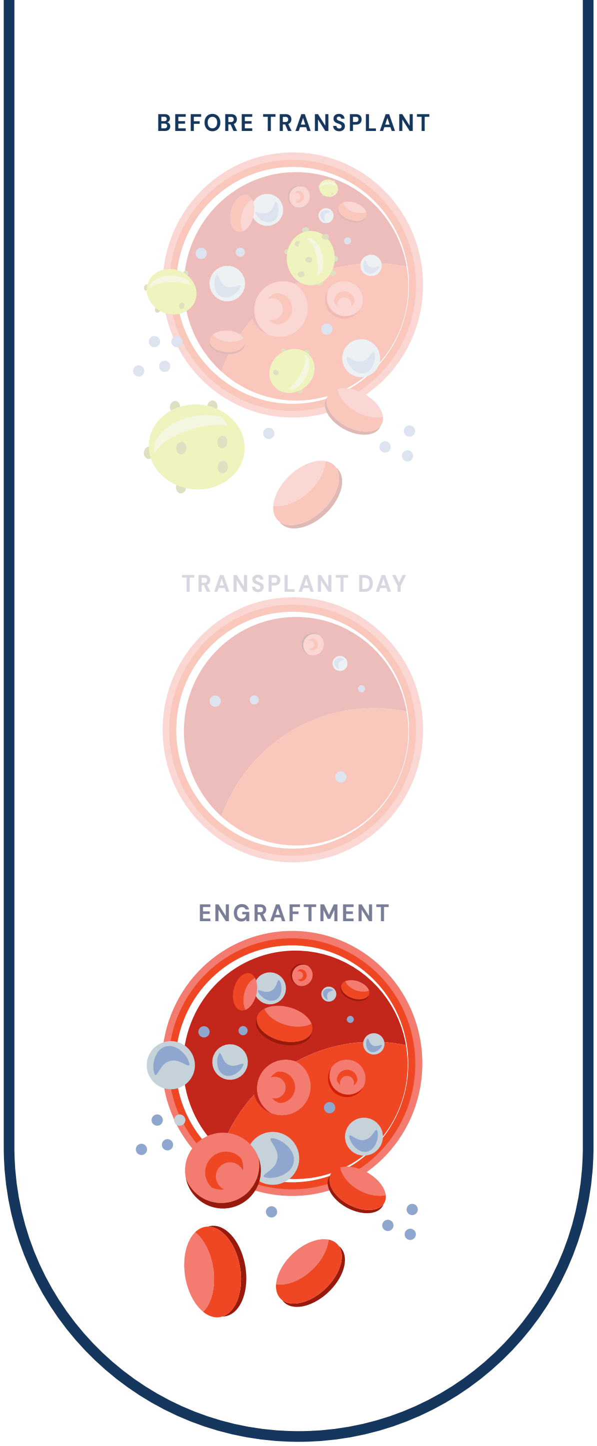
Your transplant team will watch you closely for signs of infection and other problems. Graft-versus-host disease (GVHD) is a common complication of an allogeneic transplant. GVHD happens because of differences between the donated cells (the graft) and your body's cells (the host). The donor cells might see your body's cells as different and attack them. That's how it gets the name, graft-versus-host disease. See page 32 for more information on GVHD.

Jack, transplant recipient

To protect you from infection while you're in the hospital:

- Visitors will need to wash their hands before and after each visit.
- Visitors may need to wear masks and gloves.
- Anyone who is sick will not be allowed to visit you.
- Young children might not be allowed to visit.

Visitor policies vary by hospital. Ask your transplant center about their policies.



Each transplant center has its own rules for when a person is ready to leave the hospital. Common rules include:

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

This usually happens during the first 100 days.

Even after you leave the hospital, you'll likely need to visit the hospital or clinic regularly, even daily, for weeks or months. If your transplant center is far from your home, expect to stay nearby during this time.

Each person will have a different experience transitioning to outpatient care. Many people have side effects or complications that require a hospital stay. However, not everyone needs to re-enter the hospital.

Returning home after your transplant

When you return home after transplant, you enter a new stage of your recovery process. It's important you have a safe and healthy place to stay. Reduce your contact with dust, dirt, mold and germs to help you stay infection-free.

Before you return home, your family or friends may need to:

- Clean your house. Remove all mold and dust thoroughly.
- Change air conditioner and furnace filters.
- Turn off humidifiers.
- Keep windows and doors closed to lower your exposure to dust from outside.
- Complete or stop any remodeling or renovations.
- Talk with your transplant team about having your children in daycare and school when you return home.

Your transplant center will provide you with detailed information and steps to take to prepare your home based on your particular situation.

Food safety

Good nutrition is a key part of gaining strength after transplant. While your immune system is still getting stronger, some foods and drinks could put you at higher risk for infection. Always follow your transplant team's instructions for food safety after transplant.

Find tips for food safety at **nmdp.org/FoodSafety**

Long-term recovery

Recovery after transplant has been described by many transplant recipients and caregivers as a marathon, not a sprint. The amount of time it takes to recover varies from person to person. Recovery time can be affected by many different factors including the intensity of your preparative regimen, and whether or not you have any complications like infection or GVHD.

No matter what your path to recovery is like, you'll likely have some ups and downs, both physically and emotionally. You might not be able to do all of the things you used to do, and that might be frustrating to you.

Remember, it often takes a year or more for people to feel physically recovered from transplant. Recovery of the immune system is gradual, and can take years. People who get GVHD may have weak immune systems for even longer because of the medicines used to treat GVHD.

> My recovery went a lot better due to exercise. Start as soon as you can and do whatever you can because there's going to be a tremendous long-term benefit from it.
>
> **—DAVID,**
> **TRANSPLANT RECIPIENT**

Take precautions around visitors

Friends, family and other well-wishers may want to come to see you when you're home. But to keep you healthy, some well-wishers should not visit:

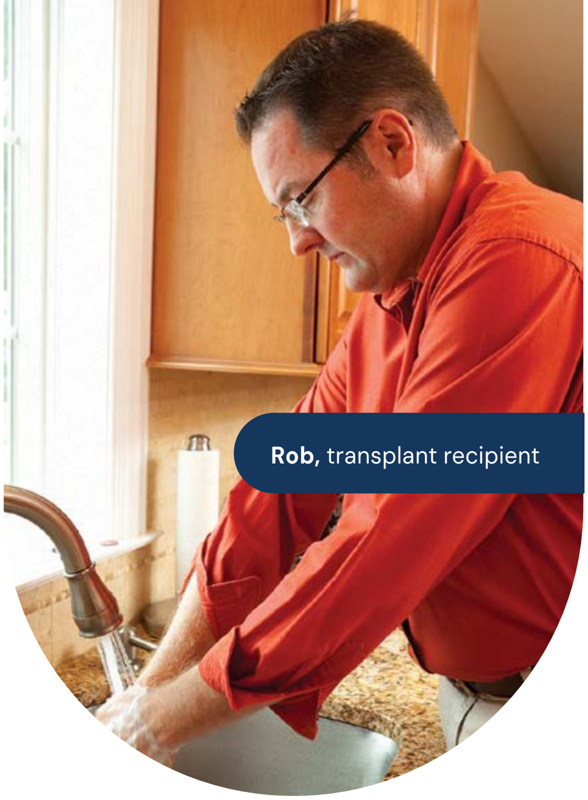
- Don't let anyone visit who has a rash or symptoms of a cold or flu.
- Don't allow visitors who have been in close contact with sick children.
- Avoid contact with anyone who has had a live vaccine (immunization) in the past 2–4 weeks, as recommended by your doctor.
- Don't have visitors who recently had a stomach bug. Symptoms would include nausea, vomiting or diarrhea.

Whenever possible, your caregiver should share these rules with your visitors before they arrive so they understand why they might not be allowed to visit.

When your visitors arrive, ask them to take off their shoes to avoid tracking in dirt, and insist that they wash their hands right away. Once a visitor leaves, be sure to wash your hands.

Tips for recovering at home

- Get enough rest. You will be tired because your body will be working hard to recover from the intense treatment you received during your transplant.
- Get some exercise every day, as you are able. Many people who have had a transplant say it helped them to get up and walk each day, even if they could only walk a short distance. Over time your strength will grow and you will be able to do more.
- Be patient with yourself and with the time it may take for your body to heal.


Rob, transplant recipient

Lower your risk of infection

You may take daily anti-infection medicines for a year or more after transplant. The best thing you can do to lower your risk of infection is to take your medicines exactly as your doctor orders. Call your doctor if you are unable to take your medicines for any reason.

Along with taking anti-infection medicines, here are some things you can do to lower your risk of getting an infection:

- Wash your hands often. It's one of the best ways to lower your risk of infection.
- Wear a mask when you go out.
- Brush your teeth with a soft toothbrush twice a day. And if your doctor says it's okay, gently floss every day.
- Avoid cleaning up after pets, taking out the garbage or changing diapers while your immune system is getting stronger.
- Avoid dust, dirt, soil and plants as much as possible. That's because you could be exposed to fungus, molds and bacteria, which can cause infections. You may not be able to garden or do yard work for a year or more after transplant.
- Ask your doctor when it's safe for you to get re-vaccinated.

For more tips on preventing infections after transplant, including food safety, visit the Life after transplant section of **nmdp.org/patient**. Click on Physical health and recovery.

Take all your medicines as prescribed

The medicines you will take after transplant are very important to your health and recovery. If you ever have trouble paying for any of them, let your doctor know right away. NMDP and other organizations can help cover the costs of medicine.

Watch for signs of infection

After your transplant, your immune system won't be able to protect you fully from germs that cause infections. While some infections can be minor, others can be life-threatening.

You know your body better than anyone else, so you're the best person to watch for symptoms or signs of infection, such as:

- Fever or chills
- Diarrhea
- Having to go to the bathroom (urinate) often
- Having pain with urination or with a bowel movement
- Blood in your urine or stool
- Stomach pain
- Confusion or decreased alertness
- Severe fatigue (tiredness)
- Bleeding
- Coughing or shortness of breath
- Chest pain
- Severe headaches
- Increased pulse, or feeling like your heart is "racing"
- Lightheadedness

If you're caring for a child who received a transplant, encourage your child to tell you if they notice any changes. Ask your child how they feel and if they have any of these symptoms.

These are some of the signs and symptoms of infection, but if you experience anything that doesn't seem quite right, tell your doctor. It could be an infection, a sign of GVHD or a side effect from your treatment.

Remember, even if you do everything "right" you may still get an infection. Tell your doctor right away about any changes so you can be diagnosed and treated quickly.

> Transplant isn't a walk in the park, but it is manageable and there is life on the other side. Don't take to heart the laundry list of complications you read about or that your doctor tells you about. Not all of it will happen to you — some of it might, but not all of it.
>
> **—LORI, CAREGIVER**

Our NMDP 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 **nmdp.org/PeerConnect**.

You can also connect with other transplant patients and caregivers on the **NMDP Patients Connect** Facebook page.

> Transplant is a highly specialized treatment, and primary care doctors may not be familiar with caring for patients after transplant. Share your concerns with your primary care doctor and use the after-transplant guidelines to help you talk with your doctor.
>
> **—NAVNEET MAJHAIL, MD, MS, TRANSPLANT DOCTOR**

Ask your doctors these questions to help you know who to call:

- Who will manage which parts of my care?
- How will you share information with my other doctors?
- How will you share information with me?

NMDP offers free after-transplant care guidelines that can help you get ready for your 6-month and 12-month checkups. The guidelines give information on the recommended tests and exams for your checkups.

The guidelines are available in a free mobile app, online or in print. Learn more at **nmdp.org/careguide**

Regular checkups after transplant

Even if you're feeling well, your regular checkups are very important to staying healthy after transplant. For at least the first year after transplant, you will continue to see your transplant team for checkups. Eventually, you may go back to your primary care doctor or see other specialists, like a physical therapist.

Some patients may see their primary care doctor for most of their care and their transplant doctor for treatment of GVHD and other transplant-related issues.

When can I contact my donor?

If your donor is not related to you, you may be interested in contacting them after your transplant. Having contact is a personal choice for both you and your donor.

If you want to connect, talk to your transplant center coordinator. Contact between you and your donor will depend on NMDP confidentiality policies. If your donor lives outside the United States, contact will also depend on that country's registry and its policies. Your transplant center coordinator can tell you the specific policies that apply to you and your donor.

Cord blood donations will always remain anonymous. That means if you had a cord blood transplant, you won't be able to have any contact with your donor.

More information is also available at **nmdp.org/patient** in the section on Life after transplant.

Tom, transplant recipient, with one of his doctors

Graft-Versus-Host Disease

Graft-versus-host disease (GVHD) is a common, and sometimes serious side effect of an allogeneic transplant. GVHD can range from mild to severe. Many patients will have some symptoms of GVHD after transplant.

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

There are medicines to help lower your risk of getting GVHD. But even with medicine, some people still get GVHD.

Having some GVHD is not always bad. If your transplant was for a blood cancer, your doctor may see mild GVHD as a good thing. It's a sign that the new cells are working to destroy any remaining cancer cells in your body. Patients who have some GVHD may have a lower risk of the cancer coming back after transplant.

This section will help you learn about the 2 types of GVHD:

- Acute GVHD
- Chronic GVHD

Acute GVHD

Acute GVHD usually happens in the early weeks and months after transplant. It's called Late Acute GVHD when it develops 3 or more months after transplant. Some transplant recipients don't have any acute GVHD.

Chronic GVHD

Chronic GVHD usually develops within 1 year after transplant. It's called Overlap Chronic GVHD when signs and symptoms of chronic and acute GVHD appear together. You are more likely to develop chronic GVHD if you've had acute GVHD.

> Every day is a wonderful gift that I enjoy to the fullest, but with this gift comes GVHD and its effect on my body. Side effects influence how I do things but do not take away the joy of being alive. It is a 'new normal,' not the end of living.
>
> **—CHRISTINE, TRANSPLANT RECIPIENT**

You can learn more about GVHD prevention, signs and symptoms, and treatment at **nmdp.org/patientGVHD**

GVHD is serious

There are treatment options, and early detection is very important.

Watch videos at **nmdp.org/LearnTheBasics**

What are the signs of GVHD?

Not everyone experiences all of these warning signs, but many transplant recipients experience some of them. Some symptoms might develop into long-term problems. Others are temporary and will go away with treatment.

Many of the early warning signs for GVHD could also be caused by infection or another side effect. That's why it's important to tell your doctor about any changes in your body that you see or feel.

Acute GVHD

SKIN

- Very faint to severe sunburn-like rashes
- Blisters

STOMACH

- Nausea that doesn't go away
- Loss of appetite
- Vomiting
- Feeling full after eating very little

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

Chronic GVHD

SKIN AND NAILS

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

JOINTS AND MUSCLES

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

EYES

- Dry eyes
- Irritation that doesn't go away
- Blurred vision
- Teary eyes

MOUTH

- Trouble opening your mouth
- Sores
- Irritation that doesn't go away
- Chapped lips
- Pain

LUNGS

- Cough that doesn't go away
- Shortness of breath
- Trouble breathing

DIGESTIVE SYSTEM

- Nausea or vomiting
- Diarrhea
- Stomach pain or cramping

GENITALS

- Irritation or dryness
- Rash
- Painful intercourse

For parents

If your child had a transplant, look for early warning signs of GVHD every day. Ask your child specific questions about any changes or problems they may be having. Explain to your child how important it is that you know about any changes right away.

> Support groups provide people with GVHD an opportunity to make connections and share experiences with each other. Participating in a support group can help you feel empowered and less isolated.
>
> **—BEN, MSW, LGSW,**
> **BMT SOCIAL WORKER**

Questions to ask your doctor

As you prepare for your allogeneic transplant and learn more about GVHD, you may want to ask your doctor:

- What is my risk for GVHD after transplant?
- Is there anything I can do to lower my risk for GVHD?
- What signs and symptoms will I need to watch for?

What is the treatment for GVHD?

Starting treatment as early as possible can lead to the best results. Steroids, like prednisone, are the main treatment for GVHD. Steroids weaken your new immune system so it doesn't attack your body.

Because your new immune system is weaker, you may have limitations on what you can do, even if your transplant was one or more years ago. Ask your transplant team what you may need to avoid (for example, yard work and large crowds).

Follow your doctor's instructions carefully when taking medicines. Do not stop taking them without talking to your doctor. If you can't take them for any reason, tell your doctor. If you can't swallow your medicines, you may need to get them through your central line (directly into your bloodstream) temporarily.

The treatment for GVHD works well for many patients. However, you may need to be treated anywhere from weeks to months. This is because it can take time to find the best type and dose of medicine with the fewest side effects to treat your GVHD.

How can I lower my risk of developing GVHD?

Many people who had a transplant will experience some symptoms of GVHD. But, there are some steps you can take to help lower your risk.

1. Take your medicine

Your doctor will give you medicine to help prevent GVHD. Keep taking that medicine as directed, even if you're feeling healthy. Call your doctor right away if you can't take the medicine for any reason.

2. Watch for early warning signs and tell your doctor

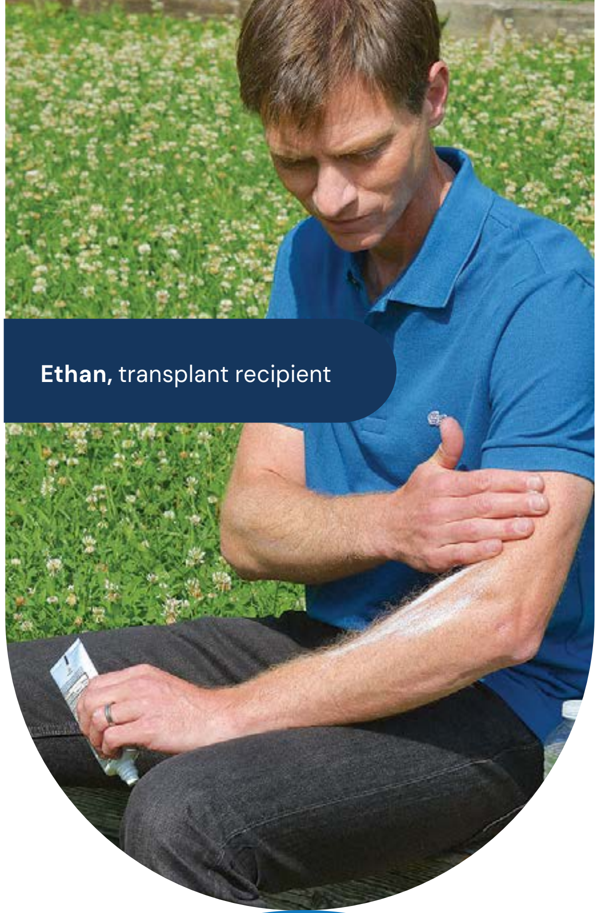
Do not ignore the early warning signs of GVHD. Early treatment of GVHD, infections and other side effects from treatment can make a big difference in your long-term recovery.

3. Protect yourself from the sun

Exposing yourself to the sun increases your risk of developing GVHD. To limit your exposure to the sun:

- Avoid the sun as much as possible.
- Wear a hat, sunglasses, long sleeves and pants when you go out.
- Apply SPF 30 or higher sunscreen on any skin that is not covered. You can also wear SPF clothes.

Don't forget, even on a cool, cloudy day the sun is just as harmful as on a hot, bright day.



Ethan, transplant recipient

> There were extremely hard days, but through all the suffering there were many blessings.
>
> —KRISTA,
> TRANSPLANT RECIPIENT

Checklists to Get Ready For Transplant

These checklists can help you get ready for transplant. Not everything in these checklists will apply to you. You can use the checklists to help you come up with questions to ask as you prepare. There are also special checklists for caregivers and parent caregivers starting on page 39.

Before leaving home

☐ Make a packing list. Bring clothes for different temperatures and seasons, if appropriate. Include some family photos or posters to brighten your hospital room or temporary living space.

☐ Get phone numbers, email addresses and mailing addresses of people you want to stay in touch with.

☐ Arrange for someone to look after your home or apartment (and any pets) while you are away.

☐ Think about how bills will be paid. When possible, pay ahead. Check with your loan company (such as car or student loan) about temporary deferment of payments (grace period) due to medical disability.

☐ Have your mail forwarded or have someone collect it for you.

☐ Ask your doctor how long you might need to stay in the hospital and how long you might need to stay near the hospital.

Plan for being away from work

☐ Make plans with your employer for being away from work. Talk to your Human Resources (HR) representative to help you understand your benefits. Ask about any requirements to keep your health insurance and other benefits active.

☐ Ask HR about: COBRA insurance, Family Medical Leave, short and long-term disability plans, and employee assistance programs.

☐ Ask your disability representative to help you apply for Social Security Disability (SSD).

Discuss faith and spirituality

☐ Set up a time to talk with your family about what each of you believe. Consider talking about what gives you comfort and strength.

☐ Arrange to keep in touch with your faith community. Community members could send cards, organize a prayer chain or give encouragement in another way.

☐ You might ask your faith leader to offer special prayers, anointing services or other healing rituals for you and your family.

☐ Find out if there is a local contact for your faith community in the city where your transplant will take place.

Communicate with family and friends

☐ Set up family meetings to talk openly about the transplant. Consider meeting with a counselor to help you and your family prepare emotionally for transplant.

☐ If you have children or grandchildren, you might use books, pictures or videos to help them understand why you're going to the hospital. Super Sam versus the Marrow Monsters is an animated video that helps explain transplant to children.
Visit **nmdp.org/supersam** to view Super Sam online or order the free DVD.

☐ Talk to your children about how they will be cared for while you are in the hospital. Explain who will be with them, their schedules and how you will stay in touch. If you want help talking with your child, contact your hospital social worker or child life specialist.

☐ Plan how you will stay in touch with family and friends. Some people find it helpful to use social media or free websites, such as **CaringBridge.org** to post updates. Ask if you can use online video streaming services, such as Skype, in the hospital.

☐ Your child might benefit from meeting other children who have a family member getting a transplant. Ask your transplant center social worker about available support.

☐ If friends and family want to know what they can send, consider snacks, meal certificates, or notes of encouragement.

☐ Make a list of tasks you need help with and share with family and friends. Your list might include: cook meals for family members or drive kids to school.

Organize your finances

☐ Keep track of the out-of-pocket costs related to your transplant. Use worksheets to help you get started. See the blue box below for more information.

☐ Consider fundraising to raise money for out-of-pocket costs. Find trusted fundraising organizations on page 43.

☐ Talk to your transplant center financial coordinator and your health insurance company to learn what your health insurance will and won't cover.

☐ Ask your transplant center social worker about:

- Local organizations that may offer financial assistance
- Whether you qualify for Social Security programs or Medicaid

☐ If you are a veteran, contact the U.S. Department of Veterans Affairs at (800) 827-1000 to ask about eligibility for any programs based on service record and disability.

We offer resources to help you understand and plan for the financial aspects of transplant. A series of short, easy-to-read fact sheets gives information on financial planning, health insurance, and raising money to pay for transplant.
You can download or order the fact sheets at **nmdp.org/request**

Access legal resources

- ☐ Complete a will, trust, planning guardianship (if you are a single parent) and advance directive (a living will). Consider naming a trusted person as your medical power of attorney or health care proxy. This person can make decisions for you if you become too sick to do so.
- ☐ Consider assigning someone to handle your finances temporarily. If you do not share a joint checking or credit account, talk with your bank to find out how to give someone temporary access to your accounts.
- ☐ Talk with a financial or family law attorney if your financial or legal affairs are complicated. Contact your local bar association for a referral.
- ☐ If you have children under age 18 who will be away from both parents, give written permission for another adult to take them for medical care (emergency or routine) while you are in the hospital and recovering. Generally, a signed statement is all that is needed, but check with your child's doctor.

Plan for appointments and prescriptions

- ☐ Schedule any routine dental or medical appointments before your transplant if your transplant center is far from home. Make sure your caregiver does this, too.
- ☐ Make a plan for you and your caregiver to get prescriptions renewed or refilled while you're away.

Arrange travel and lodging

- ☐ Check with your health insurance company to see if your policy covers travel, meals and lodging for you and/or your caregiver.
- ☐ Ask your transplant center social worker about lodging resources near the transplant center. Ask for costs and whether you need to put your name on a waiting list.
- ☐ Make arrangements for traveling to your transplant center. If you need to fly there, you might want to ask family members if they have frequent flier miles available to help you.
- ☐ Find more travel and lodging resources on page 43.

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

Checklists For Your Caregiver

Your caregiver will be an important person in your transplant and recovery. The following checklists can help your caregiver understand what some of their responsibilities may be.

Support your medical care

- ☐ Be with you in the hospital or clinic during doctor visits to listen and ask questions.
- ☐ Ask your doctors to explain treatment choices, test results and medicines.
- ☐ Keep a notebook to write down treatment information and notes from doctor visits.
- ☐ Ask for copies of any treatment summaries and written care instructions.
- ☐ Talk with you to understand your treatment goals.

Help with finances

- ☐ Find out what insurance will pay and what you will need to pay.
- ☐ Ask your social worker or financial coordinator about other financial help.
- ☐ Make sure household bills are paid on time.

Offer emotional support

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

Support after your transplant

- ☐ 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.

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

☐ ______________________________
____

Checklists For Parents

These checklists can help you prepare for your child's transplant and hospital stay. Some of the suggestions might not apply to you but they may help you think of things that aren't listed here.

Prepare your child

☐ Talk honestly with your child in words he or she will understand. You might use books, videos or pictures to help tell the story. If you want help talking with your child, contact your hospital social worker or child life specialist. Talk about:

- Who will be at the hospital, and who will care for brothers, sisters or pets at home.
- What will happen at the hospital and what the schedule might be like.

☐ Reassure your child that Mom, Dad or another caregiver will be available to help with whatever he or she needs.

☐ Help your child make a list of items he or she would like to take along.

☐ Talk with your child's teachers and principal about the plan for schoolwork while your child will be away.

☐ Talk about ways to keep your child connected with school and friends.

☐ Check with the Ronald McDonald House near your transplant center to see what prior arrangements can be made for lodging.

Prepare siblings

☐ Talk with your children to tell them what will be happening within the family while their sibling is going through a transplant.

☐ If children are staying home, talk with them about who will take care of them. Reassure them they will be taken care of during this time and that you love them.

☐ If you are a single parent with more than one child, think about who will care for your other children if you must travel for your child's treatment. For example, who can consent for your children's medical care or contact the school while you are away. Talk about this with your child's doctor, teachers and family.

☐ Talk with your children about planned family visits to the transplant center.

☐ School enrollment might be available at the hospital, Ronald McDonald House or in the community. Talk with your transplant center social worker to see if this option is available.

Think about ways you can take care of yourself so that you can better care for your child.
Find resources at **nmdp.org/caregiver** or call **1 (888) 999-6743**

Transplant Team Contact Information

This chart can help you know who to call if you need help.

Team member	Name	Phone number	Contact for
Transplant doctor			Help with medical and treatment questions
Transplant center coordinator			Updates on progress of search
Financial representative			Insurance questions
Social worker			Help preparing for transplant, including finding resources and getting emotional support
Patient advocate			Help with your concerns
NMDP	Patient Support Center	1 (888) 999-6743	Support and resources
Other			Help with
Other			Help with

Resources

Transplant organizations

(S) Blood & Marrow Transplant Information Network (BMT InfoNet)
(888) 597-7674
bmtinfonet.org

(S) National Bone Marrow Transplant Link (nbmtLINK)
(800) 546-5268
nbmtlink.org

(S) Bone Marrow & Cancer Foundation
(800) 365-1336
bonemarrow.org

Social support

Bone Marrow Transplant Support Group
bmtsupport.org

CaringBridge®
(651) 789-2300
caringbridge.org

Lotsa Helping Hands
lotsahelpinghands.com

General cancer resources

(S) American Cancer Society®
(800) 227-2345
cancer.org

(S) CancerCare®
(800) 813-4673
cancercare.org

Cancer Hope Network®
(877) 467-3638
cancerhopenetwork.org

Cancer Support Community
(888) 793-9355
cancersupportcommunity.org

(S) Livestrong®
(855) 220-7777
livestrong.org

National Cancer Institute's (NCI's) Cancer Information Service (CIS
(800) 422-6237
ivehelp.cancer.gov/app/chat/chat_launch

(S) National Coalition for Cancer Survivorship
(877) 622-7937
canceradvocacy.org

Disease organizations

(S) Aplastic Anemia and MDS International Foundation (AAMDSIF)
(800) 747-2820
aamds.org

(S) Fanconi Anemia Research Fund
(888) 326-2664
fanconi.org

Immune Deficiency Foundation
(800) 296-4433
primaryimmune.org

(S) International Myeloma Foundation
(800) 452-2873
myeloma.org

Leukemia Research Foundation
(847) 424-0600
allbloodcancers.org

(S) Lymphoma Research Foundation
(800) 500-9976
lymphoma.org

Multiple Myeloman Research Foundation
(203) 229-0464
themmrf.org

National Organization for Rare Disorders (NORD®)
(800) 999-6673
rarediseases.org

(S) Sickle Cell Disease Association of America, Inc. (SCDAA®)
(800) 421-8453
sicklecelldisease.org

(S) THE Leukemia & Lymphoma Society® (LLS)
(800) 955-4572
lls.org

The Neuroblastoma Children's Cancer Society
(800) 532-5162
neuroblastomacancer.org

For children

(S) American Childhood Cancer Organization
(855) 858-2226
acco.org

Chai Lifeline
(877) 242-4543
chailifeline.org

Children's Health Insurance Program
(877) 543-7669
medicaid.gov/chip

(S) Children's Organ
Transplant Association® (COTA)
(800) 366-2682
cota.org

The National Children's
Cancer Society
(800) 532-6459
thenccs.org

For teens & young adults

Crititical Mass
criticalmass.org

Stupid Cancer
(877) 735-4673
stupidcancer.org

The Ulman Fund
(888) 393-3863
ulmanfund.org

Clinical trials
Jason Carter Clinical
Trials Program
(888) 814-8610
jcctp.org

U.S. National
Institutes of Health
clinicaltrials.gov

Fertility

Livestrong
(855) 844-7777
livestrong.org/fertility

Save My Fertility
savemyfertility.org

Financial

Cancer Financial
Assistance Coalition (CFAC
cancerfac.org

NeedyMeds
(800) 503-6897
needymeds.org

Fundraising

HelpHopeLive
(800) 642-8399
helphopelive.org

National Foundation
for Transplants (NFT)
(800) 489-3863
transplants.org

Insurance

Health Insurance Marketplace
(800) 318-2596
healthcare.gov

(S) Patient Advocate Foundation
(800) 532-5274
patientadvocate.org

Social Security Administration
(800) 772-1213
ssa.gov

Legal & employment

(S) Cancer and Careers
(646) 929-8032
cancerandcareers.org

(S) Cancer Legal
Resource Center
(866) 843-2572
disabilityrightslegalcenter.org

Transportation

Air Care Alliance
(888) 260-9707
aircarealliance.org

Healthcare Hospitality
Network, Inc.
(800) 542-9730
hhnetwork.org

Miracle Flights For Kids
(800) 359-1711
miracleflights.org

Mercy Medical Angels
mercymedical.org

(S) = Spanish language support

Word List

Allele
One of the different forms of a specific gene. Genes are instructions that tell the body how to make all the different proteins the body needs to work properly. Alleles are part of the HLA markers used to match patients and donors.

Allogeneic transplant
A type of transplant where a patient receives healthy blood-forming cells from a donor.

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

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.

Confirmatory typing
Blood tests for a potential donor to make sure they are the best match for you.

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.

Donor work-up
A process that a potential donor goes through to make sure they are healthy and ready to donate blood-forming cells.

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 NMDP Registry. This search shows whether a potential donor or cord blood unit is truly the best match for you. This search is not free. Your insurance may or may not pay for these costs.

Graft failure
When the donated cells do not make 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.

Acute GVHD
Usually happens 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
Usually develops within 1 year after transplant. It's called Overlap Chronic GVHD when signs and symptoms of chronic and acute GVHD appear together.

Haploidentical transplant
A type of transplant where your donor matches exactly 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 a volunteer donor to be used for an allogeneic transplant.

HLA (Human leukocyte antigen)
A protein, or marker, 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.

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.

Intravenous
A way of giving medicine, fluids or blood through a needle or tube inserted into a vein. Also called IV.

Peripheral blood stem cells
Blood-forming cells from the bloodstream.

Platelets
Parts of the blood that help the blood clot.

Preliminary search
A free search of the NMDP Registry. This search shows the potential donors and cord blood units on the registry 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.

Recipient
A patient who has had an allogeneic transplant.

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.

White blood cells
Blood cells that fight infections.

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.

nmdp℠
FIND CURES. SAVE LIVES.

About NMDP℠

For people with life-threatening blood cancers—like leukemia and lymphoma—or other diseases, a cure exists. NMDP 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 NMDP Registry℠ financial contributor or volunteer. NMDP provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

NMDP is a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved.

Visit **nmdp.org/one-on-one** or call **1 (888) 999-6743.**

| 677; JULY 2024