

Welcome to Transplant Resource Services

Helping you find care at one of the nation's leading transplant programs



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For helpful questions to ask your transplant team, see pages 11–13.



Transplant Resource Services 1-888-936-7246, TTY 711



Welcome to Optum and Transplant Resource Services

Welcome to Transplant Resource Services (TRS), offered as part of your health plan. We help people who may need a transplant find the care that's right for their needs.

As part of TRS, you have access to one of the nation's leading transplant programs through the Optum® Transplant Centers of Excellence (COE) network. Receiving a transplant from a COE means you'll get care from professionals with extensive expertise in transplantation.

This guide is meant to help answer your questions about the transplant process.

Coverage for transplant and transplant-related services is based on your health plan. If you have questions, please check your benefit plan document or call the customer service number on your health plan ID card.

Frequently asked questions about transplants

Solid organ transplants

When is a solid organ transplant needed?

This type of transplant is done when an organ is not working properly. When medical or surgical treatments cannot repair an organ, it will need to be replaced.

Where do transplant organs come from?

Transplant organs come from either:

- 1. A living donor (related or unrelated to you)
- 2. Someone who has passed away and agreed to donate their organs

Who decides when people can get a solid organ transplant?

Your doctor and other health care professionals at your transplant center make the choice about using living donors and scheduling that type of transplant. Your transplant center care team decides who to add to the waiting list for deceased donors. The distribution of solid organs from deceased donors is managed by the United Network for Organ Sharing (UNOS).

UNOS is a private, nonprofit membership organization. It operates under the Organ Procurement and Transplantation Network. UNOS matches donors to recipients using the national transplant waiting list. UNOS establishes the rules that decide which patients on the list will be offered organs from deceased donors. All U.S. organ transplant facilities must belong to UNOS. This means they have to follow UNOS's organ procurement and transplantation procedures.

Your doctor makes the decision about using living donors and how to schedule transplants from living donors.

Who is on a typical care team?

A typical solid organ transplant team includes:

- A case manager who guides you through the clinical aspects
- A nurse who provides medical assistance before and after surgery
- The transplant surgeon who places the healthy organ into your body
- A pharmacist who can answer any questions about your prescriptions
- A dietitian who can provide healthy nutrition advice
- · A social worker who can assist you with financial and community resources

What happens after a solid organ transplant?

You'll typically stay in the hospital for a recommended period of time to make sure your body has accepted the new organ. You will also receive diet, exercise and medication instructions to take care of your body going forward with the new organ. Follow these instructions carefully.



Bone marrow/stem cell transplants

When is a bone marrow/stem cell transplant needed?

These types of transplants are done to replace or rescue damaged and diseased marrow. They are done after chemotherapy and/or radiation to help restore the immune system. In some cases, they are also used to treat solid tumors.

What are the different types of bone marrow/stem cell transplants?

Depending on who donates the stem cells, there are two types:

- Autologous: When a patient uses his or her own stem cells.
- Allogeneic: When a patient receives stem cells from donor. Donors can be related or unrelated to you. Stem cells can even come from umbilical cord blood that has been donated by parents after their baby is born.

What is the difference between allogeneic related and allogeneic unrelated bone marrow/stem cell transplants?

You would receive an allogeneic related transplant if your donor is related to you. If your donor is not related to you, then it would be an allogeneic unrelated transplant.

How are you matched to a donor?

Your doctor will work with you to find a suitable donor. Doctors typically test your DNA to match your human leukocyte antigen (HLA) to potential donors. HLA is a unique marker that stimulates immune responses from the body. HLA types are inherited, so there is a higher chance of finding a match when the donor is related to you or of the same race and ethnicity.

How is a donor search started for unrelated allogeneic transplants?

People using their own stem cells or those from a relative do not need to do an unrelated donor search. If you need an unrelated allogeneic transplant, your care team will search the Be the Match registry for a donor.

The National Marrow Donor Program (NMDP) is a private organization contracted by the federal government. It manages the registry for all allogeneic stem cell donors in the United States. This registry has matching information for over 39 million stem cell donors. It also has nearly 806,000 units of donated umbilical cord blood.* The NMDP works with stem cell registries around the world to find donor/recipient matches.

Source:

*National Marrow Donor Program. Be the Match Registry. bethematch.org/about-us/how-we-help-patients/be-the-match-registry/. Accessed March 3, 2022.



The Transplant Centers of Excellence network

In 2019, more than 300 facilities performed over 60,000 solid organ and stem cell transplants.* With so many places to choose from, one of the most important decisions you can make is where to go for care.

Through TRS, you have special access to our Centers of Excellence (COE) network. The programs in this network all meet our criteria in 3 key areas:

- Transplant program outcomes: Patient and organ (graft) survival number of transplants performed yearly
- Transplant program structure: Doctor and program experience, program accreditation, involvement in new research
- Transplant program process: Medical protocols, eligibility criteria, peer-reviewed publishing, continuous quality improvement, patient education

For the most up-to-date transplant network maps, visit:

myoptumhealthcomplexmedical.com/gateway/public/transplants/transplantLinks.jsp

*Sources:

Organ Procurement and Transplantation Network. Advanced report built for counts of facilities reporting transplants in 2019. optn.transplant.hrsa.gov/data/view-data-reports/build-advanced/. Accessed March 3, 2022.

Ibid. National Data. optn.transplant.hrsa.gov/data/view-data-reports/national-data/. Accessed March 3, 2022.

Center for International Blood & Marrow Transplant Research. Current Uses and Outcomes of Hematopoietic Stem Cell Transplantation – 2020 Summary Slides. cibmtr.org/referencecenter/slidesreports/summaryslides/Pages/index. aspx#DownloadSummarySlides. Accessed March 3, 2022.

Be the Match. Transplant Center Search Results. bethematch.org/tcdirectory/search/advanced. Accessed March 3, 2022.

Key resources throughout the transplant process

The following people are here to help make your transplant experience as successful as possible.



Health plan case manager:

Your day-to-day contact who works with you and your family to help coordinate your care. They are usually assigned to you by your health plan.



Transplant coordinator:

Manages both the clinical and logistical aspects of your transplant. They are usually from the facility performing your transplant surgery.



Transplant surgeon:

The doctor who will perform your transplant. They can answer questions about the procedure and help you get prepared for the surgery.



Social worker:

Helps you identify any difficult circumstances affecting your mental health or daily environment and find resources to address them. They can also help you in coping with your feelings about your illness.



Other doctors:

Throughout the transplant process, you may see other doctors in important sub-specialties. They make sure your body is able to handle the transplant and that your organ keeps working properly. They are also here to support you, your transplant doctor and your transplant surgeon.



Transplant financial coordinator:

Handles matters such as hospital billing. Also works with the social worker to help you take care of any out-of-pocket costs.



Transplant doctor:

A specialist (cardiologist, nephrologist, hepatologist) who does your initial evaluation and refers you for a transplant. They can answer questions about the process.



Dietitian:

Helps you create a nutrition plan to maintain a healthy weight and reduce any side effects of anti-rejection drugs.



Pharmacist:

Helps you understand how to manage and take your medications. Can also identify potential interactions among your current medications and those you'll be taking during the transplant process.

What to expect during the transplant process

Deciding if and where to have a transplant is a big deal. Your TRS team will be with you every step of the way. They'll explain your options and make sure you're comfortable with your care.



Step 1: Eligibility

Once we're notified that you need a transplant, you can access our transplant network. Your case manager will work with you and your doctor to identify the most appropriate network programs for your needs.



Step 2: Notification

After you've chosen a program, your doctor will send a referral to the program for evaluation. If you have benefit questions, contact your customer service representative at the number included in your enrollment information or call the number on your health plan ID card.



Step 3: Evaluation

All transplant types:

You should work with your case manager to identify your needs in the following areas:

- · Knowledge about your condition
- Relationship with your doctor, including dates and purposes of most recent and upcoming appointments
- Type of prescription drugs prescribed for you, including making sure your medications are appropriate for your condition and that you know how to take them
- Medical equipment available in the home
- · Coping skills and support structure

For solid organ transplants:

- Your evaluation is led by the transplant doctor and transplant surgeon. This may
 mean one to three days of testing done at the transplant facility. Often, it is easier
 if parts of the evaluation are taken care of by your primary care doctor. In that
 case, he or she will work with the transplant center to make sure all of the needed
 tests are completed.
- Evaluation tests are usually done on an outpatient basis. At times, depending on the transplant program, you may need to travel to the facility and arrange for lodging. Your case manager can help plan for these needs, if covered by your benefit plan. After your evaluation, a hospital committee will decide if you're a good candidate.
- Once selected, your case manager, referring doctor and doctors at the transplant center will work together to handle your care (see step 4).



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What to expect during the transplant process (continued)

For bone marrow/stem cell transplants:

- · Your evaluation includes a physical exam with diagnostic tests
- If you're donating your own stem cells (autologous transplant), they will be harvested from your bone marrow or blood. If you are not your own donor (allogeneic transplant), you will need to have a related donor or be listed with the National Marrow Donor Program (NMDP) (see step 4)
- If necessary, you will undergo chemotherapy and/or radiation to prepare you to receive the new stem cells. This pre-treatment is called "conditioning" or a "preparative regimen."

After you've been accepted by a transplant program, your case manager will work with you to understand:

- Any changes in your diagnosis or condition
- · Your relationship with new doctors and/or caregivers
- How you fill your prescriptions
- Changes in any medical equipment in the home
- The important role of your caregivers before and after your transplant
- Access to travel and lodging, if applicable, to help offset the costs when traveling to receive transplant related care away from your home



Step 4: Registration and listing

For solid organ transplants:

The process of registering to receive an organ is called "listing." While you wait for a donor to be found, you'll receive treatment for your condition and testing. This may be done at your local doctor's office, at the transplant facility or both. Your transplant doctors will coordinate your plan of care.

Organ recipients are selected by UNOS based on:

- Medical urgency
- Time on the wait list
- Biological similarities between donor and candidate (such as organ size and blood type)
- · Candidate's immediate availability

These factors all affect your wait time. Some patients receive an organ the day they're added to the wait list, while others may wait years.

In some cases, you may be able to receive an organ from a living donor. If not, it will come from someone who has passed away. Once the organ is recovered, you will be asked to be available via phone at any time.

For bone marrow/stem cell transplants:

If you will be donating your own bone marrow or stem cells, you don't have to find a donor. If not, your doctor will determine the ideal donor for you. About 40% of transplants come from a family member or someone unrelated to you. This is known as an allogeneic transplant. If there is not a related match, your transplant program will contact Be the Match to start a search. The chance of finding an unrelated donor depends on your tissue type.

*Source:

Center for International Blood & Marrow Transplant Research. Current Uses and Outcomes of Hematopoietic Stem Cell Transplantation – 2020 Summary Slides. https://www.cibmtr.org/referencecenter/slidesreports/summaryslides/Pages/index.aspx#DownloadSummarySlides. Accessed March 03, 2022.

What to expect during the transplant process (continued)



Step 5: Transplant and recovery

Once a donor has been found, you and your family will travel to the transplant facility for the procedure. This may require a hospital stay of several weeks. After surgery, you may also need to complete physical therapy at the center. This is especially true if you were very weak at the time of your transplant.

After your transplant, your case manager will make sure you understand:

- · Your hospital discharge instructions
- Your follow-up appointment schedule
- When to contact the transplant team between appointments
- · How to work new exercise and diet habits into your lifestyle
- How to take your medications properly

Your case manager and/or health plan administrator can also work with you to make sure you understand:

- · Home medical equipment
- · Rehabilitation care
- · Specialty nurse care
- How to fill your prescriptions



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Monday through Friday, 7 a.m. to 6 p.m. CT For faster service, please have your nurse's name or extension available.



SPECIAL NOTE IF TAKING IMMUNOSUPPRESSANT MEDICATION:

These drugs help your body accept the new organ. Taking them consistently is **critical** to your health. Make sure you know the following:

- How to take them
- Where to get them
- How to refill them

- When to take them
- How to pay for them

If you go to the hospital for any reason after your transplant, bring all of your medications and doctor information with you.

Questions to ask Notes Getting answers about your transplant surgery can be overwhelming. There are questions you want to remember - and information you don't want to forget. Use the following questions as a starting point to help you get the answers you need. Questions to ask your case manager about how to prepare for a transplant evaluation: • Will my benefits cover my transplant? What about post-transplant care? • Do I have coverage for my family and me to travel? · How will my prescriptions be covered and will they require a specialty pharmacy? Is there an approval process for my transplant? • Are there any educational materials, classes or websites you can share with me about transplantation? How should I prepare for a transplant evaluation? • How can I prepare myself and my family for care before and after transplant? • Do you have resources to address my mental health during this stressful journey? · Can you tell me more about the options to have a friend or family member donate to me through living donation? • For kidney: – What are my options related to double listing? - How does double listing increase my chances of receiving an organ transplant? For paired donation: - What if I have a living donor who is not the best match for me? - What more can you tell me about paired donation? Questions to ask your doctor or transplant coordinator about the transplant program at the medical center: · How many deceased and living donor transplants are performed at this hospital each year? What are the patient and organ survival rates at this hospital? How long can I expect to wait before receiving my transplant at this hospital? Will I need to move close to the hospital as I move up the list? Do I have to remain close to the facility after the transplant and for how long? For kidney or liver: What are my options when it comes to living donors? For kidney: What options do I have when it comes to paired donation? Is there a dedicated transplant unit to care for transplant patients? Are there any visitor restrictions at this transplant center? Could I get a tour before my surgery?

Questions to ask your transplant coordinator **Notes** about your transplant: How will you coordinate my care before and after my transplant? • Are there any educational materials, classes or websites you can share with me about transplantation? Can you describe the members of the transplant team and what their roles are? What does the evaluation and testing process include? · How long will it take to complete my evaluation? When or how do I find out about my evaluation results? How do I get on the waiting list for a transplant? · How does the waiting list work? Do I need to stay close to the hospital after I am put on the waiting list? Do I have to move close to the hospital if it is far from where I live? When would I have to move and how long would I have to stay? • If I don't live close to the hospital, how will I get there? Who will pay for it? Will travel expenses be covered? How soon do I need to be at the hospital after being called for the transplant? • What happens when I get "the call" for my transplant? What limitations will I have after my transplant? What medications will I be taking after my transplant? What happens if I forget my medications? How do I organize my medications? · What is required of my caregiver? Questions for your social worker: • What happens if I'm not able to return to work? Who will assist me with insurance and return to work/FMLA paperwork? • Will I be eligible for disability benefits? • Are there any other ways to pay for this? • Who do I call with financial questions? • Is housing available for my family and me? How is this paid for? • Are there community support services available (counseling, transportation, meals, financial services, childcare, fundraising, etc.)? • Will I be able to work after my transplant? When will I be able to return? • Is childcare assistance available? • If I am unable to return to my current job, am I eligible for vocational rehabilitation? • Do I need to apply for Medicare? How do I apply? • Do you have any resources or support for my caregivers? Questions for your transplant surgeon: What are the potential risks and benefits of having a transplant? How many transplants have you personally performed? How do I prepare for the surgery?

What does the surgery involve?

What kind of follow-up will I have with you after the surgery? **Notes** How much pain can I expect after surgery? • How will my pain be managed after the surgery — in the hospital and after discharge? • For kidney or liver: Is living donation an option for me? • For kidney or liver: What are the advantages and disadvantages of a deceased donor versus live donation? • What happens to me after the surgery? • How long will I be required to stay in the hospital? • What is rejection? What symptoms should I look for? **Questions for your pharmacist:** · What are the side effects of the medications? • How often and at what time of day do I have to take the medications? • How long will I have to be on the medications after the transplant? • What do I do if I miss a dose? • Are there any dietary restrictions while taking any of the medications? • Do I need to take my medications with meals? • How much will my medications cost monthly? • Is there financial assistance available? Questions for your dietician: • Are there any dietary resources for transplant patients? • Do I need to be on a special diet after my transplant? • When can I eat after my transplant surgery? • What happens if I lose or gain weight after my transplant? • Are there any dietary restrictions before or after my transplant? **Questions for your employer:** • Do I qualify for the Family Medical Leave Act (FMLA) and how do I apply? • Do our benefits include short-term and long-term disability and how do I apply? • Who are important points of contact, including their contact information? • What is the Paid Time Off (PTO) policy and flexible schedule work hours?



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Helpful resources and websites

General transplant

American Society of Transplantation <u>myast.org/patient-information</u>
Organ Procurement Organizations
OrganDonor.gov
Scientific Registry of Transplant Recipients
United Network for Organ Sharing (UNOS) & OPTN unos.org
UNOS Transplant Living transplantliving.org
General support
Caring Bridge caringbridge.org
Friends' Health Connection friendshealthconnection.org
National Organization for Rare Disorders <u>rarediseases.org</u>
UnitedHealthcare Healthier Lives

There is a wealth of patient education available on the UNOS website unos.org. Patients can access this information online or can order free patient education materials to be sent to their home.

- From the home page, click on "Donation and Transplantation"
- Select "Patient Education" from the drop-down menu
- Click on "Patient Brochures"
- For hard copy materials, click the "shop now" link for the UNOS online store

General eldercare resources

Food

Meals on Wheels Association of America mealsonwheelsamerica.org
Supplemental Nutrition Assistance Program (SNAP)
WhyHunger whyhunger.org
Housing
Home Modifications homemods.org
Housing and Urban Development <u>hud.gov</u>
Healthcare Hospitality Network hhnetwork.org
New Lifestyles <u>newlifestyles.com</u>
Ronald McDonald House Charities rmhc.org
Medications
Centers for Medicare & Medicaid Services cms.gov/medicare/prescription-drug-coverage/limitedincomeandresources Information on applying for subsidy to help defray Medicare Part D prescription drug costs.
Good Rx goodrx.com
Needy Meds needymeds.com
Partnership for Prescription Assistance medicineassistancetool.org
Rx Assistance
Rx Hope

Transportation

Air Care Alliance aircareall.org
Air Charity Network <u>aircharitynetwork.org</u>
Angel Flight angelflight.com
American Organ Transplant Association aotaonline.org
Mercy Medical Angels mercymedical.org
Public Transportation
Support and education by illness
Bone, blood and cancer
American Cancer Society cancer.org
Aplastic Anemia & MDS International Foundation, Inc. aamds.org
Blood and Marrow Transplant (BMT) Information Network <u>bmtinfonet.org</u>
Cancer Care, Inc. cancercare.org
Leukemia and Lymphoma Society <u>lls.org</u>
Leukemia and Lymphoma Society: Copay assistance
Leukemia and Lymphoma Society: Financial Support <u>lls.org/support/financial-support</u>



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National Bone Marrow Transplant Link nbmtlink.org
National Cancer Institute <u>cancer.gov</u>
Be the Match <u>bethematch.com</u>
NIH Bone Marrow and Stem Cell Transplant <u>cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant</u> Fact sheet on blood-forming stem cell transplants.
Patient Access Network Foundation panfoundation.org
Diabetes
American Diabetes Association diabetes.org
National Diabetes Information Clearinghouse <u>niddk.nih.gov/health-information/diabetes</u>
Heart
American Heart Association americanheart.org
NIH Heart, Lung and Blood Institute nhlbi.nih.gov/health/dci
Intestine
Oley Foundation oley.org



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Kidney

American Association for Kidney Patients aakp.org
American Kidney Fund kidneyfund.org
National Kidney Foundation kidney.org
Liver
American Association for the Study of Liver Disease aasld.org
American Liver Foundation liverfoundation.org
Help-4-Hep help4hep.org
Hepatitis Foundation International myaccesshealth.com/hepatitis-overview
Lung
American Lung Association lung.org
Cystic Fibrosis Foundation off.org
National Jewish Medical and Research Center's LUNG LINE <u>nationaljewish.org</u>
Second Wind Lung Transplant Association 2ndwind.org



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UnitedHealthcare

This program should not be used for emergency or urgent care needs. In an emergency, call 911 or go to the nearest emergency room. The information provided through the nurse support service is for informational purposes only and provided as part of your health plan. The nurse cannot diagnose problems or recommend treatment and is not a substitute for your doctor's care. Your health information is kept confidential in accordance with the law. This nurse support service is not an insurance program and may be discontinued at any time.

The Centers of Excellence (COE) program providers and medical centers are independent contractors who render care and treatment to health plan members. The COE program does not provide direct health care services or practice medicine, and the COE providers and medical centers are solely responsible for medical judgments and related treatments. The COE program is not liable for any act or omission, including negligence, committed by any independent contracted health care professional or medical center.

UnitedHealthcare Freedom Insurance Company. Oxford insurance products are underwritten by Oxford Health Insurance, Inc. Oxford HMO products are underwritten by Oxford Health Plans (CT), Inc. and Oxford Health Plans (NJ), Inc. Administrative services provided by Oxford Health Plans LLC.

Administrative services provided by United HealthCare Services, Inc. or their affiliates, and UnitedHealthcare Service LLC in NY. Stop-loss insurance is underwritten by All Savers Insurance Company (except CA, MA, MN, NJ and NY), UnitedHealthcare Insurance Company in MA and MN, UnitedHealthcare Life Insurance Company in NJ, UnitedHealthcare Insurance Company of New York in NY, and All Savers Life Insurance Company of California in CA.

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