

Living Donation Made Easy

A Guide for the Transplant Candidate



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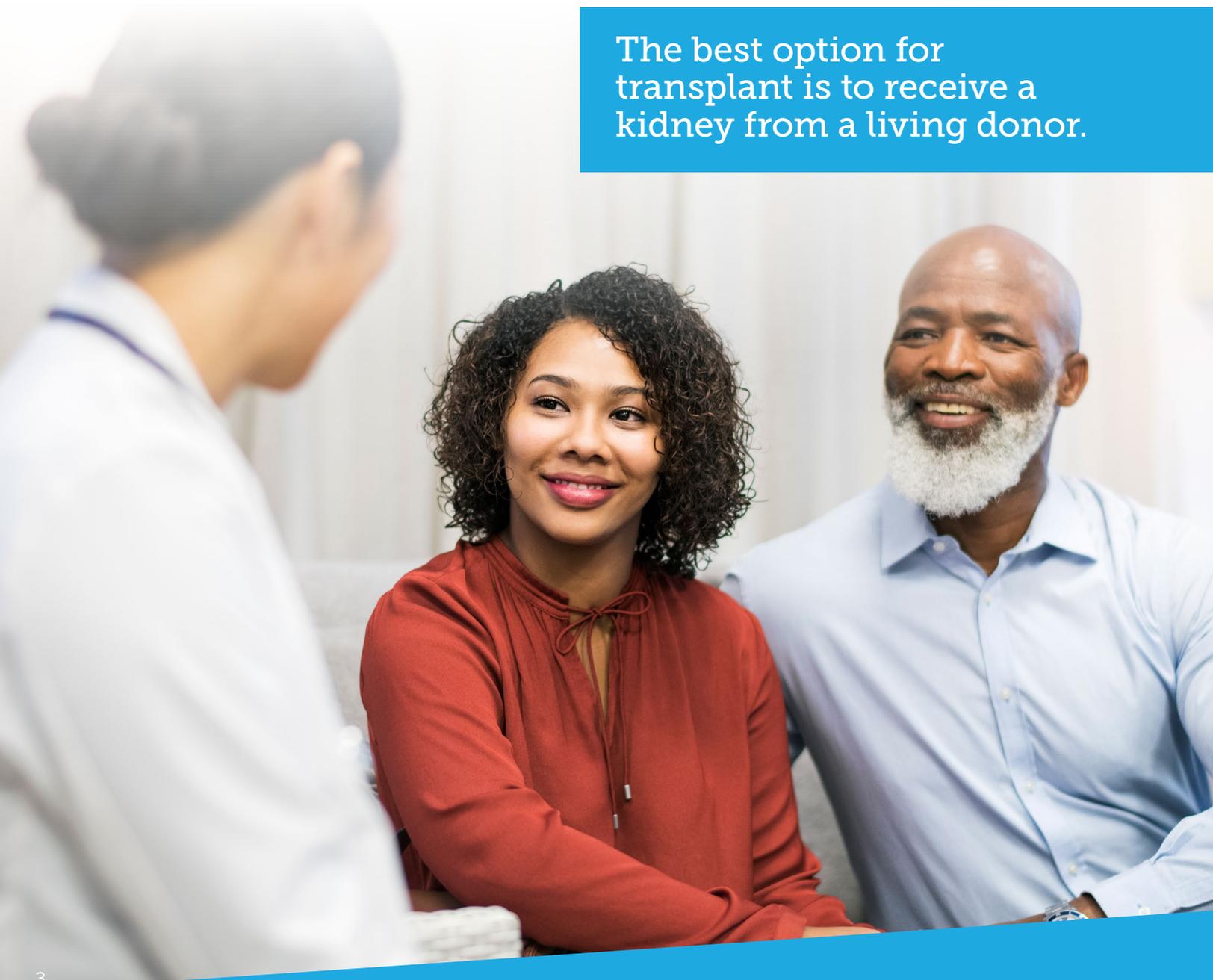
Transplant Journey

AdventHealth is a leader in transplant having begun our program in 1973 and performing over 5,000 lifesaving organ transplants since. You've taken the first step by choosing an expert team to guide you, and we are honored to be allowed to care for you and your family

During your evaluation you will learn quite a bit of information about transplant including preparing for the waitlist, types of donors, benefits and risks, recovery, medications, and life after transplant. This guide is designed to build upon that information to provide you with all the options available to you so you can make informed decisions as you proceed through the journey of transplant.

The United Network for Organ Sharing (UNOS) national waiting list for deceased donor transplantation is the first option that most nephrologists will suggest when referring you to transplant. The average waiting time in the U.S. for kidney transplant is approximately four years. Some areas of the country may have longer wait times and will depend on your blood type, length of time on dialysis, and antibodies. This option is the most common choice for many patients however, it is not the best.

The best option for
transplant is to receive a
kidney from a living donor.



Benefits of Living Donation

Living donor kidneys have the following benefits:

- Functions twice as long (12 to 20 years) as the average deceased donor kidney (8 to 12 years).
- More than 98% of transplanted kidneys from living donors are still working well one year after transplant.
- Tend to function immediately when transplanted.
- Prevents dialysis altogether in some cases if transplant is timed early enough.
- Prevents long term dialysis when waiting on the list.
- Living longer than those who stay on dialysis.
- Offer advanced scheduling as it is considered elective for the donor.
- If the donor is related, could be a close match and offer longer function, may even decrease the amount of medication required to prevent rejection.
- May provide the donor with an emotional benefit to be able to help.
- A living donor transplant from someone that is not related may even function longer than a perfect matched deceased donor.



Who Can Be a Living Kidney Donor?

The first consideration for deciding who can be a donor is to know that there is a **Living Donor Program at AdventHealth Transplant Institute** that will evaluate and care for the donor. This means that you do not need to evaluate who may or may not be a candidate to be a donor. The Living Donor Program has a process for screening and evaluating potential donor candidates beginning with an online health screening at **AHLivingDonor.com**.

The living donor program is responsible for the following:

- Protecting the donor's private medical information
- Providing donors with education about the risks and benefits of donation
- Completing a thorough evaluation that follows all regulatory and state guidelines
- Evaluating the donor for short term and long term medical, surgical, social, and financial/insurance risks after donation
- Ensuring donors are not being pressured, coerced, or paid to donate
- Evaluate all donors for increased risk behaviors and infectious diseases

Our Living Donor Program completes a very thorough evaluation to make sure the surgery and recovery of each donor is low risk. The operation is done through the belly button single incision with laparoscopic instruments. The full recovery can be up to six weeks but patients that have a less physical job role can be back to work in a couple weeks.

General Living Donor Criteria

- 18yrs of age or older and able to make medical decisions
- Be genuinely willing to donate voluntarily
- Be in good physical and mental health
- Ideally have a body mass index (BMI) < 30 or <35 and willing to decrease weight with healthy lifestyle modification long term
- Have adequate social support to help them during the recovery period
- Recommendations: have medical coverage or access to healthcare long term, non-smoker or willing to stop, have a supportive employer, carry short term disability or savings to cover time off

Don't exclude an interested donor until they talk with the living donor program!

Sharing Your Story and Finding a Donor

The first step in finding a donor is to share your story. Simply using a bumper sticker with your contact information “Need Kidney” is not always the best approach. Many transplant patients that approach finding a donor this way, end up finding a donor much closer to home either from a distant relative, coworker, or church friend. These are the people that need to be made aware that you are in need of a kidney transplant.

Here are a few ways of sharing:

- Sending or emailing a letter to relatives and friends
- Writing a post on your favorite social media site that relatives and friends only can see
- Speaking to your church group, community group/club, coworkers, or at your next family event

It doesn't have to be a formal conversation. Here is an example:

“As you know, I have been started on dialysis and they tell me that the best treatment option is to pursue a kidney transplant. The best type of kidney is from a living donor. They work better and longer and if anyone is interested in learning more, I would be glad to give you more information. No hard feelings if you change your mind or cannot do it. I appreciate the consideration.”

Donor Champions

Some patients may feel like they are advertising themselves and not interested in sharing such private information. In these instances, a close friend or relative could help you and be your voice. These persons are called Transplant or Donor Champions. If you decide this is the best approach for you, we recommend choosing someone that you trust who will have your best interests at heart. Their purpose would be to help get the word out about your need. This person may be someone that wants to help but perhaps is not a candidate do donate themselves. The Living Donor Program at AdventHealth has resources that can be provided to a Donor Champion to assist them in being conscious of donor criteria, patient privacy, and what to do when someone offers to donate.

Thank you for considering donation even if you can't!

Social Media

Social Media is growing every day and with so many ways to share our interests and lives it can be somewhat overwhelming if you've never used it. Facebook remains the most popular outlet. Here is a QuickStart guide:

- Create a profile on Facebook or other social media
 - Profiles are free of charge
- Confirm your email address and contact information
- Setup privacy settings
- Request to add friends but make sure to only include:
 - Family or friends that you know and trust

If you prefer not to use your personal social media page, another option is to create a group Facebook page that you can use specifically for this purpose.

- Create a Group page with Facebook
- Create a group name
- Invite friends and family to your group
- Choose privacy settings for your group



Security

Your privacy is our top priority in healthcare. Protect yourself against identity theft when using any online platform. Remember to keep your personal information private including:

- Home address
- Date of birth
- Social Security Numbers
- Credit card or financial information

Posting

When you or your Donor Champion creates the first post make sure that it is genuine and to the point. Avoid using terminology that could be scary to someone that has never faced a serious medical condition.

- Provide a brief summary of the medical events leading to transplant
- Explain that that transplant from a living donor is the best treatment option
- Give some facts why this is best for you
- How the need for transplant has changed your life
- Offer them more information via AdventHealthTransplantInstitute.com
- Tell them thank you for thinking of you in your time of need
- Offer them ways to contact you for more information
- Remind them it's okay if they are unable to help and that conversations with the transplant team are private

Sharing your story is another way to gain support from your loved ones and community and can help lift your spirits through the journey of transplant by staying connected. Other ways to stay connected online:

- Posting photos and sharing positive progress
- Liking comments when others give support
- Respond to others when they have a question
- Share what you are looking forward to after transplant
- Tag friends in posts if they are being supportive
- Continue the momentum by posting weekly or as often as you like
- Make it enjoyable!

Costs

Remember that it is illegal to give money or any other item of value in exchange for a donated organ. Most evaluation expenses are covered by insurance, sometimes even travel. It may be okay for you to help a donor with the following if you are able:

- Travel and lodging expenses
- Lost wages related to evaluation and recovery time

If your insurance does not cover donor travel and lodging expenses, you may be able to apply for Living Donor Travel assistance through the National Living Donor Assistance Center. It is an income-based program that is based on the transplant patients household income. If approved the program can cover multiple trips for the donor including:

- Cost of flights, gas, taxi, or other transport
- Lodging including hotel or transplant house donations
- Meals if lodging is not needed
- Travel and lodging for an accompanying caregiver for up to two trips

The program must receive your application from the transplant institute and be approved before the donor travel takes place.

Pediatric Transplant

When a transplant patient is placed on the waiting list, below the age of 18 years, they are provided with pediatric priority points giving them an opportunity to be matched quicker for a deceased donor kidney. The priority points last until a transplant occurs, even if they pass the age of 18 years while waiting.

Although, pediatric priority is given, there is no guarantee that the patient will receive an organ in any expected time frame.

There are many medical factors that weigh into matching of every donated organ on the list for all patients including:

- Blood type
- Waiting time
- Donor/recipient immune antibody compatibility
- Pediatric status
- Donating an organ in the past
- Distance from the donor hospital
- Survival benefit (Estimated Post Transplant Survival EPTS)

Waiting for a transplant is not like standing in line, waiting for someone to call your number. You may want to think of it as a pool of people, waiting for an organ that fits their medical profile. The transplant institute will review medical information about available organs to find a good match for your child. Sometimes, an organ may become available, but your doctor may decide to wait for a better match.

In the case of a pediatric patient with a less common blood type such as B, the patient may

still wait 12 to 18 months for a matched deceased donor organ. Living Donation again is the best option for pediatric transplant patients. Pediatric patients have a critical need to have a successful transplant the first time that will last the longest as they may eventually require a second transplant in their lifetime. Other benefits in addition to those previously mentioned in this booklet:

- Living donation from a relative can possibly give them a better match increasing longevity
- Living donor organs tend to function immediately decreasing or eliminating need for any further dialysis

Potential living donors should not be excluded for age. Parents and grandparents are viable options either for direct living donation or within paired exchange. Older siblings are sometimes good candidates but due to their young age, may be recommended to wait to donate when they are older if the recipient requires another transplant as they have a higher chance to be a good match. The Pediatric Transplant Program and Living Donor Program can review all your specific needs to recommend the best treatment option.





How to Accept a Donor Offer

For some patients they have already had a friend or family member express their interest in donation. For others, it can be hard to start that conversation. Most donors that come forward have known they wanted to donate long before the recipient became a transplant candidate. For transplant patients the thought of someone undergoing surgery at their benefit, can bring mixed emotions including excitement, guilt, fear, or obligation. Many donors say that the donation provided them with joy in being able to help another person and that they were able to get back to normal activities with a few weeks after surgery.

Donation is definitely a personal decision, but when the right donor for you comes forward and proceeds it can benefit both sides.

People who donate kidneys can lead normal, active lives after recovering from surgery without any special restrictions. The body can function well with only one kidney, assuming all the testing done before donation show that the donor is healthy and has two normal kidneys. A donor does not have to follow a special diet or take special medicines once the recovery is complete.

Once a donor candidate makes their wishes known, provide them with more information and thank them for considering donation. At times a friend a family may initially be thinking of donation but after more research find out its not for them. We find this happens often even during the donor evaluation. We thank these persons for coming forward and being willing to learn more.

About 90 to 95 out of every 100 donors say they would not change anything about their decision to donate. They would make the same decision to help someone. They would go through all the screenings, tests, and the surgery. They would take time away from their lives, jobs, and other commitments to recover. They would do all of that to help someone.

Compatibility

Compatibility is the most common misunderstood topic in transplant. Let's begin with some basic information.

Blood Type

Compatibility begins with blood type. Your donor does not have to be the same blood type but will need to be a compatible one. The +/- called the Rh Factor, is not considered for kidney transplant. See below:

Recipient Blood Type	Acceptable Blood Types
A	A or O
B	B or O (possibly A*)
AB	A, B, AB or O
O	O (possibly A*)

If a compatible blood type is not possible, a paired donation is the next best option.

*In some instances, we can proceed with transplant even if the blood type is not perfectly compatible. This requires us to check the level of antibodies one has against the other non-compatible blood types. It may require treatments for the transplant patient before and sometimes after the surgery but can be very successful.

We don't expect every patient to memorize this chart so know that you are not required to find a donor that is always the perfect blood type. Let the transplant team evaluate who can be a donor for you.

Immune System

The second part of compatibility is based on the immune system. Recipients that have had a previous blood transfusion, multiple pregnancies, or previous transplant may have developed antibodies against human blood or human tissue markers. These are called donor specific antibodies (DSA). Each of these antibodies are measured on a scale of strength that can predict if they will cause incompatibility or rejection of the organ after transplant. A crossmatch is the test performed to determine if a donor is a match for you.

A Panel Reactive Antibodies (PRA) measurement can predict how difficult you may be to match a donor. The result is defined as a percentage from 0 to 100% depending on how common those tissue markers may be in the community.

- If your PRA is zero you will likely be compatible with anyone that has the right blood type
- If your PRA is >50% it may be difficult to find a donor match for you but not impossible
- If your PRA is 99% to 100% you will receive priority points on the waiting list

There are treatments for patients that find it difficult to find a donor match, we call this desensitization.



Desensitization

At AdventHealth Transplant program we began our Desensitization program in 2008. Desensitization is the process of trying to remove antibodies that make it hard for a recipient to match a donor. This is usually done with home treatments such as injections or intravenous (IV) infusions that help to decrease or remove the antibodies. The most common medication used is called Intravenous Immunoglobulin (IVIG). Other medications or plasmapheresis (plasma exchange) treatments may be used in conjunction with this therapy.

Depending on multiple medical factors you may qualify for this program if:

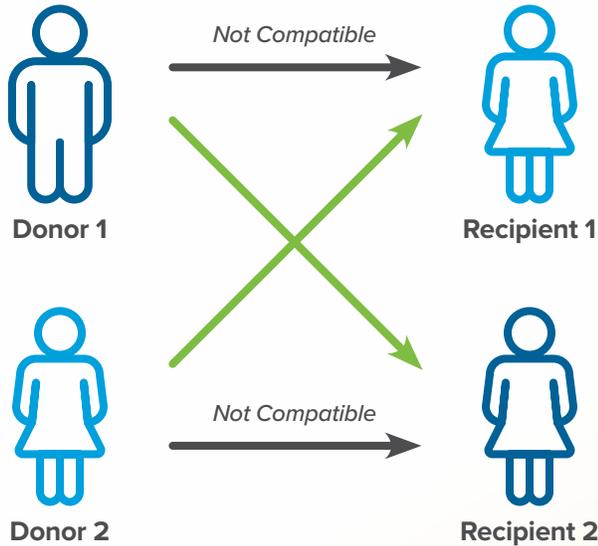
- You have a crossmatch incompatible living donor
- You have a high antibody level (PRA) and have been waiting some time for a match

The treatments for desensitization may be required for 3 to 6 months or longer. During this time your antibodies will be reviewed monthly by our specialized Tissue Typing Laboratory to monitor for changes in the presence and strength of your antibodies.

If you believe you may qualify for this program, contact your Kidney Transplant Coordinator for more information or talk with you Transplant Surgeon.

Paired Donation

Kidney Paired Donation (KPD) has many names, paired exchange, paired donation, whatever you decide to call it, everyone should consider seeing if this option is right for them. This approach to living donor transplant starts when patients with incompatible living donors swap kidneys to receive a compatible one. The first KPD in the United States occurred in the year 2000 and has only grown since then. In 2007 AdventHealth began participating and performing these types of transplants.



The following are reasons to participate:

- You have a living donor who is the wrong blood type
- You have a living donor who is much older and not the best age match
- You have a living donor who is not compatible due to crossmatch or antibodies

We currently participate with two KPD programs:

- Alliance for Paired Kidney Donation (APKD)
- Organ Procurement and Transplant Network (OPTN) KPD Program

When you and your donor are placed on these lists for matching, the Living Donor Program will be alerted when a match is found. Both hospitals will then share medical information of the donor to decide if the match is favorable on both sides. Sometimes the match that is found can include multiple pairs across the country and results in multiple transplants. These can be chains that start with a single donor who is a good Samaritan or Non-Directed Donor who does not have a recipient.

Depending on many medical factors it can take three months or longer to find a match and the transplant can also be planned in advance for the convenience of the donor and recipients included in the match.

A donor is not matched until the recipient is also found a compatible donor.

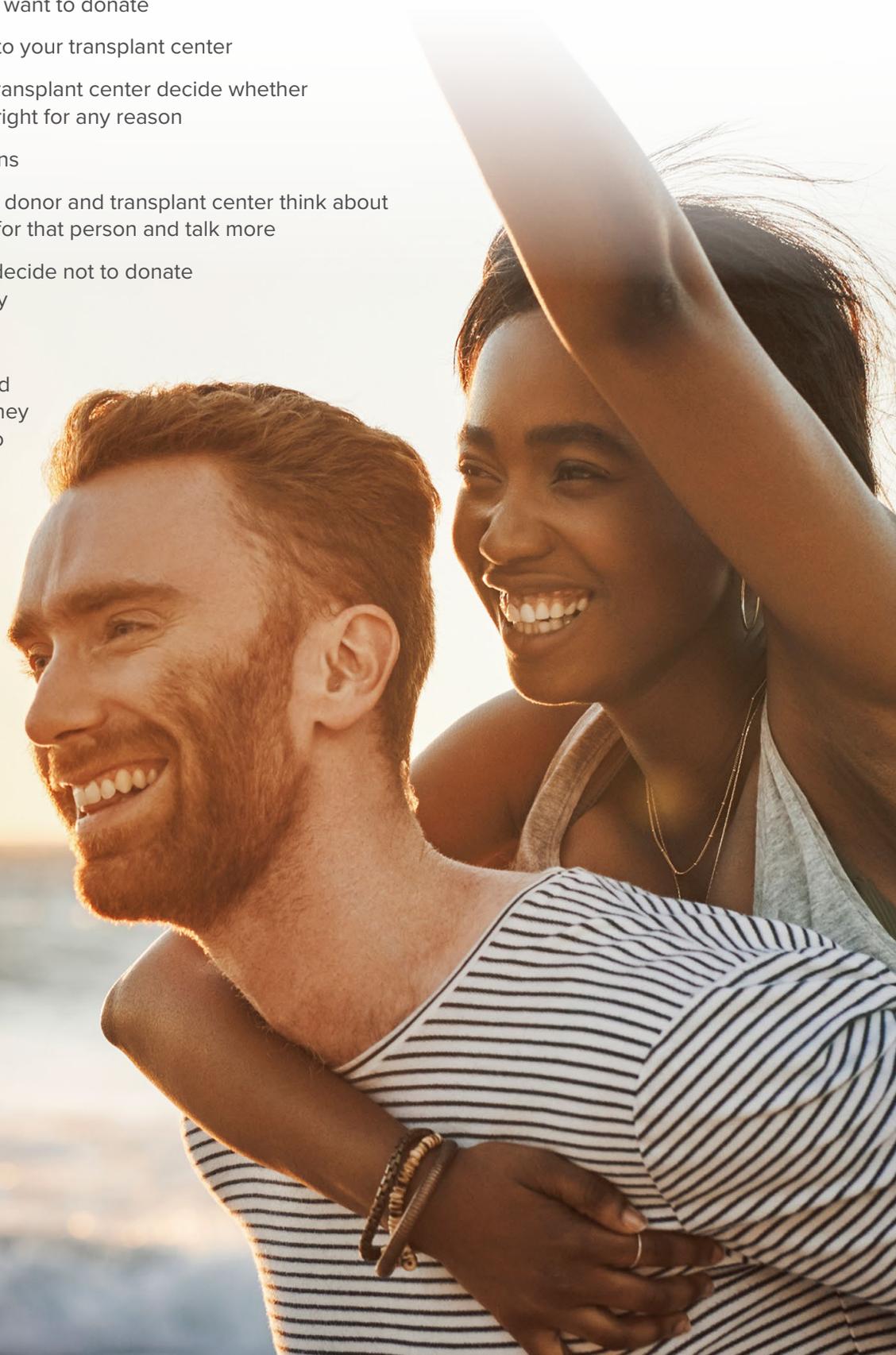
Know the Living Donation Process

What happens when someone says they might be interested in being my living organ donor?

Once someone says they're interested in being a living donor, a long process begins with education. The potential donor and the transplant center must figure out if living donation is right for that person.

1. Someone says they might want to donate
2. The potential donor talks to your transplant center
3. The potential donor and transplant center decide whether to test or whether it's not right for any reason
4. If both agree, testing begins
5. After testing, the potential donor and transplant center think about whether donating is right for that person and talk more
6. The potential donor may decide not to donate up until the time of surgery
7. Donation and transplant

When someone steps forward to consider living donation, they are really stepping forward to learn more about the process from transplant professionals. The education process also lets your transplant center staff learn about that person. Decisions about whether living donation is right for that person are still a long way off for both the potential donor and the transplant center.



Learn More

The following organizations provide trustworthy information about organ disease, living donation and organ transplantation:

United Network for Organ Sharing (UNOS)

unos.org and transplantliving.org

UNOS' Evidence Supplement about Living Donor Education

optn.transplant.hrsa.gov/resources/living-donation

UNOS' "Stories of Hope" by Living Donors and Transplant Recipients

transplantliving.org/community/stories-of-hope

U.S. Department of Health and Human Services

organdonor.gov/about/process/living-donation.html

National Kidney Foundation

livingdonors.org

National Institutes of Health

nih.gov

National Living Donor Assistance Center

livingdonorassistance.org

The National Kidney Foundation: PEER Program

855-653-7337 (855-NKF-PEER)

nkfpeers@kidney.org

kidney.org/transplantation

kidney.org/patients/peers



Our Health Equity Promise

Patient Protection and Affordable Care Act: Section 1557

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- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

AdventHealth provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

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You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at hhs.gov/ocr/office/file/index.html.

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ATENÇÃO: Se você fala português, disponibilizamos serviços lingüísticos gratuitos. Ligue para o número abaixo.

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注意: 日本語でお話になりたい場合には、無料の通訳サービスをご利用いただけます。下記の番号にお電話してください。

ໄປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອ ດ້ານພາສາ, ໃດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ກະລຸນາໃຫ້ນັ້ງເບິ່ງຮູ້ຂ້າງລຸ່ມ

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