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# Waiting for a kidney

## and how to get one sooner

## Getting listed and waiting for transplant

### How long will I wait for a transplant?

Waiting time is how long a patient has waited for a transplant. Waiting time is based on the day you started dialysis or if you are not on dialysis, the day you were placed on the waiting list. Each year doctors only transplant about 11,000 kidneys from donors who have died. This is because it's rare for people to die in a way that allows their organs to be donated. This means there aren't enough kidneys for the more than 95,000 people waiting.

How long you wait depends on many factors, including:

- Your blood type.
- Presence of antibodies in your blood.
- How long you've spent on dialysis.
- Living donor availability.
- Combined organ transplant.
  - ▷ Liver/kidney
  - ▷ Heart/kidney
  - ▷ Kidney/pancreas

### Southern California kidney wait times by blood group

#### O Blood Group

10 years

#### A Blood Group

6-8 years

#### B Blood Group

8-10 years

#### AB Blood Group

4-6 years

## Is the waiting list fair?

National rules decide who gets a kidney from the waiting list first. The rules are based on factors like blood type, medical condition, where the patient lives, and how long the patient has been on dialysis and the waiting list. If you are listed for a kidney transplant, your waiting time will be calculated from when you started dialysis to treat your kidney failure, even if this was many years ago. The rules don't consider income, ethnicity, gender, or sexual orientation.

Once you are on the waiting list, a few things may happen:

- You may get a transplant.
- You may keep waiting until a matching kidney is available.
- You may never find a match.

Your chance of getting a kidney increases over time. The longer you wait, the higher the chance you'll get a transplant.

## Can I be waitlisted at more than one center?

You can be listed at multiple centers, and doing so may improve your chances of getting a transplant. To do this, you will need to submit paperwork that your care team can help you with. To be listed at centers in addition to UCLA, you will need to select other centers outside of the Los Angeles/Orange County/Inland Empire area.

Keep in mind that multiple listing may not be right for everyone. Each center has its own requirements, and may require additional medical tests. You should check with your insurance to see if multiple listing is covered. It may not be feasible for you to travel to other centers for required tests and evaluation.

## How do I know when I am listed for a kidney on the national UNOS waiting list?

The national waitlist is managed by the United Network for Organ Sharing (UNOS), a non-profit organization that manages organ matching, recovery and placement. You will get a letter from UNOS and your transplant coordinator telling you that you are listed. Usually you will also receive a phone call from your coordinator with this news. After you are listed, you may need to return to the transplant center once a year for medical tests to stay active.

## What are the various waitlist statuses and what do they mean?

There are two waitlist statuses: **Active** and **Hold**. When you are Active, that means the transplant center can call you for transplant. Hold means you cannot receive any organ offers. It is important to do everything you can to keep your status as Active!



## What does it mean to be on Hold?

Your transplant center may change your status to Hold, or Temporarily Inactive, because your center has decided that you:

- Are temporarily unavailable, not healthy enough, or for some other reason do not meet the necessary criteria for transplantation at the time.
- Should not receive any kidney offers.

If your status changes from Active to Hold, contact your Transplant Coordinator as soon as possible to find out why. We cannot keep transplant candidates on Hold for very long and you may be taken off the waitlist. Your transplant program can change your status back to Active once you have resolved the reason for your hold.

## How do I stay Active?

When you are first put on the waitlist, your transplant center will tell you. Afterwards, if your status changes, you will be notified via the contact information that you provided. You can also call your care team anytime if you have a question about your status.

The most important thing to do to stay Active is make sure all of your medical records are updated and that you communicate regularly with your care team about any changes in your health or contact information. You need to stay up-to-date on all your mandatory medical tests. Tell your care team if you need to change any of your personal information, such as your address, phone number, health, and insurance.

## How might I get a kidney faster?

You may have a shorter wait time if you're willing to take a kidney with a higher KDPI score or PHS high risk kidney, meaning that it may not last as long or may have a very low chance of carrying an infection, which can usually be treated after transplant. You will work with your care team to decide which types of kidneys you're willing to accept.

**TIP** If you're open to accepting all types of deceased donor kidneys, you have a better chance of getting a kidney transplant, and could even get one years sooner.

As you choose what's right for you, you'll need to think about how long you're willing to wait and the quality of the kidney you're willing to accept. The more types of deceased donor kidneys you're willing to take, the higher the chance you'll get a transplant and the shorter your wait time might be.

## Why should I consider a living donor kidney transplant?

Waiting for a deceased donor kidney to become available can take years. For many patients a living donor transplant is the best treatment option because it can happen much quicker and also living donor kidneys last longer. Most healthy adults can live just fine with only one kidney. Nationally over 5,000 people become living kidney donors every year.

## How can I let people know that I am looking for a living donor?

It can be hard to think about asking someone to be your living donor. There are many ways to start the conversation, to make your need known without making a direct request, or to allow a friend or family member to help you in your search by serving as your voice.

Here are a few ideas to help you get started:

- Talk to friends and family about your kidney health and interest in a transplant.
- You can share about your need for a transplant in person, by email or mail, in a bulletin or newsletter, at your place of worship or work, through social media
- Give friends and family the 'Living Donor Information' handout from UCLA. If you have not received this handout, ask your coordinator for a copy.
- Record a story about your need at [explorelivingdonation.org](https://www.explorelivingdonation.org) and share it on social media.
- If you have an interested living donor, give them the transplant center phone number so they can make an appointment to begin testing. If 2 or more people offer to donate, have all of them call the transplant center because some may not be a good match or be able to donate.

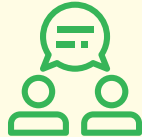
Bringing up the topic of needing a living donor can feel awkward and scary. Start with talking to your close family and friends if that makes you more comfortable. You can talk to them face-to-face, or write even a letter or email! Even if you don't find a donor among your immediate family or friends, they can always help by spreading the word out!



**TIP** Remember, a donor does not have to be the same age, gender, race, or blood type as you!

## Starting the conversation...

Asking someone to be your living donor may seem scary and difficult. Even though there's no one right way to do it, try following these tips when speaking to your loved ones to help you out:



Tell them about your diagnosis and your kidney function.



Explain the different donation options and why a living donation is best for you.



Remind them that your donor does not have to be the same age, gender, race, or blood type as you.



Reassure them that you will not treat them differently if they choose not to be your donor and that if they do agree to be your donor, they can change their mind at any time.

**TIP** Check out this video with tips from past recipients about how they brought up living donation with friends and family [youtube.com/watch?v=WLChHMWAtgw](https://www.youtube.com/watch?v=WLChHMWAtgw).

Record your own story to share by going to [exporelivingdonation.org](https://www.exporelivingdonation.org)

# Find a living donor: Get the word out about your need for a kidney

## It is important to make a plan.

If you decide that you want to look for a living donor, then you should make a plan about how to get the word out. Think about how you would feel most comfortable. Use the questions below to start planning:

### Who will you talk with?

- Family
- Friends
- Coworkers or classmates
- Faith or community leaders
- Other: \_\_\_\_\_
- No one, at this time

### How will you invite others to talk?

- Face to face
- Phone call
- Text message
- Email or letter
- In person
- Social media

### When would be a good time to talk?

- Over a meal or coffee
- At the next social gathering
- At a family meeting
- During the next holiday
- Other: \_\_\_\_\_

## Allow others to share your story and your interest in a living donor transplant.

You may feel uncomfortable talking about your health situation with others, but often a loved one can step forward to do the talking for you. Who would you feel comfortable speaking about your health for you?

## List specific people you want to share your story with:

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### Plan what you want to say. Here are a few suggestions on how to start:

*So, I asked you to meet me here to talk about something that has been on my mind for a long time — kidney donation.*

*I'd like to start by asking you a few questions. I'm curious to know what you have heard about kidney disease? What have you heard about kidney donation?*

*I'd like to tell you about what's going on with my health and my need for a kidney donation. Is it okay if I share my story with you today?*



### Other ways you could share your story:

- In person at a family meeting
- Through email or by mail
- In a bulletin or newsletter
- At work or your place of worship
- Through social media (Facebook, Twitter). Many patients use social media to share their story to try to reach more people. You can also ask others to share your posts. You can create and invite others to a social media page specifically for your donation search.

Be careful with social media. Some people have tried to donate a kidney for money. This is illegal. Ask your transplant center for their policy about finding living donors on social media.

## I have someone who might be willing to be my donor. What do I do next?

Anyone who is healthy and willing to donate may be considered as a donor.

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### Those interested in donation may complete our online screening questionnaire:

Available at: [uclakidneydonor.org](http://uclakidneydonor.org)

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### For any questions:

Call toll free: 866-672-5333

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### Email:

[UCLAKidneyDonor@mednet.ucla.edu](mailto:UCLAKidneyDonor@mednet.ucla.edu)