

# UHN Kidney Transplant Program: Your Path to a Kidney Transplant



## Welcome!

Your kidney care team referred you to us to assess you for a kidney transplant. Thank you for choosing the UHN Kidney Transplant Program to support you through your transplant journey.

This handout answers questions you may have about getting a deceased donor kidney offer (a kidney from someone who has died). It also describes how we decide if a kidney transplant is the right treatment for you.

## What happens now?

There are many steps before you get a kidney offer from the deceased donor list.

1. We use your medical information to estimate how long you will wait to get a kidney offer from the deceased donor list.
2. You will have a transplant assessment with us when you are 2 years or less from getting your first kidney offer. The assessment lets us decide if a kidney transplant is the right treatment for you.
3. You will be added to Ontario's deceased donor kidney transplant waiting list if your assessment shows it is the right treatment for you.
4. We will call you when you have a kidney offer.

## What happens if I find a living donor?

If you find a living donor, they must submit their health history form to the Living Kidney Donation office. If they are found suitable by the living donor team, your transplant assessment will start.

**Note:** We may find your living donor is not a good match or not healthy enough to donate after starting your transplant assessment. We will only continue your assessment if you are less than 2 years from your first deceased donor kidney offer. It will not affect your wait for a deceased donor kidney.

## Estimating how long you will wait for a kidney offer

### How do you know how long I'll wait for a kidney offer?

We can estimate how long you will wait for your first kidney offer by looking at how long patients similar to you have waited.

### What factors affect how long I'll wait for my first kidney offer?

How long you will wait for your first kidney offer from the deceased donor wait list depends on:

1. Your allocation points. Allocation points are calculated from:
  - a. The number of months since you first started kidney dialysis treatment.
  - b. Your calculated Panel Reactive Antibody (cPRA) level. cPRA is a measure of how difficult it is to find a matching donor. It is measured through a blood test.

2. Your blood group (A, B, O, or AB).

Getting a kidney offer is not affected by when you get referred to a transplant clinic or when you have the transplant assessment.

**Note:** Some patients are eligible for the Expanded Criteria Donor (ECD) or the “older donor” waiting list. Your transplant nephrologist (kidney specialist) will tell you more about ECD if you qualify for it.

### What are allocation points and how are they calculated?

Allocation points are used to sort patients on the deceased donor kidney wait list.

Allocation points are calculated the same way for everyone in Ontario waiting for a deceased donor kidney. Allocation points are **(number of months on dialysis x 0.1) + (cPRA ÷ 25)**

For example:

Chris has been on dialysis for 36 months and has a cPRA of 90%.

$$\begin{aligned}\text{Allocation points} &= (36 \times 0.1) + (90 \div 25) \\ &= 3.6 + 3.6 \\ &= 7.2\end{aligned}$$

Chris has **7.2** allocation points.

Yuki has been on dialysis for 10 months and has a cPRA of 0%.

$$\begin{aligned}\text{Allocation points} &= (10 \times 0.1) + (0 \div 25) \\ &= 1.0 + 0 \\ &= 1.0\end{aligned}$$

Yuki has **1.0** allocation points.

### How many allocation points do I have?

Your nurse coordinator will calculate your allocation points when we receive your completed initial referral package and the results of your cPRA test. Your blood will be drawn for the test during your first visit to the UHN Kidney Transplant Program. Once the results are available, we will tell you how many allocation points you have.

We will update your allocation points as you spend more time on dialysis and/or your cPRA level changes.

### How does my blood group affect how long I'll wait?

Waiting times are different for different blood groups. You must receive a kidney from a donor who has a compatible blood group to yours.

For example:

Chris has 7.2 allocation points and is blood group O.

Patients in blood group O get their first kidney offer at 8.7 allocation points.

Yuki has 1.0 allocation points and is blood group A.

Patients in blood group A get their first kidney offer at 6.9 allocation points.

Based on current waiting times, and when he first started dialysis, Chris is **1.2 years** away from his first kidney offer.

Chris starts the transplant assessment right away.

Based on current waiting times, and when she first started dialysis, Yuki is **4.8 years** away from her first kidney offer.

Yuki waits to start the transplant assessment.

## While you wait for your transplant assessment

### I will wait more than 2 years for my first kidney offer. Why can't I start my transplant assessment now?

It takes a lot of your time and energy to do a kidney transplant assessment. There is no benefit to doing extra tests now. Doing extra tests now means:

- Having to re-do the tests later
- More discomfort for you
- More inconvenience and cost for you

**Remember:** getting a kidney offer depends on how long you've been on dialysis, your cPRA level, and blood group.

It is not affected by when you have your transplant assessment.

Waiting to start your transplant assessment until you are closer to your first kidney offer means we can focus on finishing the evaluation for patients who are close to receiving a kidney transplant in the near future.

### What medical care will I get while I wait?

Your kidney care team will continue to care for you. They will:

- Send us a sample of your blood every 3 months so we can test your cPRA level. They will take this sample when they do your regular blood tests.
- Tell us if there are changes to your health that might increase the risks of having a transplant, such as having an infection that requires you to take antibiotics or if your heart becomes weaker.

Your transplant nurse coordinator will:

- Check your cPRA results every 3 months
- Speak with you and your dialysis centre regularly to get updates about your health
- Answer questions you may have about your transplant status

**Note:** We will call you to start your transplant assessment if your cPRA level is 95% or higher.

### What do I do while I wait?

- Stay healthy and active
- Follow all recommendations from your kidney care team and your family doctor
- Keep looking for a living donor

- Read the “Kidney Transplant Guide” patient binder regularly so you know what to expect when you get a kidney transplant

Call us right away if you:

- Have any major changes in your health
- No longer want to have a transplant
- Change your phone number(s), home address, or dialysis centre
- Find someone who may be willing to donate a kidney to you. Tell that person to complete the mandatory health history form and send it to the Living Kidney Donation Office.

### **How do I know when to start my transplant assessment?**

We will call you and your kidney care team when it is time to start your transplant assessment. You may need to have some tests with your kidney care team.

## **When you start your transplant assessment**

### **What happens during the transplant assessment?**

You will have some tests such as blood tests and an ultrasound of your blood vessels.

You will have appointments with a transplant nephrologist, transplant surgeon, anaesthetist, transplant coordinator, social worker, and any other specialists that are required.

### **What happens when I finish my assessment?**

Together, our team will review your medical information and decide if a transplant is right for you.

## **Getting on the deceased donor kidney wait list**

### **How do I get on the deceased donor wait list?**

We will add you to the waiting list after your assessment if we decide it is kidney transplantation is the right treatment for you.

We will call you when you have been added to the waiting list. You will also get a confirmation letter.

**Remember:** getting a kidney offer is not affected by when you are put on the wait list.

### **Is there any other way to get on the deceased donor waiting list?**

No. You must have a transplant assessment, and cleared by the kidney transplant team, before your name can be added to Ontario’s deceased donor kidney waiting list.

## **For more information**

Go to [UHNtransplant.ca](http://UHNtransplant.ca) and click on “Kidney Transplant” for more information.