

# The United Network for Organ Sharing Waitlist

UNOS is a group that manages the national waiting list. All transplant centers in the United States must be an active member of UNOS. Waiting for the transplant may take days, months or years. There are many things taken into account when matching a heart to the right recipient. In general, the heart will be offered to the sickest person that has been on the list the longest with the same blood type and similar body size. This section will review in depth the factors considered when matching a heart.

## Listing Status

There are six levels of listing for heart transplant based on how sick your heart is. Status 1 is the most urgent and Status 6 is the least urgent. Below is a general list of reasons that qualify for each status but there are many other reasons that are not listed. It is important to know that even if you have one of the conditions that meet a listing status, there is still more criteria that need to be met to get you that urgency. If you have any questions about your condition and listing status, please talk to your heart transplant coordinator.

**Status 1:** Total support in the hospital or LVAD with life-threatening arrhythmias. Examples of support in this category include:

- ECMO (extracorporeal membrane oxygenation): Heart/lung machine that pumps and oxygenates blood outside of your body, letting the heart and lungs rest
- Nondischargeable BiVAD (biventricular assist device): Surgically implanted heart pump

**Status 2:** Hospitalized with support or life-threatening arrhythmias without support. Examples of support in this category include:

- IABP (intra-aortic balloon pump): A pump that increases oxygen to the heart, while decreasing the work of the heart
- TAH (total artificial heart): Surgically implanted total heart
- LVAD (left ventricular assist device) with device malfunction

**Status 3:** Hospitalized or home with an LVAD complication, total support after 7 to 14 days, "30 day" LVAD time, hospitalized with inotrope support and monitoring. Examples of LVAD complications include:

- Hemolysis: destruction of red blood cells
- Pump thrombosis: blood clot in pump
- Right heart failure treated with IV inotropes
- Device related infection
- GI bleed (Must be hospitalized)

**Status 4:** Stable at home supported by LVAD or inotropes, retransplantation or certain cardiac diseases including:

- Amyloid
- Congenital heart disease
- Ischemic heart disease with intractable angina
- Hypertrophic or restrictive cardiomyopathy

**Status 5:** Listed for heart plus additional organ(s).

**Status 6:** Home without support and does not meet any of the above criteria.

**Status 7:** In addition to the above statuses, there is Status 7 which means you are temporarily inactive on the heart transplant list. While you do not continue to build time on the heart transplant list, you do not lose time you have already accrued. Reasons why someone might be made Status 7 include:

- Recent LVAD implant, to give time to recover from surgery
- Health declines, too sick for transplant
- Health improves, too well for transplant
- Substance abuse or smoking
- Noncompliance with medications and/or appointments
- Loss of social support, transportation or insurance
- Weight gain, BMI above threshold
- Uncontrolled diabetes

## Other Factors in Matching a Heart

**Blood type:** Below is a table of how hearts are matched by blood type.

| Your blood type: | You can receive a heart from a donor with blood type: |
|------------------|---|
| O                | O   |
| A                | A, O  |
| B                | B, O  |
| AB               | A, B, AB, O   |

**Height and weight:** Body size is very important when choosing the right donor. The donor's heart must fit comfortably inside the recipient's chest. Complications can happen if the donor heart is too big or too small for the recipient.

**Waiting time:** Waiting time is taken into consideration if a donor heart is available and more than one person comes up as a match.

**Presence of antibodies (cytotoxic antibodies):** *What are antibodies?* Our immune system naturally forms antibodies to protect ourselves against bacteria and viruses. Antibodies are good when they are ready to fight foreign invaders that can lead to illness, but when it comes to transplantation, antibodies can also attempt to fight or reject a transplanted organ. We will check your antibodies on a routine basis while you are actively listed. When organs become available for transplant, if you have antibodies against the donor organ, that organ will not be offered to you.

**How do you get antibodies?** Pregnancy, blood transfusions, prior transplants, LVADs and certain infections can cause people to develop or build up antibodies.

**Distance:** Donated hearts are most likely to work if they're transplanted within four hours of being recovered from the donor. We want to keep preservation time as short as we can. This means we may not be able to take a donor heart that is too far from us.

## Donor Organs

Potential donors go through a screening process to make sure their organs are appropriate to be transplanted, included being tested for these infectious diseases:

- HIV
- Hepatitis B
- Hepatitis C
- Cytomegalovirus (CMV)

Despite this process, you could be at risk for some diseases from the organ you receive. You can also be at risk for disease or cancers that were not detected in the organ donor. There is no way to test for all potential diseases. Some diseases or cancers may not be found until after transplant. When an organ offer is made, the transplant team will discuss the known risks of that organ. Your post-transplant follow up, disease screening, and management may change depending on the donor's evaluation and screening results. You can decline any organ offer without penalty.

## Organ Donor Types

**Standard criteria donors:** All donors who died from brain death except as stated below.

**Risk criteria donors:** Many organs become available from donors that meet certain risk factors that could place the recipient at increased risk for hepatitis B, hepatitis C or HIV. Examples of these include jail time in the past month, high-risk sexual activity and IV drug use.

All donor blood is tested to rule out infections that could be given to the recipient. But there can be a short period of time (usually a few days or weeks) where the individual could have been exposed to an infection and it could not be detected with the most sensitive testing. Because of this, the chance that an infection could be given to you that was not detected in the donor is very small, but still exists. While the risk is not exactly known, the estimates for hepatitis B, hepatitis C and HIV are shown below:

| Virus             | Estimated Risk        |
|-------------------|-----------------------|
| Hepatitis C virus | 1 in ~ 5000 (0.02%)   |
| Hepatitis B virus | 1 in ~ 300 (0.3%)     |
| HIV               | 1 in ~16,000 (0.006%) |

**Hepatitis C positive organ:** The organ is from a donor that has tested positive for hepatitis C. Hepatitis is a virus that is transmissible through blood and body fluids. It can cause damage to the liver (cirrhosis) if left untreated. The risk of contracting hepatitis C from hepatitis C positive donor is close to 100%.

*What does this mean for you if you accept a hepatitis C positive organ?* You will be tested for hepatitis C on a frequent basis after transplant for up to one year. If you test positive for hepatitis C, you will be seen by hepatology to evaluate for and start treatment. Treatment usually lasts 12 weeks. The success rate to treatment is 95% to 100%. It is important to know that if you test positive for hepatitis C at any time, you are contagious to others. Precautions include but are not limited to not sharing toothbrushes or shaving accessories, practicing safe sex and proper handling and disposal of insulin or other needles.

**Why would you want to accept a hepatitis C positive or risk criteria organ?** There are some advantages to getting an organ from a donor that meets risk criteria or hepatitis C positive donor. The quality of these organs is typically better and patients typically get transplanted sooner. You are being offered this organ because it is considered to be of good quality and should improve the length and quality of your life, compared to remaining on the waitlist. Thus, it's important to balance this anticipated significant benefit compared to the risks.

## The Right Organ for the Right Recipient

Our goal for heart transplantation should be the same as yours: to have a successful surgery and a good outcome. Whichever organ is offered to you, it is because your surgeon believes that it is the right organ for you. You will have the chance to discuss your organ offer with the transplant team at the time of your offer.