

# Questions & Answers About Heart Allocation for Adult Transplant Candidates

## How do I register as a heart transplant candidate?

A doctor who specializes in heart disease must first refer you to a transplant hospital. The transplant team will decide whether and when to register you for a heart transplant. They will perform a series of medical tests on you. You will discuss transplantation with a coordinator, and often with a social worker as well. These professionals use your medical information and details about your current treatment to calculate your urgency status.

## How are hearts distributed for adult candidates?

If you are an adult listed at a hospital for a heart transplant, the transplant program will assign you an urgency status. This status is based on specific medical criteria that estimates how urgently you need a transplant. Your urgency status may go up or down based on changes in your overall health or current treatment you are getting.

You might have special medical needs or issues that the standard policy does not address. In this case, your transplant team can ask for an exception to list you in a status that better reflects how urgently you need a transplant. A review board of medical experts considers your team's request based only on your medical information, not other personal information about you.

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As donor hearts become available, they are offered first to candidates who:

- are listed at a transplant hospital near to the donor hospital
- are a match with the donor's blood type
- are the most medically urgent

For any candidates who match a nearby donor, the transplant team gets more detailed medical information about the organ offer. The team may accept the offer or decline it. They might decline the offer because the candidate is too sick at the moment to be transplanted, or because certain medical facts suggest the organ wouldn't be a good match.

If there are no local matches for urgent candidates, or if no local programs accept a heart offer, candidates who match the donor but are listed at hospitals farther from the donor hospital will get offers next.

The most medically urgent candidates (Status 1) are considered first, followed by less urgent candidates who are a good match to the donor. At any level of match, if two or more candidates share the same status, then the person who has been waiting the longest in their status gets priority.

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## Why and how are statuses changing?

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For several years, heart candidates have been grouped according to three statuses –1A (most urgent), 1B (somewhat urgent) and 2 (least urgent). As we learn more about heart disease and successful treatment of it, we need more specific criteria that reflects a patient’s current health and care they are getting.

Beginning October 18, 2018, candidates will be listed according to six medical urgency statuses. Status 1 is the most urgent and Status 6 is the least urgent. While there are highly detailed criteria for status assignments, several basic factors will be considered:

- If you are on one or more advanced support therapies (such as ECMO, VAD or an artificial heart), and/or if you have a difficult to control, life- threatening condition such as ventricular arrhythmia, tachycardia or fibrillation, then you will have higher priority.
- If your current treatment is complicated by an infection or clotting, and/or if your treatment requires you to stay in the hospital, then you will generally be in a higher status than those who are not having complications and can leave the hospital.

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Your transplant program must report data to UNOS about your current treatment and symptoms. The program then lists you in the applicable status.

If you are in the new Status 1 or 2, you are in the most urgent need for a heart transplant. As a result, you would be considered first for heart offers from a wider geographic area (up to 500 miles from the donor location) before candidates with Status 3, 4, 5 or 6.

Your status may change if your symptoms get better or worse, or if your form of treatment changes. If you had been in a higher status but no longer meet the criteria for it, your transplant team will change your status as appropriate. Your transplant team is the best source of current information regarding your status and any treatment options.

## How is your urgency status determined?

Only medical information is used to determine how urgently you need a heart. No other personal information, such as your insurance type or cause of your heart disease, goes into deciding your status.

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## **These key factors help determine your urgency status.**

- Do you have an implanted device to replace or stimulate circulation, such as a total artificial heart or VAD? If so:
  - Can you leave the hospital, or do you need to stay in the hospital?
  - Are you having device-related complications such as clotting or infection?
  - Has your device recently been replaced?
- Are you receiving other support for circulation or breathing, such as ECMO or an intra-arterial balloon pump?
- Are you on medications to stimulate heart function?
- Do you have life-threatening irregular heart function, such as tachycardia, fibrillation or arrhythmia?
- Do you need one or more other organ transplants (such as a heart-lung or heart-liver)?

In general, you are more likely to be in a high urgency status if you are on advanced treatment and are having complications or very severe symptoms. If your medical condition is currently stable, you are likely to be in a somewhat lower status. Your transplant team can discuss with you more specifically how these factors affect your status.

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## What does the heart allocation system mean for me?

The heart allocation system responds to your individual medical needs. Your current medical information is used to determine when you may get a donor offer based on your specific condition. It reflects how immediate your need is as compared to others who need a transplant.

## How often should my medical information be updated?

Your transplant team will report any major change in your medical condition or the treatment you are getting. This information could change your urgency status.

*It is important that your transplant center has your most current information and test results.* Please work with your transplant team to schedule appointments and tests that will allow them to keep your information up to date. If you are at the highest level of medical urgency, your transplant team must frequently re-certify your information. This is done to ensure that patients in that status are still in urgent need of a transplant. Other status criteria require recertification of medical information every few weeks or months.

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## Does a child under age 18 have the same urgency statuses as an adult?

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No. Children younger than age 18 will continue to have the three statuses 1A, 1B and 2. The medical criteria used to prioritize them is somewhat different from the adult criteria.

## Will the heart allocation system change in the future?

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The transplant system is designed to be flexible and allow for improvements. New forms of treatment, and new understanding of patient care, help us learn how to save more lives and help enhance people's quality of life through transplantation.

Transplant professionals review the heart allocation system regularly and adjust it to better meet the needs of transplant candidates. Your transplant team will keep you informed of changes in the system and what they may mean for you.

## What if I have more questions?

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You should contact your transplant team first if you have questions or concerns. They will have the most detailed information about your medical status and treatment options.

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You may also contact UNOS Patient Services at 1-888-894-6361. In addition, you can find details about allocation policy and patient information on the following websites:

[optn.transplant.hrsa.gov](https://optn.transplant.hrsa.gov)

[www.unos.org](https://www.unos.org)

[www.transplantliving.org](https://www.transplantliving.org)