

Selecting a Transplant Center

Greg Ciaciura
Luke Preczewski
Gwen McNatt, PhD

AMERICAN SOCIETY OF
TRANSPLANTATION

1120 Route 73, Suite 200
Mount Laurel, NJ 08054
Phone: 856-439-9986
E-mail: info@myAST.org
Website: myAST.org

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Selecting a Transplant Center

One of the biggest decisions you will make as a transplant candidate is choosing a transplant center. There are nearly 250 transplant centers in the U.S. and all of them must meet strict professional standards. Go to <http://optn.transplant.hrsa.gov> to access transplant center listings and links.

You do have choices when it comes to transplant care. The most important consideration in any choice includes the individual's specific situation. Each patient has different needs, preferences and desires that need to be taken into consideration when selecting the appropriate transplant center. For some, geographic and economic factors are important. For others, center success rates and facilities are important in their decision. If you can, we suggest that you visit more than one transplant center to find out what they recommend and what their plan would be for you.

Many patients simply choose the transplant center closest to them, but there are many other factors to consider before making a decision. The following are some important factors that patients should carefully consider:

INSURANCE COVERAGE

Although many insurance companies offer coverage for transplant costs, the terms and benefits of different insurance policies vary widely. Some insurance companies establish agreements with certain transplant centers where the insurer may cover more of the costs for certain centers than others. Many transplant centers have different policies about the insurance that they accept for the transplant you need. It will be important that you find out any restrictions that your policy may have.

Your insurance company may require you to go to a specific transplant center. Your insurance company may also require a higher co-payment or deductible at some centers. Before going to any center, it is important to check with your insurance company to determine the cost of a transplant. Be sure to ask that the costs include preliminary testing, the surgery itself and post-operative recovery costs. These costs vary across the country by hospital and organ type. Be sure to find out if you have travel benefits which can help pay the costs of going to a center that is not close to where you live.

It's very important for the long-term success of your transplant for you to have insurance or other financial resources to cover needed expenses. Even after the transplant operation, you will

take anti-rejection drugs and need follow-up medical care for the life of your transplant. Every transplant program has a social worker and/or financial coordinator who can advise you on insurance or funding options. The financial counselor at the transplant center may also be able to help you find out how much you will need to pay that the insurance company does not pay for. You may also be able to use the services of a case manager.

PROFESSIONAL RECOMMENDATION

You may be able to suggest your own transplant center (self-refer), however many patients rely on the expertise and recommendation of their doctor, dialysis unit or case manager who may recommend specific transplant centers based on their knowledge and experience. Do what you're most comfortable with.

THE EXPERIENCE OF THE TRANSPLANT TEAM AND SUPPORT PERSONNEL

It is important to know how much experience a hospital and transplant team has with the type of care you need. Ask about the number of years the transplant program has been in existence.

You should also consider how many years the surgical and medical transplant team have been at the center. Is there more than one surgeon and/or transplant physician at the center?

LOCATION OF THE CENTER AND TRAVEL TIME

The distance and time to travel to the transplant center is important when you are waiting for an organ. Depending on where you live, you may have to travel to receive a transplant. Contact the transplant center to see if there is low cost housing or if hotel options are available near the center. Ask if temporary and long term housing is available near the transplant center.

ACCESS

Some transplant centers are located in large cities where parking can be expensive. It is important to inquire if free or discounted parking is available and if they have other clinics outside of the downtown. Some transplant centers will send their team to other clinics they have established in the state to perform transplant evaluations.

TRANSPLANT CENTER HOSPITAL

The quality of the hospital in which the transplant center is located may be an important consideration. You can check out

rating sites such as Leapfrog (<http://www.leapfroggroup.org/data-users/leapfrog-hospital-safety-grade>) or Healthcare Compare (<http://www.medicare.gov/>).

The quality of the nursing care is also important. Studies show that patients may have better outcomes at hospitals that have achieved Magnet status for excellence in nursing. You can check out the Magnet web site below (http://www.nursecredentialing.org/Magnet/FindaMagnetFacility?utm_source=Resource%20Guide&utm_medium=content&utm_campaign=Healthcare-Magnet-Guide&utm_content=2017).

TRANSPLANT CENTER VOLUME

When choosing a transplant center, you may want to compare the number of transplants performed, waiting list size, and survival rates at the centers you are considering. Go to <http://optn.transplant.hrsa.gov> (Data>View Data Reports>Center Data) for the number of transplants and waiting list size by transplant center.

COMPARING TRANSPLANT PROGRAMS

SRTR (Scientific Registry of Transplant Recipients) provides measures of ways to compare transplant programs. Visit www.srtr.org for the median wait time and survival rates by transplant center. The SRTR risk adjusts its information based on national averages, and publishes information on whether results are statistically significant.

The SRTR reports contain considerable information about centers, including the types of patients (for instance, ages, races, primary disease leading to need for transplant) they have transplanted, the types of donors they have used, and other aspects of care, such as average length of stay. Some centers feel the risk adjustment does not fully account for the types of patients they see. You can review these reports in detail and then ask the center any questions they may have to help decide whether a program is right for you.

LIVING DONOR TRANSPLANT

A living donor may give one kidney, a part of the liver, or a portion of the intestine. If you are in need of one of these organs, you should ask if the transplant center you are considering offers living donations. Be sure to discuss the benefits of getting an organ from a living donor with your transplant team.

A paired kidney donation is a transplant option for people who have a living donor who is medically able, but cannot donate a kidney to the intended candidate because they are poorly matched. If you are a kidney candidate and have possible living

donors, ask if the center that you are considering participates in paired kidney donation. This will also expand your access to living donation, especially if you have a certain blood type or special antibodies. If you have a living donor, the center needs to be the right place for both you and for your donor.

OPTIONS FOR CHALLENGING PATIENTS

Does your situation require special care? For example, are you highly sensitized (have a lot of antibodies that will make finding an organ for you difficult)? Other special issues include having additional medical problems, such as bad heart disease, liver cancer or needing more than one transplanted organ. If any of these situations apply to you, ask what experience and special treatments the center has to deal with these problems.

PATIENT SATISFACTION

You need to find a place where you feel comfortable with the transplant team. Some of this is your “gut feeling”, but you may also want to talk with a patient who has been in the center. Looking at the results of the patient satisfaction surveys may also help. Most centers can arrange for a new patient to talk to other patients that have been previously transplanted at the center. Many centers may also have a patient support group or other “buddy” system.

THE QUALITY AND AVAILABILITY OF PRE- AND POST-TRANSPLANT SERVICES

Offering a complete system of support services to meet the special needs of patients and their families is important. Education and emotional support can help you feel informed about your health care decisions. Is your transplant center prepared and capable to meet your own personal needs.

CULTURAL AND LINGUISTIC SENSITIVITY

If you are not fluent in English you will want to know if the transplant center has bilingual staff members (physicians, nurses, social worker, etc.) and/or access to translators if needed. Patients always need to feel understood and informed throughout treatment.

POST-TRANSPLANT CARE

The long-term success of a kidney transplant depends on many things. These include watching you immediately after your operation and care that continues long after your transplant.

Ask what the short-term care is at the center immediately after the transplant. Additionally, after you get released and transition to your local doctor, ask about the ongoing involvement and joint care your local doctor has with the transplant center.

Most transplant centers are only able to take care of their own patients after transplant. This means if you receive your transplant from another transplant center, you will probably need to go to that center for your care after your transplant operation. This is an important issue to think about if you are being listed at more than one center and do not have transportation to get to the center for care after your operation. Exceptions to this may be if you move or relocate for work, your transplant center can talk with the physicians at the center you will be close to about providing care for you after you receive your new organ.

Centers also differ in how long they want to care for a patient after the operation. Some centers prefer to manage the patient for a long time. Others want the patient to return to the non-transplant physician at some point after transplant and to only go to the transplant center for certain issues such as organ rejection. Ask your center about how it manages care after receiving a new organ. You can then determine how well that works for you.

DEDICATION TO RESEARCH AND INNOVATION

Transplant centers offering new ideas and research techniques in organ transplantation tend to have clinicians who are well trained in the most advanced techniques and treatments. Transplant candidates should find a transplant center that offers the most up-to-date treatment options. You should also ask about any new methods and treatment techniques offered, especially those that may relate to your specific medical situation. Many facilities are involved in the National Institutes of Health (NIH) funded protocols that must meet rigid requirements prior to approval and in research protocols that are sponsored by pharmaceutical firms. These are often designed to test the latest medications.

SOME FINAL NOTES:

Four ears are better than two. Bring a family member or support person with you to the evaluation visit. They may think of questions you didn't think to ask, and they will also need to understand what role they will play in your follow-up care.

Here are some tips to help you prepare for your evaluation visit.

- Learn as much as you can about transplant before your first visit, and come prepared with a list of questions
- Don't trust your memory to ask all your questions and remember all the answers
- Keep any educational materials that you received
- Take notes of important points that during your visits you can refer to later

Don't be afraid to ask questions! This is your life and you need to feel satisfied that your questions are fully answered. Your support person can also help. The more engaged you are in your care the better off you will be.

You always have the right to say no. All transplant centers must seek "informed consent" from each patient before any transplant operation. This means you have the right to know what's going on and to decide for yourself whether that's okay. It is wise to get as much advice from the knowledgeable doctors, nurses, and other professionals at the centers. But in the end, the choice of transplant center and the choice of whether to have a transplant are yours!